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Potential use of routine databases in health technology assessment

J Raftery, P Roderick and A Stevens

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The website also provides information about the HTA Programme and lists the membership of the various committees.

British Cardiovascular Intervention Society (BCIS) Database

Description

BCIS was established in 1988 to organise 6-monthly meetings for those interested in interventional vascular procedures. At that time percutaneous coronary angioplasty (PTCA) was still in its relative infancy in the UK with just over 5000 procedures undertaken in that year. The Society has collected data on interventional activity in the UK each year since then, with the results available on the BCIS website (listed in Contact details below).

BCIS covers both NHS and private facilities in the UK and has been active in the development of guidelines and making recommendations on the practice of interventional cardiology and in supporting research. It has served as a forum for advice to the Medical Devices Agency.

In late 1999, BCIS had an active membership of over 500 interventional cardiologists, radiologists, nurses, radiographers, physiological measurement technicians and those working in industry.

Since 1992, BCIS has used the database to carry out an annual audit of interventional procedures. This has included data on the number of centres carrying out interventions, the types of PTCAs, broken down by single and multivessel, PTCA for grafts, restenosis, PTCA for chronic occlusion, unstable angina, or following thrombolysis or for acute infarction. In addition, the number of stents and other interventional procedures has been collected.

Centres contributing to the database grew from 52 in 1988 to 61 interventional centres and 65 diagnostic-only centres by 1998. Audit data for 1999 reported a further 13% increase in UK procedures, compared with 1998, to 28,133. The use of stents has increased to 79% of all procedures although the range reported by centres remains wide (30–>90%) (see BCIS website, March 2001).

Data

Data are collected under several headings (hospital details, patient data, procedures, outcomes and stents used. Fuller details are given on pp. 95–7. Procedures are distinguished in detail; outcomes are reported by hospital/procedure.

A switch from aggregated hospital data to patient-specific data collection is planned via electronic submission (see list on pp. 96–7) as proposed by the CCAD pilot project. This is planned whether or not CCAD proceeds (M de Belder, personal communication).

Completeness and accuracy

There are around 150 interventional and diagnostic centres, of which 22% of NHS and 39% of private centres do not return data. Of the 61 interventional centres providing data, all give the aggregated number of PTCAs carried out in that centre, but fewer (14–17) are able to provide patient-level data. Ten centres have fully computerised forms with details necessary for case-mix analysis.

A 1998 audit report stated that "data collection was still fundamentally poor but improving" following a review of the 1997 data (report to NICE; see website) which identified weaknesses and made recommendations for change. In particular, whereas data on infrastructure and to some degree process were considered adequate, data on appropriateness and outcomes were poor. There was limited coverage for some data headings, including the relation between stenting and need for emergency re-intervention (data available for 16 centres) and outcome after repeat intervention (data from 7–8 centres).

Similar weaknesses applied to the data returned on acute coronary. A number of recommendations were made including provision by BCIS of appropriate definitions, including standard definition of morality and factors pertaining to case mix.

Uses

In addition to annual reports, BCIS annual audit data have been used in a report to NICE (see BCIS website), which analysed data on stents for the period 1992–98. The limitations of the BCIS audit, in relation to appropriateness and outcomes (acknowledged in its NICE submission) plus its restricted coverage of units in detail, limited its use for assessment of effectiveness.

Only one study of diffusion of PTCA has been located.[1] Annual reports of PTCA activity have been published by BCIS since 1988[2–6] (website).

Although the lack of patient-specific data precludes its use for equity analysis, such analysis could be done via HES at the cruder level of overall PTCAs (but not by indication for treatment such as type of acute coronary syndrome). The lack of risk adjustment data in BCIS, although

planned as part of CCAD, prevents analysis by age or sex. No published analyses have been located.

Although BCIS is the only source on stent activity, which is an important component of unit cost, no published cost studies have been located. Variations in HRG reference costs for PTCA (HRG E15) take no account of whether stenting was included or not.

Funding

BCIS is unfunded. Its estimated cost is between £0.25 million and 0.5 million per annum (25,000 procedures per annum at £10–20 each record); see Chapter 9.

Access

Reports to two scientific meetings of the Society each year.

Contact details

Dr M de Belder (Audit Secretary)
South Cleveland Hospital
Middlesbrough
TS4 4BW
Tel.: 01642 854620
Fax: 01642 854613
Website: http://www.bcis.org.uk/index.html

Publications

Annual audit reports (see website for 1992–96, 1997, 1998 and 1999 reports).
Submissions to NICE on stents and on glycoprotein IIb/IIIa inhibitors (see NICE website: http://www.nice.org.uk/).

Council of the British Cardiovascular Intervention Society. Cardiac intervention procedures in the United Kingdom in 1991. *Br Heart J* 1993;**70**:201–3. The 1992–98 reports are on the BCIS website.

References

1. Gray HH, Cardiac interventional procedures in the UK 1992 to 1996. *Heart* 1999;**82** (Suppl 2):II10–17.
2. Hubner PJB, for Council of the British Cardiovascular Intervention Society. Cardiac interventional procedures in the United Kingdom during 1988. *Br Heart J* 1990;**64**:36–7.
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5. Parker DJ, Gray HH, Balcon R, Birkhead JS, Boyle RM, Hutton I, *et al*. Planning for coronary angioplasty: guidelines for training and continuing competence. *Heart* 1996;**75**:419–25.
6. Smith LDR, Dean JW. Primary angioplasty in the district general hospital: interim analysis of the Exeter primary angioplasty pilot study [abstract]. *Heart* 1997;**77** (Suppl 1):P46.

BCIS data headings

BCIS Domain	CCAD Domain	ID	Parameter
General	Demographics	BCIS001	Surname
	Demographics	BCIS002	Forename
	Demographics	BCIS003	DOB
	Demographics	BCIS004	Gender
	Demographics	BCIS005	NHS number
	Demographics	BCIS006	Postcode
	Demographics	BCIS007	Hospital ID number
	Demographics	BCIS008	Hospital
Indication for procedure	Pre-procedure	BCIS009	Clinical syndrome
	Pre-procedure	BCIS010	Clinical syndrome (specify)
	Pre-procedure	BCIS011	Urgency
Clinical factors	Pre-procedure	BCIS012	Angina status
	Pre-procedure	BCIS013	Dyspnoea status
	Pre-procedure	BCIS014	Previous MI
	Pre-procedure	BCIS015	Diabetes aetiology
	Pre-procedure	BCIS016	Peripheral vascular disease
	Pre-procedure	BCIS017	Cerebrovascular disease
	Pre-procedure	BCIS018	Cardiogenic shock (pre-intervention)

continued

BCIS Domain	CCAD Domain	ID	Parameter
Diagnostic catheter data	Pre-procedure	BCIS019	LV function
	Pre-procedure	BCIS020	LV ejection fraction (if measured)
	Pre-procedure	BCIS021	Extent and severity of native CAD – Duke coronary score
Coronary anatomy	Pre-procedure	BCIS022	Extent of coronary vessel disease
		BCIS023	Left main stem disease
	Pre-procedure	BCIS024	Previous CABG
Intervention procedure	Procedure	BCIS025	Date of procedure
	Procedure	BCIS026	Name of operator 1
	Procedure	BCIS027	Status of operator 1
	Procedure	BCIS028	Number of vessels attempted
	Procedure	BCIS029	Number of lesions attempted
	Procedure	BCIS030	Restenosis lesion
	Procedure	BCIS031	Chronic occlusion
	Procedure	BCIS032	ReoPro used?
	Procedure	BCIS033	Stent(s) used
	Procedure	BCIS034	Devices used
	Procedure	BCIS035	Specify device
	Procedure	BCIS036	Post-procedural CAD score
Laboratory outcome	Outcome	BCIS037	Laboratory outcome
In-hospital outcome	Outcome	BCIS038	Time to bypass
	Outcome	BCIS039	Transfer to theatre
	Outcome	BCIS040	Post-AMI final TIMI flow
	Outcome	BCIS041	Death
	Outcome	BCIS042	Date of death
	Outcome	BCIS043	Q-wave MI
	Outcome	BCIS044	Non-Q-wave MI
	Outcome	BCIS045	Re-infarction
	Outcome	BCIS046	Re-intervention (PCI)
	Outcome	BCIS047	Emergency CABG
	Outcome	BCIS048	Elective in-house CABG
	Outcome	BCIS049	Was post-PCI CPK measured?

AMI, acute MI; CABG, coronary artery bypass; CPK, creatine phosphokinase; DOB, date of birth; LV, left ventricle; MI, myocardial infarction; PCI, percutaneous coronary intervention; TIMI, Thrombolysis in Myocardial Infarction Study Group.

BCIS additional data headings – proposed by CCAD

Domain	CCAD Domain	ID	Parameter
General	Demographics	BCIS101	Ethnic origin
	Demographics	BCIS102	Patient status
	Demographics	BCIS103	Employment status
Clinical factors	Pre-procedure	BCIS104	Smoking
	Pre-procedure	BCIS105	Family history of CAD
	Pre-procedure	BCIS106	Hyperlipidaemia
	Pre-procedure	BCIS107	Hypertension
	Pre-procedure	BCIS108	Renal status
	Pre-procedure	BCIS109	Creatinine level
	Pre-procedure	BCIS110	Number of previous MIs
	Pre-procedure	BCIS111	Previous PCI
	Pre-procedure	BCIS112	Number of previous PCIs
	Pre-procedure	BCIS113	Number of previous CABG operations
	Pre-procedure	BCIS114	Cardiac transplant
	Pre-procedure	BCIS115	Previous other heart surgery
	Pre-procedure	BCIS116	Significant valve disease
	Pre-procedure	BCIS117	Ventilated
	Pre-procedure	BCIS118	Other relevant data

continued

Domain	CCAD Domain	ID	Parameter
Investigations	Pre-procedure	BCIS119	Q-wave MI on resting ECG
	Pre-procedure	BCIS120	Resting ECG evidence of ischaemia
	Pre-procedure	BCIS121	Stress test evidence of ischaemia
	Pre-procedure	BCIS122	Drug therapy
	Pre-procedure	BCIS123	Number of anti-anginal classes
Procedural data	Procedure	BCIS124	Hospital procedural ID number
	Procedure	BCIS125	Procedural organisation
	Procedure	BCIS126	Follow-on (‘*ad-hoc*’) procedure
	Procedure	BCIS127	Surgical cover
	Procedure	BCIS128	Consultant cardiologist
	Procedure	BCIS129	Name of operator 2
	Procedure	BCIS130	Name of operator 3
	Procedure	BCIS131	Training procedure
	Procedure	BCIS132	Research study
	Procedure	BCIS133	Research study title
	Procedure	BCIS134	Route for access
	Procedure	BCIS135	LMS lesion attempted
	Procedure	BCIS136	Reference diameter
Peri-procedural problems	Procedure	BCIS137	Loss of side branch
	Procedure	BCIS138	Coronary dissection
	Procedure	BCIS139	Cardiogenic shock
	Procedure	BCIS140	Heart block requiring pacing
	Procedure	BCIS141	DC cardioversion required
	Procedure	BCIS142	Need for ventilation
	Procedure	BCIS143	Guide wire fracture
	Procedure	BCIS144	Stent loss/embolisation
	Procedure	BCIS145	No flow or significant ‘slow-flow’
	Procedure	BCIS146	Other
Other agents/support used	Procedure	BCIS147	Insertion of IABP
	Procedure	BCIS148	Inotropes used
	Procedure	BCIS149	Other IIb/IIIa receptor blockers
	Procedure	BCIS150	Other IIb/IIIa receptor blocker name
Equipment	Procedure	BCIS151	Indication for stent
	Procedure	BCIS152	Number of stents used
For each stent	Procedure	BCIS153	Stent length
	Procedure	BCIS154	Stent list

DC, direct current; ECG, electrocardiogram; IABP, intra-aortic balloon pump; LMS, left main stem.

Human Fertilisation and Embryology Authority (HFEA) Database

Description

The HFEA was established by the Human Fertilisation and Embryology Act 1990 to monitor assisted conception and to regulate and license clinics providing:

- any fertilisation treatment involving the use of donated gametes (e.g. DI or IVF)
- storage of gametes or embryos or
- human embryo research.

The HFEA has a statutory duty to collect information about licensed treatments and their outcomes. Since 1991 it has maintained a register compiled from data provided by licensed clinics (in 1999, 118 clinics were licensed). Information is collected for the following main reasons:

- to provide information to children born as a result of such treatments
- to monitor the provision of treatments and
- to assist in the provision of information to the Government, patients, clinics and the general public.

The HFEA database is the largest database of its kind in the world. In 1998–99, details of 35,363 IVF and 7225 donor insemination treatments were added to the register. These included 7762 clinical pregnancies (21.9% of treatments started) leading to 6450 live births (18.2% of treatments started).

The HFEA has a duty to provide enquiring adults (over 16 years old) with the following non-identifiable information:

- if they were born as a result of treatment using donated gametes
- if they are related to someone they wish to marry.

Since Parliament could in the future decide to extend the donor details that must be disclosed (e.g. appearance, interests and occupation), such data are held on the register on a highly confidential basis. The HFEA intends to publish detailed, non-identifying datasets of treatments and their outcomes on their website (listed in Contact details below).

Data

Each licensed unit in the UK must complete monthly paper forms for each type of treatment and donor. A new form must be completed for each new patient and treatment cycle. The forms are processed on arrival in HFEA by data entry clerks who return incomplete or queried forms. If the forms are consistently incomplete or inaccurate, the HFEA has the power to revoke the clinic's licence.

Eight forms collect detailed data (see pp. 99–104) in addition to the following core headings:

- administrative details
- patient/donor details
- previous obstetric history
- treatment
- outcome.

The HFEA plans to transfer from its paper-based system to electronic data collection by 2005 for all but the smallest licensed centres.

Coding systems

No formal disease or treatment coding systems are used (see pp. 99–104).

Completeness and accuracy

The completeness of both clinic and patient treatment notifications is reported to be 100%. However, data on individuals are less than 100% complete as some clinical pregnancies are lost to follow-up so outcomes are missing/incomplete (2.3% reported in 1997–98).

Internal audit estimate transcription errors are between 3 and 3.5%, with 5% errors the maximum 'acceptable'. The HFEA uses a range of internal checks [double data entry, software systems audit, data collection process audit, accuracy check (random samples are returned to the unit and the data double checked against the clinical notes), annual verification process (at the end of the financial year, each clinic is informed of its total number of treatment cycles held on the HFEA database, allowing any inconsistencies to be corrected), computer-assisted validation checks (illogicality and inconsistency searches)].

Clinics are also subjected to HFEA visits on a rolling basis which may be a form of external audit.

Uses

The HFEA database was used[1] in an analysis of factors associated with success in IVF. Annual reports from HFEA show the number of cycles of IVFs disaggregated between different methods (micromanipulation, ICSI or SUZI and frozen embryo replacements). Donor insemination information distinguishes between GIFT and intrauterine insemination using donor gametes. Births by type are linked back to number of embryos implanted.

The HFEA annual reports show the number of procedures carried out by type and over time indicating the diffusion of the relevant technologies. No analysis of diffusion outside the annual reports has been located.[2]

Equity analysis is limited by lack of linkage of IVF recipients to Health Authorities (only county of residence was recorded to 1996, with only limited postcode information pre-1999) and also because of the inability of postcoded data to separate out foreign patients using UK addresses while attending private clinics.

Although the HFEA is the only source providing data on the total number of cycles of IVF carried out, regardless of how funded (publicly or privately), no cost analysis has been located. Prices for IVF are not provided by HFEA but are available from clinics.

Funding

The cost of the register is unknown. The HFEA's annual income was at £1.559 million in 1999–2000), met mainly from licence fees. Applying a notional unit cost of £10 per record to the just over 43,000 new registrations in 1999–2000 would put its annual cost at £0.43 million; see Chapter 9. The cost to the clinics of

complying with regulatory returns to HFEA is unknown but likely to be considerable.

Access

Access to the database is confined to HFEA members.

Contact details

The Human Fertilisation and Embryology Authority
Paxton House
30 Artillery Lane
London
E1 7LS
Tel.: 020 7377 5077
Fax: 020 7377 1871
Website: http://www.hfea.gov.uk

Publications

The HFEA publishes an annual report. The most recent report (2000) details activity for the years 1998–99 (see website).

Human Fertilisation and Embryology Authority, Annual Report 2000.

References

1. Templeton A, Morris JK, Parslow W. Factors that affect outcome of *in vitro* fertilisation treatment. *Lancet* 1996;**348**:1402–6.
2. Lanchester PAP. Registers of *in-vitro* fertilisation and assisted conception. *Hum Reprod* 1996; **11** (Suppl 4):89–104.

Patient and partner registration form (99).1.0

Administrative details					
HFEA Centre number					
New individual or changes to existing					
Type of individual			Patient	Donor	
Patient/donor number					
Date of birth					
Full names					
Names at birth					
Place of birth					
Partner details					
Previous partner number					
Date of birth					
Full names					
Names at birth					
Place of birth					
Previous obstetric history (IVF patients)					
Total No. of previous pregnancies					
No. of IVF pregnancies					
Total of live births					
Date started trying to become pregnant					
Date of last pregnancy					
No. of previous IVF treatments			At this clinic	In total	
Previous obstetric history (DI patients)					
Total No. of previous pregnancies					
No. of DI pregnancies					
Total live births					
No. of previous DI treatments			At this clinic	In total	
Infertility					
Female					
Male					
Couple					
Cause of infertility	Tubal disease	Ovulatory disorder	Male factor	Unexplained	Other
Last UK centre for a new donor/patient treated elsewhere					
Previous patient/partner numbers			Patient	Donor	

Treatment and embryo creation and use form (99)T.1.0

Administrative details

HFEA Centre number				
Patient or donor name	Number			
Is this a surrogate?	Yes	No		
Donor sperm from	Centre no.	Donor no.		
Eggs from	Centre no.	Donor no.		
Main reason for intending to produce embryos and/or collecting eggs	Treatment now	Storing embryos	Storing eggs	
	Research	Donation	Other	
Includes the use of donated eggs?	Centre No	Form No		
Date eggs collected				
Stimulation used	None	Anti-oestrogens	Gonadotrophins	
If 0 were collected, why?	Risk of OHSS	0 retrieved	Other	
If eggs were collected, No.	Discarded	Stored		
Donated for	Treatment	Research		

History

IVF history – number of previous treatments	At this clinic	In total			
Obstetric history – No. of previous pregnancies	No. of IVF pregnancies	Total live births			
Year started trying to become pregnant					
Year of last pregnancy					
Infertility	Female	Male	Couple		
Cause	Tubal disease	Ovulatory disorder	Male factor	Unexplained	Other
Mixed date	Thawed date				

Use & treatment type	Sperm from partner donor	Eggs mixed with sperm		No. of frozen embryos used		No. of embryos for use by patient		No. of eggs/embryos donated				No. of eggs/ embryos discarded
								For use by		For research		
		No. of eggs used	No. of embryos developed	Thawed	Viable	Transferred	Stored	Fresh transferred	Embryos stored	Now	Stored for later	

Reasons for non-transfer of embryos	Positive PGD	Risk of OHSS	Other			
Date of embryo transfer						
Outcome	None	Biochemical pregnancy	Miscarriage	Ectopic	Hetratopic	Molar
Intrauterine fetal pulsation seen						

Frozen embryos removed from store for other than treatment

Date of removal	Reached end of permitted storage period
No. thawed for research and found to be viable	
No. thawed for research and found to unsuitable for use	
No. sent to another UK centre	Centre No.
Received from another UK centre	Centre No.
No. exported	Where to?
No. imported	Where from?

OHSS, ovarian hyperstimulation syndrome.

DI/donor gamete treatment form (99)I.1.0

Administrative details				
HFEA Centre number				
Patient name	Patient number			
History				
Obstetric history	Previous pregnancies	DI pregnancies	Total live births	
DI history	Previous treatments		At this clinic	Total
Person providing sperm for treatment 1	Centre no.		Donor no.	
Person providing sperm for treatment 2	Centre no.		Donor no.	
Person providing sperm for treatment 3	Centre no.		Donor no.	
Treatment 1, 2 & 3				
Type of treatment	IVI	IUI	ICI	GIFT
Type of ovulation induction	Gonadotrophins	Anti-oestrogens	None	Other
Treatment date				
Home insemination date				
Outcome				
None				
Biochemical pregnancy only				
Miscarriage				
Ectopic pregnancy				
Heterotopic				
Molar				
Intrauterine fetal pulse seen				
ICI, intracervical insemination; IUI, intrauterine insemination; IVI, intravaginal insemination.				

Pregnancy outcome form (99)O.1.0

Administrative details				
HFEA Centre number				
Additional fetal hearts to those recorded on form				
The outcome of the IVF treatment noted on form				
The outcome of the DI/Donor Gamete treatment notified on form				
Number of 1st insemination treatment which pregnancy resulted				
Number of gestational sacs with detected fetal pulsation				
Pregnancy outcome (fetal heart 1–5)				
Gestation weeks				
Miscarriage				
Ectopic/hetratopic pregnancy				
Termination				
Reason for termination				
Embryo reduction				
Still birth				
Live birth				
Neonatal death				
Lost to follow-up				
Other				
Baby born (baby 1–5)				
Weight	Sex	Delivery date	Method of delivery	NHS no.
Congenital abnormalities if present				
Place of birth				
Town		Registration district	Country	

Donor information form (99)D.1.0

Administrative details
HFEA Centre number
New individual or changes to existing
Date of form completion
Donor number
Patient/Partner number

Personal details
Date of birth
Current names
Names at birth
Place of birth
Date gametes first used or supplied in treatment
Any donation at other centres?
Own children? Height Weight

Ethnic group	White	Black Caribbean	Black African	
	Black other	Indian	Pakistani	
	Bangladeshi	Chinese	Other	

Eye colour	Blue	Brown	Green	Grey	Hazel	Other
Hair colour	Black	Brown dk	Brown lt	Red	Blonde	Other

Skin colour	Light	Medium	Dark	Other

Religion
Occupation
Interests
Last UK centre for new donor/patient/partner known elsewhere
Previous donor number
The space below is provided for you to give a brief description of yourself as a person.

Embryo storage or research form (91)5

Administrative details
HFEA Centre number

Fertilisation details
Clinic reference code of egg donor
Clinic reference code of sperm donor (if applicable)
HFEA Centre reference number of sperm donor if different from above
Date eggs mixed with sperm
Number of eggs mixed with sperm

Embryos for use in research
Number used for immediate research
HFEA research project licence number
Number stored for use in research
HFEA research project licence number

Embryos for use in treatment
Number stored for treatment of woman providing eggs
Number stored for treatment of others
Number of egg(s)/embryo(s) discarded

Form for consent to storage and use of sperm and embryos (96)6

Patient details		
Full name		
Other names by which known		
Use		
Consent to use of sperm for:	Yes	No
Treatment of partner		
Treatment of others		
Any project of research		
Particular conditions (describe)		
Consent to sperm fertilising eggs *in vitro*, and use of resultant embryos for:	Yes	No
Treatment of self/named partner		
Treatment of others		
Any project of research		
Particular conditions (describe)		
Signature		
Date		
Storage		
Consent to storage of sperm:	Yes	No
Maximum (10 years)		
If less, specify		
Consent to storage of resultant embryos:	Yes	No
Five years		
Ten years		
More than ten years		
Other (state)		
On death/mental incapacitation		
Sperm:	Yes	No
Allowed to perish		
Continue in storage for use of above purposes		
Continue in storage for other purposes (specify)		
Embryos:		
Allowed to perish		
Continue in storage for use of above purposes		
Continue in storage for other purposes (specify)		
Any other conditions of storage (specify)		

Form for consent to use eggs and storage of embryos (96)7

Patient details		
Full name		
Other names by which known		
Use		
Consent to use of egg(s) for:	Yes	No
Own treatment		
Treatment of others		
Any project of research		
Particular conditions (describe)		
Consent to *in vitro* fertilisation of egg(s) for:	Yes	No
Treatment of self/named partner		
Treatment of others		
Any project of research		
Particular conditions (describe)		
Signature		
Date		
Storage		
Consent to storage of embryo(s):	Yes	No
5 years		
10 years		

continued

More than 10 years		
Other (state)		
On death/mental incapacitation embryo(s):	Yes	No
Allowed to perish		
Continue in storage for use of above purposes		
Continue in storage for other purposes (specify)		
Any other conditions of storage (specify)		

Intensive Care National Audit and Research Centre (ICNARC)

Description

ICNARC was established following the success of the Intensive Care Society's UK Acute Physiology and Chronic Health Evaluation (APACHE II) study that assessed patient outcomes from 26 ICUs. Formed in January 1994, the objectives of ICNARC were to assemble, maintain and develop a national, observational database for the purpose of evaluating outcomes from ICUs and high dependency units (HDUs) in England, Wales and Northern Ireland (Scotland has initiated its own intensive care audit). Participation with the audit is voluntary and recruitment is estimated to be around 50% of Trusts with ICU.

ICNARC provides a national comparative audit of patient outcomes through its case programme. The ICNARC Case Mix Programme Dataset Specification (ICMPDS) was developed and used from 1995 (see 'Coding systems' below). Whilst the Case Mix Programme Database (CMPD) currently holds data on approximately 90,000 admissions from 135 adult units, its analysis is based on validated data for 46,587 admissions from 91 units (Annual Report 2000).

ICNARC have Medical Research Council (MRC) funding to develop and validate an optimal risk adjustment method in intensive care using data from the CMPD. They have also received an NHS R&D HTA grant to evaluate the cost-effectiveness of pulmonary artery flotation catheters.

Data

Participating units must send up to three members to attend a 2-day training course covering all aspects of data collection and data definitions. Following training, the unit undergoes a 6-week pilot data collection period. If no problems are encountered, the unit continues the collection of data (the Centre also provides ongoing data collection support and re-training on a regular basis).

Participating units abstract all physiological and laboratory data from the ICU/HDU charts and submit to ICNARC every 6 months. Within 4 weeks from receipt of the data, ICNARC sends the unit a Data Validation Report (DVR) on the completeness and accuracy of the data. Invalid or incomplete data items are updated and resubmitted to ICNARC where a revised DVR is produced. This is an iterative process, which in some cases requires four or more DVRs.

Once the data have been fully validated, they are incorporated into the CMPD and ICNARC produces a Data Analysis Report (DAR) covering data accuracy, case mix, outcome and unit activity. The average length of time taken to produce the final report from the first submission of data is reported to be 37 weeks for first cycles of data.

The data are collected under nine main headings (admission identifiers, past medical history, reason for admission, MPM II_0 – admission model, physiology, MPM II_{24} – 24-hour model, other conditions, unit outcome and hospital outcome). See pp. 106–8 for full list.

A considerable number of data items are collected to facilitate the calculation of a range of case-mix adjustment measures. It is hoped to ascertain the most viable case-mix adjustment measure for the comparative audit of ICUs and consequently cease the collection of data items for all other case-mix adjustment measures. When the number of data items recorded is reduced, there are plans to collect other information for a variety of research projects.

Coding systems

The database employs a unique five-tiered, hierarchical structured coding system empirically developed and tested by ICNARC, known as the ICNARC Case Mix Programme Dataset Specification (ICMPDS). The tiers include type surgical (reason for surgery)/non-surgical, body system (e.g. respiratory), anatomical site (e.g. lung), physiological/pathological process (e.g. infection) and condition (e.g. pneumonia).

The ICNARC codes can be mapped to Read codes, and then mapped to ICD-9CM.

Completeness and accuracy

Approximately 50% of Trusts with ICUs participate in ICNARC. Of the 91 participating units reported on, the completeness of notifications is reported to be 100% based on chronological ICU admission data so that any missing admissions are immediately picked up in internal validation checks.

The completeness of data items is also reported to be very high. Overall, the completeness varies between 95 and 100% for admission variables, between 90 and 100% for outcome variables and between 40 and 50% for physiology variables (Annual Report, 2000). The low figures are for physiological variables, which are not routinely tested in all admissions – ICNARC does not encourage unnecessary haematological/ biochemical investigations.

The ICMPDS contains internal validity checks which are incorporated into data entry software to ensure data are validated at the point of data entry.

Following submission to ICNARC, data undergo an automated validation process that searches for a number of illogicalities. The computer software also searches for inconsistencies which may be possible, but are nevertheless unlikely (e.g. a planned admission at 2 a.m.). Such inconsistencies are flagged for further verification.

Every 6 months, data collection for a sample of 20 records (randomly selected by ICNARC) is repeated, allowing an assessment of reliability (this is voluntary rather than mandatory).

External validation checks are also carried out. ICNARC holds the UK APACHE II study dataset, which was a study carried out between 1988 and 1990 and holding over 10,000 patient records. This information is compared to the current database. There are also plans to compare information with the intensive care Global International Database, should this be introduced.

Uses

Long-term plans exist to use the database for a range of HT assessments and to collect more specific intervention data items for project funded research (e.g. data on the use of pulmonary artery flotation catheters funded by an NHS R&D HTA grant but not yet reported by 2001).

The CMPD is primarily used for comparative audit between units. The reports (which are confidential) include mortality comparisons within ICU/HDU and within the hospital stay. Mortality is carefully defined by ICNARC owing to the necessity for legal definitions, particularly in relation to organ harvesting. Inter-unit mortality comparisons require risk adjustment, which in turn requires a range of relevant clinical data, which ICNARC collects. Observed in-hospital mortality by unit is compared with expected mortality using the UK APACHE II equation, with summary results published in the annual report.

Diffusion of techniques within ICU and HDU can be picked up in aggregate in ICNARC reports but incomplete coverage limits the use of ICNARC for diffusion studies. The relative newness of ICNARC has prevented its use for diffusion in time.

Equity analysis is made possible by the postcoding of patients in ICNARC but is limited by coverage of ICUs and HDUs. No analyses of equity have been located.

ICNARC provides the only data on resource use as ICU and HDU use is not captured elsewhere (HES does not identify ICU, ITU or HDU). ICNARC data, by providing length of stay data and also details of interventions, could be used to estimate costs. However, no cost studies have been located.

Funding

ICNARC's total budget was £320,000 in 1998–99. This includes not only the cost of the database but also the comparative audit service. ICNARC is self-funded through charges to units using the service.

Access

ICNARC has entered into a series of legal agreements with each participating ICU to ensure the participating unit is not identified. In addition, ICNARC is registered with the Data Protection Act, ensuring the confidentiality of patients. Access to a subset of the data is possible, as long as the sources of data are kept confidential. To request data, a formal research proposal must be submitted to ICNARC. Each proposal is assessed on its own merits. Charges for data analysis requests are based on a daily rate.

Contact details

Intensive Care National Audit and Research Centre
Tavistock House
Tavistock Square
London
WC1H 9HR

Tel.: 020 7388 2856
Fax: 020 7388 3759
E-mail: icnarc@icnarc.org
Website: http://www.icnarc.org

Publications

Annual Report from the Case Mix Programme Database, 2000. London: ICNARC; 2000 (also available for 1998 and 1999).

ICNARC. Proposal for audit of intensive care and high dependency care. London: ICNARC; 1997.

Jones J, Rowan K. Is there a relationship between the volume of work carried out in intensive care and its outcome? *Int J Technol Assess Health Care* 1995;**11**:762–9.

ICNARC data items

Admission details
ICNARC number
Admission number
ACP local identifier
Postcode
Date of birth
Sex
ACP speciality function code
Date of admission to hospital
Date of admission to unit
Time of admission to unit
Total number of staffed beds in unit at the time of admission
Managed by unit team
Date first managed by unit team
Time first managed by unit team
Planned admission to unit
Admission for pre-surgical preparation
Source of admission to unit
Classification of surgery
Transferring unit admission number
Date of original admission to a unit
Date of original admission to hospital
Location immediately prior to source of admission to unit
Cardiopulmonary resuscitation within 24 hours prior to admission to unit
Past medical history
Evidence available to assess past medical history
Past medical history present
Biopsy proven cirrhosis
Portal hypertension
Hepatic encephalopathy
Very severe cardiovascular disease
Severe respiratory disease
Home ventilation
Chronic renal replacement therapy
AIDS
Steroid treatment
Radiotherapy
Chemotherapy
Metastatic disease
Acute myelogenous leukaemia or acute lymphocytic leukaemia or multiple myeloma
Chronic myelogenous leukaemia or chronic lymphocytic leukaemia
Lymphoma
Congenital immunohumoral or cellular immune deficiency state
Reason for admission
Primary reason for admission to unit
Secondary reason for admission to unit
continued

MPH II_0		
Systolic blood pressure at admission to unit		
Heart rate at admission to unit		
Mechanical ventilation at admission to unit		
Coma or deep stupor at admission to unit		
Intracranial mass effects at admission to unit		
Physiology		
Central temperature:		
Lowest		
Highest		
Non-central temperature:		
Lowest		
Highest		
Blood pressure:		
Lowest systolic:		
Blood pressure		
Paired diastolic		
Highest systolic:		
Blood pressure		
Paired diastolic		
Lowest diastolic:		
Blood pressure		
Paired diastolic		
Highest diastolic:		
Blood pressure		
Paired diastolic		
Heart rate:		
Lowest		
Highest		
Respiratory rate:		
Non-ventilated		
Lowest		
Highest		
Ventilated		
Lowest		
Highest		
Arterial blood with lowest PaO_2:		
PaO_2		
Associated FiO_2		
Associated $PaCO_2$		
Associated pH/H^+		
Associated intubation status		
Intubated arterial blood gas with highest FiO_2		
FiO_2		
Associated PaO_2		
Associated $PaCO_2$		
Associated pH/H^+		
Arterial blood gas with lowest pH/H^+:		
pH/H^+		
Associated $PaCO_2$		
Highest pH/H^+		
pH/H^+		
Associated $PaCO_2$		
CPAP administered during the first 24 hours in unit		
Serum:	Highest	Lowest
Bicarbonate		
Sodium		
Potassium		
Urea (highest only)		
Creatinine		
Glucose		
Bilirubin (highest only)		

continued

Total calcium		
Ionised calcium		
Albumin		
	Highest	Lowest
Haematocrit		
Haemoglobin		
White blood cell count		
Platelet count (lowest)		
Prothrombin time (highest)		
Partial thromboplastin time (highest)		
Pupillary reactions		
Sedated or paralysed and selected for whole of first 24 hours in unit		
Glasgow Coma Score:		
Pre-sedation documented		
Pre-sedation total		
Lowest total		
Associated eye component from lowest total		
Associated motor component from lowest total		
Associated verbal component from lowest total		
Associated intubation status from lowest total		
Expected neurological status		
MPM II_{24}		
Infection confirmed in the first 24 hours in unit		
Continuous intravenous vasoactive drug treatment for 1 hour or more in the first hours in unit		
Coma or deep stupor at the 24 hour mark in unit		
Other conditions		
Other condition relevant to this admission 1		
Other condition relevant to this admission 2		
Unit outcome		
Ultimate primary reason for admission to unit		
Surgery up to 1 week before and/or 1 week after admission to unit		
Classification of surgery up to 1 week before and/or 1 week after admission to unit		
ACP maximum number of organ systems supported simultaneously during this unit stay		
ACP number of days of intensive care during this unit stay		
ACP number of days of high dependency care during this unit stay		
ACP main hospital speciality function code		
Treatment withdrawn:		
Date of first decision		
Time of first decision		
Discharge from unit:		
Status at discharge from unit		
Time		
Reason		
Destination		
Transfer unit identifier		
Date of ultimate discharge		
Brainstem death declared:		
Date of declaration		
Time of declaration		
Date body removed from the unit		
Time body removed from unit		
Organ donor		
Death outside unit		
Date of death		
Time of death		
Hospital outcome		
Date of discharge from hospital		
Status at discharge from hospital		
Destination following discharge from hospital		
Date of ultimate discharge from hospital		
Status at ultimate discharge from hospital		

National Breast Implant Registry

Description

The National Breast Implant Registry was established in July 1993, collating a body of data suitable for research into the use, advantages and problems of silicone breast implants. The register was set up in response to recommendations by the Department of Health's Independent Expert Advisory Group on silicone gel breast implants.[1]

The National Breast Implant Registry comprises a prospective registry and a retrospective registry. It covers both the private and the National Health sectors. The MDA funds the Registry and owns the data but has no direct access to confidential information such as patient names. In September 1999 there were over 36,000 cases held by the Registry.

Data

The Registry receives information from centres in both public and private sectors that carry out breast implantation in England, Scotland, Wales and Northern Ireland. Registration forms are normally completed at the time of operation, then returned to the Registry where they are validated and all data are entered into the database. The information is received on a continuous basis and from receipt of the information, the data input is usually completed within 3 working days. Reporting is on a voluntary basis and requires permission from patients. Retrospective notifications may arrive from any sources, including the patients.

Information is collected under four main data headings (details on patient and prosthesis, details on operation for implantation and operation for removal). A more detailed list of data items collected is given on p. 110. The name and any other classifying information on the surgeon performing the implantation are not currently collected. Activity reports are sent back to participating units.

Coding systems

The Registry uses a customised coding scheme used to identify reporting centre, prosthesis manufacturer and operation indication.

Completeness and accuracy

There are around 280 centres reporting to the Registry in varying numbers each year. These cover a large proportion of the centres undertaking breast implantation in the UK, although around 80% of the work is done in about 30 centres.

The main registration form for the prospective register is designed to be used for implantation and/or explantation. However, based on the numbers received, the Registry may not be receiving notification of all explantations carried out. A number of reasons may explain this, such as the incident being remote from the registration of the original implant or those involved being unaware that this is a registerable event. About 3% of the registrations are associated with repeat procedures of some sort.

There is a potential problem with voluntary registration in that the denominator (the actual total number of implants) remains unknown. Furthermore, if there is any selection bias inherent in registration, then interpretation of the data that emerge, on complications (either local or of long-term health consequences) could be compromised. There are a number of limitations preventing simple measurement of the registration rate. Manufacturers' sales figures do not provide an accurate measure of compliance since most hospitals keep a stock of implants on a 'sale or return' basis rather than ordering and using implants for individual patients. The recording of information within individual reporting centres may not allow the identification of all breast implant recipients. In the Registry's own centre, compliance has been measured at about 90%. This has also been checked in studies involving another two collaborating units and the estimate from these exercises is in excess of 65–70% of the implant procedures being recorded. This is believed to be a representative sample of procedures being carried out in the UK.

Details of the retrospective registry were circulated to interested patient groups and there were initially a number of retrospective implant registrations (website, July 2001).

Access

All patient records are restricted from disclosure to third parties. Aggregated data may be requested by letter. No charges are currently made for this service.

Funding

Funded by the MDA. The annual costs of running the Registry are as follows: professional and technical staff 0.7 whole time equivalents (wte), administrative and clerical staff 0.64 wte and budget costs of approximately £30,000 per annum.

Contact details

Dr P Shakespeare
Plastic Surgery Department
Salisbury District Hospital
Salisbury
SP2 8BJ

Tel.: 01722 335262, Ext. 2059
Fax: 01722 336405
E-mail: pgs@burnsjournal.demon.co.uk
Website: http://www.silicone-review.gov.uk/registry/index.htm

Department of Health-funded Breast Implant Research (2001–02):
Mr D Double
Department of Health Policy Research Programme
Research and Development Department
Skipton House
80 London Road
London
SE1 6LW
E-mail: david.double@doh.gsi.gov.uk

Publications

The National Breast Implant Registry produces annual reports of its activities and in addition provides quarterly reports to reporting centres on their registration activities

See website: http://www.silicone-review.gov.uk/registry/

Reference

1. Independent Review Group. Silicone gel breast implants; the report of the Independent Review Group. London: Department of Health; 1998.

National Breast Implant Registry data items

Hospital		
Town		
Patient details		
Surname		
Forename		
Medical record number		
Date of birth		
Address		
Prosthesis details		
Side of implant	Left	Right
Manufacturer		
Size		
Catalogue number		
Lot/batch number		
Serial number		
Operation details for implantation		
Date of operation		
Primary indication		
Reconstruction after mastectomy for:		
Malignant disease		
Benign disease		
Congenital/developmental		
Cosmetic augment		
Other: describe		
Technique		
Implant only		
Implant + myo-cutaneous flap		
Position of implant		
Sub-mammary		
Sub-muscular		
Is this a replacement operation?		
Operation details for removal		
Date of operation		
Reason for removal		
Side (left/right)		

National Pacemaker Database

Description

The database, started in 1974, is managed by the British Pacing and Electrophysiology Group (BPEG). It collects implant and explant data on patients in the UK and Republic of Ireland who have pacemakers or ICDs. It receives information on over 25,000 patients per year from 187 pacing centres (of which 139 are in England).

BPEG is a registered charity and an affiliated working group of the British Cardiac Society. It has a membership of about 300 and links professionals working within pacing and electrophysiology in the UK. It has links with the European Working Group on Cardiac Pacing (EWGCP) and works closely with the MDA, which funds it, in post-market surveillance.

The database is in the process of linking all new registrations to the NHS Central Register (Southport), allowing capture of mortality data.

Data

Data are collected at individual patient level; 70% are submitted electronically, mostly using BPEG software. Registration forms and electronic data transfers are sent to Glasgow. Data are collected (see pp. 112–13) under four main headings (patient details, type of pacing, pacing mode and explants), by reason and by type of lead.

Completeness and accuracy

No data are available on completeness of recruitment of centres, but it is thought to be close to 100%.

In 1997, completeness of registration was reported to be 90%, based on a bi-annual survey of centres on the total number of implants, which is supplemented by manufacturers' estimates for non-responding centres.

Completeness by heading varies with that for mode of pacing, being high owing to assessment from the hardware implanted. ECG and symptoms are less fully recorded.

Regular 'sanity checks' are carried out on the data received by BPEG. Invalid data are excluded and sent back to centres for checking.

Data are provided back to units annually as part of national audit. Reports are also sent to the MDA. No reports were located of external validation.

Uses

The annual report (see CCAD website) contains data on total and new implants by centre, country, age of recipient, physiological pacing, pacing mode and ECG indications, aetiology and presenting symptoms, plus details by type of pacemaker, and explants by type and limited follow-up data are provided. Published articles include a review of the database[1] and assessment of ICDs,[1] diagnostics and computers[2,3] and standards in pacing.[4]

Although the database is potentially valuable for analysis of equity and diffusion due to inclusion of demographic data and type of disease, no published analyses have been located. However, an analysis of regional variations in pacemaker implantation was reported to be in preparation in late 2000.

One study was located which used this database for costing.[5]

Funding

Funded by the MDA, £0.17 million per annum (25,000 implants per year at £7 per registration).

Access

Contact D Cunningham (Project Manager) at the address below.
E-mail: adc@bio.gla.ac.uk

Contact details

A Rickards (Director), D Cunningham (Project Manager), M Cunningham (Data Coordinator)
PO Box 9205
Bridge of Weir
Strathclyde
PA11 3DZ
Tel./Fax: 01505 612829

Publications

Campbell RW, Charles R, Cowan JC, Garratt C, McComb JM, Morgan J, Rowland E, Sutton R. Clinical competence in electrophysiological procedures. *Br Heart J* 1997;**78**:403–12.

Cunningham D, Rickards T, Nathan A, Cunningham M. National Pacemaker Database, UK and Republic of Ireland, Annual Report (Pacing and ICD), 1998 and 1999. National Pacemaker Database; 2000 (see http://ccad3.biomed.gla.ac.uk/bpeg/).

Rickards AF. Computer storage of pacemaker data. In Thalen H, Harthorne J, editors. *To pace or not to pace*. The Hague: Martinus Nijhoff; 1978. p. 14.

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1. Rickards A, Cunningham D. From quantity to quality: the central cardiac audit database project. *Heart* 1999;**82** (Suppl 2):II18–22.
2. Cunningham AD, Rickards AF. A new evidence base for implantable defibrillator therapy [letter; comment]. Comment on: *Eur Heart J* 1998; **19**:189–91. *Eur Heart J* 1998;**19**:1410–11.
3. Rickards AF, Miller GAH. Design of a diagnostic code with special reference to computer processing. In Anderson R, Shinebourne E, editors. *Paediatric cardiology*. London: Churchill Livingstone; 1977. p. 13.
4. Clarke M, Sutton R, Ward D, *et al*. Report of the working group of the British pacing and electrophysiology group on pacing standards. *Br Heart J* 1991;**66**:185–91.
5. Jilllings A. Complex, dual chamber rate responsive pacemaker literature review. A report by the N. Yorkshire Collaborating Centre for Health Services Research. Leeds: York Health Economics Consortium, Nuffield Institute for Health, University of Leeds; 1994.

National Pacemaker Database headings

Domain	NPDB ID	NPDB parameter name	Title
Demographics	NPDB001	PAT_NHS_Number	NHS number
Demographics	NPDB002	PAT_SURNAME	Surname
Demographics	NPDB003	PAT_FORENAME	Forename
Demographics	NPDB004	PAT_INITIAL	Initial
Demographics	NPDB005	PAT_TITLE	Title
Demographics	NPDB006	PAT_ID	Hospital number
Demographics	NPDB007	PAT_HOSPITAL	Hospital
Demographics	NPDB008	PAT_DATE_OF_BIRTH	Date of birth
Demographics	NPDB009	PAT_SEX	Sex
Demographics	NPDB010	PAT_ADDRESS	Address
Demographics	NPDB011	PAT_POST_CODE	Postcode
Pre-procedure	NPDB012	PAT_GP_ID	GP
Pre-procedure	NPDB013	PAT_HOSP_PHYS	Consultant
Pre-procedure	NPDB014	PAT_PM_1ST_PACED	Date first implant
Pre-procedure	NPDB015	PAT_PM_AETIOLOGY	Aetiology code 1
Pre-procedure	NPDB016	PAT_PM_AETIOLOGY_2	Aetiology code 2
Pre-procedure	NPDB017	PAT_PM_ECG	Presenting ECG 1
Pre-procedure	NPDB018	PAT_PM_ECG_2	Presenting ECG 2
Pre-procedure	NPDB019	PAT_PM_SYMPTOM	Symptoms 1
Pre-procedure	NPDB020	PAT_PM_SYMPTOM_2	Symptoms 2
Demographics	NPDB021	PAT_COMMENT	Comment
Procedure	NPDB022	OP_OP_DATE	Procedure date
Procedure	NPDB023	OP_COMMENT	Procedure comment
Procedure	NPDB024	OP_OPERATOR1	First operator
Procedure	NPDB025	OP_OPERATOR2	Second operator
Procedure	NPDB026	OP_PM_INTERVENTION	Type of procedure
Procedure	NPDB027	OP_PM_MODE	Pacing mode at end of procedure (NASPE–BPEG code)
Procedure	NPDB028	OP_PM_GEN_MFG	Generator manufacturer
Procedure	NPDB029	OP_PM_GEN_MODEL	Generator model
Procedure	NPDB030	OP_PM_GEN_SERIAL	Generator serial number
Procedure	NPDB031	OP_PM_GEN_SITE	Generator implant site
Procedure	NPDB032	OP_PM_VLEAD_MFG	Ventricular lead manufacturer
Procedure	NPDB033	OP_PM_VLEAD_MODEL	Ventricular lead model
Procedure	NPDB034	OP_PM_VLEAD_SERIAL	Ventricular lead serial number
Procedure	NPDB035	OP_PM_VLEAD_CODE	Ventricular lead code (NASPE–BPEG code)
Procedure	NPDB036	OP_PM_VLEAD_SITE	Ventricular lead access and site
Procedure	NPDB037	OP_PM_VLEAD_ADAPTOR	Ventricular lead adaptor (if used)
Procedure	NPDB038	OP_PM_ALEAD_MFG	Atrial lead manufacturer
Procedure	NPDB039	OP_PM_ALEAD_MODEL	Atrial lead model
Procedure	NPDB040	OP_PM_ALEAD_SERIAL	Atrial lead serial number
Procedure	NPDB041	OP_PM_ALEAD_CODE	Atrial lead code (NASPE–BPEG code)
Procedure	NPDB042	OP_PM_ALEAD_SITE	Atrial lead access and site
Procedure	NPDB043	OP_PM_ALEAD_ADAPTOR	Atrial lead adaptor (if used)
Outcome	NPDB044	OP_PM_DATE_GEN_CHANGE	Date generator explanted
Outcome	NPDB045	OP_PM_WHY_GEN_CHANGE	Reason for generator explant

continued

Outcome	NPDB046	OP_PM_DATE_LEAD_CHANGE	Date ventricular lead removed/capped
Outcome	NPDB047	OP_PM_WHY_LEAD_CHANGE	Reason for ventricular lead removal/capping
Outcome	NPDB048	OP_PM_DATE_ALEAD_CHANGE	Date atrial lead removed/capped
Outcome	NPDB049	OP_PM_WHY_ALEAD_CHANGE	Reason for atrial lead removal/capping
Outcome	NPDB050	TST_DATE	Date of file closure/death
Outcome	NPDB051	TST_COMMENT	Outcome comment
Outcome	NPDB052	TST_PM_EOF	Reason for file closure or death
Outcome	NPDB053	TST_PM_CAUSE	ICD coded cause of death

National Prospective Monitoring System (NPMS) (HIV)

Description

The NPMS dataset was established in 1994 and data collection began in 1996. The dataset was set up to monitor prospectively the effectiveness, efficiency and acceptability of service provision in participating HIV units in England and provides feedback at national and local level.[1]

The objectives of the database are as follows:[2,3]

- to allow clinical units to monitor their own performance, enabling them to enhance the quality and efficiency of services provided
- to allow informed choices to be made by purchasers of HIV services and to encourage effective contract monitoring
- to allow for the implementation of NHSE performance management at regional and central level
- to enable the impact of new interventions to be predicted on the use, cost and outcome of service provision
- to measure the impact of new interventions after their introduction into routine clinical practice and monitor the intermediate/long-term side-effects of drugs
- to allow different models of care to be assessed and the results of these assessments to be disseminated
- to encourage appropriate resource allocation at local, regional and national level
- to achieve accountability of purchasers and providers of HIV services to local populations and through the NHSE Chief Executive and Secretary of State to Parliament.

In 2000, 13 English clinics (including the larger clinics) participated in the database, covering more than half of the HIV-infected patients seen in England. The dataset holds over 5000 patient records.

In 1999, the NPMS merged with the HIV Health-economics Collaboration, the NPMS–HHC 2000. (The HHC was established in 1997 as a collaboration of three major HIV units within England, the Royal Free Centre for HIV Medicine, the Chelsea and Westminster Hospital HIV Unit and the Brighton HIV Unit. Its aims were to evaluate issues regarding health economics in HIV disease with specific focus on the relationship between changing patterns of care and the effects of new therapies.) The Coordinating and Analytic Centre (CAC) is located in the St Stephen's Centre of the Chelsea and Westminster Healthcare Trust.

Data

Following notification, an initial assessment is carried out by the doctor in the clinic using a standard form which is passed to a data entry clerk in the clinic. NPMS collects this information every 6 months and the data are processed and analysed on an individual clinic basis and an aggregate basis. The data are confidential by clinic. The individual clinic analyses are usually returned to the clinics within 3 months.

The form collects data under nine main headings (including demographic information on HIV-positive patients, self-reported risk factors, test, drugs and diagnosis details). See pp. 115–17 for full list. Data are collected and analysed by area of residence and centre of treatment.

Coding systems

The NPMS has developed a coding system based on the Communicable Disease Surveillance Centre (CDSC) classification of HIV and AIDS. Some of the clinics use ICD-9 and ICD-10 coding schemes, which are translated by the NPMS head office on receipt of the information.

Completeness and accuracy

Coverage of units is limited to London and seven other units (Birmingham, Brighton, Manchester, Newcastle, Oxford, Reading and Sheffield). The completeness of notifications of the participating clinics is reported to be 98%. This figure is based on variable 'spot checks' by NPMS throughout the year at selected clinics.

The completeness of information gathered for each patient is estimated at 98%. Some clinics have not entered full information on to the database, particularly ethnic origin and sexual orientation. Analyses stratified by sexual orientation or ethnic origin would exclude information for clinics where missing cases amounted to 30% or more.

Downloads take place twice a year and validation checks are also carried out at this point. There is constant feedback between the NPMS and participating clinics, which assists with accuracy. It is estimated that the accuracy of information being entered into the dataset is 99%. This is due to the thorough checking of all information at the NPMS head office.

Changes in computer systems have affected some clinics' ability to download data in time for analysis.[3]

A number of internal validation checks are carried out (random variable spot checks, incomplete data are sent back to individual clinics for completion, data are downloaded twice a year, identifying any discrepancies, continuous feedback includes telephone calls, site visits, summary letters).

NPMS has also been involved with the use of an outpatient-based satisfaction questionnaire,[4] aiming to provide a standardised acceptability dataset for use in HIV outpatient clinics.

A yearly comparison is carried out with the CDSC external dataset.

Uses

The NPMS has been used to monitor trends in treatment hospital services including increased uptake of anti-retroviral therapy in English HIV-infected individuals and mortality in HIV patients, 1996–97.[6] It has also been used to explore measurement of patient satisfaction with services.[4]

No studies were located on diffusion or equity.

The NPMS has been used to estimate the costs of retroviral use in HIV-infected individuals.[2,5]

Funding

NPMS was initially funded as a Department of Health/North Thames R&D initiative. At the end of 1999, a consortium of pharmaceutical companies was formed to support financially the core activities of the NPMS–HHC 2000 collaboration (short-term, funding arrangement). No cost data are available but it was estimated in Chapter 9 that it cost around £50,000 per annum to maintain the database (5000 records at £10 per record). Given the detail involved, this could be higher.

Access

Via contact below.

Contact details

NPMS Coordinating and Analytic Centre
Department of Epidemiology and Public Health
Imperial College School of Medicine at St Mary's
Norfolk Place
London
W2 1PG
Tel.: 020 7594 3343/3325
Fax: 020 7402 2150

Publications

Chancellor J, Hill A, Sabin C, Simpson K, Youle M. Modelling the cost effectiveness of lamivudine/zidovudine combination therapy in HIV infection. *Pharmacoeconomics* 1997;**12**:1–13.

Lacey L, Youle M, Trueman P, Staszewski S, Schrappe M, Behrens M. A prospective evaluation of the cost-effectiveness of adding lamivudine to zidovudine containing antiretroviral treatment regimens in HIV infection. European perspective. *Pharmacoeconomics* 1998;**14** (Suppl 4):39–53.

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NPMS (HIV) data items

Demographic details
Patient ID (coding system based on surname)
Date of birth
Gender
Ethnic group
Nationality at first attendance
Postcode at first attendance (truncated)
Source of referral at first attendance:
- Self-referred
- GP
- Family planning clinic
- Consultant within hospital
- Consultant elsewhere
- Other
- Unknown

DHA of patient at first attendance
Local authority at first attendance
Is patient registered with GP at first attendance (yes/no)
If yes:
- GP ID/name
- Is GP aware of diagnosis (at first attendance)

	First HIV-positive test	First AIDS diagnosis
Date		
Location:		
This clinic		
Other local service		
Other UK clinic (London)		
Other UK clinic (non-London)		
Other UK clinic (unspecified)		
Clinic outside UK		
Unknown		

Date of death

Self-reported risk factors
Risk factor:
Homosexual/heterosexual/bisexual
- IDU
- Haemophiliac
- Blood transfusion recipient [pre-October 1985 (UK) or abroad]
- Prostitute
- Child of seropositive mother
- Sexual intercourse with partner from: high endemic area/Africa/SE Asia/W Indies/USA/S America /Europe/Other
- Sexual intercourse in … (as above)
- Other
- Unknown

Visit details
Visit type:
- Outpatient

continued

Inpatient
Day ward
Date of visit/admission
Latest postcode (truncated)
Latest DHA of patient
Latest Local Authority of patient

Inpatient visit details
Date
Nature of visit:
Planned
Emergency
Unknown
Discharge date
Discharge venue:
Home alone
Home with support
Staying at friends/relatives
Hospice
Other hospital
Unknown
Outcome of episode:
Improved
Stable
Deteriorated
Death
Unknown
ITU admission date
ITU discharge date

Outpatient visit details
Date
Nature of visit: (as above)
Has patient received HIV care from any since last visit: (yes/no)
GP
Inpatient (another clinic)
Outpatient (another clinic)

Day ward details
Date of visit
Nature of visit:
Day case
Day attendance
Unknown
Location of day treatment/procedure:
Outpatients
Inpatients
Procedures:
Date
Procedure (OPCS coding)

Professionals' details
Date of visit
Professionals patient saw during outpatient/day ward visit:
List of, including: HIV consultant, Haematologist, Dentist, Social worker, Ophthalmologist, etc.

Test details
Date

	Type of test	Result
Haemoglobin		
Lymphocytes		
CD4 count		

continued

Drug details
Date prescribed
Drug name
Duration
Dose
Route of administration: (p.o./i.v./i.m./rectal/topical, etc.)
Diagnoses details
Date
HIV diagnoses (CDSC classifications)
Non-HIV diagnosis (Read/ICD-10)

National Transplant Database (NTD)

Description

The NTD is run by the United Kingdom Transplant Support Service Authority (UKTSSA). UKTSSA developed out of the National Organ Matching and Distribution Service* (established in 1972 to match and allocate kidneys). This developed into UKTS in 1979 and UKTSSA in April 1991.

By statute, the UKTSSA is required to exercise on behalf of the Secretary of State functions under the provisions of the National Health Service Act 1977 so far as they relate to assisting in, facilitating and promoting the provision of a service for the transplantation of organs. UKTSSA is a Special Health Authority from 1 April 1991 under the United Kingdom Transplant Support Service Authority (Establishment and Constitution) Order 1991 and the United Kingdom Transplant Support Service Authority Regulations 1991 (SI Nos 1991 407 and 408).

The key functions of UKTSSA, set out at Section 2-(2) of the 1991 Regulations, are:

1. acquiring, recording, updating, keeping and making available information about donors and recipients and organs which are or may be available for transplantation and other related matters
2. identifying persons who are potentially suitable recipients for organs, and notifying transplant centres of the availability or potential availability of organs
3. giving advice about or making arrangements for the transport of organs for transplantation
4. generally facilitating the standardisation of practices in respect of storage, transport and transplantation of organs
5. providing an organ matching and tissue typing service
6. supplying standardised reagents and sera to transplant centres and laboratories
7. providing education and training for persons involved or to be involved with the transplantation of organs, including identifying the need for such education or training.

The UKTSSA provides a 'clearing house' for the major solid organs (kidneys, livers, hearts and lungs) by:

- maintaining lists of patients waiting for an organ transplant at any unit in the UK or Republic of Ireland
- receiving details of potential organ donors and
- comparing the characteristics of available donors against those patients on the waiting list
- providing liaison between donor and recipient unit and facilitating transport of the organ(s) and transplant teams to ensure that the organs are able to be used within an acceptable cold ischaemic time
- following transplantation, confirming that the organs were used, and for whom, and
- documenting the donor and recipient details for the NTD which it maintains on the transplant community's behalf
- providing activity and outcome audit services, and providing facilities for the separate organ interests to meet to discuss policies and protocols for organ sharing and allocation.

UKTSSA in 1999 was serving 77 solid organ transplant units and associated tissue typing laboratories, and over 240 cornea grafting departments, the four UK Health Departments and that of the Republic of Ireland.

* It was combined with a pre-existing laboratory service: the National Tissue Typing Reference Laboratory (NTTRL).

UKTSSA provides a 24-hour support service to transplant units and is responsible for maintaining records of all patients awaiting an organ transplant and the NTD of donor and transplant activity and outcome. Data on solid organ supply and use must be supplied to UKTSSA. The NTD also contains data on patient follow-up. In 1998, around 3000 solid organs and 1900 corneas were transplanted. The database held over 2 million individual patient records.* The database is used for the matching and allocation of organs,† statistical analysis (survival, prognostic indicators and simulations predicting outcome of changes to allocation schemes) and monitoring compliance with allocation schemes.

In addition to using the database to support the data recording and reporting requirements of the Human Organ Transplant Act 1989 (HOT) and the Unrelated Live Transplant Regulatory Authority (ULTRA), it is also used to help reimburse donor hospitals for the supply of donor organs. Information from the NTD is used to create specialist databases including the UK Cardiothoracic Transplant Audit (UKCTA), Liver Transplant Register and the Renal Transplant Pregnancy Register (recently extended to cover cardiac and liver transplant patients). The establishment of a Malignancy Register was reported in 1998 to be under way.

Funding

UKTSSA is funded centrally by the Department of Health and received a top-sliced budget from the Department of Health of £3.9 million p.a. in 1997–98. This appears to cover solid organ activity only as the corneal transplant service is funded separately.‡ Given that there were around 3000 solid organs transplanted in that year, the overhead cost of UKTSSA amounts to over £1000 per transplant.

Data

A recipient waiting list containing patient registration and clinical data is maintained, with patients registered either via pre-printed forms or electronically [via the UK National Transplant Network (UKNTN§)]. Changes in patients' conditions are notified to UKTSSA, allowing modification of the waiting list. Once a donor organ becomes available, the relevant centre contacts UKTSSA (a 24-hour service), providing the necessary clinical information. Donor information is supplied over the telephone. UKTSSA performs a computerised donor matching run, providing the centre with a local list of transplant candidates and an indication of severely ill matches within the rest of the UK.

Details of subsequent transplants are notified to UKTSSA on pre-printed forms. Follow-up data (3 months post-transplantation and then annually) are supplied to UKTSSA either on pre-printed forms or electronically.

A complete list of data items is given on pp. 120–38.

Summary of data items collected

The NTD is a single database covering the range of organs transplanted. It has 1058 fields, split between the following:

- donor data (361 headings)
- duty officer log (72)
- organ details (188)
- live donor details (36)
- recipient clinical data (244)
- recipient (139)
- unused organ (18).

Coding schemes

The NTD uses the European Dialysis and Transplant Association (EDTA) coding schemes for diagnoses and cause of death for renal patients. Many of its other codes are highly specific to the relevant organs, including organ function, disease, blood type and tissue matching.

Continuity

NTD was substantially revised in 1999.

Completeness and accuracy

The level of completeness of transplant registration is put at 100% with lower figures for patient registration – 100% for kidney patients and 80–90% for heart, lung, liver and corneal patients. Follow-up at 1 year was shown in a study of kidney outcomes to be incomplete for almost 25% of patients.

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* Recording patient registration data, transplant data (kidney, pancreas, heart, lung, liver and cornea), donor details and post-transplantation clinical data (3-month follow-up and then annually).

† Kidneys are allocated primarily on the basis of tissue type whereas hearts, lungs and livers are allocated to centres with the recipient chosen according to local clinical need.

‡ The Review of the UKTSSA 1998–99. Para 12 states: "The UKTSSA has handled the finances for the transplant research department, the University of Bristol Department of Transplantation, and the Corneal Transplant Service but has not taken any management role. The Group took the view that the case for UKTSSA to retain any responsibility for these services was unclear."

§ Allowing on-line access to national transplant statistics.

The organ donor and recipient data, which must under statute be provided to UKTSSA, and which are used in the allocation of organs, are thought to be complete. The follow-up data, specifically at 12 months, have been shown to be incomplete.[1]

The organ data, which are used for matching and allocating organs to recipients, have to be accurate. Given the lack of completeness of the follow-up data, it seems likely that the accuracy of such data is also likely to be less than 100%.

All data are double entered and the input of the operators compared prior to writing to the database. In-house 'rule sets' validate data and check for completeness. UKTSSA report no consistent areas of weakness or problems with miscoding.

The use of the organ data in allocation can be seen as a form of external validation. NTD is not otherwise validated.

Access

Patient-identifiable data and individual patient records with data items necessary for record linkage are not available. Anonymised data at patient level through to aggregated national data are available following written application and permission from the relevant Advisory Groups. These include the Cardiothoracic Users Group, the Cornea Advisory Group, the Kidney Advisory Group, the Liver Advisory Group, the Multi Organ Retrieval Audit Group and the Prognostic Indicators Group. Details of the activities of these groups are provided in the annual reports on transplant activity. Some have published studies (see next section).

Use of datasets in HT assessments

The NTD is unusual in that it is used by UKTSSA for the allocation of organs for transplant, including assessing clinical factors around suitability and transport of organs to and from centres. A number of organs (kidneys and pancreas, heart, heart/lung and lung and livers) are included in the register, each with its own particular set of headings.

As noted above, UKTSSA has a number of user groups, including the Cardiothoracic Users Group, the Cornea Advisory Group, the Kidney Advisory Group, the Liver Advisory Group, the Multi Organ Retrieval Audit Group, and the Prognostic Indicators Group.

Two of these groups have assessed HTs using NTD data.[1,2] One on HLA matching led to a new national scheme for the allocation of donor kidneys from July 1998[4] (see also Ref. 3). A review after 6 months reported that the scheme was working, with the hoped-for benefits in terms of a rise in well-matched kidneys. The other study reported on kidney damage during organ retrieval, by linking kidneys (with details of damage) transplanted over a 5-year period to both 1- and 3-year survival. The results suggested that despite a high rate of damage at retrieval, most kidneys can be transplanted with no effect on survival. A *Lancet* editorial[3] noted that such analysis was not possible in the USA as data recorded by local organ procurement organisations are not aggregated at national level.

Cost of the database

No cost data have been located for the NTD, which being central to the Authority's remit would be difficult to cost separately. UKTSSA's income in 1998–99 was £5.9 million.[4] With around 3000 transplants in that year, the average cost of UKTSSA per transplant was around £2000. Other costs may have been incurred by the statutory requirements of units to provide data.

Recent and planned developments

The new NHS number, which became mandatory in the NHS in 1996, has been incorporated into NTD. Before that date, neither organ donors nor recipients appear to have been linked back to Health Authority of residence. Data in the annual reports on transplant activity continue to report retrieval rates by broad zones, with *ad hoc* 'adjustments for hospitals or health authorities in another centre's region'.[5]

Contact details

Mr D Shute
Operations Director
UKTSSA
Fox Den Road
Stoke Gifford
Bristol
BS12 8RR
Tel.: 0117 9757575
Fax: 0117 9757577
E-mail: David.shute@relay.co.uk

Publications and further information sources

Annual reports.

Annual Transplant Activity reports.

Audit reports have been carried out but not published covering renal, thoracic, liver and corneal transplantation.

User bulletins.

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5. Transplant Activity. London; 1998. p. 41.

National Transplant Database (NTD) data items

Cadaveric donor details
Admission:
- Blood urea
- Serum creatinine
- Potassium
- Sodium

Date and time of admission into hospital

Maximum adrenaline dose

Donor date of birth
Age of donor in years
Month part of donor age (if under 3 years)

Liver function:
- Albumin
- Alk. phos.
- ALT
- Amylase
- AST
- Bilirubin
- Calcium

Blood pressure:
- Average reading
- Date and time of reading

Reference code for donor blood group
Date blood tested

Brain stem tests:
- First date and time
- Second date and time

Cardiac arrest:
- Reference code
- Date and time
- Duration (minutes)

CAUSATIVE_ORGANISMS

Chest X-ray:
Date and time

continued

CIRCULATORY_ARREST_DATE	Date and time of donor circulatory arrest
CIRCULATORY_ARREST_DFLAG	Indicator for date of circulatory arrest
CMV	Cytomegalovirus test status
COD	Reference code for donor cause of death
CONSENT_CORONER_TX	Reference code for coroner's consent for tx (y/n)
CONSENT_RELATIVES_RES	Reference code for relative's consent to research (y/n)
CONSENT_RELATIVES_TX	Reference code for relative's consent to tx (y/n)
CONTRAINDICATIONS	
DOBUTAMINE_MAX_DOSE	
DONOR_HOSPITAL	Foreign key to hospital – hospital providing donor
DONOR_ID	Unique ID for donor
DONOR_ODR	Indicator whether donor on ODR
DONOR_TYPE	Reference code for donor type
DOPAMINE_MAX_DOSE	
DOPEXAMINE_MAX_DOSE	
ECG_12_LEAD	Tests – 12-lead ECG
ECG_DATE	Tests – Date and time of 12-lead ECG
ECG_DFLAG	Indicator of 12-lead ECG date/time
EST_RETRIEVAL_DATE	Estimated date and time of retrieval
EST_RETRIEVAL_DFLAG	Indicator for retrieval date
ETHNIC_ORIGIN	Reference code for ethnic origin of donor
EXCLUSION_BEHAVIOUR	
FLUID_BAL	Fluid bal reading (litres)
FORENAME	Donor forename
GAMMA_GT	Liver function – gamma GT
GIRTH	Girth of donor (cm)
GLUCOSE	Liver function – glucose
HAEMAGLOBIN	Haemaglobin result
HBCAB	
HBCAG	Hepatitis C antigen test status
HBSAG	Hepatitis B antigen test status
HCV	Hepatitis C virus test status
HEART_RATE	Heart rate
HEART_RATE_DATE	Date and time of heart rate reading
HEART_RATE_DFLAG	Indicator for heart rate date
HEIGHT	Height of donor (cm)
HIGHEST_BP	Highest blood pressure recorded
HIGHEST_BP_DATE	Date and time of highest blood pressure reading
HIGHEST_BP_DFLAG	Indicator for highest blood pressure date
HIGHEST_BP_DURATION	Duration of highest blood pressure
HIV	HIV test status
HYPERTENSION	Reference code for donor hypertensive (y/n)
HYPERTENSION_OCCASIONS	No. of occasions that donor was hypertensive
HYPOTENSION	Reference code for donor hypertension (y/n)
HYPOTENSION_OCCASIONS	No. of occasions that donor has been hypotensive
INFECTIONS_ASPIRATIONS	Infections – aspirations
INFECTIONS_CHEST	Infections – chest
INFECTIONS_OTHER	Infections – other
INFECTIONS_URINE	Infections – urine
INR	INR result
INTRAVENOUS_FLUIDS	Intravenous fluids given (y/n)
ISOPRENALINE_MAX_DOSE	
LDH	Liver function – LDH
LOWEST_BP	Lowest blood pressure recorded
LOWEST_BP_DATE	Date and time of lowest blood pressure reading
LOWEST_BP_DFLAG	Indicator for lowest blood pressure date
LOWEST_BP_DURATION	Duration of lowest blood pressure reading
MAINTAINING_UNIT	Reference code for type of unit maintaining donor
MCV	MCV result
MEAN_CVP	Mean CVP reading (cm H_2O)
NORADRENALINE_MAX_DOSE	
NORMOTENSIVE	Is the patient normotensive (y/n)

continued

NOTIFIED_DATE	Date and time donor first notified to UKTSSA
NOTIFIED_DFLAG	Indicator for notified date
PAST_ALCOHOL_ABUSE	Past history of alcohol abuse
PAST_CARDIO_DISEASE	Past history of cardiothoracic diseases
PAST_DIABETES	Past history of diabetes
PAST_DRUG_ABUSE	Past history of drug abuse
PAST_HYPERTENSION	Past history of hypertension
PAST_LIVER_DISEASE	Past history of liver diseases
PAST_OTHER	Past history – other
PAST_SMOKER	Past history of smoking
PAST_SMOKER_AMOUNT	Smoking – number per day
PAST_TUMOUR	Past history of tumour
PAST_UTI	Past history of UTI
PHOSPHATE	Liver function – phosphate
PLATELETS	Platelets
PT	PT result
RESPIRATORY_ARREST	Reference code for respiratory arrest
RESPIRATORY_ARREST_DATE	Date and time of respiratory arrest
RESPIRATORY_ARREST_DFLAG	Indicator for respiratory arrest date
RESPIRATORY_ARREST_DURATION	Duration of respiratory arrest (minutes)
RETRIEVAL_BLOOD_UREA	Blood urea at retrieval
RETRIEVAL_CREATININE	Serum creatinine at retrieval
RETRIEVAL_DATE	Date and time of retrieval (for test purposes)
RETRIEVAL_DFLAG	Indicator for retrieval date
RETRIEVAL_POTASSIUM	Potassium at retrieval
RETRIEVAL_SODIUM	Sodium at retrieval
RETRIEVAL_SURG	
RHESUS	Reference code for donor rhesus type
SECRETIONS	Secretions
SEX	Reference code for gender of donor
SURNAME	Donor surname
SYPHILIS	Syphilis test status
TEMPERATURE	Temperature
TEMP_DATE	Date and time of temperature reading
TEMP_DFLAG	Indicator for temperature date
TESTS_PRE_TRANSFUSION	If transfused when tests made prior to transfusion (y/n)
TOTAL_PROTEIN	Liver function – total protein
TOXO	Toxo test status
TRANSFUSION	Has a transfusion been given (y/n)
TRANSFUSION_O_NEG	Has group O negative blood been given (y/n)
TRAUMA_ABDOMINAL	Reference code for abdominal trauma (y/n)
TRAUMA_CHEST	Reference code for chest trauma (y/n)
TRAUMA_HEAD	Reference code for head trauma (y/n)
TRAUMA_OTHER	Reference code for other trauma (y/n)
URINE_OUTPUT_24HRS	Urine output in the last 24 hours (ml)
URINE_OUTPUT_HR	Urine output in the last hour (ml)
URINE_PERIOD	Urine output period (hrs)
URINE_PERIOD_OUTPUT	Urine output for specified period (ml)
VENTILATION_CEASE_DATE	Date and time of ventilation ceasing
VENTILATION_CEASE_DFLAG	Indicator for ventilation cease date
VENTILATION_PERIOD	Period of ventilation (if unknown ventilation date)
VENTILATION_START_DATE	Date and time of ventilation start
VENTILATION_START_DFLAG	Indicator for ventilation start date
WARM_ISCH_TIME	Ischaemic time (minutes)
WEIGHT	Weight of donor (kg)
WHITE_CELLS	White cell count
CARDIOTHORACIC_DONOR	
AORTA_XCLAMP_DATE	Date/time aorta x-clamped
AORTA_XCLAMP_DFLAG	Indicator for aorta x-clamp date
BRONCHOSCOPY	
BYPASS	Reference code for by-pass (y/n)
CARDIAC_BOX_DATE	Date/time into cardiac box

continued

CARDIAC_BOX_DFLAG	Indicator for cardiac box time
CARDIOEXTOMY_DATE	Date/time of cardioextomy
CARDIOEXTOMY_DFLAG	Indicator for cardioextomy date
CARDIOPLEGIA_DATE	Date/time of cardioplegia
CARDIOPLEGIA_DFLAG	Indicator for cardioplegia date
DONOR_ID	Unique ID for donor
HEART_BOX_DATE	
HEART_BOX_DFLAG	
HEART_LUNG_BOX_DATE	
HEART_LUNG_BOX_DFLAG	
HEART_PERFUSATE	Reference code for perfusion fluid
HEART_PERFUSATE_VOLUME	Volume of perfusate (l)
HEPARIN_DATE	
HEPARIN_DFLAG	
HEPARIN_DOSE	
LEFT_LUNG_BOX_DATE	
LEFT_LUNG_BOX_FLAG	
LUNG_PERFUSATE	
LUNG_PERFUSATE_VOLUME	
LYMPH_NODE	Indicator for lymph node available (y/n)
OFF_BYPASS_DATE	Date/time off by-pass
OFF_BYPASS_DFLAG	Indicator for off by-pass date
ON_BYPASS_DATE	Date/time on to by-pass
ON_BYPASS_DFLAG	Indicator for on by-pass date
PERFUSION_END_DATE	Date/time of end of perfusion
PERFUSION_END_DFLAG	Indicator for perfusion end date
PERFUSION_START_DATE	Date/time of start of perfusion
PERFUSION_START_DFLAG	Indicator for perfusion start date
RIGHT_LUNG_BOX_DATE	
RIGHT_LUNG_BOX_DFLAG	
SPLEEN	Indicator for spleen available (y/n)
CARDIOTHORACIC_RECIPIENT	
BODY_SURFACE_AREA	Recipient body surface area (if paediatric) (m^2)
FUP_CENTRE	Foreign key to hospital – centre for recipient cardiothoracic follow-up
HEART_REG_DATE	Date of registration for heart
HEART_REG_DFLAG	Indicator for heart registration date
HEART_STATUS	Reference code of recipient status for heart waiting list
HEIGHT	Recipient height (cm)
HOSPITAL_NO	Hospital specific reference number for patient
LUNG_REG_DATE	Date of registration for lung
LUNG_REG_DFLAG	Indicator for lung registration date
LUNG_STATUS	Reference code of recipient status for lung waiting list
ORGAN_REQD	Reference code of organ(s) required
PAEDIATRIC	Indicator whether paediatric organ required (y/n)
PRIMARY_DISEASE	Reference code of cardiothoracic disease
RECIP_ID	Unique ID for recipient
TX_CENTRE	Foreign key to hospital – recipient transplant unit
WEIGHT	Recipient weight (kg)
CARDIO_STATUS_HISTORY	
EVENT_DATE	
EVENT_ORDER	
ORGAN_TYPE	Reference code for organ
RECIP_ID	Unique ID for recipient
STATUS	Reference code for recipient status for heart
STATUS_DAYS	
TX_ID	
UPDATED_BY	User name making update
UPDATED_DATE	Date of update
CASE_DETAIL	
AGE_MONTHS	Additional months of case subject (if under 3 years)

continued

AGE_YEARS	Age of case subject in years
BLOOD_GROUP	Blood group of case subject
CASE_CONTACT	Foreign key to person referring case
CASE_ID	Unique ID for case logged by duty office
CASE_NOTIFIED	Date/time case notified to duty office
CASE_STATUS	Reference code of case status
DONOR_ID	Unique ID for donor linked to this case (if any)
DONOR_NOTIFIED	Date/time case converted to donor
FORENAME	Forename of case subject
HOSPITAL_ID	Foreign key to hospital referring case
RHESUS	
SEX	Reference code for sex of case subject
SURNAME	Surname of case subject
CASE_NOTE	
CALL_DIRECTION	Reference code of whether code in or out
CASE_ID	Unique ID of case
CONTACT	Foreign key of person to whom call is made
LOCATION	Foreign key of location of contact (e.g. hospital)
MODIFY_DATE	Date of last modification of this record
NOTED_BY	User name of person entering note
NOTE_DATE	Date/time of note (i.e. call made)
NOTE_TEXT	Textual content of note
NOTE_TYPE	Reference code of note type
CASE_NOTE_AUDIT	
AUDIT_DATE	
AUDIT_TYPE	
AUDIT_USERNAME	
CALL_DIRECTION	
CASE_ID	Unique ID for case
CONTACT	
LOCATION	
MODIFY_DATE	
NOTED_BY	
NOTE_DATE	Date note entered originally
NOTE_TEXT	Text of note prior to change
NOTE_TYPE	
CORNEA	
DONOR_ID	Unique ID for donor
ORGAN_TYPE	Reference code for organ (i.e. cornea)
SOLUTION	
CORNEA_RECIPIENT	
CORNEA_STATUS	
DAYS_ACTIVE	
DISC_37C	
DISC_4C	
FUP_CENTRE	
HIGH_RISK	
HOSPITAL_NO	Hospital-specific reference number for patient
IMMUNO_REJECTION	
KERATOPLASTY	
MATCHED_GRAFT	
ORGAN_TYPE	
PREVIOUS_GRAFTS	
PREV_GRAFTS_LEFT	
PREV_GRAFTS_RIGHT	
PREV_GRAFT_DATE	
PREV_GRAFT_DFLAG	
PREV_GRAFT_ORGAN	
PREV_GRAFT_STATUS	

continued

PRIMARY_DISEASE	
RECIP_ID	
SURGEON	
TX_CENTRE	
VASCULAR_DEEP	
VASCULAR_SUPERFICIAL	
WHOLE_EYE_ONLY	
WHOLE_EYE_TIME	
CORNEA_STATUS_HISTORY	
EVENT_DATE	
EVENT_ORDER	
ORGAN_TYPE	
RECIP_ID	
STATUS	
STATUS_DAYS	
TX_ID	
UPDATED_BY	
UPDATED_DATE	
DONOR	
DONATION_DATE	Date/time of donation
DONATION_DFLAG	Indicator for donation date
DONOR_ID	Unique ID for donor
DONOR_TYPE	Reference code for donor type
HLA_DISCREPANT	
KIDNEY_MATCH_POOL	
NHS_NO	
DONOR_AUDIT	
CHANGE_DATE	
COLUMN_NAME	
DONOR_ID	
NEW_VALUE	
OLD_VALUE	
TABLE_NAME	
USER_NAME	
DONOR_BLOOD_GASES	
BE	
BLOOD_GAS_DATE	
BLOOD_GAS_ID	
DONOR_ID	
FIO2	
HCO3	
PCO2	
PEEP	
PH	
PO2	
SATURATION	
DONOR_DRUG	
DONOR_ID	Foreign key to cadaveric donors
DOSE	Dosage given
DRUG_CATEGORY	Reference code for drug category (inotropic support/other)
DRUG_ID	
DRUG_NAME	Name of drug given
DURATION_DAYS	Duration in days
DURATION_HRS	Duration in hours
DONOR_HAEMODYNAMICS	
AO	
CI	

continued

DONOR_HAEMO_ID	
DONOR_ID	Unique ID for donor
HAEMODYNAMIC_DATE	Date and time of measurement
HEART_RATE	
LVSWI	
MEAN_A_PRESSURE	
PA	
RA	
DONOR_HLA_SAMPLE	
A_HOMOZYGOUS	
A_HOMOZYGOUS_LABS	
B_HOMOZYGOUS	
B_HOMOZYGOUS_LABS	
DEFINITIVE_TYPE	
DONOR_ID	Foreign key to donor
DR_HOMOZYGOUS	
DR_HOMOZYGOUS_LABS	
SAMPLE_CLASS	Reference code for sample class
SAMPLE_DATE	Date sample was recorded
SAMPLE_ID	Unique ID for sample
TT_LAB_ID	Foreign key to laboratory
DONOR_MATCH_POOL_TT	
BLOOD_GROUP	
DONOR_ID	
HLA_ENTITY_ID	
HLA_TEST_TYPE	
DONOR_NOTE	
DONOR_ID	Unique ID for donor
ENTERED_BY	User name entering note
NOTE_DATE	Date note entered
NOTE_TEXT	Text content of note
NOTE_TYPE	Reference code for note type
DONOR_TRANSFUSION	
DONOR_ID	Unique ID for donor
TRANSFUSION_PERIOD	Reference code for period of transfusions
TRANSFUSION_UNIT	
TRANSFUSION_VOLUME	Volume of blood transfused in units (all groups)
DUTY_OFFICE_LOG	
DECISION_DATE	Date/time decision is made
DONOR_ID	Unique ID of donor
ENTERED_BY	User name of enterer
FULL_OFFER_END	Date/time full offer ended
FULL_OFFER_START	Date/time full offer started
MODIFY_DATE	Date this record was last modified
OFFER_CENTRE	Foreign key to hospital receiving offer
OFFER_CONTACT	Foreign key to person contacted over offer
OFFER_CONTACT_NAME	
OFFER_EXPIRY_DATE	Date/time offer expires
OFFER_TYPE	Reference code for offer type
ORGAN_GROUP	Reference code of organ group
ORGAN_TYPE	Reference code of organ offered
PROV_OFFER_END	Date/time provisional offer ended
PROV_OFFER_START	Date/time provisional offer started
RECIPIENT_CLASS	Reference code for recipient class offered to
RECIP_CLASS	Reference code for classification of recipient
RECIP_ID	Foreign key to recipient for whom offer is made
SEQUENCE_NO	Sequence number of offer for this organ
TRANSPORT	Reference code for transport required

continued

DUTY_OFFICE_LOG_AUDIT	
AUDIT_DATE	
AUDIT_TYPE	
AUDIT_USERNAME	
DECISION_DATE	
DONOR_ID	
ENTERED_BY	
FULL_OFFER_END	
FULL_OFFER_START	
MODIFY_DATE	
OFFER_CENTRE	
OFFER_CONTACT	
OFFER_EXPIRY_DATE	
OFFER_TYPE	
ORGAN_GROUP	
ORGAN_TYPE	
PROV_OFFER_END	
PROV_OFFER_START	
RECIPIENT_CLASS	
RECIP_CLASS	
RECIP_ID	
SEQUENCE_NO	
TRANSPORT	
DUTY_OFFICE_LOG_NOTE	
DONOR_ID	Unique ID of donor
ENTERED_BY	User name entering note
NOTE_DATE	Date note entered
NOTE_TEXT	Text content of note
NOTE_TYPE	Reference code for note type
ORGAN_TYPE	Reference code for organ
SEQUENCE_NO	Sequence number of offer for this organ
DUTY_OFFICE_LOG_RESULT	
DONOR_ID	Unique ID of donor
FINAL_OFFER	Is this final offer (y/n)
MODIFY_DATE	Date of last modification
ORGAN_TYPE	Reference code of organ offered
PRIMARY_REASON	Reference code for primary reason for result
RECIP_ID	Foreign key for recipient for whom offer applies
RESULT	Reference code for offer result
RESULT_ORGAN	Reference code for organ applicable for result
SECONDARY_REASON	Reference code for secondary reason for result
SEQUENCE_NO	Sequence number of offer
DUTY_OFFICE_LOG_RESULT_AUDIT	
AUDIT_DATE	
AUDIT_TYPE	
AUDIT_USERNAME	
DONOR_ID	
FINAL_OFFER	
MODIFY_DATE	
ORGAN_TYPE	
PRIMARY_REASON	
RECIP_ID	
RESULT	
RESULT_ORGAN	
SECONDARY_REASON	
SEQUENCE_NO	
GRAFTED_EYE	
DONOR_ID	
EYE_GRAFTED	

continued

ORGAN_TYPE	
TX_ID	
GRAFTED_KIDNEY	
DONOR_ID	Unique ID for donor
IMMEDIATE_FUNCTION	Indicator of whether kidney functioned immediately (y/n)
OFF_DIALYSIS_DATE	Date recipient off dialysis for this graft
OFF_DIALYSIS_DFLAG	Indicator for date off dialysis
ORGAN_TYPE	Reference code for organ grafted
RESUME_DIALYSIS_DATE	Date recipient resumed dialysis following this graft
RESUME_DIALYSIS_DFLAG	Indicator for date dialysis resumed
TX_ID	Unique ID for transplant
GRAFTED_ORGAN	
DONOR_ID	Unique ID for donor
ECTOMY_DATE	Date of removal of organ from recipient post-graft
ECTOMY_DFLAG	Indicator for date of … ectomy
FAILURE_CAUSE	Reference code for cause of graft failure
FAILURE_DATE	Date of failure of this graft (if any)
FAILURE_DFLAG	
GRAFT_NUMBER	Ordinal number of graft for recipient for this organ
GRAFT_STATUS	Reference code for status of graft
LOST_TO_FUP	
MISMATCH_ON_DEFINITIVE	HLA mismatch achieved, based on definitive type for donor, if available
MISMATCH_ON_OFFER	HLA mismatch achieved, from HLA type at offer for both recipient and donor
MISMATCH_ON_RECENT	HLA mismatch achieved, based on donor definition or offer and most recent
ORGAN_TYPE	Reference code for organ grafted
RECIPIENT_UNIT	Foreign key to hospital – unit responsible for recipient
REMOVAL_DATE	Date and time of organ removal from donor (HOT forms)
REMOVAL_DFLAG	Indicator for date of organ removal from donor
RETRIEVAL_UNIT	Foreign key to hospital – unit responsible for organ retrieval
STATUS_PERIOD	Follow-up period providing graft status information
SURVIVAL_DATE	Last known date of graft survival – including death (if with a survival date)
TX_ID	Unique ID for transplant
UNSUITABLE_ORGAN	
GRAFT_FOLLOW_UP	
ACCEPTED_DATE	Date form accepted
DONOR_ID	Unique ID for donor
FORM_TYPE	Reference code for form issued or received
FUNCTION_QUALITY	Reference code for quality of graft function
FUP_PERIOD	Follow-up period (months)
GRAFT_STATUS	Reference code for graft status reported on form
GRAFT_STATUS_DATE	Date graft status applicable (e.g. last clinical assessment date)
GRAFT_STATUS_DFLAG	Indicator for date of graft status
ISSUE_DATE	Date form issued
METHOD	Reference code for method of form issue/receipt
ORGAN_TYPE	Reference code for organ
RECEIVED_DATE	Date form received
REISSUE_DATE	Date form re-issued for correction/completion
REQUEST_DATE	
SIGNED_BY	Foreign key to personnel – signatory on form
SIGNED_DATE	Date form signed
SIGNED_DFLAG	Indicator for form signed date
SKIP_FUP	
TX_ID	Unique ID for transplant
VITAL_STATUS	Reference code for recipient vital status reported on form
HLA_ENTITY	
HLA_ASSOCIATE_ID	ID of HLA entity associated with this entity (e.g. Bw4, DR52)
HLA_CLASS	Reference code for HLA class
HLA_END_DATE	Date this HLA entity removed from model
HLA_ENTITY_ID	Unique ID for HLA entity
HLA_ENTITY_NAME	Name of HLA entity

continued

HLA_LEFT	Left value for traversed tree node
HLA_LOCUS	Reference code for HLA locus
HLA_PARENT_ID	Parent ID of this HLA entity
HLA_RIGHT	Right value for traversed tree node
HLA_START_DATE	Date this HLA entity is valid from
TREATED_AS_BROAD	
HLA_MATCH_ENTITY	
END_DATE	Date this HLA entity removed from matching
HLA_ENTITY_ID	Unique ID for HLA entity
ORGAN_TYPE	Foreign key for organ type
START_DATE	Date this HLA entity included in matching
HLA_TEST	
HLA_CERTAIN	Indication of test certainty (e.g. 'fuzzy' allele test)
HLA_ORDER	Reporting order
HLA_SUPERBROAD	Indication of superbroad test
HLA_SYNONYM	ID of HLA test for which this test is a synonym (if any)
HLA_TEST_ID	Unique ID for a test
HLA_TEST_NAME	Name of test
HLA_TEST_SHORT	
HLA_TEST_MAP	
HLA_ENTITY_ID	Unique ID for HLA entity
HLA_TEST_ID	Unique ID for HLA test
HLA_TEST_REPORT	
HLA_CERTAIN	
HLA_ORDER	
HLA_SUPERBROAD	
HLA_TEST_ID	
HLA_TEST_NAME	
KIDNEY	
ARTERIES	Number of arteries on kidney
ARTERIES_ON_PATCH	Number of arteries on patch
BRANCHES_TIED	Indicator whether branches were tied (y/n)
DONOR_ID	Unique ID for donor
MACHINE_PERFUSION	
ORGAN_TYPE	Reference code for organ
PATCHES	Number of arterial patches on kidney
PERFUSATE	Reference code for perfusion fluid
PERFUSION_QUALITY	Reference code for perfusion quality
PERFUSION_START_DATE	Date/time for start of perfusion
PERFUSION_START_DFLAG	Indicator for perfusion start date
VEINS	Number of veins on kidney
XMATCH_BLOOD	Indicator of blood for x-match (y/n)
XMATCH_CELLS	Indicator of cells for x-match (y/n)
XMATCH_LYMPH	Indicator of lymph node for x-match (y/n)
XMATCH_SPLEEN	Indicator of spleen for x-match (y/n)
KIDNEY_DAMAGE	
CAPSULE_STRIPPED	Indicator whether capsule stripped (y/n)
CAPSULE_TORN	Indicator whether capsule torn (y/n)
CUT_POLAR_ARTERY	Indicator whether polar artery cut (y/n)
CUT_RENAL_ARTERY	Indicator whether renal artery cut (y/n)
CUT_RENAL_VEIN	Indicator whether renal vein cut
DONOR_ID	Unique ID of donor
ORGAN_TYPE	Reference code of organ
OTHER	
OTHER_DAMAGE	Other damage not noted above – free notes
PATCH_EXCLUDE_ARTERY	Indicator whether patch excluding an additional artery (y/n)
PATCH_REMOVED	
PERFUSION_QUALITY	

continued

REPORT_SOURCE	Reference code of report source (donor/recipient hospital)
REWARMING_EVIDENCE	
SMALL_HAEMATOMAS	Indicator whether small haematomas (y/n)
URETER_SHORT	Indicator whether ureter cut short (y/n)
KIDNEY_FOLLOW_UP	
DONOR_ID	Unique ID for donor
FIRST_REJECTION_DATE	Date of first rejection
FIRST_REJECTION_DFLAG	Indicator for first rejection date
FUP_PERIOD	Indication of follow-up period (years)
HEIGHT	Recipient height (cm) (if under 18 years)
MALIGNANCY	Has recipient developed a malignancy over indicated period (y/n)
ORGAN_TYPE	Reference code for organ
PREGNANCY	Has recipient been pregnant over indicated period (y/n)
REJECTION_COUNT	Number of rejection episodes over indicated period
TX_ID	Unique ID for transplant
WEIGHT	Recipient weight (kg)
LIVER_ANATOMY	
BILE_LENGTH	Bile duct long/short
COMMON_BILE_DUCT	
COMMON_HEP_ARTERY	
DONOR_ID	Unique ID for donor
HEPATIC_ARTERY	Number of hepatic arteries
HEPATIC_LENGTH	Hepatic artery long/short
ILIAC_ARTERY	Iliac artery present (y/n)
ILIAC_VEIN	Iliac vein present (y/n)
LEFT_AND_RIGHT_HEPATIC	
LEFT_HEPATIC_GASTRIC	
LYMPH_NODE	Lymph node present (y/n)
MAIN_PORTAL_VEIN	
NORMAL_ANATOMY	
ORGAN_TYPE	Reference code for organ
PATCH	Patch on liver (y/n)
PORTAL_LENGTH	Portal vein long/short
RIGHT_HEPATIC_SMA	
SPLEEN	Spleen present (y/n)
VENA_CAVA	
LIVER_DONOR	
BENCHWORK	
CAPSULAR_DAMAGE	
DONOR_ID	
HEPATECTOMY_DATE	
HEPATECTOMY_DFLAG	
IN_ICE_DATE	
IN_ICE_DFLAG	
LIVER_BOX_DATE	
LIVER_BOX_DFLAG	
ORGAN_APPEARANCE	
STEATOSIS	
STEATOSIS_DEGREE	
TRANSPORT_FLUID	
LIVER_RECIPIENT	
ABO_MATCH	Reference code of donor blood group match criteria (super urgent)
DONOR_MAX_GIRTH	Maximum donor girth required
DONOR_MAX_HEIGHT	Maximum donor height required
DONOR_MAX_WEIGHT	Maximum donor weight required
DONOR_MIN_GIRTH	Minimum donor girth required
DONOR_MIN_HEIGHT	Minimum donor height required
DONOR_MIN_WEIGHT	Minimum donor weight required
FUP_CENTRE	Foreign key to hospital – follow-up centre

continued

GIRTH	Recipient lower costal margin girth (cm)
HEIGHT	Recipient height (cm)
HOSPITAL_NO	Hospital specific reference number for patient
LIVER_REG_DATE	Date of registration for current waiting time
LIVER_REG_DFLAG	Indicator for registration date
LIVER_STATUS	Reference code of liver status
PAEDIATRIC	
PRIMARY_DISEASE	Reference code for primary liver disease
RECIP_ID	Unique ID for recipient
STATUS_JUSTIFICATION	Reference code for justification of liver status (particularly survival)
SUPER_URGENT_DATE	
TX_CENTRE	Transplant unit for waiting list purposes
WEIGHT	Recipient weight (kg)
LIVER_STATUS_HISTORY	
CHANGE_REASON	Reference code for reason for change
EVENT_DATE	
EVENT_ORDER	
ORGAN_TYPE	Reference code for organ
RECIP_ID	Unique ID for recipient
STATUS	Reference code for status
STATUS_DAYS	
TX_ID	
UPDATED_BY	User name making update
UPDATED_DATE	Date of update
LIVE_DONOR	
ADRENALINE_MAX_DOSE	
BIRTH_DATE	Donor date of birth
BIRTH_DFLAG	Indicator for date of birth
BLOOD_GROUP	Reference code for donor blood group
CARDIAC_ARREST	
DOBUTAMINE_MAX_DOSE	
DONOR_HOSPITAL	
DONOR_ID	Unique ID for donor
DOPAMINE_MAX_DOSE	
DOPEXAMINE_MAX_DOSE	
ETHNIC_ORIGIN	
FORENAME	Forename of donor
FORENAME_CSFLAG	Reference code indicating source of forename data
HEIGHT	
HYPOTENSION	
HYPOTENSION_DURATION	
ISOPRENALINE_MAX_DOSE	
NORADRENALINE_MAX_DOSE	
NOTIFIED_DATE	
PAST_ALCOHOL_ABUSE	
PAST_DIABETES	
PAST_DRUG_ABUSE	
PAST_HYPERTENSION	
PAST_LIVER_DISEASE	
PAST_SMOKER	
PAST_TUMOUR	
RELATED_TESTER	Foreign key to personnel – tester responsible for relationship
RELATED_TESTER_CSFLAG	Reference code indicating source of tester information
RETRIEVAL_SURG	
RHESUS	Reference code for donor rhesus
SEX	Reference code for donor sex
SURNAME	Surname of donor
SURNAME_CSFLAG	Reference code indicating source of surname data
ULTRA_CSFLAG	Reference code indicating source of ULTRA number information
ULTRA_NUMBER	Unrelated live Tx regulatory authority reference
WEIGHT	

continued

RCS_CARDIAC_FUP	
AIRWAY_COMPLICATIONS	Indicator whether airway complications present (y/n)
DONOR_ID	Unique ID of donor for transplant
FUP_PERIOD	
HOSPITAL_ADMISSIONS	
INFECTIONS	
NYHA_CLASS	
ORGAN_TYPE	Reference code of organ grafted
REJECTION_EPISODES	
TX_ID	Unique ID of transplant
RCS_CARDIAC_INFECTION	
DONOR_ID	
FUP_PERIOD	Follow-up period indicating infection (tx record = 0)
INFECTION_NO	Infection number
INFECTION_SITE	Reference code for infection site
ORGAN_TYPE	
TX_ID	Unique ID of transplant
AICD	AICD (y/n)
ANTIARRHYTHMICS	Antiarrhythmics (excluding digoxin) (y/n)
BILIRUBIN	Bilirubin (μmol/l)
CARDIAC_OUTPUT	Haemodynamics – cardiac output (l/minute)
CEREBROVASCULAR	Cerebrovascular disease (y/n)
CHOLESTEROL	Cholesterol (μmol/l)
CMV	CMV status at registration
CREATININE	Creatinine (μmol/l)
DIABETES	Diabetes status reference code
ECMO	In hospital – ECMO (y/n)
EJECTION_FRACTION	Haemodynamics – ejection fraction (%)
FEV1	Lung function – FEV1 (l)
FVC	Lung function – FVC (l)
HCV	HCV status at registration
HEIGHT	Height in cm at registration
HOME_OXYGEN	Home oxygen (y/n)
HYPERTENSION	Hypertension requiring treatment in last 5 years (y/n)
IABP	In hospital – IABP (y/n)
INOTROPES	In hospital – on inotropes (y/n)
IN_HOSPITAL	In hospital (y/n)
NYHA_CLASS	NYHA class reference code
ORGAN_REQUIRED	Organ type registered for
PA_MEAN	Haemodynamics – PA mean (mmHg)
PA_SYSTOLIC	Haemodynamics – PA systolic (mmHg)
PCW	Haemodynamics – PCW or LAP (mmHg)
POSTCODE	Postcode of recipient at registration
PREDNISOLONE	Daily dose of prednisolone (mg)
PREV_HEART_SURGERY	Number of previous open heart surgery operations
PREV_MALIGNANCY	Previous malignancy (y/n)
PREV_SUDDEN_DEATH	Previous sudden death episode (y/n)
PREV_THORACOTOMY	Whether thoracotomy received previously (y/n)
PRIMARY_DISEASE	Reference code for primary cardiac disease at registration
PVR	In hospital – PVR reference code
RECIP_ID	Recipient ID
REGISTRATION_DATE	Date of registration on cardio-thoracic waiting list under RCS
SIX_MIN_WALK	Lung function – 6-minute walk test (m)
SMOKER	Smoker (>5 per day in last 6 months) (y/n)
TAH	In hospital – TAH (y/n)
VAD	In hospital – VAD reference code
VASCULAR_DISEASE	Peripheral vascular disease with intervention performed or planned
VENTILATED	In hospital – ventilated (y/n)
VO2_MAX	Lung function – VO_2 max. (ml/kg/minute)
WEIGHT	Weight in kg at registration
RCS_CARDIAC_TX_RECORD	

continued

ALG_INDUCTION	Immunosuppression – ALG/ATG induction (y/n)
ALG_REJECTION	Immunosuppression – ALG/ATG for rejection (y/n)
ANAESTHETIST	Reference code of anaesthetist grade
AZATHIOPRINE	Immunosuppression – azathioprine (y/n)
B_CELL	Reference code for B-cell results
CORTICOSTEROIDS	Immunosuppression – corticosteroids (y/n)
CREATININE	Creatinine at Tx (μmol/l)
CROSS_CLAMP_DATE	Date/time of donor cross clamp on
CROSS_CLAMP_DFLAG	Indicator for cross clamp date
CYCLOSPORIN	Immunosuppression – cyclosporin (y/n)
CYCLOSPORIN_DAY	Day cyclosporin started (date of Tx = day 0)
ECMO	In hospital – ECMO (y/n)
FIRST_LUNG	Foreign key for organ perfused first
FK506	Immunosuppression – FK506 (y/n)
HAEMOFILTRATION	Complications – haemofiltration/haemodialysis (y/n)
HDU_DISCHARGE_DATE	Date of discharge from HDU
HDU_DISCHARGE_DFLAG	Indicator for HDU discharge date
HEART_PERFUSATE	Reference code for heart perfusion fluid
HEART_PERFUSATE_VOL	Volume of heart perfusate (ml)
HEART_PERFUSION_METHOD	Reference code of heart perfusion method
HOSP_DISCHARGE_DATE	Date of discharge from hospital
HOSP_DISCHARGE_DFLAG	Indicator for hospital discharge date
IABP	In hospital – IABP (y/n)
IABP_POST_OP	Complications – IABP post-op. (y/n)
IMMUNO_OTHER	Immunosuppression – other
IMMUNO_OTHER_TEXT	Text for other immunosuppression
INFECTIONS	Complications – number of serious infection episodes
INOTROPES	In hospital – on inotropes (y/n)
IN_HOSPITAL	In hospital pre-Tx (y/n)
ISCHAEMIA_LUNG1	
ISCHAEMIA_LUNG2	
ITU_DISCHARGE_DATE	Date of discharge from ITU
ITU_DISCHARGE_DFLAG	Indicator for ITU discharge date
LUNG_PERFUSATE	Reference code for lung perfusion
LUNG_PERFUSATE_VOL	Volume of lung perfusate (ml)
LUNG_PERFUSION_METHOD	Reference code of lung perfusion method
METHOTREXATE	Immunosuppression – methotrexate
NYHA	Reference code of NYHA class
OKT3_INDUCTION	Immunosuppression – OKT3 induction (y/n)
OKT3_REJECTION	Immunosuppression – OKT3 for rejection (y/n)
OPERATING_SURGEON	Reference code of operating surgeon grade
ORGANISMS	Complications – organisms causing infection
ORGAN_ARRIVAL_DATE	Date/time of organ arrival
ORGAN_ARRIVAL_DFLAG	Indicator for organ arrival date
OTHER_POST_OP	Complications – other mechanical assistance post-op. (y/n)
OUT_OF_ICE_DATE	Date/time organ out of ice
OUT_OF_ICE_DFLAG	Indicator for out of ice date
PRE_OP_INFECTION	Infection requiring i.v. antibiotics in 6 weeks pre-Tx (y/n)
RECEIVED_DATE	
RECIP_DIED	Did recipient die post-op. (y/n)
REJECTIONS	Complications – number of rejection episodes
REPERFUSION_2_DATE	Date/time of second lung reperfusion
REPERFUSION_2_DFLAG	Indicator for reperfusion 2 date
REPERFUSION_DATE	Date/time of reperfusion (of first lung, if bilateral)
REPERFUSION_DFLAG	Indicator for reperfusion date
SENIOR_SURGEON	Reference code of most senior surgeon scrubbed grade
TAH	In hospital – TAH (y/n)
THEATRE	Complications – return to theatre (y/n)
TLI	Immunosuppression – TLI
TX_ID	Unique ID of transplant
T_CELL	Reference code for T-cell results
UNSEP_LYMPH	Reference code for unseparated lymphocytes result
VAD	In hospital – VAD reference code

continued

VENTILATED	In hospital – ventilated (y/n)
WEIGHT	Recipient weight at Tx
XMATCH_TEST	Reference code for cross match test type
RCS_LIVER_FUP_3MTH	
ANTIBODIES	Monoclonal or polyclonal antibodies used at any stage (y/n)
ASCITIES_SEPSIS	Sepsis confirmed – in ascities/drain fluid
BILIARY_STRICTURE_TREAT	Complications – reference code for treatment for biliary tract stricture
BILIARY_TRACT_LEAK	Complications – reference code for biliary tract leaks
BILIARY_TRACT_STRICTURE	Complications – biliary tract stricture requiring intervention (y/n)
BLOOD_SEPSIS	Sepsis confirmed – in blood
CMV_INFECTION	CMV infection (y/n)
DAYS_IN_ITU	Days in ITU post-Tx
DAYS_VENTILATED	Days ventilated post-Tx
DISCHARGE_DATE	Date of initial discharge
DISCHARGE_DFLAG	Indicator for discharge date
DONOR_ID	Unique ID for donor
FUNGAL_INFECTION	Fungal infection (y/n)
FUP_PERIOD	Follow-up period (should be 3 in all cases!)
HAEMORRHAGE	Complications – haemorrhage requiring re-operation (y/n)
HEPATIC_ART_THROMBOSIS	Complications – hepatic artery thrombosis (y/n)
IVC	Complications – IVC/hepatic vein occlusion
LIFESTYLE	Reference code for lifestyle activity score
ORGAN_TYPE	Reference code for organ
OTHER_SEPSIS	Sepsis confirmed – other site
PORTAL_VEIN_THROMBOSIS	Complications – portal vain thrombosis (y/n)
RECIP_RELISTED	Indicator whether recipient was relisted prior to death (y/n)
REJECTION_EPISODES	Number of treated rejection episodes since Tx
RENAL_STATUS	Reference code of renal status
SPUTUM_SEPSIS	Sepsis confirmed – in sputum
TX_ID	Unique ID for transplant
T_CELL_XMATCH	Result of direct T-cell cross-match performed (if any)
URINE_SEPSIS	Sepsis confirmed – in urine
WOUND_SEPSIS	Sepsis confirmed – in wound
RCS_LIVER_FUP_ANNUAL	
ACUTE_REJECTION	Readmissions – number due to acute rejection
ALK_PHOSPHATE	Liver function – alk. phosphate (μmol/l)
ALTERED_DATE	
ALT_SGOT	Liver function – ALT/SGOT (μmol/l)
AST_SGPT	Liver function – AST/SPGT (μmol/l)
BILIARY_COMP	Readmissions – number due to biliary complications
BILIRUBIN	Liver function – bilirubin (μmol/l)
BLOOD_UREA	Renal function – blood urea (mmol/l)
CHRONIC_REJECTION	Readmissions – number due to chronic rejection
DAYS_INPATIENT	Total number of days as inpatient in previous year
DISEASE_RECUR	Readmissions – number due to disease recurrence
DONOR_ID	Unique ID for donor
DYSFUNCTION	Indicator whether Tx-related renal dysfunction present (y/n)
FUP_PERIOD	Follow-up period (months)
INFECTION	Readmissions – number due to infection
LIFESTYLE	Reference code for lifestyle activity score
ORGAN_TYPE	Reference code for organ
PROTOCOL	Readmissions – number due to protocol
READMISSIONS	Number of readmissions over previous year
READMIT_OTHER	Readmissions – number due to other reason
RECIP_RELISTED	Was recipient relisted prior to death (y/n)
TUMOUR	Indicator whether Tx-related tumour detected (y/n)
TX_ID	Unique ID for transplant
VASCULAR_COMP	Readmissions – number due to vascular complications
RCS_LIVER_TX_RECORD	
ABDOMINAL_SURGERY	Indicator for previous upper abdominal surgery (y/n)

continued

ALBUMIN	Investigations – albumin (g/l)
ALTERED_DATE	
ANTI_CMV	Virology – anti CMV
ANTI_DELTA	Virology – anti delta
ANTI_FIB_THERAPY	Indicator for anti-fibrinolytic therapy (y/n)
ANTI_HBCLGM	Virology – anti HBclgM
ANTI_HBE	Virology – anti HBe
ANTI_HBS	Virology – anti HBs
ANTI_HCV	Virology – anti HCV
ANTI_HIV	Virology – anti HIV
ANTI_HSV	Virology – anti HSV
ARTERY_ANASTOMOSIS	Reference code for hepatic artery anastomosis
ASCITIES	Indicator whether clinically detectable ascities present (y/n)
BILIARY_ANASTOMOSIS	Reference code for biliary anastomosis
BILIRUBIN	Investigations – bilirubin (μmol/l)
COLD_ISCHAEMIA	Cold ischaemic time (hours)
CREATININE	Investigations – creatinine (μmol/l)
DIURETIC_THERAPY	Indicator for diuretic therapy (y/n)
ENCEPHALOPATHY_GRADE	Reference code for encephalopathy grade
FAILURE_GRADE	Reference code for liver failure grading
HB	Investigations – Hb (gm/dl)
HBE_AG	Virology – HBe Ag
HBS_AG	Virology – HBs Ag
HBV_DNA	Virology – HBV DNA antigen
HCV_RNA	Virology – HCV-RNA (PCR)
HEPATIC_ARTERY	Reference code for hepatic artery
ICP_MONITOR	Reference code for ICP monitor
INR	Investigations – INR
INTRA_BLOOD	Intraoperative blood products – blood (units)
INTRA_CRYOPRECIPITATE	Intraoperative blood products – cryoprecipitate (units)
INTRA_OPER_DEATH	Indicator for intra-operative death (y/n)
INTRA_PLASMA	Intraoperative blood products – fresh frozen plasma (units)
INTRA_PLATELETS	Intraoperative blood products – platelets (units)
IN_PATIENT	Indicator whether inpatient (y/n)
LIFESTYLE	Reference code for lifestyle activity score
LIVER_ORGAN_GRAFTED	
NUM_LIVER_DISEASES	
OESOPHAGEAL_VARICES	Reference code for oesophageal varices
OLT_NO	OLT number for liver transplant
ORGAN_APPEARANCE	Reference code for donor organ appearance
OXYGEN_PRESSURE	Investigations – PaO_2 (kPa)
PH	Investigations – pH
PLATELETS	Investigations – platelets $\times 10^9$/l
POST_BLOOD	Postoperative blood products – blood (units)
POST_CRYOPRECIPITATE	Postoperative blood products – cryoprecipitate (units)
POST_PLASMA	Postoperative blood products – fresh frozen plasma (units)
POST_PLATELETS	Post operative blood products – platelets (units)
POTASSIUM	Investigations – K (mmol/l)
PRESERVATION_FLUID	Reference code for preservation fluid
PRIMARY_LIVER_DISEASE	Reference code for primary disease
PYREXIAL	Indicator for pyrexial (y/n)
RECEIVED_DATE	
RENAL_SUPPORT	Reference code for renal support
REPERFUSION_TIME	Operative reperfusion time (hours)
SECONDARY_LIVER_DISEASE	Reference code for secondary liver disease
SEPSIS	Indicator for sepsis confirmed (y/n)
SEPSIS_SITE	Reference code for sepsis site
SODIUM	Investigations – Na (mmol/l)
TERTIARY_LIVER_DISEASE	Reference code for tertiary liver disease
TRANSPLANT_METHOD	
TX_ID	Unique ID for transplant
UREA	Investigations – urea (mmol/l)
VARICES_SHUNT	Reference code for shunt for varices (if present)

continued

VENO_VENOUS_BYPASS	Veno venous time (hours)
VENTILATED	Indicator whether ventilated (y/n)
WBC	Investigations – WBC $\times 10^9$/l
RECIPIENT	
ADDRESS_LINE1	Recipient address – line 1
ADDRESS_LINE2	Recipient address – line 2
ADDRESS_LINE3	Recipient address – line 3
BIRTH_DATE	Date of birth (if known)
BIRTH_DFLAG	Indicator for date of birth
BLOOD_GROUP	Reference code for recipient blood group
CMV	Indicator of CMV status
DEATH_DATE	Date of death (if known and applicable)
DEATH_DFLAG	Indicator for date if death
ETHNIC_ORIGIN	Reference code for ethnic origin
FORENAME	Forename of recipient
FORENAME_CSFLAG	Indicator of source of forename information
HCV	Indicator of HCV status
HLA_TYPED	Indicator of whether recipient tissue typed or not (y/n)
NATIONALITY	Reference code for country of nationality
NHS	Indicator whether eligible for NHS treatment
NHS_GROUP	Reference code of NHS eligibility group
NHS_NO	New format NHS number for recipient (if known)
PHONE1	Recipient telephone number (including note if required)
PHONE2	Alternative telephone number (including note if required)
POSTCODE	Recipient postcode
PRIMARY_COD	Reference code for primary cause of death
RECIP_ID	Unique ID for recipient
RESIDENCE	Reference code for country of residence
RHESUS	Reference code for donor rhesus type
SECONDARY_COD	Reference code for secondary cause of death
SEX	Reference code for recipient sex
SURNAME	Surname of recipient
SURNAME_CSFLAG	Indicator of source of surname information
SURNAME_SOUNDEX	Soundex value for surname of recipient
VITAL_STATUS	Recipient vital status (i.e. alive or dead)
RECIPIENT_AUDIT	
CHANGE_DATE	
COLUMN_NAME	
NEW_VALUE	
OLD_VALUE	
RECIP_ID	
TABLE_NAME	
USER_NAME	
RECIPIENT_CLASS_ORGAN	
CLASS_ID	Reference code for recipient class
ORGAN_GROUP	Reference code for organ group
RECIP_ID_REQUIRED	Indicator of whether recip_id required immediately (1) or later
RECIPIENT_HLA_SAMPLE	
A_HOMOZYGOUS	
A_HOMOZYGOUS_LABS	
B_HOMOZYGOUS	
B_HOMOZYGOUS_LABS	
DEFINITIVE_TYPE	
DR_HOMOZYGOUS	
DR_HOMOZYGOUS_LABS	
HOMOZYGOUS	
RECIP_ID	Foreign key to recipient
SAMPLE_CLASS	Reference code for sample class
SAMPLE_DATE	Date sample was recorded
SAMPLE_ID	Unique ID for a recipient HLA sample

continued

TT_LAB_ID	Foreign key to laboratories
RECIPIENT_MATCH_TT	
HLA_ENTITY_ID	
HLA_TEST_TYPE	
RECIP_ID	
SAMPLE_ID	
RECIPIENT_NOTE	
ENTERED_BY	User name entering note
NOTE_DATE	Date note entered
NOTE_TEXT	Text content of note
NOTE_TYPE	Reference code for note type
RECIP_ID	Unique ID for recipient
RECIP_ORGAN_AUDIT	
CHANGE_DATE	
COLUMN_NAME	
NEW_VALUE	
OLD_VALUE	
ORGAN_TYPE	
RECIP_ID	
TABLE_NAME	
USER_NAME	
RENAL_RECIPIENT	
DAYS_ACTIVE	Number of days active for purposes of matching
DAYS_ACTIVE_DATE	Date at which days active was calculated
DAYS_ACTIVE_DFLAG	Indicator for days active date
DIALYSIS	Dialysis status of recipient
DIALYSIS_DATE	Date dialysis started
DIALYSIS_DFLAG	Indicator for dialysis date
FUP_CENTRE	Foreign key to hospital – follow-up centre for recipient
HEIGHT	Height of recipient (cm)
HOSPITAL_NO	Hospital-specific reference number for patient
HSP	
KIDNEY_REG_DATE	Date of registration on kidney waiting list for current or last waiting
KIDNEY_REG_DFLAG	Indicator for kidney registration date
KIDNEY_STATUS	Reference code of recipient status on kidney waiting list
MATCHABILITY	
MATCH_GRADE	Reference code of match grade required
ORGAN_REQUIRED	Reference code of organ(s) required
PAEDIATRIC	
PAEDIATRIC_UNIT	Is recipient in paediatric unit (y/n)
PANCREAS_REG_DATE	Date of registration on pancreas waiting list for current or last waiting
PANCREAS_STATUS	Reference code of recipient status on pancreas waiting list
PRIMARY_DISEASE	Reference code of primary renal disease
RECIP_ID	Unique ID for recipient
RENAL_CENTRE	Foreign key to hospital – renal (i.e. dialysis) unit for recipient
RENAL_REG_NO	Renal register number
RESIDUAL_SENSITISATION	
TX_CENTRE	Foreign key to hospital – Tx unit for recipient
WEIGHT	Weight of recipient (kg)
RENAL_SENSITISATION	
BCELL_ANTIBODY	Reference code for B-cell antibody status
BCELL_FREQ	Reaction frequency against B-cell/CLL
BCELL_RESIDUAL	Reaction frequency of residual undefined activity (B-cell)
HLA_ANTIBODY_DATE	Date of antibody tests reported
NO_HLA_TAIL	All reactions accounted for (y/n)
RECIP_ID	Unique ID for recipient
SCREEN_CDC	
SCREEN_ELISA	
SCREEN_FC	

continued

TCELL_ANTIBODY	Reference code for T-cell antibody class
TCELL_FREQ	Reaction frequency against T-cell/PBL
TCELL_RESIDUAL	Reaction frequency of residual undefined activity (T-cell)
RENAL_STATUS_HISTORY	
EVENT_DATE	
EVENT_ORDER	
ORGAN_TYPE	Reference code for organ
RECIP_ID	Unique ID for recipient
STATUS	Reference code for status
STATUS_DAYS	
TX_ID	
UPDATED_BY	User name making update
UPDATED_DATE	Date of update
SAMPLE_TEST_MAP	
DISCREPANT	Reference code for test discrepancy
HLA_TEST_ID	Unique ID for HLA test
HOMOZYGOUS	
PARENT_TYPE	
SAMPLE_ID	Unique ID for sample
SAMPLE_TYPE	Reference code for sample type
TEST_CLASS	Reference code for test class
TRANSPLANT	
RECIP_ID	Foreign key to recipient – indicates who had transplant!
RECIP_ID_CSFLAG	Reference code for source of recipient ID
RECIP_TX_NO	Reference code for ordinal transplant number for recipient
TX_DATE	Date of transplant operation
TX_DATE_CSFLAG	Reference code for source of Tx date information
TX_DFLAG	Indicator for date of transplant
TX_ID	Unique ID for transplant
TX_TYPE	Foreign key to transplant type
TX_UNIT	Foreign key to hospital – unit where transplant operation was carried out
TX_DONOR	
DONOR_ID	Unique ID for donor
DONOR_ID_CSFLAG	Reference code for source of donor information
RELATIONSHIP	Reference code for relationship between donor and recipient
TX_ID	Unique ID for transplant
UNUSED_ORGAN	
DONOR_ID	Unique ID for a donor
HOT_DISPOSAL	Reference code for HOT method of disposal
HOT_NO_GOOD_CSFLAG	Reference code for HOT form notifying disposal (A, B, both)
HOT_REASON	Reference code for HOT reason for non-use
MATCH_STATUS	
ORGAN_STATUS	Reference code for status of organ
ORGAN_TYPE	Reference code for an organ
PRIMARY_REASON	Reference code for primary reason for status
RECIPIENT_UNIT	Foreign key to hospital – unit receiving organ (if any)
REMOVAL_DATE	
REMOVAL_DFLAG	
RETRIEVAL_UNIT	Foreign key to hospital – unit retrieving organ (if any)
SECONDARY_REASON	Reference code for secondary reason for organ status
TERTIARY_REASON	Reference code for tertiary reason for organ status
UNSUITABLE_ORGAN	
VALID_REASON	
CLASS	Reference code of class for which reason is valid
CLASS_DOMAIN	Domain of class for which reason is valid
REASON	Reference code of reason

Scotland and Newcastle Lymphoma Group (SNLG)

Description

The SNLG was established in 1978 to collect information regarding presentation, treatment and clinical outcome on patients suffering from lymphoma in Scotland and the Northern Region of England. SNLG has direct links to Northern UK Leukaemia Registry, being run by the same people in essentially the same way.

Data are collected from every Trust and hospital in Scotland and the northern part of the Northern and Yorkshire Health Region. In 2000, there were over 13,000 patient records/tests held on the database (10,500 cases of non-Hodgkin's lymphoma and 2800 cases of Hodgkin's disease). Since 1994, the database has been population based, registering more than 95% of lymphomas in the catchment population of 8.5 million.

SNLG aims to use the data to:

- assess where clinical trials may be needed
- form prognostic indices for clinical use in subgroups of patients
- facilitate subgroup harmonisation in rare diseases where no trials are indicated
- stimulate research questions.

Funding by Scottish CRAG from 1999 was to help develop the SNLG Register to extend coverage of the relevant patient populations; to establish mechanisms to ensure regular routine reporting of results across managed clinical networks to Health Boards and Trusts and for central requirements; and to improve the quality of data.

Data

The data are collected on paper annually from patient notes and transferred to computer.

The SNLG have developed Population-Adjusted Clinical Epidemiology (PACE), which involves establishing a geographically based census population of incident cases including diagnostic and prognostic data, in addition to outcomes, through which clinically focused trials and observational studies may be performed.

Two forms are used (see pp. 141–8). The first registers the patient's demographic details (with each patient allocated a unique identification number) and records clinical details based on presentation, pathology reports and hospital records. The second is used for an annual follow-up until death and is completed by the treating physician and GPs (if discharged from the clinic).

Coding system

The Kiel Lymphoma Classification has been used since the 1980s.

Completeness and accuracy

The level of notifications was estimated in 2000 to be 95%. The 'completeness' of forms is over 90%. In research studies each data section has been shown to have less than 10% omissions or 'not known' filled in on the forms. When SNLG publishes data on specific sub-groups of lymphoma, specific study protocol datasets are compiled and compared with the register. For studies involving patients not previously included in studies, researchers go back to the original case records to cross-check data on the forms, including specific reviews on the histopathological categories.

Internal validation comprises checks on all diagnostic pathology by a consultant haemotologist and by a medically qualified member of SNLG.

Uses

Studies undertaken[1,2] include:

- randomised trials of chemotherapy/radiotherapy
- development of prognostic indices for non-Hodgkin's lymphoma and Hodgkin's disease
- gut lymphoma dataset
- skin lymphoma dataset.

The Register was used to analyse[3] "all newly diagnosed patients with Hodgkin's disease in the Northern Health Region to prospectively assess the accuracy of staging at diagnosis, and to evaluate treatment and outcome. Radiological review revealed that only 12% of patients were staged to recognised guidelines. This combined research/audit programme has resulted in greater standardisation of care across a whole region".

Jackson *et al.*[4] analysed the long-term effects of autologous bone marrow and peripheral blood stem cell transplantation for patients with Hodgkin's disease and non-Hodgkin's lymphoma on loss of fertility.

The database has also been used[5] as the basis of a randomised trial testing whether survival for patients with high-grade non-Hodgkin's lymphoma could be improved with a non-cross-resistant regimen as compared with a CHOP-based regimen.

This is a multicentre study comprising 325 adult patients, median age 58 years, with high-grade non-Hodgkin's lymphoma: patients of any age and performance status were eligible provided that they were able to receive the drugs in the regimens.

No studies were located on diffusion, equity or costing.

Funding

There is no core funding for maintaining the database or related research programme. The total income for 1998–99 was £73,000, provided by the Scottish NHS R&D, Scottish CRAG (development), PALS groups, charitable trusts (£10,000) and a pharmaceutical company (£45,000 from Vanguard Group). Given the 13,000 records, this amounts to a unit cost of just over £5 per record.

Access

Access for patient-identifiable data through to anonymised individual patient data requires permission from the patients' consultant. Aggregated district and regional level data require the permission of all the consultants involved, whilst national level data require permission of the Working Party Consultants.

Researchers may request specific data, with no charges for a consultant's own data or for smaller tasks for consultants contributing to the database. Requests for data from outside sources are charged for the amount of work done.

Contact details

Professor SJ Proctor or Dr PRA Taylor
Department of Haematology
School of Clinical and Laboratory Sciences
University of Newcastle
Royal Victoria Infirmary
Newcastle upon Tyne
NE1 4LP
Tel.: 0191 2227791
Fax: 0191 2227632
E-mail: dept.haem@ncl.ac.uk

Publications

An annual report is published as 'cohort' data (no patient, consultant or Trust is identifiable) and includes abstracts of recent publications.

Scottish and Newcastle Lymphoma Group, Annual Report 1998–1999. Edinburgh: SNLG; 2000.

References

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2. Proctor SJ. Case for a strategic change in approach for clinical cancer trials and studies: a question of PACE (population adjusted clinical epidemiology). *Med Pediatr Oncol* 1998;**31**:527–9.
3. Taylor PR, Angus B, Owen JP, Proctor SJ. Hodgkin's disease: a population-adjusted clinical epidemiology study (PACE) of management at presentation. Northern Region Lymphoma Group. *QJM* 1998; **91**:131–9.
4. Jackson GH, Wood A, Taylor PR, Lennard AL, Lucraft H, Heppleston A, *et al*. Early high dose chemotherapy intensification with autologous bone marrow transplantation in lymphoma associated with retention of fertility and normal pregnancies in females. Scotland and Newcastle Lymphoma Group, UK. *Leukemia Lymphoma* 1997;**28**:127–32.
5. Cameron DA, White JM, Proctor SJ, Prescott RJ, Leonard RC, Angus B, *et al*. CHOP-based chemotherapy is as effective as alternating PEEC/CHOP chemotherapy in a randomised trial in high-grade non-Hodgkin's lymphoma. Scotland and Newcastle Lymphoma Group. *Eur J Cancer* 1997;**33**:1195–201.

SNLG basic data record sheet

Diagnosis details
Diagnosis:
- Lymphoma
- Not lymphoma

Newly diagnosed case (y/n):
- If yes:
  - Date of original diagnosis
  - Diagnosed outwith SNLG? (y/n)

Type of disease:
- Hodgkin's
- Non-Hodgkin's

Origin:
- Nodal
- Extranodal
- NK

Systematic symptoms (y/n/nk):
- Night sweats
- Weight loss
- Fever
- Itch

HIV related lymphoma (y/n/nk, not done/suspected, not proven)
Previous significant illness/transplant (y/n/nk):
- Auto immune disease
  - If yes, specify
- Coeliac disease
- Thyroid dysfunction
- Transplant
  - If yes, specify

Previous or concurrent malignant disease
Specify previous/concurrent malignant disease
Family history of lymphoma/leukaemia (y/n/nk)
- If yes:
  - HD
  - NHL
  - Leukaemia

Strong family history of malignant disease [≥ 2 1st-degree relatives (excluding skin cancer)] (y/n/nk)

Investigative/histological details
General condition, fitness rating (grade 1–5) modified Karnofsky
Palpation of spleen:
- Not palpable
- Palpable
- Previous splenectomy
- NK

Palpation of liver:
- Normal
- Enlarged

Biochemical details
Haematology results:
- Plasma viscosity
- ESR
- Hb
- WBC

Differential count:
- Neutrophils
- Lymphocytes
- Monocytes
- Eosinophils

continued

Basophils				
Other (specify)				
Platelets				
	Normal		Abnormal	NK/not done
		Level	Lower…Normal range…Upper	
Blood urea				
Serum LDH				
Serum AST				
Serum ALT				
Serum alk. phos. (specify type: liver/bone)				
β-Microglobulin				
Serum albumin				
Hodgkin's disease thyroid function				
TSH				

Scanning/radiology details

Radiology of chest:				
Done				
Not done				
No lymphoma				
	Right	Left	Lymphoma	Possible lymphoma
Lungs				
Mediastinum (no laterality)				
Hilar				
Pleural effusion				
	No lymphoma	Possible lymphoma	Lymphoma	Not done
Bone scan:				
CAT scan:				
Thoracic				
Abdominal				
Head and neck				
Gallium scan				
Ultrasound scan				
MRI				
Bone radiograms				

Pathology/cytology details

Pathology histology No.				
Hospital				
Lymphadenopathy:	Right	Left	(As appropriate)	
None				
Waldeyer's ring				
Cervical				
Infraclavicular				
Axillary				
Coeliac				
Para-aortic				
Mesenteric				
Pelvic (iliac)				
Inguinal				
Popliteal				
Other (specify)				
Marrow:	No lymphoma	Lymphoma	Failed	Not done
Aspirate				
Trephine				
Liver biopsy (percutaneous or laparoscopy)				
	Done		Not done	
Laparotomy				
Splenectomy				
Laparotomy (histology of) (negative/positive):				
If positive, in:				
Splenic hilum				
Coeliac nodes				

continued

Para-aortic nodes
Mesenteric nodes
Iliac nodes
Other nodes (specify)
Spleen
Liver
Other (specify)
Initial diagnostic histology (y/n):
Lymph node
Other (specify)
Evidence of disease (histologically proven):
Bone marrow
Bone
CNS
Genito-urinary
Gut
Liver
Lung
Orbit
Skin
Thymus
Thyroid
Other (specify)
Nodal (lymph nodes, etc.)

Staging
Clinical stage (I–IV) (Cotswolds and SNLG)
Clinical stage based on clinical evidence found in:
Lymph nodes
Liver
Spleen
Bone
Lung
CNS
Other (specify)
Number of involved sites (stage II only)
'B' symptoms: A/B
Extranodal disease:
'E' site
None
Stage IV
Bulk disease (y/n/nk):
If yes:
Abdomen
Other (specify)
If abdomen/other:
≥ 5,< 10 cm
≥ 10 cm
Mediastinum
(Chest diameter at T5/T6)
≤ 1/3
> 1/3
> 45%
Pathological stage:
M (marrow)
H (liver)
L (lung)
O (bone)
P (pleura)
D (skin)
Extent of staging:
Complete
Incomplete

continued

Pathological category
Hodgkin's disease:
- Lymphocyte predominant
- Nodular sclerosing
- Mixed cellularity
- Lymphocyte depleted
- Other (specify)

Non-Hodkgin's lymphoma (working formulation):
- Low-grade ML
  - A. Small lymphocytic
  - B. Follicular – predominantly small cleaved cell
  - C. Follicular – mixed small cleaved cell and large cell
- Intermediate-grade ML:
  - D. Follicular – predominantly large cell
  - E. Diffuse – small cleaved cell
  - F. Diffuse – mixed small and large cell
  - G. Diffuse – large cell (large non-cleaved, large cleaved)
- High-grade ML:
  - H. Large cell immunoblastic
  - I. Lymphoblastic
  - J. Small non-cleaved (Burkitt's)

Other (specify)

Non-Hodgkin's lymphoma (Kiel classification):
- B-cell low grade
  - Lymphocytic (CLL, PLL, HCL)
  - Lymphoplasmacytic/cytoid
  - Plasmacytic/plasmacytoma
  - Centroblastic–centrocytic–follicular
  - Centroblastic–centrocytic–diffuse
  - Centrocytic
- B-cell high grade
  - Centroblastic
  - Immunoblastic
  - Large cell anaplastic (ki I +ve)
  - Lymphoblastic
  - Burkitt's
- T-cell low grade
  - Lymphocytic, small cerebriform cell
  - Mycosis fungoides
  - Sezary syndrome
  - T-zone lymphoma
  - Lymphoepithelioid (Lennert's)
  - Angioimmunoblastic (AIL)
  - Pleomorphic small cell
- T-cell high grade
  - Pleomorphic medium cell
  - Pleomorphic large cell
  - Immunoblastic
  - Large cell anaplastic (ki I +ve)
  - Lymphoblastic
- Other (T or B cell)
  - (specify)

B-cell:
- Precursor
  - Lymphoblastic
- Peripheral
  - B-CLL/lymphocytic lymphoma
  - Lymphoplasmacytoid
  - Mantle cell lymphoma
  - Follicle centre lymphoma:
    - Follicular (grade I, II, III)
    - Diffuse predominantly small cell

continued

Marginal zone lymphoma:
Extranodal low grade maltoma
Nodal, ± monocytoid B cells
Splenic marginal zone lymphoma
Hairy cell leukaemia
Plasmacytoid/myeloma
Diffuse large B-cell lymphoma
Birkitt's lymphoma
Birkitt-like lymphoma
Other (B-cell) (specify)
T-cell:
Precursor
Lymphoblastic
Peripheral
T-CLL/prolymphocytic lymphoma
Large granular lymphocytic leukaemia
Mycosis fungoides
Peripheral T-cell lymphomas unspecified
Angioimmunoblastic T-cell lymphoma
Angiocentric lymphoma
Intestinal T-cell lymphoma ±enteropathy
Adult T-cell lymphoma/leukaemia HTVL+
Anaplastic large cell lymphoma (T and null)
Anaplastic large cell lymphoma Hodgkin's like
Other (T-cell) (specify)
Unclassifiable as T or B (specify)
Hodgkin's disease:
Lymphocyte predominance modular (diffuse)
Nodular sclerosis
Mixed cellularity
Lymphocyte depletion
Lymphocyte-rich classical HD
Other (specify)
Immunotyping at diagnosis:
T
B
Null
Histiocytic
Other
ND
NK
(y/n/nk):
Advanced immunocytogenetics
DNA studies
EB virus status
Other (specify)

SNLG annual follow-up form

Administrative details
Centre
Hospital
Consultant in clinical charge
Lymphoma diagnosis discarded (no other entry required)
Date last seen
General condition (fitness rating I–V) (modified Karnofsky)
State at date last seen:
Alive
Dead
Untraceable
Remains in complete remission

continued

Developments with dates in above 12 months

State of lymphoma (date):
- CR, no radiological
- CR(u), unconfirmed
- Part remission
- No remission
- Relapse

Appearance or reappearance of systemic symptoms:

	Yes	No	Reappearance	NK
Night sweats				
Weight loss				
Fever				
Itch				
Herpes zoster				

Presence of disease: was disease present during the above 12 months (excluding disease declared at diagnosis, unless such disease is persisting or recurring)? (y/n/unsure)

Type of new disease:

	Right	Left	Histologically proven
Nodal			
Waldeyer's ring			
Cervical			
Infraclavicular			
Axillary			
Mediastinal			
Hilar			
Coeliac			
Para-aortic			
Mesenteric			
Pelvic (iliac)			
Inguinal			
Other nodes (specify)			
Spleen			
Extranodal			
Bone marrow			
Bone			
CNS			
Genito-urinary			
Gut			
Liver			
Lungs			
Orbit			
Skin			
Thymus			
Thyroid			
Other (specify)			
Both			

Type of persisting disease:
- As above

Type of recurring disease:
- As above

Transformation to leukaemia (y/n):
- If yes, specify

Transformation to high grade (y/n):
- If yes, complete new pathological classification

Development of 2nd malignancy (y/n):
- If yes:
  - Non-haematological (specify)
  - Haematological (specify)

Change of diagnosis (y/n):
- If yes:
  - From initial specimen (y/n):
  - From second specimen (y/n/not done)

continued

Change of histological type (y/n):
- If yes:
  - From initial specimen (y/n)
  - From second specimen (y/n/not done)

Treatment

Treatment for lymphoma in above 12 months (y/n):
- If yes:
  - Initial therapy only
  - Subsequent therapy only
  - Both

Initial therapy

Started in above 12 months (y/n):
- If yes, date

Type:
- Radiotherapy
- Chemotherapy
- Surgery (specify)
- Other (specify)
- If combined modality indicate sequence

Radiotherapy:
- Localised
- Regional
- Mantle
- Inverted Y
- TBI
- Other (specify)

Chemotherapy:
- Single agent (specify)
- Other (specify)

Acute adjunctive therapy (y/n):
- If yes specify

Treatment subsequent to initial therapy

Was treatment subsequent to initial therapy started in the above 12 months (y/n)
- If yes, date

Type of subsequent therapy:
- Radiotherapy
- Chemotherapy
- Surgery (specify)
- Other (specify)
- BMT/PBSC
- If combined modality indicate sequence

BMT/PBSC:
- Date
- Allogenic
- Autologous
- Syngeneic
- Done in:
  - 1st remission
  - 2nd remission
  - Partial remission
  - Other specify

Radiotherapy:
- As above [including BMT conditioning (specify)]

Chemotherapy:
- As above [including BMT conditioning (specify)]

Therapy induced premature menopause (y/n):
- If yes:
  - Chemotherapy
  - Radiotherapy
  - Both
  - Other (specify)

continued

Death details
Date
Post mortem done (y/n):
  If yes:
    Was there a change in the histological diagnosis (y/n)
      If yes, specify
Principal cause of death:
  Lymphoma
  Treatment of lymphoma
  Other (specify)
Did treatment contribute significantly to death (y/n/nk)
At death was lymphoma clinically in:
  CR, no radiology abnormality
  CR(u) unconfirmed/uncertain
  Partial remission
  No remission
  Relapse
  Not known
At post mortem was lymphoma in:
  CR, no radiology abnormality
  CR(u) pathological abnormalities, possibly lymphoma but uncertain
  Partial remission
  No remission
  Relapse
  Not known

Comments

Scottish Hip Fracture Audit (SHFA)

Description

The SHFA was established in June 1993 to document and improve Scottish hip fracture care and outcomes. The database follows the example of the Swedish Multicentre Hip Fracture Study, developed in Sweden by Professor Thorngren. Initially set up with two participating hospitals, the Scottish audit had expanded by mid-1999 to cover 18 hospitals.

The SHFA database employs the Standardised Audit of Hip Fracture in Europe (SAHFE), based on the Swedish dataset which has standardised optional questions, which allow comparison between hospitals. In June 1999, the SHFA contained 10,000 individual patient records, including any consecutive admissions of hip fracture patients.

The main objectives of the Audit are:

- documentation of hip fracture outcomes
- improving services by providing orthopaedic units and others involved with rehabilitation of hip fracture with feedback data
- comparison of outcomes of hip fracture patients with different stratifications/managed in different units/nationally and internationally
- monitoring the effects of changes in surgical and rehabilitation policies.

Funding

The SHFA Audit Coordinator is funded through ISD Scotland. Individual centres are funded from local audit budgets, or from orthopaedic budgets through Health Boards. The cost is approximately £60 per hip fracture patient, with a half-time dedicated F-grade audit nurse usually employed to undertake the audit in each centre. The estimated total cost, based on £60 per patient and around 10,000 patients per annum, is put at around £60,000 per annum in Chapter 9.

Data

Each of the 18 participating hospitals collects the same core dataset according to set protocols on a continuous basis. Additional optional standardised

data are also collected according to local needs. Dedicated audit nurses collect the information using paper forms which are entered on to SPSS. Patients are followed up at 4 months post-fracture and in some hospitals also at 12 months. Data are analysed centrally by the SHFA Audit Coordinator and fed back to the individual departments via the audit nurses.

Data are locally owned and available to members of the respective centres. Reports are prepared 6-monthly and at any other time when specific information is required. Some hospitals use the data for research. Follow-up questionnaires for every patient are issued after 4 and 12 months.

Data collection – content
Seven different paper forms track activity relevant to each stage of treatment (see pp. 150–9).

Coding schemes
The SHFA coding scheme has been used since the database started in 1993. Dialogue in 1999 was continuing with the European Group to eradicate anomalies and make the coding flexible enough to incorporate variations.

Planned developments
There are plans to use the NHS number in SHFA to allow link-up with other datasets such as the Blood Transfusion Database. The Standardised Audit of Hip Fracture in Europe (SAHFE), of which the Scottish Hip Fracture Audit is a member, has just completed its pilot phase. International comparisons of hip fracture care and outcomes are planned.

Access
Access and use of the data held by the individual orthopaedic units are subject to the permission of the local orthopaedic surgeon involved. Any researcher should in the first instance contact the SHFA Audit Coordinator. There are no charges for supplying information.

USE of SHFA data in HT assessment
Effectiveness: SHFA is used mainly for comparative audit and contributes to the clinical indicators.

No diffusion, equity or costing studies were located.

Validation
All hip fracture admissions are recorded on the audit initially during their orthopaedic stay in each hospital. This information is cross-checked with patients' medical records before submission to SHFA. The audit nurses are trained at the Royal Infirmary of Edinburgh by the SHFA coordinating team, who also provide a back-up function for any questions or problems that arise during the data collection and computer input. Quality checks are performed on the data by the Audit Coordinator, during the first month of audit and then at regular intervals. Regular meetings are held of all the audit nurses.

SHFA includes 80% of all hip fractures treated in Scotland (CRAG annual report 1999). The completeness of information on patients received from the hospitals is reported as 99%, with the 4- and 12-month follow-ups 98% complete.

Site visits by the SHFA central coordinator review the quality of data collected, and include random tests on the accuracy of input data compared with those collected.

The database is not externally validated, but in 1999 SHFA had plans to check its returns SMR1 data held by the Information and Statistics Division of the Scottish Office.

Contact details
The Scottish Hip Fracture Audit
The Royal Infirmary of Edinburgh
Lauriston Place
Edinburgh
EH3 9YW
Tel.: 0131 5363798
Fax: 0131 5363809
E-mail: jenny21nau@aol.com

Publications
The CRAG annual report (most recent located 1999) provides details of the four audits that it funds (Hip Fracture, Scottish Surgical Mortality, Scottish Trauma Audit Group and the Scottish Renal Register).

A website in conjunction with three other National Scottish Audits was planned in 1999 but had not gone live by January 2000.

CRAG clinical outcomes indicators. Clinical Outcomes Working Group; 1999.

Grant to Dr CT Currie and Mr S Kendrick, Scottish National Hip Fracture Audit Data Base – preliminary statistical analysis of case-mix, process and outcomes: a grant of up to £13,744 over 6 months. See *Scott Exec Health Bull* 2000;**58**.

Robinson CM, Adams CI, Craig M, Doward W, Clarke MC, Auld J. OTA presentation, 13 October 2000, Session VI, Paper 37: Fractures of the femur following hip fracture surgery (http://www.hwbf.org/ota/am/ota00/otapa/OTA00637.htm).

Primary questions: form 1

Administrative details
Country and hospital code
Patient ID number
SAHFE number
Side of fracture:
- Left
- Right
- Simultaneous bilateral – use 2 forms

Date of fracture
Date of birth
Sex

Admission details
Date
Admitted from:
- Own home
- Sheltered housing
- Institutional care
- Nursing home
- Permanent hospital inpatient
- Rehabilitation unit
- Acute hospital
- Other
- Died

Living alone:
- Yes
- No
- Institutional care

Pre-fracture details

Locomotor ability:	Out of doors	Indoors only
Walked alone		
Only if accompanied		
Unable to walk		

Walking aids:
- Could walk without aids
- One aid
- Two aids
- Frame
- Wheelchair/bedbound

ASA grade
- Completely fit and healthy
- Some illness, no effect on normal daily activity (e.g. asymptomatic condition such as hypertension)
- Symptomatic illness present, minimal restriction on life (e.g. mild diabetes mellitus)
- Symptomatic illness causing severe restriction (e.g. severe chronic bronchitis)
- Moribund

Fracture details
Type of fracture
- Undisplaced intracapsular
- Displaced intracapsular
- Basocervical
- Trochanteric two fragments
- Trochanteric multi-fragments
- Subtrochanteric (any no. of fragments)

Pathological fracture
- No
- Malignant secondary bone tumour
- Malignant primary bone tumour
- Bone cyst
- Paget's disease
- Other (specify)

continued

Operation details
Date of operation
Primary operation:
- Single screw, pin or nail
- Two screws, pins or nails
- Three or more screws, pins or nails
- Single screw, pin or nail with side plate
- Intramedullary nail
- Hemiarthroplasty
- Total hip arthroplasty
- Conservative
- Other (specify)

Discharge details (if re-operation performed, details on Form 3)
Date of discharge or death from primary admission ward
Discharged to (as admitted from)

4-Month assessment[a]: form 2

Administrative details
Country and hospital code
Patient ID number
SAHFE number
Side of fracture:
- Left
- Right
- Simultaneous bilateral – use 2 forms

Date of fracture
Date of birth
Sex

4-Month assessment details[b]

Date			
Assessment done by:	Face to face	Phone	Postal questionnaire
Patient			
Carer/relative/friend			
Other (specify)			
Residential status:			
Own home			
Institutional care			
Nursing home			
Permanent hospital inpatient			
Rehabilitation unit			
Acute hospital			
Other			
Died			
Locomotor ability:	Out of doors	Indoors only	
Walked alone			
Only if accompanied			
Unable to walk			
Walking aids:			
Can walk without aids			
One aid			
Two aids			
Frame			
Wheelchair/bedbound			
Pain at hip:			
Severe and spontaneous, experienced even when not moving			
Severe when attempting to walk, prevents all activity			
Tolerable, permitting limited activity			

continued

Occurs only after some activity, disappears quickly with rest
Slight or intermittent, experiences pain when starting to walk, pain gets less with normal activity
No pain in hip
Unable to answer

Type of stay/re-admission (×6)
Type
Duration
Reason:
Surgical complications requiring re-operation
Surgical complications not requiring re-operation
Medical complications related to hip fracture
Failure to manage at place of origin due to hip fracture
Admitted for reasons not related to hip fracture
Return to place of origin
Unknown/not stated

Death
If death within 4 months of fracture – date of death

[a] Centres may choose an optional assessment 1 year after fracture, selecting questions they wish. It is recommended that they include the questions from the 4-month assessment (Form 2) and re-operation details (Form 3) for each re-operation within the year.
[b] Additional questions (abilities and social support, Form 4) may be included, which when also included in the pre-operative assessment (Form 1) will give a measure of recovery.

Re-operation: form 3

Administrative details
Country and hospital code
Patient ID number
SAHFE number
Side of fracture:
Left
Right
Simultaneous bilateral – use 2 forms
Date of fracture
Date of birth
Sex

Admission details
Date
Admitted from:
Own home
Sheltered housing
Institutional care
Nursing home
Permanent hospital inpatient
Rehabilitation unit
Acute hospital
Other
Died

Re-operation details
Date
Type of operation:
Removal implant
Hemiarthroplasty
Total hip arthroplasty
Re-osteosynthesis

continued

Girdlestone/exicision arthroplasty
Drainage haematoma or infection
Reduction dislocation
Other (specify)
Reason for re-operation:
Fracture displacement
Loss of position of osteosynthesis material without fracture displacement
Additional fracture around implant
Non-union (pseudarthrosis)
Femoral head necrosis (segment collapse, avascular necrosis in a fracture that has healed)
Local pain or tenderness at operation site or prominent implant causing discomfort with healed fracture
Wound infection
Wound haematoma
Dislocation of arthroplasty
Breakage of the implant
Dissembling of the implant
'Elective' removal of the implant. Fracture healed and no significant symptoms
Other (specify)

Discharge details
Date of discharge or death in hospital
Discharged to: (as admitted from)

Abilities of patient immediately prior to the fall or at follow-up: form 4

Administrative details
Country and hospital code
Patient ID number
SAHFE number
Side of fracture:
Left
Right
Simultaneous bilateral – use 2 forms
Date of fracture
Date of birth
Sex

Abilities[a]
Abbreviated mental test score (0–10)
For each of the following the alternatives are scored 1–5 (in order). The ADL score is the sum of the scores
Dressing:
Able to dress completely without any help from another person (excludes tying shoe laces)
Needs a little help with buttons or zippers
Needs assistance with shoes/stockings
Needs assistance with up to 3 items
Needs to be dressed by others
Bathing or taking a shower:
Able to bath or take a shower (including the use of a handrail or stool)
Needs a little help in washing a single part of the body such as back or feet
Needs assistance getting in or out of the bath tub
Needs assistance in bathing one or more parts of the body
Always needs to be bathed by others
Feeding:
Can cut and eat without any help from others
Needs help to cut hard food
Needs assistance in handling food
Needs a large amount of help to feed
Cannot feed at all and has to be completely fed by others
Toileting:
Can get on and off the toilet managing clothing, may use mechanical supports
Needs assistance with getting to and from the toilet

continued

Needs assistance getting on and off the toilet, and adjusting clothing
Needs assistance in cleaning organs of excretion
Wears pads or uses a catheter or bed pan at all times
Shopping:
Can do all shopping without the assistance of another person
Needs assistance getting to or from the shops/can only shop independently if for small items/able to shop but gets someone else to do it for them
Needs assistance with selecting shopping/unsure about what to buy/must always be accompanied due to physical, psychological or visual impairment
Needs help with two or more tasks associated with shopping
Completely unable to shop
Housework
Able to manage house alone with only occasional help
Able to perform all home maintenance tasks but needs some assistance, e.g. lifting
Light daily tasks
Needs assistance with light household duties
Unable to do housework
Laundry:
Able to wash clothes, hand or machine
Needs assistance going to laundry/hanging up laundry/able to do, somebody else does it/able to if had machine at home
Able to wash delicates or personals by hand/needs assistance loading emptying the machine
Needs a large amount of help to do the laundry
Unable to do the laundry at all
Food preparation:
Able to prepare food
Patient is able to do some but somebody else does it
Able to prepare a small meal or sandwich if supplied with ingredients
Able only to reheat foods
Must have all meals prepared
Banking and finances:
Able to manage all financial matters including going to the bank, handling cash, performing transactions and managing income
Needs assistance going to the bank or does it by mail/cannot get to the bank but can do everything else/somebody else does it
Able to manage day to day purchases but needs assistance with major purchases
Needs to be taken to the bank and requires other help for transactions, etc.
Unable to handle financial matters
Use of transport:
Able to travel independently on public transport/bus, train, drives a car
Arranges own travel by taxi, does not use bus, train
Must always be accompanied because of physical, psychological or visual impairment
Travels in a taxi or car only with assistance
Unable to travel
ADL score (the sum of the items 41–50)

Social support and assistance
Social support and assistance:
Needs no assistance in normal activities of daily living
Needs some assistance in a few aspects of the more strenuous activities of daily living
Needs assistance in preparing meals and housework but can dress and toilet independently
Needs assistance in washing and dressing but can get to toilet independently
Needs assistance in toileting and feeding
Social support and assistance is provided by:
No assistance necessary
Spouse
Other relatives
Spouse and other relatives
Paid help and private provided or from the state
Spouse and paid help
Paid help and relatives
Spouse, relatives and paid help

continued

Social support is economically provided by: Privately paid for (informal care) Provided by the state (formal care) None received Hours of social support received (average hours per week):
Medical/psychological state Psychological state, prior to hip fracture: Did you enjoy the things you used to enjoy Did you feel lonely Did you find it hard to make contact with people Did you feel there was nobody you were close to Did you feel a burden to people Did you enjoy a good book, radio or TV programme Haemoglobin, Hb (g/l) Creatine (μmol/l) Albumin (g/l) Height (m) Weight (kg) Body mass index, BMI Date of menopause (year only) Date of menarche (year only) Medical conditions present: Cardiovascular disease Previous stroke Respiratory disease Renal disease Diabetes mellitus Rheumatoid disease Parkinson's disease Malignant disease Paget's disease Smoking On oral steroids
Fall history Falls during: — No — Up to 3 — More than 3 Last 2 years before hip fracture First 4 months after operation Fear of fall (y/n)
[a] Questions from the abilities and social support and assistance sections may be included in the 4-month assessment (Form 2) if they are also used as part of the pre-operative assessment (Form 1), allowing a measure of recovery.

Additional treatment of the injury and treatment: form 5

Administrative details Country and hospital code Patient ID number SAHFE number Side of fracture: Left Right Simultaneous bilateral – use 2 forms Date of fracture Date of birth Sex
Fall details Place of fall: At home Inside but not at home or hospital
continued

- Hospital
- Outside
- No fall (spontaneous fracture which occurred without injury)

Other co-existent fractures:

- Upper limb fracture
- Additional lower limb fracture
- Other upper/lower limb fractures
- Other fractures not of limbs
- Fracture of limb(s) and other areas of the body

Surgery details

Time of admission

Time of start of operation

Delay to operation (of more than 24 hours for any one or more of these causes):

- No delay
- Prior to admission to orthopaedic ward
- To establish/confirm the diagnosis (specify)
- Diagnosis confirmed by
  - Later review
  - Repeat X-rays
  - Bone scan
  - CT scan
  - Other (specify)
- Administrative delay (specify)
- Lack of hospital bed on orthopaedic ward
- Lack of availability of theatre space
- No surgeon available
- No anaesthetist available
- Other cause delay (specify)
- The fracture was initially treated conservatively
- Operation delayed as patient was medically unfit
- Electrolyte imbalance
- Diabetes mellitus stabilise
- Chest condition (treatment of)
- Rehydration
- Transfusion for anaemia
- Congestive cardiac failure (treatment of)
- Cardiac arrhythmia (treatment of)
- Gastrointestinal bleed
- Other (specify)
- To assess medical state (get results of investigations, etc.)
- No reason apparent

Grade of surgeon:

- Qualified/specialist
- Staff grade surgeon/associate specialist
- A trainee surgeon on training scheme
- Other trainee surgeon but not on a trainee scheme
- Locum or temporary surgeon
- Other (specify)

Type of surgeon:

- Orthopedic
- Traumatologist
- General surgeon
- Other

Grade of anaesthetist:

- Qualified/specialist
- Staff grade surgeon/associate specialist
- A trainee anaesthetist
- An anaesthetic technician
- Locum or temporary anaesthetist
- Other (specify)

Length of surgery (minutes)

continued

Length of surgery and anaesthetic time (minutes)				
Type of anaesthetic:				
General				
Spinal or epidural				
Local blocks and infiltration				
Other (specify)				
Estimated operative blood loss (ml)				
Volume of blood:				
Transfused: prior to surgery				
In the 5 days from surgery				
Haemoglobin:				
Immediately after surgery				
Day one after surgery				
Cement used to fix fracture or prosthesis (y/n)				
Surgical approach for anthroplasty:				
Anterior				
Anterolateral				
Lateral with osteotomy				
Posterior				
Use of growth factor (y/n)				
Thromboembolic prophylaxis:				
Mechanical (specify if not next 3)				
Graduated stockings below the knee				
Graduated stockings above the knee				
Foot pump				
Pneumatic calf compression				
Heparin (other or unknown type)				
Conventional heparin				
Low molecular weight heparin				
Warfarin				
Dextran				
Aspirin				
No prophylaxis used				
Other (specify)				
Commencement of thromboembolic prophylaxis:				
	<6 hours	12 hours	24 hours	>24 hours
Before surgery, hrs after admission				
After surgery				
Duration of thromboembolic prophylaxis				
Antibiotic prophylaxis (y/n)				
Time (days) from surgery to mobilisation				
Time (days) to be allowed to fully bear weight				

Additional details of the type of fracture and reduction: form 6

Administrative details
Country and hospital code
Patient ID number
SAHFE number
Side of fracture:
Left
Right
Simultaneous bilateral – use 2 forms
Date of fracture
Date of birth
Sex
Fracture classification
AO classification of all fractures
Garden grade of intracapsular fracture

continued

Pauwels grade of intracapsular fracture
Jensen and Michaelsen classification of trochanteric fractures
Additional classification intracapsular fractures
  Even fracture surface
  Rostiform, indented fractures surfaces
  One extra fracture
  Several extra fractures
  Comminuted zone

Garden alignment index
Pre-operative:
  Garden alignment index on anterio-posterior radiograph
  Garden alignment index on lateral radiograph
Post operative fracture reduction on the per-operative or first post-operative radiographs:
  Garden alignment index on anterio-posterior radiograph
  Garden alignment index on lateral radiograph

Osteoporosis measures
Singh grade (1–6)
Osteoporosis as measured by Dexa:
  None
  <1 standard deviation
  <2 standard deviations
  <3 standard deviations

Additional details of complications: form 7

Administrative details
Country and hospital code
Patient ID number
SAHFE number
Side of fracture:
  Left
  Right
  Simultaneous bilateral – use 2 forms
Date of fracture
Date of birth
Sex

Pressure sores
Occurrence on buttock:
  None
  Non-blanching erythema of intact skin
  Partial thickness skin loss
  Full thickness skin loss and extension into subcutaneous fat but not underlying fascia
  Extensive destruction involving damage to muscle, bone or tendon
Occurrence on heel:
  As above
Occurrence on any other area:
  As above

Incidence of complications
Complication (y/n):
  Chest infections
  Cardiac failure
  Deep vein thrombosis
  Pulmonary embolism
  Superficial wound infection
  Deep wound infection
  Wound haematoma

continued

Urine retention
Urine infection
Acute renal failure
Gastrointestinal haemorrhage
Myocardial infarction
Cerebrovascular accident
Other (specify)

St Mary's Maternity Information System (SMMIS) Database

Description

Established in 1988 by the former North West Thames Region IT services, the SMMIS records over 200 items of pregnancy/neonatal-related data from the time of booking to the end of the neonatal period.* The original aim of the database was to provide clinically based maternity data for comparative studies, taking into account the recommendations of the National Perinatal Epidemiology Unit.

The database is held at the Department of Epidemiology and Public Health, Imperial College School of Medicine, St Mary's (London). It is an anonymised extract downloaded from each of the hospital systems with ongoing software support and local systems maintained by Ciconia Healthcare Systems Ltd.

The database is used for audit of care at the regional and hospital level and to provide data for the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI). The dataset is also used for *ad hoc* queries and more detailed clinical studies. SMMIS has analysed data on 438,982 deliveries (1988 to 1998 inclusive) from 12 maternity units.

Although the SMMIS database collects from units around North West Thames, there are 15 other units around England and Wales which use the Ciconia system.

Data

Participating hospitals have their own maternity information system that is used to collect data on a daily basis for both clinical and administrative purposes. For the purpose of the regional database, the data items required are downloaded annually from each participating unit on to a centrally held database at the Department of Epidemiology and Public Health (Imperial College, London). In most hospitals the data entry is undertaken by a range of personnel, with administrative information usually entered by clerical staff and maternity information by midwives.

Depending on the quality of data received, the validation and cleaning process can take between 1 week and 2 months to process.

Information is collected on the mother, ultrasound and screening details, antenatal conditions/complications, labour and delivery, postnatal maternal and infant health status.

A detailed list of data items collected is given on pp. 161–9.

Coding systems

ICD-9 was used since the inception of SMMIS, updated to ICD-10. OPCS procedure codes are also employed.

Planned developments

The two main projects affecting the future development of SMMIS are as follows:

Regional Reproductive Review Information Project (R^3IP)

This database holds information on around 350,000 births in the former North East Thames area. Birth information is being collected from all maternity units within this area, with all districts using the Regional Interactive Child Health System† (RICHS). The intention is for this database to run alongside the SMMIS database.

Maternal and Child Health Information Systems Project (MACHIS)

MACHIS assessed the use of Maternity and Child Health Information Systems in the two former North Thames regions, with four key objectives:

- assessing existing maternal health systems in the Thames regions (validating a proportion of these)

* SMMIS has also been used in 15 maternity units throughout the UK.[1]

† An improved version of the National Child Health System (NCHS).

- creating a regional maternal database (linking maternal data from the routine systems in use)
- assessing the existing child health information systems in the Thames regions (as a demonstration project, linking the child health data in one community trust with information from maternity systems)
- examining the utility of the maternal and the linked maternal and child health databases.

Recommendations included the use of standardised datasets for maternity and child health.[2]

Completeness and accuracy

The SMMIS database collects data from 12 maternity units in the former North West Thames region, covering all but one unit (Barnet) since 1988. Six other units which had contributed ceased, owing partly to reorganisation of hospitals.

Notifications of pregnant women from the participating hospitals are reported to be 100% because the data collection is part of patient administration.

Completeness of data varies owing to some data items not being collected from day one, or when items deemed unimportant are omitted. Some plausibility and logicality checks are made, and the computer package will not accept missing data within a data field. If data are found to be missing, the item is sent back to the original source for verification. Birth status is compared with ONS data on a yearly basis, showing close agreement.

A review of 892 maternity records from three hospitals showed that of the 17 directly recorded SMMIS data items compared with clinical notes, 15 had agreement of over 80%, with 10 of these 95% and over (J Harris, unpublished correspondence, SMMIS, July 2000).

Maternity units often validate small subsets of the data for their own use through the year. The majority of hospitals have a hand-written birth register which contains all basic demographic details in addition to basic medical information (e.g. method of delivery, complications). All data entered are checked against the hand-written registry.

Uses

The system is deemed to capture sufficient detail to be used for comparative audit[3] but no published accounts of such use have been located (despite telephone contact with Ciconia in mid-2001).

No studies were located on diffusion, equity or costing.

Funding

Originally funded by North Thames Region and Trusts, since 1997 it has been funded by Dr J Chapple (Kensington, Chelsea and Westminster Health Authority) from the CESDI budget (J Harris, unpublished correspondence, SMMIS, July 2000). The estimated cost of maintaining the database is around £300,000 (10 units with 3000 births per annum at £10 per record).

Access

SMMIS were in 2000 in the process of formalising access to the database. Medical personnel working in the NHS requiring data for audit or comparative studies are allowed access. Outside researchers requiring information would be allowed access only after approval from the ethics and advisory committees, and may need to submit a protocol outlining the requirements. Any data requests should be made to J Harris (address below).

Contact details

A Dawson (contact for operational/technical information, links to hospital PAS, HISS or other systems)
Ciconia Healthcare Systems
The Business Centre
758–760 Great Cambridge Road
Enfield
Middlesex
EN1 3RN
Tel.: 0208 443 7067
E-mail: adawson@ciconia.co.uk

Dr J Chapple
Consultant in Perinatal Epidemiology
Public Health Directorate
Kensington, Chelsea and Westminster Health Authority
50 Eastbourne Terrace
London
W2 6LX
Tel.: 020 7725 3401
Fax: 020 7725 3212

J Harris (for annual maternity figures and data requests)
SMMIS Database Manager
Department of Epidemiology and Public Health
Imperial College School of Medicine at St Mary's
Norfolk Place
London
W2 1PG
Tel.: 020 7594 3348
E-mail: jp.harris@ic.ac.uk

Publication

SMMIS in North Thames (West), Annual Maternity Figures, 1998.

References

1. Klassen AWN, Coulte A. Hospital statistics in the Oxford region. Oxford: Health Services Research Unit, University of Oxford; 1992.
2. Golightly S, Charles Z. (report written on behalf of project grant applicants J Chapple *et al.*) Towards population based maternity and child health data: findings from a detailed study of maternity and child health information systems (MACHIS) in the south east of England. Report for North Thames R&D Responsive Funding Group, Department of Epidemiology and Public Health, Imperial College of Medicine, London; July 1999.
3. Cleary R, Beard RW, Coles J, Devlin B, Hopkins A, Robert S, *et al.* The quality of routinely collected maternity data. *Br J Obstet Gynaecol* 1994;**101**: 1042–7.

SMMIS data items

Administrative details
District of residence
District entered
Month of infant's birth
Year of infant's birth
SMMIS hospital code number
Unique oracle identifier code
Mother's hospital number
Birth order of infant
Record type:
- Registration only
- Booking
- A/N complications
- A/N investigations
- A/N only archived
- A/N only completed
- Birth notification (incomplete)
- Birth notification (complete)
- Discharge incomplete
- Discharge complete
- Mother's ICD incomplete
- Mother's ICD complete
- Infant's ICD incomplete
- Infant's ICD complete
- Incomplete record (archived)
- Record complete (archived)

Reason for not booking
Date record created

Mother's/booking/antenatal details
Postcode
Date of birth
Marital status
Single parent mother
Patient category:
- Normal
- Private
- Amenity
- Overseas visitor

Ethnic group (1995 onwards)
Interpreter required
Smoker:
- Non-smoker
- Light (1–9)
- Moderate (10–19)
- Heavy (20+)

continued

History:
- Diabetes
- Epilepsy
- Hypertension
- Blood transfusions given

Any other booking complications
LMP:
- Date
- Certainty of date:
  - Certain
  - Uncertain
  - No idea

Regularity of menstrual cycle:
- Regular
- Irregular
- Amenorrhoea

Estimated date of delivery by LMP
Date of first antenatal visit
Mother:
- Height
- Weight
- Blood pressure
- Haemoglobin level
- Blood group

Intended place of delivery:
- This hospital
- Home
- Other hospital
- None

Intended care
Specified intended place of delivery:
- NHS hospital
- GP maternity home
- Private
- Other hospital
- Other

Mother's age at booking
Gestation at booking
Mother's weight at last clinic visit
Lowest antenatal haemoglobin level
Antenatal blood transfusion given
Cervical suture (y/n)
Number of antenatal clinic visits
Antenatal management
Number of antenatal inpatient nights
Number of antenatal admissions
Reasons for antenatal completion:
- Antenatal only
- Left the district
- Spontaneous abortion
- Induced abortion
- Ectopic pregnancy
- Mole
- Not pregnant
- Died

Date pregnancy ended
Antenatal operations performed

Previous pregnancy history
Parity
Number of previous:
- Live births
- Stillbirths

continued

Neonatal deaths
Miscarriages
TOPs
Caesarean sections
Last infant at delivery:
Weight
Gestation

Ultrasound scan
Date
Biparietal diameter (mm)
Estimated date of delivery by ultrasound
Number of ultrasounds given

Screening details
Rhesus status
Antibodies present
Thalassaemia or sickle cell disorders (split from 1995):
Not done
Sickle cell trait
Done – negative
Disease
Rubella susceptibility:
Not done
Immune
Susceptible
Syphilis serology: as above
Australia antigen status
Cervical cytology:
Not done
Done – abnormal
Abnormal
Unsatisfactory
Down's syndrome risk factor (1995)
Alpha-fetoprotein result:
Not done
Done – normal
Raised
Low
Amniocentesis:
Date of first
Date of second
Chorionic villus biopsy:
Not done
Done – normal
Unsuccessful
Anomaly scan (1995 onwards):
Not done
Done – no abnormality
Abnormality detected
Query abnormality
Partner's sickle cell/thalassaemia test/trait:
Not done
Done – negative
Major
Minor
Trait

Antenatal conditions/complications
Diabetes:
Established
Gestational
None

continued

Insulin required (1995 onwards)			
Urinary tract infection:			
Asymptomatic bacturia			
Pyelonephritis (acute)			
Other UTI			
None			
Cardiac disease:			
Congenital			
Acquired			
None			
Renal disease (y/n)			
Highest antenatal diastolic blood pressure			
Proteinuria:			
Persistent			
None			
Antepartum haemorrhage:			
Abruption proven			
Doubtful cause			
Local cause			
Praevia (with haem.)			
Praevia (without haem.)			
None			
Other antenatal complications (y/n)			
Medication given (1995 onwards):	y/n	Date	
Steroids			
Other			
None			
Antenatal complications: ICD coding			
Labour details			
Method of onset:			
None			
Spontaneous			
Induction			
Augmentation (y/n)			
Method of induction:			
ARM			
Oxytocin			
Prostaglandins			
Stage:	First	Second	
Date			
Time			
Length			
Total length of labour			
Membrane rupture:			
Method (spontaneous/artificial/none)			
Date			
Time			
Analgesia administered:	In labour	Delivery	Post delivery
Inhalational			
Pethidine			
Epidural			
GA			
Spinal			
CSE			
Local infiltration			
Pudendal block			
None			
Other			
Presentation of fetus before manipulation in labour:			
No manipulation			
Vertex			

continued

Breech
Transverse/oblique
Oblique
Other
Blood loss at delivery
Perineum:
Intact
1st degree tear
2nd degree tear
3rd degree tear
Episiotomy
Non-perineal tear (y/n)
Tear sutured (y/n)
Placental details (y/n):
Placenta complete
Manual removal
Membranes ragged/complete
Complications during labour
Pyrexia in labour (y/n)
Cord prolapse
Electronic fetal monitoring:
Normal
Abnormal
Not monitored
Fetal scalp pH
Meconium stained liquor (y/n)
Ward mother discharged to (to 1995 only)

Delivery details
Number of infants delivered
Infant birth:
Date
Time
Sex
Weight
Birth percentile
Gestation
Congenital abnormalities
Presentation at delivery:
Vertex
Breech
Other cephalic
Other
Delivery method:
Spontaneous
Emergency Caesarean
Elective
Lift out forceps
Rotational forceps
Ventouse
Assisted breech
Breech extraction
Outcome:
Liveborn & still living
Neonatal death
Antepartum stillbirth
Intrapartum stillbirth
Indeterminate stillbirth
Spontaneous abortion
Induced abortion
Place of delivery:
This hospital
In transit

continued

- Home
- Other

Reason for change:
- Change of address
- Unintentionally in labour
- Pregnancy – clinical reasons
- Labour – clinical reasons
- Other reasons – pregnancy
- Other reasons – labour

Person conducting delivery:
- Midwife
- Hospital doctor
- GP
- Agency midwife
- Other
- Unattended in labour

Specified place of delivery:
- NHS hospital
- GP maternity home
- Private
- Other hospital
- Other

Apgar score:
- 1 minute
- 5 minutes

Onset of regular respiration

Resuscitation positive pressure:
- Nil
- Mask
- Intubation
- Cardiac massage and intubation

Resuscitation drugs used:
- None
- Naloxone
- Sodium bicarbonate
- Other

Infant's birth complications

Infant's hospital number

Place of infant's birth:
- Domiciliary
- Specialist hospital
- Other

Anti-D requirement:
- Not required
- Required – not given
- Given

Rubella vaccination (as above)

Method of sterilisation:
- Tube division ligation
- Laparoscopy
- Other

Mother's age at delivery

Maternal operation:
- Date
- OPCS coding

Delivery complications ICD codes

Postnatal maternal complications

Eclampsia (y/n)

Thromboembolism (y/n)

Evacuation of retained products of conception (y/n)

Puerperal psychosis (y/n)

Post-partum infection:
- Genital

continued

Wound UTI Breast Chest Pyrexia (unknown causes) None Post-natal blood transfusion Puerperal ICD codes
Maternal discharge details Haemoglobin level Intended contraception: Undecided Progesterone only oral contraceptive Combined oral contraceptive IUCD Sheath Diaphragm Depo provera None For sterilisation Sterilised Vasectomy Chemicals only Postnatal stay Method of discharge
Infant details Paediatric assessment of gestational age Head circumference Birth length Hip examination: Normal Abnormal Doubtful Not examined SCBU: Date of admission Date of discharge Length of time Admission to transitional care Jaundice present: absent/present Highest bilirubin level (mmol/l) Separation of cord (y/n) Guthrie test done (y/n) BCG given Post-natal stay Ethnic group Highest level of neonatal care given: Normal Special High intensive Maximum intensive Infant complications entered Convulsions: absent/present Other abnormal behaviour noted: absent/present Congenital abnormalities Other congenital abnormalities Haemoglobinopathies Haemoglobin Blood group Coombs test
continued

Infant complications ICD codes
Infant congenital abnormality ICD codes

Infant discharge details
Date
Time
Destination of infant:
- Home
- Foster/adoption
- Unknown
- Other

Condition:
- Fit for discharge
- Still in hospital
- Neonatal death
- In another hospital

Infant discharged against medical advice
Weight
Congenital abnormality noted at discharge (y/n)
Intended feeding:
- Breast
- Artificial
- Supplemented

Infant follow-up
Condition at 28 days:
- Live
- Neonatal death

Infant death:
- Date
- Time

Autopsy performed (y/n)
Infant's age at death

A/N, antenatal; ICD, International Classification of Diseases; IUCD, intrauterine contraceptive device; LMP, last menstrual period; TOP, termination of pregnancy; UTI, urinary tract infection.

Regional Interactive Child Health System (RICHS)

Identification and demographic details
Mother:
- Date of birth
- Hospital number[a]
- NHS number[a]
- Ethnic group
- Unsupported
- Residence status
- District of residence at birth

Baby's NHS number

Previous pregnancy history
Number of previous:
- Live births
- Still births
- Abortions

Antenatal care
Gestation at booking
Alpha-fetoprotein screening
- Carried out
- Result[a]

Amniocentesis carried out

continued

Sickle cell disease screening: Carried out Result[a] Thalassaemia screening: Carried out Result[a]
Delivery details Birth: Date Time Date of notification Hospital details Description of delivery unit Original intention for delivery unit type Reason for change Onset of labour[a] Method of delivery[a] Outcome of delivery Number of babies born
Infant Sex Gestation at birth Birth rank Birth weight Length at birth[a] Head circumference after 3 days[a] Onset of regular respiration Apgar score at 1, 5 and 10 minutes Admission to SCBU[a] Resuscitation method used[a] Congenital abnormalities at birth
[a] Not standard National Child Health System data items.

UK Cardiac Surgical Register (CSR) of the Society of Cardiothoracic Surgeons (SCTS)

Description

The UK CSR was established in 1977 by the SCTS "to improve quality of care for cardiac patients by allowing comparison of clinical performance with national and international standards". It seeks unit, patient-related and surgeon-specific data on surgical activity and in-hospital mortality on all cardiac procedures, but with a focus mainly on CABGs, performed in NHS hospitals, including paediatric surgery.

The bulk of research using the database has focused on risk assessment, following similar developments in the USA. This database collects some 150 datapoints on all adults undergoing cardiac treatment with the aim of developing reliable comparative UK-oriented risk stratification models in conjunction with the MRC Biostatistics Unit in Cambridge.[1]

Data

Data collection is based on voluntary and anonymous reporting of activity and hospital mortality for cardiac surgical procedures. A single surgeon in each unit generally collates the surgical activity of the whole unit by completing a proforma supplied by SCTS. Data have traditionally been aggregated at this level. Unit-specific data are collected electronically under three main sections: acquired cardiac, congenital and miscellaneous.

Patient-specific data are collected under five main headings (demographic, diagnosis, by CABG, previous myocardial infarction and outcomes) and cross-tabulated by a number of factors including risk stratification. A detailed list of data collected is given on pp. 171–3.

Since 1997, all NHS units have also been asked to return annual, raw, surgeon-specific mortality data on marker operations for adult thoracic surgery, thoracic surgery and paediatric cardiac surgery.

Data are anonymised in terms of patient, surgeon and unit. Analysis of unit-level data is sent back to each unit via the designated surgeon responsible for data collection locally. The collated data are used in the annual reports to show national trends in annual activity.

Surgeon-specific data are independently analysed and the results scrutinised through an internal mechanism within SCTS.

Completeness and accuracy
About 71% of all UK Trusts undertaking cardiac surgery return data. Some centres provide only aggregated data. The patient-specific data required for the simplest score (Euroscore) are available for only 45% of all patients.

No central validation of unit data is carried out (other than attempts to correct internal inconsistencies). Some units check records against case notes. The Society has acknowledged this as a serious weakness which limits the possible uses of the database. It is working towards a formalised external scrutiny system.

Following analysis of surgeon-specific data request forms (internal audit), individual surgeons are notified and required to respond to SCTS if their performance appears to fall outside predetermined limits.[2–4]

Uses
The annual report analyses patient-specific data for comparative audit, including in-hospital mortality rates by procedure and linked to a range of risk profiles.

Diffusion of different types of surgery is outlined in the annual reports. In addition to the annual CSR reports, one other notable use of the data was in the Bristol Inquiry, where it was shown to correspond closely with HES data and to indicate similar results for in-hospital mortality (but in less detail than HES).

The CSR data permit the analysis of trends in the number of CABGs carried out by age and sex. The increase in the number of procedures has been largely due to increases among the elderly. The proportion carried out on women remains around 25%, similar to that in the USA, despite concern over unequal access to CABG by gender in both the USA and UK. Female surgical mortality rates are roughly double those of males, and sex is a factor in some of the risk adjustment models.

The register has not been used in costing studies.

Funding
Unfunded. The estimated cost of running the database is £300,000 (30,000 records at £10 per record per annum).

Access
Contact Dr B Keogh, SCTS (see below).

The database is managed by Dendrite Clinical Systems (UK) Ltd and all statistical analysis is carried out by the MRC Biostatistics Unit in Cambridge.

Contact details
The Society of Cardiothoracic Surgeons of Great Britain and Ireland (SCTS)
c/o Concorde Services
10 Wendell Road
London
W12 9RT
Tel.: 0208 743 3106
Fax: 0208 743 1010
E-mail: scts@concorde-uk.com
Websites: Society of Cardiothoracic Surgeons of Great Britain and Ireland: http://www.scts.org/
Cardiothoracic Surgery Network: http://www.ctsnet.org

Publications
Annual report, 1998, 1999 and 2000.

Edwards FH, Albus RA, Zajtchuk R, Graeber GM, Barry MJ, Rimisek JD, *et al*. Use of a Bayesian statistical model for risk assessment in coronary artery surgery. *Ann Thorac Surg* 1988;**45**: 437–40.

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Lovegrove J, Valencia O, Treasure T, Sherlaw-Johnson C, Gallivan S. Monitoring the results of cardiac surgery by variable life adjusted display. *Lancet* 1997;**350**:1128–30.

Marshall G, Shroyer L, Grover F, Hammermeister K. Bayesian-logit model for risk assessment in coronary artery bypass grafting. *Ann Thorac Surg* 1994;**57**:1492–500.

Omoigui NA, Miller DP, Brown KJ, Annan K, Cosgrove D, Lytle B, *et al*. Outmigration for

coronary bypass surgery in an era of public dissemination of clinical outcomes. *Circulation* 1996;**93**:27–33.

Treasure T. Risks and results of surgery. *Br Heart J* 1995;**74**:11–12.

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2. Poloniecki J, Valencia O, Littlejohns P. Cumulative risk adjusted mortality chart for detecting changes in death rate: observational study of heart surgery, *BMJ* 1998;**316**:1697–700.
3. Bridgewater B, Neve H, Moat N, Hooper T, Jones M. Predicting operative risk for coronary artery surgery in the United Kingdom: a comparison of various risk prediction algorithms. *Br Heart J* 1998;**79**:350–5.
4. Society of Thoracic Surgery. 1995 coronary artery bypass risk model: the Society of Thoracic Surgeons adult cardiac surgery national database. *Ann Thorac Surg* 1998;**65**:879–84.

SCTS data items

SCTS Domain	ID	Parameter
Demographic	SCTS001	Hospital number
	SCTS002	Surname
	SCTS003	First names
	SCTS004	Date of birth
	SCTS005	Age at surgery
	SCTS006	Sex
	SCTS007	Ethnic data
	SCTS008	Date of admission
Cardiac history	SCTS009	Angina status by the Canadian Cardiovascular Society (CCS)
Cardiac history	SCTS010	Dyspnoea status by the New York Heart Association (NYHA)
	SCTS011	Congestive cardiac failure
	SCTS012	Previous Q wave MIs
	SCTS013	Last Q wave MI
	SCTS014	Recent myocardial infarction
Previous non-surgical intervention	SCTS015	Previous PTCA ± stent
	SCTS016	Recently failed intervention
	SCTS017	Date of last intervention
	SCTS018	Thrombolysis within 24 hours prior to surgery
Previous surgical intervention	SCTS019	Previous cardiovascular or thoracic surgical intervention?
	SCTS020	Describe previous surgical intervention
	SCTS021	Date of last cardiac operation
Risk factors for coronary disease	SCTS022	Diabetes
	SCTS023	Hypercholesterolaemia
	SCTS024	Hypertension
	SCTS025	Smoking
Additional medical history and risk factors	SCTS026	GI tract
	SCTS027	Renal system
	SCTS028	Pulmonary disease
	SCTS029	Cerebrovascular disease
	SCTS030	Neurological dysfunction
	SCTS031	Peripheral vascular
	SCTS032	Pre-op. arrhythmia (within 2 weeks of the procedure)
Catheterisation data	SCTS033	Was the patient catheterised?
	SCTS034	Date of catheterisation
	SCTS035	Catheter during same admission as surgery

continued

Coronary anatomy	SCTS036	Extent of coronary vessel disease
	SCTS037	Left main stem disease
Indices and pressures	SCTS038	PA systolic
	SCTS039	Aortic valve gradient
	SCTS040	LVEDP
	SCTS041	PAWP/LAP
Ejection fraction	SCTS042	LV function (EF)
Preoperative support	SCTS043	Pacemaker
	SCTS044	Intravenous nitrates or heparin
	SCTS045	Cardiogenic shock
	SCTS046	Intravenous inotropes
	SCTS047	Intra-aortic balloon pump
	SCTS048	Ventilated
Operation status	SCTS049	Operative priority
	SCTS050	Operation sequence
Operation	SCTS051	Date of operation
	SCTS052	Cardiopulmonary bypass
	SCTS053	Procedures
	SCTS054	Other cardiac procedure
	SCTS055	Other non-cardiac procedure
Surgical training	SCTS056	Operation performed by
	SCTS057	Type of trainee
	SCTS058	Calman year
Coronary artery bypass surgery data	SCTS059	Total number of distal anastamoses
	SCTS060	Coronary artery
	SCTS061	Local procedures
	SCTS062	Conduit
	SCTS063	Other conduit
Valve surgery	SCTS064	Number of valves replaced/repaired
	SCTS065	Diseased valves replaced/repaired
	SCTS066	Haemodynamic pathology
	SCTS067	Valve pathology – reason for replacement
	SCTS068	Prosthetic valve explant
	SCTS069	Explant type
	SCTS070	Procedure
	SCTS071	Valve implant code
	SCTS072	Implant type
	SCTS073	Valve repair/conservation
	SCTS074	Valve/ring serial numbers
	SCTS075	Valve/ring size
Aortic and vascular surgery	SCTS076	Concomitant carotid endarterectomy
	SCTS077	Aortic procedure
	SCTS078	Aorta
	SCTS079	Aortic pathology
	SCTS080	Aortic procedure
Myocardial protection	SCTS081	Predominant method of myocardial protection
	SCTS082	Cardioplegia solution
	SCTS083	Cardioplegia infusion mode
	SCTS084	Cardioplegia infusion temperature
	SCTS085	Cardioplegia infusion timing
	SCTS086	Non-cardioplegic myocardial protection

continued

Bypass-related data	SCTS087	Cumulative bypass time
	SCTS088	Circulatory arrest time
	SCTS089	Cumulative cross clamp time
	SCTS090	Longest ischaemic period
	SCTS091	Patient height
	SCTS092	Patient weight
	SCTS093	Body surface area
	SCTS094	Body mass index
Post-operative complications	SCTS095	Low cardiac output
	SCTS096	Arrhythmias
	SCTS097	Blood used
	SCTS098	Reoperation
	SCTS099	Sternal resuturing
	SCTS100	Ventilation
	SCTS101	Time to extubation (days)
	SCTS102	Pulmonary complications
	SCTS103	Neurological complications
	SCTS104	Infective complications
	SCTS105	Renal complications
	SCTS106	Gastrointestinal complications
	SCTS107	Multisystem failure
Summary of post-operative course	SCTS108	Length of stay on ITU
	SCTS109	Readmitted to ITU
	SCTS110	Status at discharge
	SCTS111	Date of discharge or death
	SCTS112	Post-operative LOS
	SCTS113	Post-discharge date of death
	SCTS114	Died on post-op. day
	SCTS115	Discharge to
	SCTS116	Cause of death

EF, ejection fraction; LOS, length of stay; LV, left ventricle; LVEDP, left ventricular end-diastolic pressure; MI, myocardial infarction; PAWP/LAP, pulmonary artery wedge pressure/left atrial pressure; PTCA, percutaneous transluminal coronary angioplasty.

UK Cystic Fibrosis (UKCF) Database

Description

The Clinical Resource and Audit Group (CRAG) in the then Scottish Office piloted the UK Cystic Fibrosis Data Centre (UKCFDC) from 1992 to 1996 in response to an approach from the Scottish Cystic Fibrosis Group (SCFG). Following the success of the pilot, the United Kingdom Cystic Fibrosis (UKCF) Database was initiated in 1997.

The database aims to collect data to help provide a high level of cystic fibrosis care and record the health of the cystic fibrosis population. The dataset is based on audit of care but is planned to evolve into a research tool for new treatments in cystic fibrosis. Information is held on over 5000 patients[1] from 45 clinics, comprising over 95% of the major clinics in the UK.

At the time of writing, analysis tools for patient tracking and national demographic/therapy profile matching are waiting to complete testing. Once the system is running smoothly, the Centre would like to start collecting information on other diseases and the use of the Internet for the collection, dissemination and support of cystic fibrosis.

Data

Detailed information is collected on an ongoing basis from hospitals and clinics, and annual review information is collected from the main hospitals in each area. To participate, a clinic must register with the UKCFDC and provide background information on the number of patients, annual reviews and facilities available within the clinic.

Patient demographic data are used to generate a unique patient number using an in-house system that has been produced specifically for this purpose. This identification number is then inserted into the patient's notes.

Software sent to each clinic involved allows entry of clinical details at patient level. Patient identities are 'scrambled' to prevent any possible breaches of confidentiality, using methods which comply with the Data Protection Act and which are thought likely to have relevance for other similar clinical databases.

Four forms are used. The first form collects administration and patient details, the second a patient biography with genotype and diagnostic information, the third is an annual review and the fourth covers the routine clinic visit and its facilities. Details are given on pp. 175–80.

Coding systems

A US coding system, Cystic Fibrosis International Data Standard (CFIDS), is used.

Completeness and accuracy

Of the estimated 6000–7000 cystic fibrosis patients in the UK, the database holds information on over 5000. Completeness of notifications to the database is reported to be 100% for Scotland but the figure is lower for England owing to non-participation by some clinics in London and the South.

Paper forms are inspected for completeness of information and returned to the clinic for completion if necessary. Data will only be input into the system if the whole form is fully complete.

All information is validated by comparison of paper forms and electronic information. Internal validation checks are as follows:

- inspection of forms by data clerk
- computer-generated consistency checks
- return of any information to clinics for checks on inconsistencies, completeness, accuracy
- checking of data by clinic nurses
- duplicate copies checked
- *ad hoc* audit of systems in the Scotland area.

Clinical audits include routine outpatient clinic visits (generally on a quarterly basis) and annual review check-ups. These systems produce data anonymised at both the clinic and patient levels. Clinics audit the clinical data using analysis tools provided by UKCFDC. The main completed assessment has been a confidential audit[1] of dosage of pancreatic enzyme replacement therapy, arising from CSM advice.

The UKCFDC has plans for use in comparative audit but this is likely to be limited by its poor coverage in London.

Uses

The original cystic fibrosis survey (1977–85, preceding the UKCFDC) was used in a number of published assessments including analysis of the cystic fibrosis population[2,3] and cohort mortality studies[4] showing improvements in survival for younger age groups.

The UKCFDC was used in 1999–2000 to track the use and effectiveness of Dnase in patients based at Western General Hospital, Scotland, but the results were made available to the Scottish Office only. A confidential report, 'Confidential audit of dosage of pancreatic enzyme replacement therapy in cystic fibrosis versus Committee on Safety of Medicines' advice – a ticking bomb or a damp squib?', was produced for the MCA.[1]

No studies were located on diffusion, equity or costs.

Funding

The database is funded by the United Kingdom Cystic Fibrosis Trust and maintained by approximately three full-time equivalents. The total cost is unknown but is likely to be between £100,000 and £150,000.

Access

All data belong to each participating clinic as the data at the Centre are purely for audit purposes. Any consultant requiring information from another clinic will need to gain permission from the clinic.

Contact details

Mrs G Mehta
Department of Child Health
Ninewells Hospital
Dundee
DD1 9FY
Tel.: 01382 660111, Ext. 3555
Fax: 01382 645783
E-mail: g.mehta@dundee.ac.uk
Websites: http://www.cf.org.uk (under development)
http://www.childhealth.dundee.ac.uk/
cf-server/index.html

Publications

An annual report is produced but not published.

Cystic fibrosis in the United Kingdom 1977–85: an improving picture *BMJ* 1988;**27**:1599–602.

Evans D. National Services Division paper (CSA Scotland). Information on the needs of the Scottish Cystic Fibrosis population (unpublished); c/o Trinity Park House, Edinburgh; 1999.

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UKCF Database data items

New patient registration

Administrative details
Clinic code
NHS ID
NHS ID type
Patient details
Day and month of birth
Sex at birth
Family name
First initial
Order in birth:
Singleton
Order in birth (if multiple)
Country of birth
Town of birth

Database patient biography

Administrative details
Patient code
Clinic code
Initials
Date
Patient details
Month and year of birth
Sex at birth
Ethnicity:
Of mother
Of father
Genotype details
Not done
Patient refused
Results:
Allele 1
Allele 2
Diagnosis details
Age at diagnosis
Method of diagnosis:
Unknown
Meconium ileus needing surgery

continued

Meconium ileus managed medically
Prolonged jaundice
Failure to thrive and/or malnutrition
Steatorrhoea and/or abnormal stools and/or malabsorption
Rectal prolapse
Sinus disease and/or nasal polyps
Lower respiratory infection
Family history
Screening
Electrolyte imbalance
Infertility
Other (specify)

Annual review

Patient/administrative details
Patient code
Clinic code
Clinician initials
Date (today)
Date of review

Complications in the last period
Complications: (tick all that apply)
- No complications
- Elevated respiratory rate at rest
- Regular coughing at rest
- Chronic *Pseudomonas* infection (> 2 isolates/year)
- Chronic *Staphylococcus aureus* (> 2 isolates/year)
- Nasal polyps
- Allergic bronchopulmonary aspergillosis
- Asthma
- Pneumothorax requiring chest drain
- Massive haemoptysis
- Distal intestinal obstruction syndrome
- Haematemesis
- GI reflux requiring treatment
- Colonic stricture
- Barium enema looking for colonopathy
- Gallbladder disease requiring surgery
- Pancreatitis
- Abnormal liver function tests
- Cirrhosis with portal hypertension
- Diabetes requiring insulin/oral hypoglycaemic
- Arthropathy
- Clubbing
- Raised IgG
- Cancer
- Had IV port replaced
- Others (specify)

Antibiotics administered in last period
Nebulised antibiotics administered:
- None
- Colistin
- Gentamycin
- Tobramycin
- Other (specify)

Oral antibiotics received:	Prophylactically	Continuously	Intermittently
Anti-staphylococcal			
Anti-pseudomonal			

continued

Anti-haemophilus		
Other (specify)		
Patient has IV port (y/n)		
Intravenous antibiotics received:	No. courses	Total no. days
None		
Home IVs		
Hospital IVs		
Organisms cultured in last period		
Organisms cultured:	Sputum culture	Cough swab
No cultures performed		
Normal flora		
Staphlococcus aureus		
Haemophilus influenzae		
Pseudomonas aeruginosa		
Other *Pseudomonas* species		
Burkholderia (Cepaciae)		
Aspergillus		
Candida		
Other (specify)		
Supplemental feeding in last period		
Method:		
None		
Oral supplements		
Nasogastric		
Gastrostomy		
Parental		
Other (specify)		
Evidence of fertility in last period		
Child and/or no evidence of fertility detected (y/n)		
Self/partner currently pregnant (y/n)		
Number of:		
Spontaneous abortions		
Induced abortions		
Pre-term births		
Full-term births		
Still births		
Other evidence of fertility (specify)		
Social impact of CF in last period		
Total no. days off work/school in last period:		
Does not attend		
None		
Less than 2 weeks		
Less than 2 months		
2 months or more		
Total no. days patient in hospital because of CF in last period:		
None		
Less than 2 weeks		
Less than 2 months		
2 months or more		
Number of times patient visited CF clinic in last period		
Number of other clinics patient attends for shared care		
Glucose intolerance in last period		
Glucose tolerance level:		
Not performed		
Normal (< 8 mmol/l)		
Equivocal (8–11 mmol/l)		
Diabetic (> 11 mmol/l)		

continued

Transplant status in last period
Transplant status:
- Not referred
- Active list
- Reserve list
- Currently being evaluated
- Rejected by transplant centre
- Patient refused offer of transplant
- Transplant performed

Type of transplant performed:
- Bilateral lung
- Unilateral lung
- Heart–lung
- Liver
- Other (specify)

Clinical trials in last period
Patient not taking part in trials (y/n)
Patient taking part in trial(s) (specify)

Treatment compliance in last period
Patient compliance:
- Non-complier
- Average complier
- Does everything told to do

Most recent X-ray in last period
No X-ray measured
Northern score
Chrispin Norman score

Shwachman score at review
Scores (/25):
- General activity
- Physical examination
- Nutrition
- Chest X-ray
- Total (/100)

Fat-soluble vitamin plasma at review
Measured/not measured

Pubertal status at review
Male: patient's voice has broken (y/n)
Female: Patient has had first period (y/n)

Marital status at review
Status:
- Single (child/never married)
- Living together
- Married
- Separated
- Divorced
- Widowed
- Unknown

Employment/school status at review
Status:
- Pre-school
- At school
- Higher education
- Unemployed

continued

Full-time work Part-time work Full-time homemaker Unknown
Domicile at review First half of postcode
Genotype details at review Not done Refused Results: Allele 1 Allele 2

Routine clinic visit

Patient/administrative details			
Patient code			
Clinic code			
Clinic visit details			
Last clinic visit date			
This clinic visit date			
Clinician initials			
Specialist/non-specialist			
Hospital admissions since last clinic visit			
	Length of admissions (days)		
	1st	2nd	3rd
Elective investigation (specify)			
Chest infection			
Bowel obstruction			
Haemoptysis			
Haematemesis			
Pneumothorax			
Other reasons (specify)			
Short-term drugs since last clinic visit			
Short-term antibiotics:			
IV			
Oral			
Length of course:	1st		
	2nd		
	3rd		
Other short-term drugs			
Most recent laboratory and social data since last clinic visit			
Height			
Weight			
FEV1			
FVC			
PEF			
O_2 saturation			
Exercise tolerance score			
Number of recent days off school/work			
Most recent bacteriology culture result			
Date of culture			
Result			
Normal flora			
Pseudomonas aeruginosa			

continued

Burkholderia (Cepaciae) *Haemophilus influenzae* *Staphlococcus aureus* MRSA Other (specify) Unknown			
Status of long-term administered therapies	Start date	Ongoing	Stop date
Inhaled/nebulised bronchodilator			
Nebulised antibiotic			
Oral antibiotic			
Inhaled steroid			
Oral steroid			
DNase			
NSAID (arthropathy)			
NSAID (anti-inflammatory)			
H_2 antagonist			
Proton pump inhibitor			
N-Acetylcysteine			
Lactulose			
Gastrograffin			
Urso-deoxycholic acid			
Taurine			
Insulin			
Oral hypoglycaemic			
Pancreatic enzymes			
Brand			
Capsules/day			
When taken: Before/during/after meals/unknown			

CF, cystic fibrosis; FEV, forced expiratory volume; MRSA, methicillin-resistant *Staphylococcus aureus*; NSAID, non-steroidal anti-inflammatory drug; PEF, peak expiratory flow.

UK Haemophilia Centre Directors' Organisation (UKHCDO)

Description

The UKHCDO has been compiling information on haemophilia patients from Haemophilia Centres (93 out of a total of 102) since 1969.[1]

Data are collected on:

- haemophilia A and haemophilia B (Christmas disease) included in the original collection (1969)
- von Willebrand disease: first collected 1976
- haemophilia A carriers requiring treatment: from 1976
- acquired haemophilia A: from 1985
- acquired von Willebrand disease: from 1985
- carriers of haemophilia B requiring treatment: from 1976
- combined disorders
- other rare congenital blood coagulation defects.

Just over 11,000 patients were registered at the end of 1996.[1]

From 1989, the register has also collected data, via the Adverse Events Working Party, on adverse events and viral transmission events related to treatment of haemophilia patients. Serious adverse events are reported to the MCA.

The UKHCDO plans to expand to include information on hepatitis C (HCV) infection and also to include patients' postcode for geographical analysis. It also plans to collect new blood product information.

Data

The UKHCDO collected data in paper format only until 1997. It began to accept data electronically from 1997. However, not all Centres had computerised data by the end of 1999. Data on new registrations, deaths, diagnosis changes, name changes and development of inhibitors are returned to the Secretariat continuously. Each year the Secretariat sends the centres computerised summaries of those treated for checking.

Quantities of therapeutic materials (blood factor products) used by each patient are not held on the database, although the total amount of each type of therapeutic material used annually by each of the UK Haemophilia Centres for the treatment of

specified blood coagulation defects is recorded and analysed. The UKHCDO form collects data at patient level on the type but not the quantity of material used.

The Adverse Events Working Party sends out forms to the Haemophilia Centres every quarter for numerical values of adverse events. All viral transmission events are notified to the Working Party as soon as possible after detection. The two forms used to collect the data (UKHCDO and the Adverse Events Working Party) include patient details, diagnosis, HIV status and treatment. A summary list of data headings is given on p. 182. No further details of the forms are available.

Coding systems

The system is a mixture of standard and customised codes. To prevent identification of individual patients, a coding system devised by UKHCDO in 1969 is used for all records. The patient's name is entered only once in a secure file. ICD coding is used for causes of death. Individual Haemophilia Centres are identified by code number.

Completeness and accuracy

For 1996, data were not returned by nine Centres, including one of the 22 larger Comprehensive Care Centres.[1] In 1999, an alternative database was being developed for optimising genetic services in haemophilia A in a London teaching hospital[2] that does not contribute to the UKHCDO database.

The data are checked by the Haemophilia Centres internally before being returned to the UKHCDO, where they are scrutinised before entry into the computer system. Queries on data are referred back to the reporting Haemophilia Centre Director for clarification. New patient registrations are checked to ensure that they are not duplicates of already registered patients. Data are returned annually to the originating Centre for checking.

A survey in 1987 by the UKHCDO revealed that some Centres had lost trace of their patients and, for some patients who had died, the Centre reporting the death had no details on the cause of death. This led the UKHCDO to make arrangements with the Office of Population Censuses and Surveys (OPCS) for England and Wales, now ONS, and the General Register Offices (GRO) for Scotland and Northern Ireland, for flagging of UKHCDO registered patients, forwarding death certificates to the Secretariat. This improved the mortality data and also identified patients no longer living in the UK.

On the initiative of the UKHCDO Genetics Working Party, Haemophilia Centres were asked in 1995 to submit information on whether the genetic defect had been identified to their individual patients. A total of 29 (out of 102) Centres did not return the genetics forms for either 1995 or 1996, including nine (of the 22) Comprehensive Care Centres. Of the 73 Centres which returned the forms, 34 said they had no details of gene mutations. The 39 Centres which reported information on gene mutation gave details for 380 haemophilia A and 280 haemophilia B patients.[1]

UKHCDO carry out a clinical audit of all (22) Comprehensive Care Centres every 3 years (website, January 2001).

Uses

The UKHCDO uses the database in various analyses, including the quantity and type of treatments (current and predicted), patterns of usage and causes of death.[3] Through the UKHCDO, working parties have been set up to examine various topical aspects of bleeding disorders (e.g. the incidence and treatment of patients with factor VIII antibodies, AIDS and hepatitis, and therapeutic treatments).

The UKHCDO Annual Report is the only available source of information regarding trends in types of blood factor being used.

The case for equitable use of rFVIII was made by UKHCDO Executive Committee (1997).[4]

No cost studies were located.

Funding

The database is unfunded. It derives its income from the sale of annual returns, surpluses from scientific meetings and annual subscriptions from individual Centres (website, January 2001). The estimated cost of maintaining the database of around 11,000 patients would be £110,000–220,000 at £10–20 per record. One half-time clerical officer is employed centrally to collate the returns (not just paper – see Data section above).

Access

Any requests for information from the National Register must be made in writing to the Secretariat, giving full details of the reason(s) for the information request. Patient-identifiable data are not released.

Contact details

UKHCDO Secretariat
Oxford Haemophilia Centre
The Churchill Hospital
Headington
Oxford
OX3 7JL
Tel.: 01865 225304
Fax: 01865 225608
Website (Oxford Haemophilia Centre):
http://www.medicine.ox.ac.uk/ohc

Publications

Annual reports.

UKHCDO reports (confidentially) to the Public Health Laboratory Service Communicable Disease Surveillance Centre (CDSC) (Collindale, London) on haemophiliac AIDS cases and deaths of HIV-positive haemophiliacs. It also provides information to the UK Haemophilia Society, the World Federation of Haemophilia, the World Health Organization and the Department of Health.

The website provides details of UKHCDO publications.

United Kingdom Haemophilia Centre Directors' Organisation Executive Committee. Guidelines on therapeutic products to treat haemophilia and other hereditary disorders. *Haemophilia* 1997;**3**:31–7.

References

1. United Kingdom Haemophilia Centre Directors' Annual Report. Report on the annual returns for 1996. Oxford: UKHCDO; 1998.
2. Waseem NH, Bagnall R, Green PM, Giannelli F, Haemophilia Centres. Start of UK confidential haemophilia A database: analysis of 142 patients by solid phase fluorescent chemical cleavage of mismatch. *Thromb Haemost* 1999;**81**:900–5.
3. Hay CR, Ollier W, Pepper L, Cumming A,. Keeney S, Goodeve AC, *et al*. HLA class II profile: a weak determinant of factor VIII inhibitor development in severe haemophilia A. UKHCDO Inhibitor Working Party. Oxford: UKHCDO; 1997.
4. Ludlam CA, Hay CRM, Dolan G. Treatment for haemophilia by postcode [letter]. *BMJ* 1997;**314**:749.

Summary of data headings collected

Name of patient Date of birth Coagulation defect Severity of coagulation defect Presence/absence to factor VIII or factor IX (inhibitors) HIV status Date and cause of death Genetic information held at patient's Haemophilia Centre (y/n) Type of therapeutic material used each year
Adverse Events Working Party Reporting of events including: HIV transmission Non-A, non-B or hepatitis C transmission Hepatitis B transmission New inhibitor Thrombotic event/DIC Transfusion reaction Other events (specify)
Source: UKHCDO Annual Report, 1998.[1]

UK Heart Valve Registry (UKHVR)

Description

Established by the Department of Health and the Society of Cardiothoracic Surgeons, the Registry began collecting prospective data in 1986 on patients receiving artificial heart valve implants in NHS hospitals. Initially using a simple dataset and restricting outcome indicators to in-hospital death and re-operation, the voluntary cooperation of all UK cardiac surgical units was gained. Patient-based data are collected on around 5000 patients each year. At the end of 1995, data on more than 45,000 patients had been entered.

The Registry is funded by the Medical Devices Agency and is based in Hammersmith Hospital, London. Annual reports are distributed to all participating units. Links with the Office for National Statistics (ONS) allow recording of mortality outcomes.

Data

The Registry uses the Patient Analysis and Tracking System (PATS), a clinical information management tool, to record patient and valve details. PATS also tracks and analyses patient data over time, conducts analyses of specific demographic or clinical data so that entire populations may be studied, tabulates data, computes averages and calculates patient survival curves.

In the first 10 years (until 1996), paper forms were input into the database manually on a daily basis, but it has since become electronic. Re-operation is recorded by a new registration form completed for each valve operation subsequent to the initial registered valve replacement.

Data are collected under six main headings (patient and hospital details, clinical and valve details, patient outcomes and trends) (see below).

Patients are traced through the ONS (England, Scotland and Wales) and the Central Services Agency (CSA) (Northern Ireland). All patients entered into the database are 'flagged' for follow-up by either the ONS or the CSA, which process the death certificates for persons dying within the UK. Both agencies flag each valve replacement patient's details on the national mortality database so that 'flagged' death certification details are copied back to the Heart Valve Registry. The link with these agencies provides the Registry with the date and certified cause(s) of death, including date and place of death and post-mortem information (if carried out) for each heart valve replacement patient.

Completeness and accuracy

From the outset, the emphasis has been on achieving maximum cooperation from the UK centres and completeness of patient registration. The Registry does not seek to obtain follow-up data on patients apart from the occurrence of death and re-operation.

Uses

Annual reports, which are not publicly available, provide comparative audit-type data by centre. Additional articles have assessed a number of specific technologies including artificial versus human valves,[1] fatigue and wear in valves,[2] and survival and cause of death after mitral valve replacement in patients aged 80 years and over,[3] in addition to long-term survival trends.[4]

No published studies were located on equity or costing.

Funding

The MDA funds this database, which costs around £150,000 per annum, equivalent to around £25 per record.

Access

All participating centres can request information at any time about their own centre's performance. A centre may not, however, receive any information about another centre's implant history or performance.

Contact details

Professor KM Taylor
Cardiac Surgical Unit
Hammersmith Hospital
London
W12 0HS
Tel.: 020 8846 1234
Websites: Society of Cardiothoracic Surgeons:
http://www.scts.org/
UK Heart Valve Registry:
http://www.ctsnet.org/doc/917
Central Cardiac Audit Database:
http://ccad3.biomed.gla.ac.uk/ccad/Default.htm

Publications

UK Heart Valve Registry Annual Report: each year since 1986.

Annual Report to the Society of Cardiothoracic Surgeons of Great Britain and Ireland: since 1986.

Asimakopoulos G, Edwards MB, Taylor KM. Aortic valve replacement in patients aged 80 years and over: survival and cause of death based on 1100 cases. Collective results from the UK Heart Valve Registry. *Circulation* 1997;**96**:3403–8.

Taylor KM. The clinical aspects of heart valve replacements. *Eng Med* 1987;**16**:63–5.

Taylor KM. The UK Heart Valve Registry. In Bain WH, editor. *Current topics in heart valve surgery*. London: ICR; 1990.

Taylor KM. Heart valve surgery in the UK: present practice and future trends. *Br Heart J* 1991;**66**:335–6.

Taylor KM, Gray SA, Livingstone S, Brannan JJ. The UK Heart Valve Registry. *J Heart Valve Dis* 1992;**1**:152–9.

Taylor KM. Overview: a cardiac surgeon's perspective. *J Heart Valve Dis* 1996;**5** (Suppl I):S7–8.

Taylor KM. The United Kingdom Heart Valve Registry: the first 10 years [editorial]. *Heart* 1997; **77**:295–6.

References

1. Taylor KM. Acute failure of artificial heart valves. (leading article) *BMJ* 1988;**297**:996–7.
2. Taylor KM. Fatigue and wear in prosthetic heart valves – a surgeon's perspective. *J Heart Valve Dis* 1996;**5** (Suppl):57–8.
3. Azimakopoulos G, Edwards MB, Brannan JJ, Taylor KM. Survival and cause of death after mitral valve replacement in patients aged 80 years and over: collective results from the UK Heart Valve Registry. *Eur J Cardiothorac Surg* 1996;**11**:922–8.
4. Edwards MB, Ratnatunga CP, Dore CJ, Taylor KM. Thirty-day mortality and long term survival following surgery for prosthetic endocarditis: a study from the UK Heart Valve Registry. *Eur J Cardiothorac Surg* 1998;**14**:156–64.

VKHVR data headings (from CCAD proposed dataset)

ID	Domain	SCTS/ACTA	Parameter	HV Registry name
HV001	Demographics	SCTS001	Hospital number	Hospital number
HV002	Demographics	SCTS002	Surname	Surname
HV003	Demographics	SCTS003	Forename	Forename
HV004	Demographics		Address	Address
HV005	Demographics		Postcode	Postcode
HV006	Demographics	SCTS006	Sex	Sex
HV007	Demographics	SCTS004	Date of birth	Date of birth
HV008	Procedure		Surgeon	Consultant surgeon's name
HV009	Procedure	SCTS051	Date of procedure	Date of operation
HV010	Procedure	SCTS065	Valve site	Valve(s) position
HV011	Procedure	SCTS071	Valve manufacturer	Valve(s) name
HV012	Procedure	SCTS071	Valve model	Valve(s) number & type
HV013	Procedure	SCTS074	Valve size	Valve(s) size
HV014	Procedure	SCTS075	Valve serial	Manufacturers' serial number(s)
HV015	Procedure		Valve sequence	Valve sequence
HV016	Pre-procedure	SCTS067	Valve pathology – reason for replacement	What pathology necessitated this valve replacement?
HV017	Pre-procedure		Reimplant	Reimplant(s) since 1 Jan. 1986
HV018	Pre-procedure		Previous valve manufacturer	Previous valve(s) name
HV019	Pre-procedure		Previous valve model	Previous valve(s) number or type
HV020	Pre-procedure		Previous valve size	Previous valve(s) size
HV021	Pre-procedure		Reason for reimplant	Reason(s) for reimplant(s)
HV022	Pre-procedure		Other reason for reimplant	
HV023	Pre-procedure	SCTS091	Height	Height in metres
HV024	Pre-procedure	SCTS092	Weight	Weight in kilograms

continued

HV025	Pre-procedure	SCTS027/024/022/097	Risk factors	Has the patient a history of any of the following: (multiple answers allowed)
HV026	Pre-procedure	SCTS042	LV function	LV ejection fraction (can be number or range)
HV027	Procedure	SCTS038	PA systolic	PA pressure (mmHg or range)
HV028	Pre-procedure	SCTS039	Aortic gradient	Aortic gradient (mmHg or range)
HV029	Pre-procedure	SCTS047	Preop. IABP	Was an IABP inserted preoperative?
HV030	Outcome	SCTS095	Postop. IABP	Was an IABP inserted postoperative?
HV031	Pre-procedure	SCTS020	Previous cardiac surgery	Previous other cardiac surgery
HV032	Pre-procedure	SCTS020	Other previous cardiac surgery	Describe previous other surgery
HV033	Pre-procedure	SCTS049	Urgency	Urgency of operation
HV034	Procedure	SCTS073	Valve repair at same time as replacement	Valve repair(s)
HV035	Procedure	SCTS078	Aortic repair	Associated ascending aorta repair
HV036	Procedure		RV/pulmonary conduit	RV/pulmonary conduit
HV037	Procedure	SCTS059	CABG number of distal anastomoses	CABG number of distal anastomoses
HV038	Procedure	SCTS054	Other repair performed during valve surgery	Other repair
HV039	Outcome		Valve op. success	Success of operation

UK Hydrocephalous Shunt Registry

Description

The UK Hydrocephalous Shunt Registry was established in October 1994, collecting data from 1995 on the approximately 3000 shunt operations performed annually in the UK. Each centre performing shunt implantation in the UK performs only 100–150 insertions per year, with several surgeons performing the procedure in each centre. Some 81% of shunts fail within 12 years for multifactorial reasons. The Registry provides an 'overview mechanism' and contains data on around 12,000 procedures (Annual Report, 1998).

The Registry has the support of several major bodies: the Council of the Society of British Neurological Surgeons, the Executive Committee of the British Association of Paediatric Surgeons, the United Kingdom Hydrocephalous Group and the Association for Spina Bifida and Hydrocephalous. Data are also collected from the Republic of Ireland and the Channel Islands.

The objectives are to:

- define current state-of-the art shunt management
- provide data on different types of shunt
- develop risk stratification criteria
- identify substandard shunt systems
- allow anonymised audit of individual centres.

Data

Data are received on a continuous basis from all UK neurosurgery centres and most paediatric centres following an operation for any of the following procedures:

- shunt insertion
- shunt revision, including:
- shunt removal
- reconnection
- ligation
- externalisation
- insertion of reservoir
- third ventriculostomy.

A paper form is completed by the hospital and forwarded to the Registry offices where the data are entered into the database.

The data are collected under seven main headings (demographics, clinical diagnosis, revision/removal details, operation details, device details, antibiotic strategy and surgical technique for assembly and insertion). For a detailed list of the data collected, see pp. 186–8.

Coding systems
In 2000, ICD-10 and OPCS4 were being used plus additional details on shunt specifics:

- completeness and accuracy
- the completeness of recruitment of relevant units is unknown.

The register is estimated to be 75–80% complete for individuals. No details were available on how complete each record was. There are no reports of external validation.

Internal database checks for duplication and restricted entry fields are carried out within 3 weeks of receipt of the data.

Uses
No effectiveness, diffusion or cost studies have been located.

Funding
The registry is funded by the MDA and costs around £50,000 annually, equivalent to £17 per record (see Chapter 9).

Access
Anonymised data at the patient level through to aggregated data at the national level can be obtained on written request to the Registry. However, patient-identifiable data or individual patient records are not released. Currently no charges are made for data provision.

Contact details
M Madakbas
UK Shunt Registry
Academic Neurosurgery Unit
PO Box 167
Addenbrooke's Hospital
Cambridge
CB2 2QQ
Tel.: 01223 217092
Fax: 01223 216926
E-mail, data manager: hkr10@medschl.cam.ac.uk

Publications
An Annual Report is produced but not published. The Registry does not have its own website but some information on the Registry can be accessed through the MDA website: http://www.medical-devices.gov.uk/

United Kingdom Hydrocephalous Shunt Registry

Patient identification
Hospital number
Hospital
Surname
Forename
Address
Postcode
Date of birth
Sex

Clinical diagnosis
Reason for shunt insertion

Revision/removal details
Revision reasons:
- Underdrainage:
  - Proximal
  - Valve
  - Distal
- Disconnection:
  - Proximal/valve
  - Valve/distal
  - Other (specify)
- Fracture:
  - Proximal
  - Distal
- Migration:
  - Up
  - Down

continued

Infection[a]: (y/n)				
Culture				
Overdrainage:				
Subdural hygroma				
Craniostenosis				
Subdural haematoma				
Slit ventricle				
Date revised shunt originally inserted				
Shunt removal:				
Replace with extraventricular drain				
Shunt still functioning on removal				
Operation details				
Date				
Time:				
Start				
Finish				
Operating surgeon:				
Name				
Trainee/consultant				
More than one surgeon?				
Consultant surgeon				
Subtemporal decompression (y/n)				
III ventriculostomy (y/n)				
Choroid plexectomy (y/n)				
Site of insertion of proximal catheter:		Right		Left
Frontal				
Parietal				
Occipital				
Cerebral cyst				
Lumbar				
Other (specify)				
Drainage to:				
Peritoneum				
Atrium				
Thorax				
External				
Other (specify)				
Device details				
	Manufacturer	Type	Cat. number	Serial number
Ventricular catheter				
Distal catheter				
Valve				
If programmable:				
Setting				
Reservoir:				
Integral				
Separate				
Additions:				
Antisiphon device				
Other (specify)				
Manufacturer				
Antibiotic strategy				
Antibiotics:	Specify	Route	Dosage	
Preoperative				
Shunt soaking				
Intraoperative				
Postoperative				

continued

Surgical technique for assembly and insertion
Assembly:
Preassembly
In situ assembly
Glove change
Instrument mediated
Neither
Instruments:
Specific
Standard
[a] Not of wound

UK Renal Registry

Description

The UK Renal Registry was established by the Renal Association with support from the Department of Health, the British Association of Paediatric Nephrologists and the British Transplant Society. It operated as a pilot project between 1995 and 1997, becoming a functional Registry in April 1997. The Registry aims to be able to remain an independent source of data and analysis on national activity in renal disease. It was based on the lack of success with the European Renal Register, which proved of little value to clinicians for comparative audit.[1]

The Registry provides a focus for the collection and analysis of standardised data relating to the incidence, clinical management and outcome of renal disease. The regular collection and analysis of biochemical and haematological information are a unique feature of the UK Registry. The primary purpose of the Registry is to "carefully monitor the quantity and quality of renal care in the UK, thus improving the quality and efficiency of this care" by:

- collection of demographic and descriptive data for planning
- facilitation of comparative audit by means of a carefully defined data set
- collection of data on indicators of quality care to facilitate:
- audit against recommended national standards
- improved care
- identification of good practice
- production of national and local outcome data.

Funding

The Registry aims to become self-funded within 2 years through participating renal units paying annual fees (£10) per patient registered. With 15,000 records this implies a cost of around £150,000 per annum.

Population covered

Participation is voluntary and includes sites from England, Wales and Scotland. The Registry in 2000 holds around 15,000 patient records, over 60% of the 23,115 patients undergoing renal replacement therapy in England and Wales in 1995. All quarterly information is returned for every centre participating with the Registry.

Process of data collection

Each participating unit's computer is linked to laboratory and PAS systems and has extraction routine software installed. Patient data are automatically extracted quarterly using encryption and transmitted via the NHSNET. Data management and error processing are carried out at the Registry with feedback provided to the renal units. The NHS number has been used from the Registry's inception and this is judged to have reduced the occurrence of duplicate patient registrations.

Summary of data items collected

- administration data
- renal unit details
- patients' data, including name, date of birth, NHS number and address
- end-stage renal failure (ESRF)
- annual co-morbid disease
- malignancy
- serology
- erythropoietin dosage
- quarterly treatment history
- hospital admission
- Kt/v or urea reduction ratio calculation
- treatment time line
- peritonitis details
- transplant follow-up.

A more detailed list of data items collected is given on pp. 190–2.

Coding schemes
Data are coded using ICD-9, ICD-10, ICD-CM and OPCS4, which can be converted to Read 4. EDTA (European Dialysis and Transplant Association) coding schemes are also used.

Continuity
There have been no significant disruptions or breaks in the collection of the data.

Completeness
There are no specific figures available concerning the completeness of data items. There are plans to improve the levels of completeness of ethnicity and co-morbidity data by follow-up telephone calls.

Accuracy
Data are loaded into the central database by computer download, hence the information is an exact copy of that on the renal unit database. The accuracy of the information on the renal unit database varies depending on the items, but as clinical decisions are made on this information it is deemed to be accurate. There are plans to improve the accuracy by validating the computer system against the notes for a random sample of records.

Internal validation
The Registry uses bespoke software with a QAS postcoding package. The software has numerous in-built validation functions and has identified a weakness in missing diagnosis, ethnicity and laboratory data items and has highlighted poor collection of blood pressure readings. There are no miscoding problems and the overall validity of the data has not changed from year to year.

External validation
No other national renal registry collects data to the extent of the UK system; data are compared with the United States Renal Data System (USRDS), the closest comparison.

Uses
The main uses of the Register are for comparative audit, for which it provides data to participating centres. An annual report is published with detailed analyses of modalities of treatments and clinical markers.

Quality standards have been proposed, based on analysis of the register.[2]

Future developments
There are plans to expand the Registry, including other forms of treatment. The Registry plans to carry out a retrospective study of the outcomes of cohorts of patients starting renal replacement therapy in the UK over the last 10 years.

Access
Aggregated data are available at district, regional and national levels via the Registry Annual Reports, 6-monthly audit reports of each unit and the UK Renal Registry website. For access to individual patient data (identifiable or with data items necessary for data linkage) and anonymised individual records, application must be made to the Renal Registry subcommittee with both study and funding proposals.

There are no facilities for researchers to request specific data and there are no plans to make this facility available. Charges for use of the data are decided at the subcommittee stage of application.

Contact details
Dr D Ansell
UK Renal Registry
Southmead Hospital
Bristol
BS6 6DN
Tel.: 0117 9595665
Fax: 0117 9595664
E-mail: ansell@renalreg.com
Website: http://www.renalreg.com

Information sources
Information was extracted from a questionnaire and the references quoted.

Publications
Annual report.

Six-monthly audit reports of each renal unit.

Renal Association. The UK Renal Registry 2000. Renal Association; 1998, 1999 and 2000.

References
1. Mallick NP. What do we learn from the European Registry: what will be the underlying problems in the year 2000? *Nephrol Dial Transplant* 1995; **10** (Suppl 7):2–6.

2. Renal Association. Treatment of adult patients with renal failure. Recommended standards and audit measures. Renal Association; 1998.

UK Renal Registry data items

Administration data
Date of details
Centre code

Renal unit details
Number of:
- Dialysis stations
- Inpatient-dedicated renal beds
- Dialysis shifts per week
- Dialysis sessions per week

Number of posts for:
- Consultants
- Specialists
- Training grades
- SHOs
- HOs
- RGNs
- SENs
- Ancillaries
- Technical
- Senior management
- Secretarial

Vacant posts for:
- Specialists
- Juniors
- RGNs
- SENs
- Ancillaries
- Technical

Patient data
Name
Date of birth
Sex
Address
Postcode
Marital status
Ethnic group
Adult height at age 20
Height at first visit
Weight at first visit
Identifying numbers/codes, including:
- NHS
- CHI
- UKTSSA

ESRF flag
Paediatric flag
Date seen by renal physician
Creatinine when first seen
Date of death
Cause of death
Transfer date

End-stage renal failure (ESRF)
First treatment:
- Date
- Weight
- Creatinine

Primary disease code
EDTA disease code
Cause of ESRF

continued

Treatment modality
Other conditions/factors (y/n):
- Angina
- CAGB or coronary angioplasty
- Smoking
- Chronic obstructive pulmonary disease
- Cerebrovascular disease
- Diabetes
- Malignancy
- Liver disease
- Claudication
- Ischaemic/neuropathic ulcers
- Angioplasty (non-coronary)
- Amputation for PVD
- Antenatal diagnosis/treatment
- Preterm
- Cerebral palsy
- Developmental/educational handicap
- Congenital heart disease
- Other major congenital abnormalities
- Down syndrome
- Other chromosomal abnormalities
- Other syndromal diagnosis
- Neural tube defect

Annual co-morbid disease
Date of co-morbid disease
Co-morbid disease:
- Angina
- Previous CAGB or coronary angioplasty
- Smoking
- Chronic obstructive pulmonary disease
- Cerebrovascular disease – symptomatic
- Diabetes not causing ESRF
- Malignancy
- Liver disease
- Claudication
- Ischaemic/neuropathic ulcers
- Angioplasty (non-coronary)
- Amputation for PVD

Malignancy
Date of diagnosis
Malignancy code EDTA/Read 2

Serology
Date of test
HBV antibody status
HBV surface antigen status
HCV antibody status
CMV antibody status

Erythropoietin dosage
Start/end date of period
EPO dosage per week
Total units transferred in period
Parenteral iron in period
EPO drug name and dosage

Quarterly treatment history
Start/end date of period
Treatment centre code
Treatment supervision code

continued

Biochemical details				
Blood pressure:				
Systolic				
Diastolic				
Weight				
Treatment details (including dialyser used, length of time)				
Hospital admission				
Date of admission/discharge				
	Primary	2nd–5th codes		
Admission diagnosis				
Primary procedure				
Kt/v or urea reduction ratio calculation				
Calculation details				
Treatment time line				
Treatment details including dates, length of time, dialyser used, catheter site				
Peritonitis				
Start/end date of treatment				
Organism 1, 2				
WBC count				
Antibiotics:				
Intraperitoneal				
IV				
Transplant follow-up				
Clinical assessment				
Date of last assessment				
Serum creatinine and date				
Immunosuppression:	Dose	Date of change	Prophylaxis	Acute rejection
Azathioprine				
Cyclosporin				
Steroids				
OKT3				
ATG				
ALG				
Tacrolimus				
RS61443				
Other				
Date of last immunosuppression				
Organ transplanted (K) – may be pancreas in future				
Transplant date				
Transplant number				
Failure of transplant (y/n)				
If yes:				
Date				
Cause				
Description				
Date of end of dialysis				
Date return to dialysis if graft failed				
Date graft nephrectomy if graft failed				
Occurrence of data record in transmission				

EPO, erythropoietin; HBV, hepatitis B virus; HCV, hepatitis C virus; PVD, peripheral vascular disease.

UK Thalassaemia Register

Description

The UK Thalassaemia Register was initially established in 1970 and ran to 1982, when it lapsed but resumed in 1991. The Register aims are to:

- evaluate the prevention of thalassaemia in the UK
- facilitate research on thalassaemia patient care.

The Register includes all patients resident in Great Britain with β-thalassaemia major and intermedia, haemoglobin E/β-thalassaemia and α-thalassaemia (haemoglobin H disease). The Register uses the data to help produce treatment protocols and patient information materials. Around 1000 patient records are held on the Register.

In 1999 the Register was planning to change the existing *ad hoc* DNA coding scheme (as used by DNA diagnostic laboratories), to harmonise with that of the nomenclature of the Human Genome Project. The Register intends to extend data collection including DNA diagnosis in parents and patient, quality of care and quality of life indicators. There were also plans to link with the UK Register of Prenatal Diagnoses for Haematological Disorders. Electronic data extraction was also being explored.

Data

Information is obtained from a variety of sources (the original Register, reproductive histories of couples attending for prenatal diagnosis, the UK Register of Bone Marrow Transplantation, enquiries through the UK Forum on Haemoglobin Disorders and the Sickle Cell and Thalassaemia Association of Counsellors, questionnaires issued in 1989 through the British Paediatric Association and the British Society for Haematology, patient tracking through the NHS Central Register and clinician reports).

Profile data are received in paper format on an *ad hoc* basis with 18-monthly updates returned from clinicians. Data are entered into the database on the same day they are received.

An initial profiling form collects data on demographic information, diagnosis, treatment and care. The 18-month update covers vital status and name of new doctor if transferred. The full list of data headings collected is given on pp. 194–5.

Coding systems

A mixture of standard and customised codes is used.

Completeness and accuracy

The Thalassaemia Register is estimated to cover 97% of thalassaemia patients treated by by the NHS (allowing for a delay in the registration of new cases, it may take up to 2 years to diagnose and register a new case). Non-responders to the 18-month update request are followed up to increase coverage. Although some doctors treating thalassaemia patients have been missed, most patients are in contact with specialists, most of whom collaborate with the Register. Only one clinician (treating three patients) has refused to participate. Patients moving abroad may have data included if they/their doctor maintain contact with the Register.

There was a break in the collection of data and processing of data between 1982 and 1991 as noted above. Data collection for the re-established Register was intermittent until funding was obtained in 1997. Owing to the nature of thalassaemia as a chronic lifetime disorder, the Register was able to trace almost all patients.

Core data items (name, date of birth) are at least 97% complete for the 3 years from 1997. Other data items are less complete (the NHS number is present in only 75% of cases).

The Register performs internal random checks on specific data fields. Patients' records are regularly returned to the clinician for checking. The checks have highlighted some inaccuracy in precise diagnosis (e.g. haemoglobin E/β-thalassaemia incorrectly classified as β-thalassaemia major).

The Register is checked with the UK Register of Prenatal Diagnosis of Haemoglobin Disorders. Again, this has highlighted the Register's accuracy of diagnosis as a problem area.

In the UK, thalassaemias occur mainly in certain ethnic minority communities with different prevalence rates (Indians 3–10%, Pakistanis 4.5%, Bangladeshis 8%, Cypriots 0.5–1% and indigenous British around 0.1%). Census of Population data on the number and distribution of ethnic minorities are used to calculate expected numbers of thalassaemia births.[1]

Uses

The Register was used[2] to estimate the degree of informed choice in a confidential enquiry on genetic screening in the UK. It was also used to

explore survival in β-thalassaemia in UK, based on data from the Register.[3]

No studies on diffusion, equity or cost were located.[1]

Funding

Funding was obtained in 1997 from The Sir Halley Stewart Trust and The Wellcome Trust. It is maintained by one whole-time equivalent (a curator and IT support) with allowances for postage, telephone and IT input. The estimated cost is £10,000–30,000 (1000 records at £10–30 per record). The Register has received R&D grants for research projects. Future funding beyond 2001 was highly uncertain.

Access

Researchers can approach the Register for information and a research proposal must be submitted. If data are requested concerning, for example, how many living patients are resident in a given area, the numbers are supplied, anonymised. If the request is to facilitate clinical patient research, the data custodian and curator evaluate the request. If the research is beneficial to patients, the Register will contact doctors with relevant patients. Doctors who may be interested in the research project will collaborate directly with the researcher(s). Researchers should contact Professor B Modell at the address below.

Contact details

Mrs M Khan, UK Thalassaemia Register
Department of Primary Care and Population Sciences
Royal Free and University College Medical School
University College London, Archway Resource Centre
Holborn Union Building
Highgate Hill
London
N19 3UA
Tel.: 020 7288 3597
Fax: 020 7288 8004
E-mail: b.model@ucl.ac.uk

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UK Thalassaemia Register data items

Patient identification
Surname
Forename
Date of birth
Sex
Hospital number
NHS number
Register number
Country of birth
Postcode of current residence
Diagnosis
Beta thalassaemia major
Beta thalassaemia minor
Haemoglobin E/beta thalassaemia
Haemoglobin H disease
DNA study results
Alpha
Beta
Xmn I
Investigations done by

continued

Treatment
Transfusion status:
- Regularly transfused
- Occasionally transfused
- Rarely transfused
- Never transfused

Iron chelation therapy:
- Desferrioxamine
- Deferiprone

Bone marrow transplantation:

Date	Successful (y/n)

Family background
Mother:
- Surname
- Forename
- Date of birth
- Ethnicity

Father
- As above

Affected sibling:
- Surname
- Forename
- Date of birth
- Diagnosis

Pattern of care
General practitioner:
- Name
- Address

Local hospital:
- Hospital
- Name
- Specialty

Secondary referral:
- Hospital
- Consulted every ? months
- Name
- Specialty

Tertiary referral:
- Hospital
- Consulted every ? months
- Name

Circumstances of birth[a]
Was this birth the result of informed parental choice?[b]
If yes:
- At what gestation was prenatal diagnosis offered (weeks)
- What was the outcome:
- Prenatal diagnosis declined
- Pregnancy continued after affected fetus diagnosed at ? weeks

If no:
- How did this happen

Has the obstetrician responsible for the pregnancy been informed of the diagnosis? (y/n)

[a] UK born only.
[b] Both parents' haemoglobin status known and prenatal diagnosis offered in this pregnancy in accordance with best practice.

Appendix 2

Clinical–administrative databases

Contents

Hospital Episode Statistics

Hospital Activity Statistics: Hospital Episode Statistics (HES) England

Description

The HES database contains patient-level records of all inpatients treated in NHS hospitals in England since 1989.* HES is a subset of the Contract Minimum Data Set (CMDS) to which all English NHS Trusts are obliged to record details of service activity (100+ data headings) through their Patient Administration Systems (PASs).

The data for CMDS are collected by the NHS-wide Clearing Service (NWCS). NWCS is also responsible for abstracting the HES data headings from the CMDS database on a quarterly basis. The HES data are then transferred to the Statistics Division of the Department of Health via IBM Global Services UK who are contracted to clean and validate the data before analysis.[1]† HES is administered by the Statistics Division in the Department of Health.

HES collects 12 million records per year and is the source of official figures for England. (Scotland, Wales and Northern Ireland have their own equivalents: COPPISH, PEDW and CAIN, respectively – see separate accounts.)

Data

Each HES record contains 50 (of the 100+) data items collected on the full CMDS (via PAS), HES website (http://www.doh.gov.uk/hes, May 2001). Data not transferred to HES include most of the CMDS personal identifiers (including patient's name, NHS number, full consultant code and GP identifier). HES data headings cover hospital details; patient's age, gender and ethnic group; diagnoses; operations (including day case surgery); length of stay; waiting time; admission method; maternity care; psychiatric care; and discharge details (see HES website).

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* In 1969, the Ministry of Health instigated a 100% collection of all inpatient episodes. This was known as HAA (Hospital Activity Analyses). However, the published volumes of Hospital Inpatient Enquiry (HIPE) remained a 10% sample. In 1982, three changes took place which mean that data for 1982–85 cannot be compared directly with data for earlier years. The main changes were:

1. Wales developed an independent statistics collection system (its inpatient statistics were no longer included in the HIPE systems).
2. Geographical boundary changes were implemented.
3. Patients were grouped according to the region of treatment, rather than region of residence.

In 1985, all central collections of hospital inpatient statistics in England were halted (maternity data collection, however, continued until 1986) to implement the Körner Committee's proposals. Central collection did not recommence until 1987, leaving a 2-year gap in the continuity of data collection. Data collection was changed to financial years. The problem of continuity is further intensified by 2 years of serious invalidity issues. The Department of Health Statistics Division 2 (HES division) advises that requests for information only backdate to the year 1989–90.

† More recently, HES has been subject to further changes. From 1987 to 1995 the Department of Health had responsibility for the collection and dissemination of the HES database. Each provider entered the data items specified in the Körner Minimum Data Set from their PAS. From 1991, provider data items specified in the CMD District Information Systems were downloaded to District and Regional Information Systems (RIS). The HES subset was extracted from the regional systems and sent to ONS to be further cleaned and validated for publication. Regional variations existed in these processes. In 1995, the reorganisation of regional boundaries, the abolition of regional health authorities and the decision to discontinue the ICL mainframe system led to further changes. An NHS-Wide Clearing Service, ClearNET, was established to standardise and streamline the data collected for the CMDS from all English NHS Trusts, with the Department of Health maintaining overall responsibility. Maintenance and control of ClearNET was contracted first to Data Sciences Ltd in 1995 and changed to HBO in 1997. Responsibility for processing, validation and cleaning of HES data was contracted to AT&T Instel in 1995 and transferred to IBM Global Services in 1997. From 1 April 1997, ClearNET has been used to collect the CMDS data items from all Trusts in England. The HES data items in 2001 were abstracted from ClearNET on a quarterly basis and sent to IBM Global Services to clean and validate the data.

Coding systems

The HES database employs OPCS4 codes and ICD-10 (from 1995). Analyses of HES over time require allowance for changes to codes.*

Completeness and accuracy

HES has 100% coverage of inpatient care in NHS Trusts in England. HES does not provide details of the drugs used in hospitals or of outpatients. Although operations performed and diagnoses are detailed in the records, data on the effectiveness of treatment are limited to in-hospital mortality. Private hospitals are not covered, although HES does include private patients treated in NHS hospitals, but it has been shown to underestimate the level of privately funded patient activity.[2]

While HES records surgical procedures as picked up by OPCS4 (PTCAs, pacemaker implants), there is insufficient detail to pick up diffusion of particular new HTs (such as stents or types of pacemakers fitted).

HES provides a fixed picture of each record set at the time the extraction is taken from the evolving Minimum Dataset. The quality of HES data depends on the records generated by the PASs within NHS Trusts. Care has to be exercised when comparing HES figures for different years, particularly if labelled 'provisional'. Fluctuations occur for a number of reasons: organisational changes, the adoption of new coding schemes (detailed above) and data quality problems, which are often year specific.

Studies[3,4] have identified the limitations of using HES data for audit, mainly to do with describing interventions, patients and outcomes. The coding systems, OPCS4 for surgical interventions and ICD for diagnoses, lack measures of complexity and severity. About 5% of HES records lack a usable diagnosis code. Secondary diagnoses are given in only around 1% of records. To compensate for lack of shortfalls in coverage of these items, 'grossing factors' are calculated.[5]

A comparison between UK and US data on hospitals[4] suggested that although the UK resembled the USA, important differences existed: different classification of procedures (OPCS4 for CPT), use of ICD-10 rather than ICD-9CM, use of a different denominator (finished consultant episodes not spells) and greater completeness and precision in the USA.

Reproducibility of HES coding, as judged in a unique study that recoded samples of records, showed fairly high levels of 'approximate' agreement (over the first three characters of the ICD-9 and OPCS4 codes but less so for more detailed coding).[6]

The HES Data Quality Indicator (DQI)

The DQI, introduced in 1999, assesses data coverage and component indicators in support of the NHS Performance Assessment Framework. It provides a summary measure of data quality for Health Authorities of residence and NHS Trusts, and is planned to be linked to data accreditation statute and data audit.

DQI is made up of 13 component indicators which are summarised in *Table 20*. All indicators are weighted equally with the exception of the two maternity indicators (which have a combined weight = 1).[7]

The values for DQI have been computed for 1997–98 and 1998–99 (although the latter year is incomplete owing to delays†). Taking the 12 available indicators gives a composite DQI for 1998–99 of 94. The figures for each indicator are high – all over 90% with the four indicators with lowest scores being administrative, diagnosis 2, practitioner and maternity.

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* The main code changes were:

1. In 1968 the eighth version of the *International Classification of Disease, Injuries and Causes of Death* (ICD-8) was introduced. This caused certain disease groups to be incomparable. The resultant recounting of disease spells per diagnostic group "proved unreliable when extended to trends for age and sex" (HIPE, 1982).
2. On 1 January 1979, ICD-8 was replaced by ICD-9, affecting the comparability of certain disease groups.
3. In 1991, the NHS was again reorganised. Hospitals moved to become Trusts and some GPs became Fundholders. Codes for hospitals and GPs had to be updated.
4. From 1 April 1995, ICD-10 was implemented. This again affected the comparability of certain disease groups.
5. In 1995, District Health Authorities merged with Family Health Service Authorities that resulted in further changes of the coding scheme.

† Up to 1999, the completeness of notifications of all finished consultant episodes was evaluated by comparison with the Körner. The last year KP70 was collected was for 1998–99. However, the 1998–99 KP70 will not be released for use outside the department or NHS as in 2000 HES became the only source of activity counts. Aggregate return KP70 (Summary Return of Patient Activity – no longer collected) was completed independently of HES. KP70 figures were filled in by information departments at Trusts. The latest publication for KP70 is for 1997–98.

TABLE 20 *Component indicators of DQI*

Component indicator	Includes/refers to
Coverage	KP70
Administrative	Episode order, episode start, main specialty
Record linkage	Date of birth, home address, sex
Ethnic coding	Ethnic group
Admissions	Admission date, source of admissions, decision to admit date
Discharge	Discharge date, destination on discharge, discharge method
Diagnosis 1	Missing, invalid or 'not known' codes
Diagnosis 2	Dagger and asterisk codes
Operations 1	Invalid codes
Operations 2	Missing codes
Practitioner	Consultant code, referrer code, registered GP
Maternity 1	Delivery records with a 'baby tail'
Maternity 2	Labour/delivery onset method, delivery place type, person conducting delivery

Before submission to the database, all records undergo thorough automatic checks.[7] To be accepted, a record must contain an appropriate hospital provider code, patient classification and record type. If the episode has ended, then the episode end date must also be included. A record that fails one or more of these criteria will be rejected. Verification error reports enable the data provider to rectify and resubmit as appropriate. For each data submission, feedback reports are generated for each of the above checks, summarising items such as number of records supplied, the number of missing records, how many times the autocleaning was used, a breakdown of errors and summary of the quality of submission after autocleaning.

Uses

Overall, HES is the largest database with patient-level data in England and has major potential in HT assessment which is beginning to be realised via clinical indicators, data quality indicators (discussed above) and national audit. Its main deficiencies have to do with the quality of its data.[8]

NHS clinical indicators have been developed from HES data to be used at both national and local levels within the NHS.[9–11] In 1999, NHSE published six clinical indicators.* Scotland has longer experience with clinical indicators, both through linkage to mortality records and with validation.[12]

The Bristol Royal Infirmary Inquiry into raised mortality in paediatric cardiothoracic surgery explored the value of routine datasets, including HES, in identifying problems. HES was shown to have captured the poor performance better than the UK Cardiac Surgical Register as it allowed for comparisons of in-hospital mortality by age.[13]

HES has been much used[14] in analyses of variations and health inequalities between age, sex, geographical area and organisations. HES provided the basis of an equity needs indicator used in funding health authorities.[15,16] HES has also been used in relation to specific diseases, including cardiac revascularisation by sex.[13,17–20] It has also been used to explore variations and appropriate levels of provisions for elective surgical procedures.[21–26]

HES provides the basic data for Healthcare Resource Group (HRG) (unit) costing. Episodes are grouped into HRGs using ICD, OPCS plus age and sex to construct HRGs which aim to be homogeneous in terms of cost.[27,28]

Funding

No information is available on the cost of HES. In Chapter 9, it was estimated that HES cost the Department of Health around £12 million per year (12 million at a notional cost of £1 per record).

Access

Standard data tables (most recent (1999–2000, 1998–99) are on the HES website (see Contact details below) and a CD-ROM version (from 1996 onwards) is available to NHS-related agencies,

* These are: (a) 30-day mortality covering emergency and non-emergency admissions (all ages); (b) emergency admission with a hip fracture (ages 65+); (c) emergency admission with a heart attack (ages 50+); (d) emergency re-admission to hospital within 28 days of discharge from hospital (all ages); (e) discharge to usual place of residence within 56 days of emergency admission with stroke (ages 50+); and (f) discharge to usual place of residence within 28 days of emergency admission with a hip fracture (ages 65+).

containing statistical information including length of stay, waiting times and number of episodes occurring for ranges of diagnoses and operating procedures. Information is presented at national, regional and Health Authority levels. The CD-ROM consists of a large number of tables, fronted by an easy-to-use Windows-based system. HES CD-ROMs are currently available for the 1994–95 and 1995–96 data years. Further information can be obtained from the SD2HES (data quality team) given below.

Contact details

Richard Kemp/C Yates
SD2HES (data quality team)
Department of Health
Skipton House
80 London Road
London
SE1 6LH
Tel.: 020 7972 5563/5532
Fax: 020 7972 5662
E-mail: richard.kemp@doh.gsi.gov.uk or chris.yates@doh.gsi.gov.uk
HES website: http://www.doh.gov.uk/hes
Department of Health Statistics Division website: http://www.statistics.gov.uk/
Department of Health Clinical Indicators website: http://www.doh.gov.uk/indicat/indicat.htm

ClearNET (access via NHS Net only – a secure wide area network connecting NHS organisations)
NHS-Wide Clearing Service: NWCS Help Desk
Tel.: 0845 6061020
NHS Information Authority – Portal Site: http://nhsia.nhs.uk/
Hospital Inpatient Data based on HES, 1999–2000 Key Facts and Figures, HES website (see Access section above)

Publications

HES summary data tables are published annually on the HES website, in hard copy and on CD-ROM (see above).

For all years between 1989 and 1996 two volumes are available for each year (Department of Health publications). Data are also published in the *Hospital Activity Bulletin* and *Statistical Bulletin*.

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HES data items

Patient details			
Ethnic origin			
Address			
Postcode			
Date of birth			
Age on admission			
Sex			
AIDS indicator			
Marital status (pre-1995. From 1995 onwards, if psychiatric patient)			
Age of baby on admission, in days			
Legal status classification			
Administrative and legal status:	NHS	Private	Amenity
Not formally detained			
Detained (Part II Mental Health Act)			
Detained (Part III Mental Health Act)			
Detained (Part X Mental Health Act)			
Other maternity event			
Residence:			
County			
DHA			
LA			
RHA			
Standard region			
RHA of treatment			
Electoral ward of residence, as at 1 April of data year			
Admission details			
Date			
Patient classification:			
Ordinary admission			
Day case			
Mothers and babies using only delivery facilities			

continued

Method:
- Elective
  - From waiting list
  - Booked
  - Planned
- Emergency
  - A&E services
  - GP
  - Bed bureau
  - Consultant outpatient clinic
  - Other
- Maternity
  - Baby delivered after mother's admission
  - Baby delivered before mother's admission
- Other
  - Transferred from another healthcare provider
  - Babies born inside healthcare provider
  - Babies born outside healthcare provider (except intended home births)
- Other maternity event
- Not known

Source:
- Usual residence
- Temporary residence
- Order of penal establishments
- Special hospital
- Another NHS hospital provider
  - General ward/A&E/younger physically disabled ward
  - Maternity/neonatal ward
  - Mentally ill/learning disabilities
- NHS-run nursing/residential care/group homes
- Local authority care
- Babies born in/on way to hospital
- Other NHS hospital/home, etc.
- Other maternity event
- Not known

District of treatment
Date of decision to admit
Waiting time (from decision to admittance)
Provider code
Purchaser code
Bed days within HES year

Maternity details
First antenatal assessment date
Gestation period in weeks, at the date of the 1st antenatal assessment
Antenatal days of stay
Initial intended delivery place type

Delivery place change, reason:	Pregnancy	Labour
Clinical reasons		
Other reasons		
	Address changed	Unintentionally

Status of person conducting delivery:
- Hospital doctor
- GP
- Midwife
- Other
- Not known

continued

Delivery place type:
- Domestic address
- NHS hospital
  - Consultant ward
  - GMP ward
  - Consultant/GMP ward
  - Without delivery facilities
- Private hospital
- Other hospital/institution
- Other
- Not known

Labour/delivery onset method:
- Spontaneous
- Caesarean
- Surgical induction
- Oxytoxic drugs
- Surgical induction and oxytoxics
- Not known

Anaesthetic given during labour/delivery:
- General
- Epidural/caudal
- Spinal
- General and epidural/caudal
- General and spinal
- Epidural/caudal and spinal
- Other
- None

Anaesthetic given post-labour/delivery:
- As above

Anaesthesia indicator, derived from anaesthetic pre- and post-labour/delivery

Delivery method:
- Spontaneous vertex
- Spontaneous other cephalic (without instruments)
- Low forceps (not breech)
- Other forceps (not breech)
- Ventouse, vacuum
- Breech (spontaneous)
- Breech extraction (not otherwise specified)
- Elective Caesarean
- Emergency Caesarean
- Other
- Not known

Birth order: sequence of births in multiple delivery

Birth resuscitation method:

Positive pressure	Drugs
Nil	Nil
Nil	Administered
Mask	Nil
Mask	Administered
Endotracheal tube	Nil
Endotracheal tube	Administered

- Not known
- Not applicable

Birth state:
- Live
- Still birth
  - Antepartum
  - Intrapartum
  - Indeterminate

Length of gestation

Number of babies (registrable) at delivery (1–6+)

Birth weight

continued

Date of birth of baby Sex Mother's age Mother's birth date Number of previous pregnancies resulting in registrable birth (0–19) Postnatal stay Indicator of level of nursing care neonate requires
Diagnosis details Diagnosis (ICD-10), up to 7 External cause of injury or poisoning Consultant 1 & 2: Main specialty
Operation details Operation code (up to 4) Date of operation (up to 4 dates) Number of days between: Start of episode and date of principal operation Date of principal operation and end of finished episode
Psychiatric census details Date of detained and/or long-term psychiatric census Diagnosis (on psychiatric census date) Duration of care (to psychiatric census date) Duration of detention Date detention commenced Age at psychiatric census Status of patient included in psychiatric census: Detained Long-term Detained and long-term Ward type (at psychiatric census date) Mental category: Mental illness Mental impairment Severe mental impairment Psychopathic disorder Not specified Not known Not applicable
Discharge details Date of discharge Destination on discharge: As for admission source Method: On clinical advice/consent Discharged themselves/or relative By mental health review/Home Secretary/court Died Stillborn baby
Episode details Date episode started Date ended Duration Episode order
continued

Type: General Delivery Birth Formally detained Other delivery event Other birth event Age at end Status: Finished Unfinished Record type: amalgamation of episode type and status Episode is first in-hospital spell, and whether the spell started in the current or previous data year Duration of spell Indicates whether the episode is the last in a spell Flag to show whether record would be included in a 25% sample
DHA, District Health Authority; RHA, Regional Health Authority; LA, Local Authority.

Scottish Morbidity Records (SMR): SMR01 Inpatient and Day Case Records, SMR02 Maternity Discharge Records and SMR04 Inpatient and Day Case Records (Mental Health)

Description

The SMR system is run by the Information and Statistics Division (ISD) of the CSA, part of the NHS in Scotland (NHSiS). From 1993, a project 'Core Patient Profile Information in Scottish Hospitals' (COPPISH) reviewed and upgraded the various SMR systems to accommodate the changing needs of NHSiS and the introduction of ICD-10 in 1996 (ISD Scotland, 1997).

The revised SMR system had the following purposes:

- provision of information on inpatient and day case episodes in general and acute wards to be used in health service management planning and costing, with
- feedback on completeness and quality of data to management at Trust and Health Board level
- with scope for use in accountability reviews, management information systems, analysis of ministerial and parliamentary questions, research studies, annual and periodic publications and other *ad hoc* analysis.

SMR aims to provide a comprehensive core dataset with a standard set of data definitions and codes for:

- patient identification and demographic data
- episode management data
- clinical data
- development data.

The use of patient identification core datasets in each SMR return should allow linkage and therefore tracking of patients, and analyses of patient flow through the hospital system and linkage to other datasets. For example, all admissions for each mother during pregnancy may be linked to General Record Office (Scotland) providing links to occupational data as well as to birth and neonatal records. The collection of data is broken into various sections which include the following (ISD Scotland, 1996, 1997).

SMR00 Outpatient Record

Outpatients receiving specialty care when attending a consultant or other medical outpatient clinic or meeting with a consultant (or senior member of the team) outside an outpatient clinic, other than Accident and Emergency and Genitourinary Medicine, are recorded in SMR 00.

During April 1991–March 1996 a basic dataset for new outpatients only was collected (SMR0). Records were completed for each new attendance and 'did not attend' (DNA) occurrence for a new appointment, producing over 1 million records per year.

From April 1996, SMR00 replaced SMR0, allowing collection of follow-up diagnostic and procedure information.

SMR01 Inpatient and Day Case Records

These are generated for each inpatient and day case admission, and/or change of inpatient/day case care.

SMR02 Maternity Discharge Records

Patients receiving care in the obstetrics specialties

(including a modified version covering home births) are recorded in SMR 02. A record is generated for each episode (about 125,000 annually, of which 50% are non-delivery episodes) (ISD Scotland, 1996).

SMR04 Inpatient and Day Case Record (Mental Health)
Patients receiving care in the psychiatry and mental illness specialties are recorded in SMR04. Previously SMR4, SMR04 returns information on approximately 32,000 admissions and 32,000 discharges annually.

SMR06 Cancer Registration
Patients diagnosed/receiving treatment for cancer are recorded in SMR06. Responsibility for cancer registration data transferred to ISD from 1997.

SMR11 Neonatal Discharge Record
Babies requiring medical care (other than resuscitation or routine screening) or having a congenital anomaly (irrespective of treatment) are recorded in SMR11.

SMR11 was piloted in 1971–74, covering 30–50% of live births. By 1980 this had risen to 75% (ISD Scotland, 1996) and was increased further to 'full coverage' following the Lenehan Inquiry* (1987) and the pressures ensuing. Before the COPPISH project, SMR11 was used for all live births in NHSiS. This return has changed and is an episode-based record for sick babies; the section of the original SMR11 dealing with live births is no longer required as it is available under SMR02. The current SMR11 also records measures of neonatal intensive care.

The Congenital Anomaly Register will be made up of information from SMR11 together with data from SMR1 (for the first year of life) and the Stillbirth and Neonatal Death Enquiry.

SMR20 Scottish Cardiac Surgery Register
The Registration Form lists all patients accepted on to cardiac surgery waiting lists or admitted as emergencies to cardiac units.

It was established as a result of the Kay Committee's recommendations for the monitoring of new units and the creation of a clinical and epidemiological database. Linkage to mortality data is possible to facilitate long-term follow-up.

SMR30C Accident and Emergency Waiting Times Census and Survey
This is a series of bi-annual week-long surveys of patient waiting times in the larger A&E departments.

Established in November 1994, the surveys collect information for central monitoring of waiting times at various stages of treatment in A&E departments, for use in service and activity planning.

SMR50 Inpatient Record (Geriatric Long Stay)
SMR50 records patients receiving care in the specialty geriatric medicine or in-stay units for care of the elderly.

Previously the data were collected by SMR1 for specialty 51 (Geriatric Long Stay); however SMR1 only collected discharge data. COPPISH SMR50 commenced 1 April 1995 and provides diagnostic data on both admission and discharge.

The following returns were planned to be included in COPPISH:

- SMR34 Day Hospital Attenders
- SMR36 PAM Outpatient Attendance
- SMR38 Haemodialysis Patients.

Funding
NHS Scotland. No information has been located on the costs of the various returns.

Population covered
Residents of Scotland.

Process of data collection
Data are collected from every Trust in Scotland and from some GP practices.

SMRs can be submitted on paper forms, 1/2-inch magnetic tapes, 3 1/2-inch floppy disks or over the NHS-Net. Data submitted on paper forms are sent to a commercial company who carry out a data preparation service. The majority of records keyed by the data preparation bureau relate to SMR00, outpatient information. NHS-Net is used to transmit around 50% of SMR data.

Data accreditation was introduced from 1999 with data validated at the sending site before submission as part of central processing. To become accredited, sites must comply with a number of rigorously enforced prerequisite

* Investigation of eye defects of babies born to mothers living near the Rechem processing plant in Bonnybridge.

conditions, including achievement of quality levels for preparatory periods and up-to-date submissions, and install validation systems.

Summary of data items collected

SMR00 Outpatient Record
- patient identification, including name, date of birth, NHS and CHI numbers
- episode management
- clinical details.

SMR01 Inpatient and Day Case Record
- patient identification, including name, date of birth, NHS and CHI numbers
- episode management
- clinical details
- discharge data
- operation/procedure details
- development data.

SMR02 Maternity Discharge Record
- patient identification, including name, date of birth, NHS and CHI numbers
- episode management
- clinical details
- previous pregnancies
- general clinical maternal condition
- maternal discharge data
- operation procedure
- current pregnancy
- record of labour
- baby record including CHI number.

SMR04 Inpatient and Day Case Record (Mental Health)
- patient identification, including name, date of birth, NHS and CHI numbers
- episode management
- general clinical details
- admission
- clinical details
- discharge data.

SMR06 Cancer Registration
- patient identification, including name, date of birth, NHS and CHI numbers
- diagnosis, site, morphology, behaviour
- grade of tumour
- stage of tumour (sited tumour sites only)
- initial treatment indicators.

SMR11 Neonatal Discharge Record
- patient identification, including name, date of birth, NHS and CHI numbers
- episode management
- clinical/diagnosis other than congenital anomaly
- operation/procedure
- discharge data
- baby record
- problem record to define intensive care
- procedures
- congenital anomaly.

SMR20 Scottish Cardiac Surgery Register
- name, date of birth and NHS number
- administrative data
- clinical data
- exit from waiting list
- details of stay in hospital
- disposal from cardiac surgery unit
- follow-up.

SMR30 Accident and Emergency Waiting Times Census and Survey
- hospital details
- patient reference and type
- time of activities (triage, seen by a doctor, etc.)
- outcome

SMR50 Inpatient Record (Geriatric Long Stay)
- patient identification, including name, date of birth, NHS and CHI numbers
- episode management
- admission
- discharge records
- condition/principal diagnosis/problem managed.

Details of the contents of each of these returns are given on pp. 210–21.

Coding schemes

Standard coding systems are used for all forms. All hospitals use the ICD-10 codes, introduced on 1 April 1996, except one hospital that uses Read, mapping back to ICD-10.

Continuity

There have been no discontinuities in the processing or collection of the data.

Completeness

The completeness of notifications is reported at 100%. Regular comparisons are made with other statistics produced by SMR.

No figures are available for the completeness of the forms provided, but it is estimated to be high owing to the mandatory fields and the ongoing process of validation. Annual clean-ups are carried out to monitor the number of errors and queries on file. Any items missing at the end of the year are submitted back to the appropriate Trust for completion.

Accuracy
A quality assurance team identifies any unusual occurrences during visits to the Trusts and provides feedback. No figures are available for accuracy.

Internal validation
All information received, whether on disk or paper format, is put through the same validation process. Each record is subjected to a computerised validation to agreed national standards. These standards are reviewed regularly and changed in agreement with the NHSiS.

The QUIBBLE (Crown Copyright) system is used for computer validation, which was set up specifically for the ISD. The system searches for descriptions and valid codes and carries out various cross-checks, along with ICD-10 applicability checks.

Other validation checks include:

- validation at Datacred
- quality assurance team visits
- analysis team investigations
- annual clean-ups
- mandatory fields
- analysis on bed occupancy – comparison between forms.

External validation
The SMR1 section is compared with the Scottish Cancer Registry.

Uses
The SMR returns have been used in a number of research projects which would qualify as HT assessments, including comparative audit and the derivation of equity indices for capitation funding, and in clinical trials.

Access
Anonymised information from the SMRs is available on request for bona fide medical research. ISD charge for the supply of information. Published information is available from the ISD Customer Support Desk or via the ISD website.

Contact details
Information and Statistics Division
Common Services Agency
The National Health Service in Scotland
Trinity Park House
South Trinity Road
Edinburgh
EH5 3SQ
Tel.: 0131 552 6255
Fax: 0131 551 1392

Data processing:
M Brown
Tel. 0131 551 8667

Statistics:
J Telfer
Tel.: 0131 551 8046

A&E waiting times:
D Murphy
Tel.: 0131 551 8075

Publications and further sources of information
Ad hoc analyses are available on request.
Data are also published in Scottish Health Statistics and in health board and specialty tables. Copies or further information can be obtained from the ISD Customer Support Desk (Tel. 0131 551 8899) or the website www.show.scot.nhs.uk/isd

Information sources
Data were extracted from an interview and references.

Core patient profile information in Scottish Hospitals: Scottish Morbidity Record Project (COPPISH SMR)

Outpatient Record: COPPISH SMR00

Hospital
Patient identification Health records system ID Hospital patient identifier COPPISH SMR episode record key Surname Forenames Previous surname Date of birth Gender Marital status Ethnic group Address Postcode Central Index (CI)/CHI number NHS number Alternative case reference number GP practice code GMC no. of referring GP/GDP/consultant
Episode management Spell/care package ID Location/hospital Time (a.m./p.m./all day) Clinic date Clinic code Specialty/discipline Significant facility Clinical facility (start) Consultant/HCP responsible for care Patient category GP referral letter number Waiting time guarantee exception Referral received date Referral type Referral source Referral reason (×4) Attendance status Attendance follow-up Contract identifier: Provider Purchaser Contract serial number Contract service number Iso resource group Invoice number Invoice line Contract charge
General clinical Main condition/principal diagnosis/problem managed (ICD-10) Other conditions/co-morbidity/complication (ICD-10) Main operation/procedure Other operation/procedure OPCS4 (as appropriate) Date Clinician responsible

Outpatient Record (Short[a]): COPPISH SMR00

Hospital Spell/care package ID Location/hospital Time (a.m./p.m./all day) Clinic date Specialty/discipline Clinic name Clinic code Significant facility Consultant name GMC no. of consultant/HCP responsible for care
Patient identification Health records system ID Patient identifier Surname Initials Date of birth Sex CHI number Postcode GP practice code
Episode Management COPPISH SMR episode record key Patient category Waiting time guarantee exception Referral received date Referral type Referral source Attendance status Contract identifier: Provider Purchaser Contract serial number Main operation/procedure Date of main operation GMC no. of clinician/HCP responsible
[a] This short version of SMR00 is used in most circumstances where only the abbreviated set of data items is required for collection. Patient identification and episode management are reproduced four times allowing up to four outpatient attendances (same clinic, date, specialty and consultant) to be entered.

Inpatient and Day Case Record: COPPISH SMR01

Hospital

Patient identification
Health records system ID
Patient identifier
COPPISH SMR episode record key
Surname
Forenames
Previous surname
Date of birth
Sex (gender)
Marital status
Ethnic group
Address
Postcode
Central index (CI)/CHI number
NHS number
Alternative case ref. number
GP practice code
GMC no. of referring GP/GDP/consultant

Episode management
Spell/care package ID
Specialty/discipline
Significant facility
Clinical facility start
Consultant/HCP responsible for care
Management of patient
Patient category
Location/hospital
Admission:
- Date
- Type
- Reason

Admission/transfer from
Admission/transfer from – location
GP referral letter number
Waiting list guarantee exception code
Waiting list date
Waiting list type
Contract identifier:
- Provider
- Purchaser
- Contract serial number
- Contract service number
- Iso resource group
- Invoice number
- Invoice line
- Contract charge

General clinical
Main condition/principal diagnosis/problem managed (ICD-10)
Other condition/co-morbidity/complication (ICD-10–2) (×5)

Discharge data
Ready for discharge date
Clinical facility end
Discharge date
Discharge type
Discharge/transfer to
Discharge/transfer to (location)

continued

Operation/procedure		
	Main operation/procedure	Other operation/procedure (×3)
Code		
Date		
Clinician responsible		

Development data
Chronic sick/disabled
Clinical problem of spell/care package
Lifestyle risk factors (×2)
Outcomes measures (×2)
Dependency/severity measures (×2)

Maternity Discharge Record: COPPISH SMR02

Hospital
Patient identification
Health records system ID
Patient identifier
COPPISH SMR episode record key
Surname
First forename
Second forename
Previous surname
Date of birth
Sex (compulsory 2)
Marital status
Ethnic group
Address
Postcode
Central index (CI)/CHI number
NHS number
Alternative case ref. number
GP practice code
GMC no. of referring GP/GDP/consultant
Episode management
Spell/care package ID
Specialty/discipline
Significant facility (compulsory 11)
Clinical facility start
Consultant/HCP responsible for care
Management of patient
Patient category
Location/hospital
Admission:
Date
Type (compulsory 42)
Reason
Admission/transfer from
Admission/transfer from (location)
GP referral letter number
Contract identifier:
Provider
Purchaser
Contract serial number
Contract service number
Iso resource group
Invoice number

continued

Invoice line
Contract charge

Previous pregnancies
Numbers of:
Total number of pregnancies
Spontaneous abortions
Therapeutic abortions
Caesarean sections
Stillbirths
Neonatal deaths

General clinical maternal condition
Main condition/principal diagnosis/problem managed (ICD10)
Other condition/co-morbidity/complication (ICD 10) (×5)

Maternal discharge data
Ready for discharge date
Date of discharge
Clinical facility end
Condition on discharge
Discharge type
Discharge/transfer to
Discharge/transfer to (location)
Booking smoking history
Smoker during pregnancy
Diabetes

Operation procedure

	Main operation/procedure	Other operation/procedure
Code		
Date		
Clinician responsible		

Current pregnancy
Number of previous admissions to any hospital in this pregnancy
Date of booking
Original booking

	Delivery plan	Booking change
Place		
Management		
Feeding intention at booking		
Height (cm)		
Type of abortion		
Management of abortion		
Last menstrual period (LMP)		
Estimated gestation at abortion or delivery		
Certainty of gestation based on LMP		

Record of labour
Induction of labour (not augmentation)
Duration of labour hours
Analgesia in labour
Analgesia during delivery
Sterilisation after delivery
Date of delivery
Number of births this pregnancy
Episiotomy
Tears
Indication for operative delivery (baby 1)
Senior doctor present at delivery
Senior midwife present at delivery

continued

Midwife to consultant transfer			
Antenatal steroids			
Baby record			
Baby	1	2	3
CHI			
Presentation at delivery			
Mode of delivery			
Outcome of pregnancy			
Birthweight (g)			
Resuscitation			
Apgar score at 5 minutes			
Sex			
Occipito-frontal circumference (cm)			
Crown/heel (cm)			
Neonatal indicator			
Baby discharged to			
Feed on discharge			

Maternity Record (Home Births): COPPISH SMR02(D)

SMR02(D) is used for home births, patient not admitted to hospital. The data collected are very similar although certain data items have compulsory values (e.g. location/hospital, admission type and reason).

Inpatient and Day Case Record (Mental Health): COPPISH SMR04

Hospital
Patient identification
Health records system ID
Patient identifier
COPPISH SMR episode record key
Surname
Forenames
Previous surname
Date of birth
Sex (gender)
Marital status
Ethnic group
Address
Postcode
Central index (CI)/CHI number
NHS number
Alternative case ref. number
GP practice code
GMC no. of referring GP/GDP/consultant
Episode management
Spell/care package ID
Specialty/discipline
Significant facility
Clinical facility start
Consultant/HCP responsible for care
Management of patient
Patient category
Location/hospital
Admission:
Date
Type
Reason

continued

Admission/transfer from
Admission/transfer from (location)
GP referral letter number
Waiting list:
  Guarantee exception code
  Date
  Type
Contract identifier:
  Provider
  Purchaser
  Contract serial number
  Contract service number
  Iso resource group
  Invoice number
  Invoice line
  Contract charge

Admission
Status on admission
Admission referral from
Previous psychiatric care

General clinical
Main condition/principal diagnosis/problem managed (ICD-10)
Other condition/comorbidity/complication (ICD-10) (×3)

Discharge data
Ready for discharge date
Clinical facility end
Discharge date
Discharge type
Discharge/transfer to
Discharge/transfer to (location)
Type psychiatric care provided
ECT: first treatment date
ECT: treatments – number
Arrangements for after care (×4)
Care plan arrangements
Date last mental health census
Main condition/principal diagnosis/problem managed
Other condition/co-morbidity/complication (×3)
Dependency/severity measures

Cancer Registration: COPPISH SMR06

Record number
Date of registration
CRO

Patient identification at diagnosis
Person ID number
Surname
Forenames
Previous surname
Date of birth
Date of death
Sex
Marital status
Ethnic group

continued

Address Postcode CI/CHI number NHS number Case ref. no. GP practice code
Diagnosis Method of 1st detection Histological verification Most valid basis of diagnosis Hospital/GP of diagnosis Incidence date Death certificate only Death certificate initiated Independent primary status
Site, type, behaviour and grade Site [ICD-10[a], ICD(0)2] Type [ICD(0)2] Side Grade cell: Classification Cell type Duke's stage colorectal Figo stage cervix
Size and stage of tumour Clinical T stage Pathological tumour size (mm) Nodes positive Clinical N stage Nodes examined No. of positive nodes Clinical M stage No. of nodes examined Oestrogen receptor status
Initial treatment indicators Radiotherapy: Referred Treated To primary To metastasis To other Date of 1st radiotherapy Hospital/GP 1st radiotherapy Surgery: Date 1st surgery Hospital/GP 1st surgery Chemotherapy: Date of 1st chemotherapy Hospital/GP 1st chemotherapy Hormone therapy: Date 1st hormone Other therapy: Type of other therapy Date 1st other therapy Hospital/GP 1st other therapy Intended therapy objectives Treatment protocols Comments

[a] Pre-1997 and death certificate only registrations use ICD-9 and ICD(0) classifications. CRO, Cancer Registration Officer.

Neonatal Discharge Record: COPPISH SMR11

Hospital

Patient identification
Health records system ID
Patient identifier
COPPISH SMR episode record key
Surname
Forenames
Previous surname
Date of birth
Sex (gender)
Ethnic group
Address
Postcode
Central index (CI)/CHI number
NHS number
Alternative case ref. number
GP practice code
GMC no. of referring GP/GDP/consultant

Episode management
Spell/care package ID
Specialty/discipline
Significant facility
Clinical facility start
Consultant responsible for care
Management of patient
Patient category
Location/hospital
Admission:
- Date
- Type (compulsory 43)
- Reason

Admission/transfer from
Admission/transfer from (location)
GP referral letter number
Contract identifier:
- Provider
- Purchaser
- Contract serial number
- Contract service number
- Iso resource group
- Invoice number
- Invoice line
- Contract charge

General clinical/diagnosis other than congenital anomaly
Main condition/principal diagnosis/problem managed (ICD-10)
Other condition/co-morbidity/complication (ICD-10) (×5)

Operation procedure

	Main operation/procedure	Other operation/procedure
Date		
Clinician		

Discharge data
Ready for discharge date
Clinical facility end
Discharge:
- Date
- Type

continued

Discharge/transfer to Discharge/transfer to (location)
Baby record No. of births this pregnancy Birth order (this baby) Estimated gestation Birthweight (g) Jaundice Phototherapy Max. bilirubin (μmol/l) Hypoglycaemia Lowest glucose (μmol/l) Discharge weight Feed on discharge
Problem record to define intensive care (×15) Code Date on Date off
Procedures Procedures carried out
Congenital anomaly ICD-10 (×3)

Scottish Cardiac Surgery Register: Registration Form: SMR20

General information SCSR number Surname First name Other initial Sex Date of birth NHS number Maiden name (for married women with no NHS number) Home address Postcode
Administrative data Accepting hospital code Accepting case ref. no. Date accepted for surgery Category of patient Urgency code Revised urgency code Date of revision
Clinical data Cardiac diagnosis (×3) Procedure(s) required (×2) Number of previous procedures under C/P bypass Number of previous closed cardiac procedures
Exit from waiting list Reason Date of exit from waiting list
continued

Details of stay in hospital
Name of consultant surgeon
Date of first operation
Procedure(s) performed and procedure category (×3)
Additional procedure performed and date (×3)
Date of discharge from cardiac surgery unit

Disposal from cardiac surgery unit
Destination

Follow-up
Date of death

Option boxes
National
Local

Accident and Emergency Waiting Times Census: SMR30C

Hospital details
Hospital name
Hospital code
Date (for paper returns enter the day only)

Patient reference and type
Patient's case reference number (either casualty no. or main hospital CRN)
Patient type:
- Resuscitation
- Trolley case
- Walking wounded

Time of activities
Time of arrival at reception
Time at triage/1st clinical assessment
Time first seen by doctor
Time of completion of treatment in A&E Department
Time left A&E Department

Outcome
Means of leaving A&E Department:
- Left by own means
- By ambulance on transfer
- By ambulance – other
- Ward admission within same hospital

Patient left before treatment complete

Inpatient Record (Geriatric Long Stay): COPPISH SMR50

Hospital

Patient identification
Health records system ID
Patient identifier
COPPISH SMR episode record key
Surname
Forenames
Previous surname
Date of birth
Sex (gender)

continued

Marital status Ethnic group Address Postcode Central index (CI)/CHI number NHS number Alternative case ref. number GP practice code GMC no. of referring GP/GDP/consultant
Episode management Spell/care package ID Specialty/discipline Significant facility (compulsory 1E) Clinical facility start Consultant/HCP responsible for care Management of patient Patient category Location/hospital Admission: Date Type Reason Admission/transfer from Admission/transfer from (location) GP referral letter number Waiting list guarantee exception code Waiting list date Waiting list type Contract identifier: Provider Purchaser Contract serial number Contract service number Iso resource group Invoice number Invoice line Contract charge
Admission Main condition/principal diagnosis/problem managed (ICD-10) Other condition/co-morbidity/complication (ICD-10) (×2) Main contributory social factor (ICD-10)
Discharge records Ready for discharge date Clinical facility end Discharge: Date Type Discharge/transfer to Discharge/transfer to (location) Type long stay care provided Date last long stay census
Condition/principal diagnosis/problem managed Main condition/principal diagnosis/problem managed Other condition/co-morbidity/complication (×3) Dependency/severity measures

Patient Episode Database for Wales (PEDW)

General description

Established in April 1991, the database replaced the Hospital Activity Analysis (HAA) for non-psychiatric patients and the Mental Health Enquiry (MHE) for psychiatric patients. PEDW is run by the Welsh Health Common Services Authority (WHCSA) through the Welsh Health Information Services (WHIS*) on behalf of NHS Wales and the Welsh Office.

PEDW is the principal source of patient-based data on hospital activity in Wales and is used for the following purposes:

- supporting the management and planning of services
- evaluation of NHS performance and trends
- supplying epidemiological data at the national and local level
- contributing to the cancer registration process
- assisting in the resource allocation process
- answering parliamentary questions
- to prepare briefings for ministers
- *ad hoc* requests and research.

PEDW has also been used in the new set of clinical indicators being developed by the Department of Health and the Welsh Office.

Funding

The Welsh Office provides funding through a service level agreement with WHCSA.

Population covered

The PEDW contains demographic, administrative and clinical records for all inpatient and day cases in NHS hospitals in Wales, and for some Welsh residents who have received treatment in Great Britain.

Process of data collection

Data are collected from all NHS Trusts in Wales and for any Welsh resident treated in Great Britain. Individual patient records are collected for each finished consultant episode.

WHIS receive information on a monthly basis from NHS Trusts in Wales, extracted from their PAS systems.† The information includes records for all finished consultant episodes in the previous month and amendments for records that have previously been submitted. All new records include demographic and administrative information that is entered when a patient is admitted to hospital. Other information such as clinical coding may be submitted later on an amended record. Information is supplied in disk/cartridge form or by electronic file transfer.

Information for Welsh residents treated in Great Britain is received via ClearNET (a voluntary system, so not necessarily complete).

Once all information has been received at the PEDW office, the checking and processing of data take around 3 months to complete, but this may be subject to further changes as amendments are received fairly often.

Summary of data items collected

Patients' details, including name, address, date of birth and NHS number:

- admission details
- maternity details
- diagnosis details
- operation details
- discharge details
- episode details

A more detailed list of data items collected is given on pp. 223–7.

Coding schemes

ICD-10 and OPCS4 coding schemes are used; in addition, some HMIS Reference data codes are used including:

- organisation
- specialty
- diagnosis
- procedure
- derivation of unitary authority codes.

Continuity

Coverage by PEDW was incomplete in its early years.

Completeness

Coding levels vary widely between Trusts and specialties. A summarised report of completeness can be found on the NHS CymruWeb.

Accuracy

No figures have been located on accuracy of data provided.

* Previously Healthcare Management Information Services (HMIS).
† Small sites not using PAS may use PC-based data capture software developed by HMIS, WHCSA.

Internal validity
To enter the PEDW dataset, all information must contain certain key identification fields. Records not containing these fields are sent back to the participating hospital for amendment and resubmission.

Information is transferred to the main analysis database on a monthly basis. Data cleaning is carried out, and any additional data items and flags are derived such as matching a patient's postcode to a unitary authority, deriving diagnosis related groups (DRGs) and length of stay.

External validation
PEDW data are compared with paper returns for total activity when producing monthly. Selected fields are extracted and passed to the National Casemix Office, where they are used in the creation of a DRG database for Wales. Aggregate information is used in the Public Health Common Dataset and its presentation package 'Health Show'.

Future developments
The scope for using PEDW as a source of information for the Congenital Anomalies (CARIS) database has been discussed.

Access
Ad hoc information from PEDW is available on request from Information Request and Analysis (IRAS). A quota of hours work per year is assigned 'free' to the Welsh Office, each Health Authority, NHS Trust and some other customers. Requests above this quota and from other organisations are potentially chargeable.

All patient-identifiable information, including anonymised data, is confidential and release requires authorisation from the Medical Director or Director of Public Health Medicine and the Medical Adviser at WHCSA (data custodian). The same procedure applies to GP- and consultant-identifiable information. Other aggregate information is available on request, and some charges are made according to the data required. Researchers should contact the database in the first instance.

Contact details
M Preston/R Richards
Welsh Health Common Services Authority
Crickhowell House
Pierhead Street
Capital Waterside
Cardiff
CF1 5XT

Website: http://www.wales.nhs.uk

Information sources
Data were extracted from NHS Wales (1998) and from publications available on the Wales NHS website.

Publications and further information sources
Annual summary: the 'PEDW Spreadsheet'.
HealthShow.
Public Health Common Dataset.
Health Statistics Wales.

PEDW data items

Patient details
Name
Address
Postcode
Birth date
Sex
Ethnic group
Marital status
NHS number
Case record number: patient's case record number unique to that patient within a hospital or healthcare provider

continued

Category of patient:	NHS	Private	Amenity
Not formally detained			
Detained (Part II Mental Health Act)			
Detained (Part III Mental Health Act)			
Detained (Part X Mental Health Act)			
Other maternity event			
Chronically sick or disabled indicator (y/n)			
Overseas visitor status			
Exempt from payment; subject to reciprocal health agreement			
Exempt from payment; other reason			
To pay hotel fees only			
To pay all fees			
Not applicable (not an overseas visitor)			
Charging rate not known			
Health Authority of (usual) residence			
GP code:			
Antenatal care			
Registered			
Referring			
Practice code			

Admission details

- Patient classification
  - Ordinary admission
  - Day case admission
  - Regular day admission
  - Regular night admission
  - Mothers and babies only using delivery facilities
- Admission method
  - Elective
    - Waiting list
    - Booked
    - Planned
  - Emergency
    - Via A&E or dental casualty department associated with the healthcare provider
    - Via GP
    - Via bed bureau/central bed bureau
    - Via consultant outpatient clinic
    - Via other means
  - Maternity
    - Ante-partum
    - Post-partum
  - Other
    - Patients transferred from another hospital provider
    - Babies born in a hospital within the healthcare provider
    - Babies born outside hospital (except where born at home as intended)
    - Not known
- Source:
  - Usual residence
  - Temporary residence
  - Order of penal establishments
  - Special hospital
  - Another NHS hospital provider
    - General ward/A&E/younger physically disabled ward
    - Maternity/neonatal ward
    - Mentally ill/learning disabilities
  - NHS-run nursing/residential care/group homes
  - Local authority care
  - Babies born in/on way to hospital
  - Other NHS hospital/home, etc.
  - Other maternity event
  - Not known

continued

Decided to admit date
Duration of elective wait
Ward type:
- General
  - Intensive therapy
  - Normal therapy
  - Limited therapy
- Younger physically disabled
  - Spinal unit
  - Other
- Neonates
  - Regionally designated
  - Non-maternity
  - Maternity
- Maternity
  - Consultant ward
  - Mixed GP/consultant ward
  - GP ward
- Mental illness
  - Intensive care, a regionally designated or interim secure unit
  - Short stay
  - Long stay
- Mental handicap
  - Regionally designated or interim secure unit
  - Short stay
  - Long stay
- Home leave
  - Non-psychiatric
  - Psychiatric
  - Terminally ill/palliative care

Provider code
Provider spell number
Purchaser code

Maternity details
First antenatal assessment date
Initial intended delivery place type
Intended management
- Stay in hospital for at least one night
- Not intended to stay in hospital overnight
- Planned sequence of admissions each involving at least one overnight stay
- Planned sequence of admissions which do not involve an overnight stay
- Planned sequence of nights, returning home for the remainder of the 24-hour period
- Not applicable, i.e. non-elective admission

Delivery place change, reason:	Pregnancy	Labour
Clinical reasons		
Other reasons		
	Address changed	Unintentionally

Status of person conducting delivery
- Hospital doctor
- GP
- Midwife
- Other than above
- Not known

Delivery place
- Domestic address
- NHS hospital
  - Midwife ward
  - Consultant ward
  - GP ward
  - In ward or unit without delivery facilities

continued

- Private hospital
- Other hospital or institution
- Other, i.e. none of the above
- Not known

Labour onset method
- Spontaneous
- Planned Caesarean section of one of the following types:
  - Surgical induction; by amniotomy
  - Medical induction by drugs
  - Combination of surgical induction and medical induction
- Not known

Anaesthetic given during labour/delivery/post-delivery
- General anaesthetic
- Epidural or caudal anaesthetic
- Spinal anaesthetic
- General anaesthetic and epidural or caudal anaesthetic
- General anaesthetic and spinal anaesthetic
- Epidural or caudal and spinal anaesthetic
- Other
- No analgesic or anaesthetic administered
- Unknown

Delivery method:
- Normal, spontaneous vertex vaginal delivery, occipito-anterior
- Cephalic vaginal delivery with abnormal presentation of head at delivery, without instruments, with or without manipulation
- Forceps, low application, without manipulation, forceps delivery not otherwise specified
- Other forceps delivery (high and mid)
- Vacuum extraction
- Breech delivery, spontaneous, assisted or unspecified
- Breech extraction
- Elective Caesarean section
- Other and unspecified (emergency) Caesarean section
- Other and unspecified method of delivery

Birth order

Birth resuscitation method:

Positive pressure	Drugs
Nil	Nil
Nil	Administered
Mask	Nil
Mask	Administered
Endotracheal tube	Nil
Endotracheal tube	Administered

Not known

Not applicable

Birth state:
- Live
- Still birth
  - Ante-partum
  - Intra-partum
  - Indeterminate

Gestation

Number of registrable births (1–6+)

Birth weight

Birth date (baby)

Sex

Number of previous pregnancies

continued

Diagnosis details
Diagnosis (ICD-10)
Diagnosis related group (Administration Diagnosis Related Groups, version 12)
Histological diagnosis (Morphology of Neoplasms ICD-10)
Source of histological diagnosis
- Diagnosis obtained from a pathology lab. report
- Diagnosis obtained from medical opinion
- Other source or not known
- Not applicable

Consultant code
Consultant code of shared care consultant
Main specialty code of consultant
Specialty code (shared care)

Operation details
Operation/operative procedure code (OPCS)
Operation/operative procedure date

Discharge details
Discharge date
Discharge destination
- As for admission source

Discharge method
- Patient discharged on clinical advice or clinical consent
- Patient discharged self (includes patients who abscond) or was discharged by a relative or advocate
- Patient discharged by Mental Health Review Tribunal (MHRT), Home Secretary or court
- Patient died
- Stillbirth
- Not applicable (not discharged)
- Hospital provider spell not yet finished

Hospital discharge code

Episode details
Age at start of episode

Duration of episode
Duration of hospital provider spell
Duration of ward stay
End date of episode/consultant episode
Episode number in provider spell
Record ID:
- New (first submission)
- Amendment (subsequent submission)
- Deletion (previously submitted)

Record type	Finished	Complete	Incomplete
General episode			
Delivery episode			
Birth episode			
Other maternity events			

Serial number (part of code used to produce a unique identifier for each healthcare arrangement (i.e. the Contract Identifier)
Ward code
Ward stay:
- End date
- Start date

Start date of consultant/additional episode
Start date of provider spell

GP morbidity databases

The General Practice Research Database (GPRD)

Description

The GPRD is the world's largest computerised database of anonymised patient data with approximately 35 million patient years of data. GPRD is a main source of data linking patients to prescriptions in primary care. It has collected patient records in the UK continuously since 1987 from contributing general practices. In 2001 it had information on 2.7 million patients, just over 5% of the UK population.

The GPRD was established in 1987 as the VAMP Research Databank. Participating GPs received practice computers and the VAMP Medical, text-based practice management system in return for submitting anonymised patient data to VAMP. The number of practices participating in this arrangement grew rapidly and the first research studies using GPRD were published during the early 1990s.[1,2]

In 1993, Reuters Health Information acquired VAMP. In 1994, Reuters donated the database to the Department of Health, where it was renamed GPRD. In 1995, Reuters launched Vision, a new Windows-based practice management software application which become the dominant software used by GPs in GPRD.*

Between 1994 and 1999, the database was managed by the Department of Health's Statistics Division and operated by the ONS. In 1999, the MCA took over GPRD and initiated a major redevelopment programme, aimed at enabling broader research usage of the data both within the UK and overseas (this has included the launch of the 'Full Feature' GPRD – see Access section below).

Data

Just under 400 UK general practices contribute to the GPRD (GPRD website, 2001). Contributing practices are required to register all active patients. They are required to record information on consultations where there is evidence of significant morbidity (although in many instances minor morbidity is recorded, particularly in practices that are 'paperless'). Full medical history summaries are not mandatory but the first onset of any chronic disease or recurrent condition must be noted (including details of hospitalisation or referral to any specialist along with the outcome of the referral, prescription or withdrawal of a drug or other treatment, and other events where the patient has received consultation on more than one occasion, or for which the GP requires a reminder).

The information gathered in a patient consultation can be entered into the VAMP software either during the consultation or later. All practice staff are allowed to update the VAMP software. Data are collected on a 6-weekly cycle, via disk, from each of the participating centres. The licensees receive updates on a quarterly basis.

GPRD records are anonymous. Each patient has a unique patient identifier assigned by the computer when the patient first registers. Records transferred to GPRD contain only this identifier. A practice identifying code is contained within the patient identifier code, so the practice can be contacted for enquiries about specific records.

Data are collected under four main headings (patient records, medical records, therapy records and prevention records – see pp. 238–9 for full details). A list of all publications related to GPRD is given on pp. 230–8.

Coding systems

GPRD originally employed the OXMIS Medical Dictionary, an amalgamation of ICD-8 and the surgical operation codes of the ONS. The OXMIS coding system could be mapped to Read, and through Read to ICD-9. OXMIS was replaced by Read 2 in 2000.

Drug codes were entered using a drug dictionary supplied by VAMP and based on PPA codes, but from 2000 the Multilex drug dictionary has been used. Both can be mapped to BNF codes.

Completeness and accuracy

The database covers 6.4% of the population in England, 5.1% in Wales and 5.8% in Northern Ireland. Scotland is under-represented at 2.8%.[2] The contributing general practices did not constitute a random sample as they were being linked to the take-up of VAMP.

Various validation studies suggest that the completeness and accuracy of the database is high.[1,3,4]

* In 1999, Reuter's practice management software business was acquired by Cegedim, a European healthcare software and research company, and renamed In Practice Systems (GPRD website, 2001).

Two full-time personnel ascertain the accuracy of selected data items within the GPRD both on a continuous basis and for specific research projects. The GPRD Processing Unit conducts a number of quality checks on the data sent by each practice following each data collection (including checks on the completeness of recording of demographic/registration data, percentage of acute and repeat prescriptions that have appropriate indications recorded, recording of the fact and cause of death, recording of pregnancy outcome on maternal child records, completeness of recording of contraception and monitoring of trends in rates of consultations and prescriptions). GPs receive validation reports allowing resubmission of incomplete or invalid records.

Epidemiology and Pharmacology Information Core (EPIC), a research organisation linked historically to GPRD, also conducts additional validation checks (see Access below). An external validation has been carried out by comparing data with the 4th National Morbidity Survey in General Practice,[5] showing close agreement.

Uses

GPRD has been used mainly to explore risk of adverse events (see pp. 230–8 for the list of GPRD publications; GPRD website, 2001). GPRD has been used to develop needs indicators for primary care prescribing.[6,7]

GPRD/VAMP[8] has been used to identify predictors of prescribing[9] and to develop performance indicators leading to capitation funding for prescribing.[10]

Funding

No data are available on the costs of running GPRD, but with nearly 3 million patients it would cost £3 million per annum at a notional £1 per record per annum. The MCA pay participating general practices £0.25 per patient[2] (GPRD website, 2001). Given that this database was donated to the Department of Health, and that its staffing when located in ONS was minimal, its actual running costs are likely to be considerably less. Running costs are recouped in fees for accessing data and database licence fees. The MCA plans to invest £3 million in GPRD (2000–05) to improve service delivery. The database was run by the Department of Health on a self-financing, non-profit-making basis but its status under the MCA remains to be clarified.

Access

GPRD has been licensed to two non-profit-making organisations: EPIC (London), headed by the original founder of VAMP, and the Boston Collaborative Drug Surveillance Program (BCDSP) (USA). These organisations, the ONS and the MCA may provide data or perform studies for selected purposes. The West Midlands Regional Office of the NHS Executive holds a licence for a sub-set of the GPRD data covering that region.

In 2001, the MCA introduced the new 'Full Feature' GPRD and associated research services. 'Full Feature' GPRD is accessed through a secure on-line mechanism and provides advanced query tools to access the database. It is available, under licence, to academics, regulators, pharmaceutical organisations and research service providers (MCA website, 2001). The minimum cost of access is £25,000, however, with higher charges for greater access.

Putative researchers are required to submit requests in a project protocol. Protocols are vetted by a Scientific and Ethical Advisory Group (SEAG). Approval depends on meeting specified standards. Running costs for research projects have been recouped in licence fees and/or overall project charges. SEAG is to be reconstituted in compliance with Nolan Guidance (GPRD website, 2001).

GPRD provides the facility to seek individual record follow-up via GPs, on a doctor-to-doctor basis via a third party. This enables researchers to receive, subject to an additional charge, anonymised validation and/or additional information on GPRD patients.

Contact details

GPRD:
Medicines Control Agency
Market Towers
1 Nine Elms Lane
London
SW8 5NQ
Tel.: 020 7273 0206
Fax: 020 7273 0041
E-mail: admin@gprd.com

SEAG secretary:
A Rubino
GPRD: address as above
E-mail: Annalisa.Rubino@gprd.co.uk

ONS website: http://www.ons.uk
GPRD website: http://www.gprd.com
MCA website: http://www.open.gov.uk/mca/ourwork/gprd/gprd.htm

Publications

Key Health Statistics from General Practice (ONS).
The GPRD bibliography (see the list below) is updated on a quarterly basis and listed on the GPRD website.
MCA produces an annual report.

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GPRD data items

Patient records
Patient ID
Date of birth
Family number
Sex
Marital status
Registration date
Registration status
No. of registered doctor
No. of usual doctor
Date transferred out
Extended status
Child Health Survey registered (y/n)
Child Health Survey doctor
Prescription exemption status
Screening status
Household FHSA
DHA
Capitation supplement

Medical records
Patient ID
Event date
OXMIS code
Comment: up to 19 characters allowed
Priority number
Diagnoser
Outcome (referral, etc.)
Episode type:
- Continuation/follow-up
- 1st ever episode
- New episode
- Other

Clinical specialty
Location/consultant (consultation, night visit, etc.)

Therapy records
Patient ID
Date of prescription
PPA code
Dosage instruction
Quantity prescribed
No. of days for script
Drug type flags 1 and 2
Prescriber

continued

Prescription type: Repeat Acute Number of original packs
Prevention records Patient ID Event date Prevention code OXMIS code Clinical specialty Location/consultation Location/consultant

Doctors' Independent Network (DIN-LINK)

General description

The Doctors' Independent Network (DIN) is a non-profit-making, learned society of over 250 general practices contributing all routine practice activity to a centralised database. DIN evolved from the Meditel system which was a competitor to VAMP (see GPRD, p. 228) in the 1980s. The system has been holding individual (anonymised) patient records for 9–10 years, comprising a database of over 1.7 million patient years. The network is a registered charity.

Membership to DIN is open to any working clinician. Membership fees are payable, but are substantially reduced by becoming a data provider.

The aims of DIN are:[1]

- To serve the communication needs of the medical profession and to encourage excellence.
- To facilitate local, district, regional and national clinical audit.
- To establish and promote a national, independent, clinically secure medical computer network supervised by registered medical practitioners and governed by the same strict code of ethics as used by its contributors.
- To provide a confidential medium for electronically conveying data entrusted to it by members on behalf of their patients, in accordance with the principles of medical ethics.
- To facilitate the ethical use of anonymised clinical data for epidemiology, research by Health Authorities and by the Department of Health for strategic planning. The requirements of other relevant bodies are considered by the supervisory board as appropriate.
- To comply with the requirements of the Data Protection Act.

The database is a direct download of normal working activity, designed to involve no additional work. DIN believes the system to be an unbiased fair representation of GP activities that can be scaled up to represent Great Britain.

Information from the DIN database is available to pharmaceutical companies for pharmaco-epidemiological research via CompuData, a joint venture company which has been set up with half the members originating from the DIN board and the remaining from Compufile Ltd (a market research company). Profits are split between the two organisations and those accruing to DIN are used to support the database and fund services to members.

The system can be used to assess data quality by individual GP by the following:

- list size against volume of notes recorded
- list size against volume of drugs issued
- percentage of drugs linked to prescribing reason (coded)
- proportion of acute to repeat prescriptions
- visits and drugs prescribed entered on computer
- proportion of firm diagnosis against symptoms/signs
- incidence of marker Read codes.

The database has been used to analyse patterns of adverse drug reactions.[1] Once a patient stopping medication has been identified, a detailed clinical examination of the circumstance is carried out. This system provided adverse reaction warning to Osmosin, Opren and some other withdrawn

pharmaceuticals in advance of the 'Yellow Card Scheme'.

DIN in 1999 produced an audit package, allowing GPs to:

- perform clinical audit on widely agreed performance criteria
- audit personal performance against own/nationally accepted targets
- audit comparison against partners (anonymously)
- measure changes in practice activity monthly.

The continuous patient-based clinical information held by the database allows continuous prospective clinical research to be undertaken in addition to retrospective examination of data.

Funding
One full-time data manager is funded by St George's Medical. Dr Steventon, founder of DIN, manages the system with some assistance towards the cost of computing equipment.

Population covered
The network is represented in England, Scotland and Wales, with sites ranging from Jersey to Orkney, although membership is biased towards southern England (owing to the Surrey location of DIN's core activities).[1]

Process of data collection
Most of the sites use Meditel systems. Data are provided to DIN through DIN Rapid reports* that allow fast extraction of data on a regular or automatic daily basis via a modem on to a Unix Network Dialup system. The date of the last extraction is recorded so only data added or altered are downloaded. Data for research/audit facilities may be extracted from the central computer 'deep thought' via the use of SQL.

Patients' records are continuous but patient anonymity is maintained by removing identifying data fields and using encrypted patient and practice identity numbers. DIN follows standards laid down by the Committee on Standards of Data Extraction (COSODE).

Summary of data items collected
All routine practice information is recorded (e.g. consultations, prescriptions, immunisations). The system also allows for the entry of a coded reason for prescribing or discontinuing medication.

Coding schemes
Members are encouraged to use the National Standard Clinical Codes wherever possible. The database itself is coded in Read.

Completeness
DIN downloads virtually all (>95%) clinical activity, almost all repeat prescriptions and over 95% of acute prescriptions.

Accuracy
No information has been reported regarding the accuracy of the database.

Internal validation
The practices that contribute to the database are all 'paperless', in that all information is held in an electronic format. Hence 'spot-checking' electronic files against paper ones cannot be done.

External validation
A form of validation is carried out through comparing incidence of diseases within the general population with DIN practices, and practices deviating significantly from this are examined. Most of the practices donating to the system were the 'best data providers' from the Meditel-CompuFile system.[1]

Planned developments
DIN intends to run a clinical communications network, with links to the NHSweb.

Access
Under its constitution, DIN supports medical research, allowing access to anonymised data free of charge or for a nominal fee for non-commercial research. Work for commercial organisations is managed by Compufile Ltd.

Contact details
Dr P Steventon
Fitznells Manor Surgery
Ewell
Surrey
KT17 1TF
Tel.: 020 8394 1481
E-mail: pauls@dinboard.demon.co.uk

Website: http://ourworld.compuserve.com/homepages/gesundheitsdatenschutz/dinwhat.htm

* Tested by Meditel for compatibility with their systems, and awarded third-party accreditation.

Information sources
Data were extracted from an interview and the references below.

DIN: data Items
Not available but understood to be similar to GPRD.

Publications
Humphrey KM, Cork MJ, Haycox A. A retrospective cost-effectiveness analysis of the treatment of onychomycosis in general practice. *Br J Dermatol* 1998;**139**:660–4.

Hylan TR, Dunn RL, Tepner RG, Meurgey F. Gaps in antidepressant prescribing in primary care in the United Kingdom. *Int Clin Psychopharmacol* 1998;**13**:235–43.

Treglia M, Neslusan CA, Dunn RL. Fluoxetine and dothiepin therapy in primary care and health resource utilization: evidence from the United Kingdom. *Int J Psychiatry Clin Pract* 1999; **3**:23–30.

Reference

1. DIN. Doctors Independent Network website: http://ourworld.compuserve.com/homepages/gesundheitsdatenschutz (1 November 1999).

Cancer registries

National Cancer Registry (NCR)

General description
Following the Radium Commission (1929) and the Cancer Act 1939,* NCR was established in 1945,† gaining national coverage in 1962. The NCR was established to maintain a systematic collection of data on the occurrence and characteristics of malignant neoplasms and certain non-malignant tumours. The ONS is ultimately responsible for maintaining the Registry. Data collection was initially carried out under voluntary arrangements, but in 1993 a Cancer Registration Minimum Data Set was introduced and cancer notifications became a mandatory requirement for the NHS.

The NCR provides statistics on the incidence, survival and prevalence of cancer. Subject to strict safeguards on confidentiality, individual records are used in medical research and epidemiological studies. Comparisons of regional data are published by ONS and some information on incidence and survival for the major cancers appears in the Public Health Common Data Set.

Population covered
Information is obtained from the 10 (as of the year 2000) regional cancer registries in England, covering a total population of almost 50 million.‡ The voluntary collection system in place prior to 1993 resulted in less complete coverage.

The NCR receives around 280,000 new cancer cases every year and around 140,000 cancer deaths. Around 6 million individual records are held in the database.

Process of data collection
The NCR obtains notifications from each of the 10 regional cancer registries, each of which collects slightly different data. Each regional cancer registry provides the mandatory data items (Cancer Registration Minimum Dataset) to the NCR. ONS copies all registries' details of any death certificate which mentions cancer. If the person is not already registered, the National Health Service Central Register (NHSCR)§ is informed of all new cancer notifications and 'flags' the notification on the register. If the NHSCR receives a death notification other than cancer for an NCR-flagged patient,¶ the relevant regional registry is informed. The regional registry then gathers subsequent information on the date of incidence, via the GP or Trust, and forwards this information to the NCR.

Summary of data items collected◊
- registration details
- patient details, including NHS number, name, date of birth and occupation details
- cancer details
- death details.

A more detailed list of data items collected is given on pp. 244–5.

* Not implemented owing to World War II.
† Under the auspices of, initially, the Radium Commission Statistical Bureau, followed by the General Register Office, OPCS and more recently its successor ONS.
‡ England 49.1 million, Wales 2.9 million.
§ The NHSCR obtains all birth and death notifications from across the country on a weekly basis.
¶ Whatever the cause of death recorded.
◊ The Cancer Registration Minimum Dataset was altered in 1993, so for incidences pre-1993 not all information will have been collected.

Coding schemes

The NCR employs the following coding schemes:*

- ICD-8, -9 and -10 (site and history classification)
- STATES19 (country of birth)
- Occupational Classification Component Code Index 1991 (occupational details)
- Standard Industry Classification 1980 (industry details).

Continuity

There have been no breaks in the continuity of data collection since 1962, although the collected data items have altered. The Cancer Registration Minimum Dataset in 1993 led to the following items being collected:

- basis of diagnosis
- death certificate as the only indicator
- side (laterality)
- treatment(s) (indicators)
- stage (phased introduction – initially only for breast and cervix)
- grade (phased introduction – initially only for breast and cervix).

In the early 1990s, the processing of cancer registration underwent major revisions owing to the modernisation of OPCS/ONS data systems. The cancer registry files were redeveloped to a person-based database instead of a series of annual tumour-based files. All files from 1971 were customised to a patient-based database by linking together multiple primary records for the same person. These revisions led to a backlog of processing which took until 1998 to rectify. Owing to these changes, data for 1990 registrations were only published in early 1997, and those for 1993, plus provisional information up to 1996, were published in November 1999.

The UK Association of Cancer Registries (UKACR) has adopted a set of standard indicators of registration data quality, from which key indicators can be derived, as summarised here.

Timeliness

The percentage registration of malignant neoplasms for a particular calendar year for which the complete national minimum dataset (with valid codes suitable for submission to ONS) had been collected within 18 months from the end of that year. This figure was 80% on average with a range from 29 to 103% in 1999, indicating wide variations.[1]

Completeness

The mortality to incidence (M:I) ratio is a standard indicator of the completeness of ascertainment of cases by the registries. The values observed are influenced to a limited extent by time trends in incidence and mortality and casemix, but this ratio should be fairly constant between registries. Given recent survival statistics, one would expect male M:I ratios to be about 60–65% with lesser values for females for whom the overall survival is slightly greater than men. Higher than expected values for the M:I ratio generally indicate incomplete ascertainment of cases. The average M:I ratio for males was 64 in 1999 with a range of 58–76, with the corresponding values for women, mean 59, range 52–67, indicating wide variations.[1]

Death certificate only (DCO) registrations are those for which the only information available to the registry is from the death certificate. High percentages of such cases (%DCO) may indicate incomplete ascertainment of records from other sources (such as pathology laboratories and hospital discharge records) and a poor standard of accuracy (since the death certificate contains limited data on the cancer diagnosed, and sources of more accurate information such as pathology reports are not being used). This indicator is thus relevant both to completeness and accuracy. The mean %DCO in 1999 was 5.5% for males with a range of 0.3–15.4%, with the corresponding values for women, mean 5.5%, range 0.2–15.7%, again indicating wide variations.[1]

Accuracy

Registrations supported by histology, cytology, bone marrow or haematology reports are said to be microscopically verified (MV). The percentage of cases in this type (%MV) is a standard indicator of the accuracy of data, with low values indicating use of less reliable data sources. The mean %MV for males in 1999 was 78% with a range of 69–84%, and for females a mean of 79%, range 71–85.[1] These figures again indicate wide variations between the regional registries.

Internal validation

The majority of internal validity checks are computer assisted. The following is a list of the field names that are automatically scrutinised for inconsistent coding:

- country of birth

* Coding schemes have been updated, therefore older information may use the previous versions.

- postcode
- patient occupation
- patient industry
- head of household occupation
- head of household industry
- site
- type of growth.

Cross-checks are made between:

- occupation/employment status/age at diagnosis
- patient occupation/employment status/patient industry
- patient occupation/sex
- site/sex
- site/age at diagnosis
- behaviour/type of growth.

External validation

The NCR liaises with the register maintained by the Childhood Cancer Research Group to ensure full ascertainment of childhood cancers. The flagging process carried out at the NHSCR identifies duplicate records.

During the change to a person-based registry, probability matching processes* were carried out, duplicates and true multiple primary records for the same patient were linked and the duplicates were eliminated.

Uses

Each of the regional registers produces annual reports outlining trends in cancer incidence and mortality, and each has voluminous publications, often dealing with issues around quality of data. Cancer registry data have been used to assess the influence of caseload and specialisation on cancer outcome,[2] the cost-effectiveness of treatments for oesophageal cancers[3] and for survival data by place.[4] Many studies have been carried out using the regional registers, some of which are listed below.

Future developments

Following the review of cancer registration in England,[1] the Government accepted the recommendations of that review and an action programme,[5] which re-defined the purposes of the cancer registries in relation to goals outlined in the Cancer Plan[6] (prevention, early detection, improving access to specialist care, improving treatment, better data on costs, reducing inequalities and facilitating R&D). These imply changes in both the scope and the quality of the cancer register. The action programmes proposed to take this forward by building on the existing regional registries, but making them formally accountable to the National Cancer Director.

Funding

The cost of cancer registration in 1996 was between £10 and £20 per cancer patient in the UK, less the cost of one chest X-ray (UKACR, 1998). The review in 2000 put the average cost per record at £22 with a range across the regional registries from £13 to £27.

Access

Semi-aggregated incidence figures are freely available and may be obtained by contacting either the regional registry concerned or ONS (national coverage). If individual patient data are required, approval from the local ethics committee must be obtained. The UKACR has recently agreed an update policy on the release of data, including for genetic counselling.

Contact details

Dr MJ Quimm
Office for National Statistics
B6/02
1 Drummond Gate
London
SW1V 2QQ
Tel.: 020 7553 5257
Fax: 020 7533 5252

Ms C Puckey
National Cancer Registration Bureau
Room 2300
Office for National Statistics
Segensworth Road
Titchfield
Fareham
Hants
PO15 5RR
Tel.: 01329 842511
Fax: 01329 813637

Information sources

Data were extracted from an interview and the references cited.

Publications and further sources of information

Annual reports and several series are produced.[7–9]
http://www.ons.gov.uk (national statistics)

* Based on those successfully operated by the Oxford Record Linkage Study, Statistics Canada and the Information and Statistics Division (ISD) in Scotland.

References

1. Gillis CR. Review of cancer registration in England. London: Department of Health; 2000.
2. Kee F, Wilson RH, Harper C, Patterson CC, McCallion K, Houston RF, *et al*. Influence of hospital and clinician workload on survival from colorectal cancer: cohort study. *BMJ* 1999;**318**:1381–5.
3. Farndon MA, Wayman J, Clague MB, Griffin SM. Cost-effectiveness in the management of patients with oesophageal cancer. *Br J Surg* 1998;**85**:1394–8.
4. Pollock AM, Vickers N. Deprivation and emergency admissions for cancers of colorectum, lung, and breast in south east England: ecological study. *BMJ* 1998;**317**:245–52.
5. Department of Health. Action programme for cancer registration. London: Department of Health; 2000.
6. Department of Health. The cancer plan. London: Department of Health; 2000.
7. ONS. Estimates of newly diagnosed cases of cancer, England and Wales. Series MBI 98/2. London: ONS; 2001.
8. ONS. Annual reports: cancer statistics registrations. London: ONS; 2001.
9. ONS, CRC. Cancer survival trends in England and Wales deprivation and NHS region. Series SMPS No. 61. London: ONS; 2001.

NCR data items[a]

Registration details			
Type of record			
Registry code			
Registration number			
Registration year			
Centre			
Patient details			
NHS number			
Name			
Address			
Postcode			
Sex			
Date of birth			
Country of birth			
Marital status			
Ethnic origin			
Occupation details:	Occupation	Employment status	Industry
Patient			
Head of household			
Cancer details			
Site of primary growth			
Type of growth			
Incidence date			
Multiple tumour indicator, includes previous registration details			
Laterality:			
Left			
Right			
Bilateral			
Not known			
Diagnosis from screening (no/yes/not known)			
Behaviour of growth:			
Benign			
Uncertain benign/malignant			
Carcinoma *in situ*			
Malignant primary site			
Malignant metastatic/secondary site			
Malignant, uncertain whether primary or metastatic site, microinvasives			

continued

Grade: Well differentiated Moderately differentiated Poorly differentiated Undifferentiated anaplastic Not known Stage: *In situ* Local involvement only Extension to adjacent tissues Lymph node involvement Metastases Not known Basis of diagnosis: Histology Cytology Other special tests Clinical Not known Treatment type: Surgery Radiotherapy Chemotherapy Hormonal Other
Death details Date of death Death certificate only
[a] The Cancer Registration Minimum Dataset was altered in 1993, so for incidences pre-1993 not all information will have been collected.

National Registry of Childhood Tumours (NRCT)

General description

Established in 1975 following the recommendations of a working party on childhood tumour registration of the Ministry of Health,* the Childhood Cancer Research Group (CCRG)† is responsible for the NRCT. The NRCT is the largest childhood cancer registry in the world, holding information on over 66,000 children. The primary objective was the creation of a British childhood (under the age of 15 years) cancer register containing more information and better diagnostic data than those available in general cancer registries.

The Registry is regularly used for the provision of national incidence rates, geographical incidence studies and calculation of survival rates allowing service and policy planning and forecasting, 'cluster' investigation and assessment of treatment/care impact, respectively. Projects using Registry data by CCRG members and others have included:

- systematic studies of the occurrence of second malignant neoplasms, deaths from other causes and reproductive history
- estimation of the heritable fraction of childhood cancer and the risk of occurrence of sufferers' siblings and offspring
- record linkage studies used to study cancer incidence, for example, Dounreay nuclear plant and the National Register of Radiation Workers
- studies of possible linkage between newborn vitamin K administration and subsequent occurrence of childhood cancer.

The Registry also contributes data to international collaborations:

- International Incidence for Childhood Cancer
- European Childhood Leukaemia/Lymphoma Incidence Study

* Ministry of Health Standing Medical Advisory Committee Sub-Committee on Cancer.
† Administratively part of the Department of Paediatrics, University of Oxford.

- European Childhood Leukaemia Clustering Study
- European Study of Effectiveness of Neuroblastoma Screening.

Funding

The Department of Health funds the NRCT on a continuing basis (£367,000 for 1998) with the Registry estimating running costs for the database of £170,000.

Population covered

The NRCT holds information on nearly all cases of childhood malignant disease in England, Scotland and Wales from 1962 onwards, together with most children who died of cancer during 1953–61 and a series of long-term survivors diagnosed before 1962.

Owing to the multiple notification sources, there are around 2.5 notifications per child. No prospective study of completeness of notifications has been carried out, but the Registry believes ascertainment to be 'almost complete', estimating 99% of leukaemia incidences recorded. Among 7592 children diagnosed during 1981–90 for whom no notifications of death have been received, only 1.8% have emigrated or could not be traced at NHSCR and were therefore lost to follow-up.

Clinical data (including histological diagnosis, treatment, etc.) are verified and amended (where appropriate) using hospital, GP and trial records.

Process of data collection

Cancer registration notification

Since 1962, copies of all cancer registration relating to children less than 15 years old have been forwarded to the NRCT by:

- The NCR
- The Scottish Cancer Registry
- Regional Cancer Registries
- Regional children's malignant disease registries
- UK Children's Cancer Study Group Register (UKCCSG)
- MRC leukaemia trials (Clinical Trial Service Unit, Oxford).

Death certificates

OPCS/ONS and the General Register Office (Scotland) forward copies of death certificates where a neoplasm is coded as the underlying source.

Birth records

Birth records for all registered children born in 1966 onwards and diagnosed before the end of 1986 are also held by the NRCT.

NHSCR flagging and tracking

Records of 5-year survivors are forwarded for tracing and flagging to the NHSCR. The NHSCR provides for flagged patients:

- copies of subsequent cancer registration notifications
- copies of death certificates
- notification of embarkations.

The Registry uses three types of information system:

- alphabetical record card index
- original paper documents (case folder)
- Oracle database.

Data are received both on paper and electronically in batches at varying intervals depending on the source (e.g. NHSCR quarterly, UKCCSG monthly, MRC trials weekly). Each case received is checked against the card index and the database. Identifying information and coded data are entered into a temporary database which, following internal validation and duplication sifting, is added to the main database either as additional patient information or as new cases.

Summary of data items collected

- patient details, including name, address, NHS number and date of birth
- administrative details, including flagging status, administrative numbers and clinical trial inclusion
- primary cancer details
- treatment details
- second tumour details
- death details.

A more detailed list of data items collected is given on pp. 248–9.

Coding schemes

International Classification of Diseases Oncology (ICDO) coding is used for tumour topography and morphology. Congenital abnormalities and other chronic or familial diseases are coded using the British Paediatric Association extension to ICD-9. Other neoplasm data and place of treatment are coded by 'in-house' coding schemes. The National Postcode Directory is also used.

Continuity
There have been no significant disruptions in the collection or processing of data.

Completeness
See Review of cancer registration in England.[1]

Accuracy
See Review of cancer registration in England.[1]

Internal validation
As the Registry receives multiple notifications for the same case, duplication sifting and detection are important. Internal validation software checks for various items include logicality, plausibility, chronological episodes, sensible data, valid coding and completeness of entries. All error and warning messages from the checking procedures are investigated, with the new data amended (where appropriate) before a batch of data is incorporated into the database. Sample data re-entry is not performed.

External validation
Data are routinely exchanged with regional cancer registries.* Diagnoses for most children notified via regional children's tumour registries are centrally reviewed and checked against those of the NRCT.

Future developments
See NCR (p. 243).

Access
The NRCT follows the following procedures with regards to access of data:

Information required	Procedure
Patient-identifiable information	Request in writing Signed confidentiality form and copy of study protocol Approval by the Director of the Centre Written permission of each treating consultant multicentre/local research ethics committee approval
Individual patient records with data items for record linkage	As above, although in some cases consultant and ethical permission is not required
Anonymised data with patient records	Request in writing Signed confidentiality form and copy of study protocol Approval by the Director of the Centre
Aggregated data at district level	Request in writing
Aggregated data at regional level	Request in writing
Aggregated data at national level	Request in writing

All requests† should be directed towards the Registry Advisory Group, who will consider various aspects including requirement of ethical approval, guidelines of the original data source(s) and appropriateness of the data requested. The CCRG may wish to involve themselves in the research project under consideration. There is currently no charge for data supplied.

* At the time of writing, the Registry was in the process of cross-checking data with the NCR.
† Where research using individual patient records involves cases notified by the UKCCSG (the majority), the request may also be referred to the UKCCSG Epidemiology and Registry Working Group.

Contact details

Mr CA Stiller
Childhood Cancer Research Group
57 Woodstock Road
Oxford
OX2 6HJ
Tel.: 01865 310030
Fax: 01865 514254
E-mail: enquiries@ccrg.ox.ac.uk

Information sources

Data were extracted from an interview.

Publications and further information sources

Detailed incidence tables are published on an *ad hoc* basis, with the latest in the NRCT's contribution to International Incidence of Childhood Cancer, Volume II.
At the time of writing annual reports are not produced although there are plans to do so in the future.
Website: http://www.ccrg.ox.ac.uk
The NRCT/CCRG has produced almost 250 research publications.

Reference

1. Gillis CR. Review of cancer registration in England. London: Department of Health; 2000.

NRCT data items

Patient details
Name
NHS numbers (new and old)
Is patient one of twins?
Ethnic group
Sex
Date of birth
Address
Postcode
RHA
DHA
Enumeration district
Census ward
Census tract
Ordinance survey grid reference
Date of last follow-up

Administrative details
Cancer registry
Cancer registration number
UKCCSG:
- Referral
- Registration number
- Registration hospital
- Registration hospital number
- Registration consultant

Clinical trial
Treatment centre for clinical trial
NHSCR flag
Cancer registration received from NHSCR
Embarkation (emigration) status
Flags for inclusion in various studies

Primary cancer details
Diagnosis:
- Date
- Country of residence

Primary site
Tumour morphology
Proof of diagnosis
Side

continued

Leukaemia White blood count Immunophenotype FAB classification Lymphoma: Immunophenotype Congenital abnormality/chronic disease/associated condition Neoplasm or genetic/familial/congenital disease in family member with relationship to patient Regional children's tumour registry histology review
Treatment details Surgery Radiotherapy Chemotherapy
Second tumour details Date of diagnosis Primary site Tumour morphology
Death details Date of death Source(s) of death certificate Address FHSA residence Death certificate diagnosis

UK Children's Cancer Study Group Register (UKCCSG)

Description

The UKCCSG was formed in 1977 with the intention to register those children (i.e. under the age of 16 years) with cancer seen by UKCCSG members in UKCCSG centres and to provide information to ensure that eligible patients were put forward for clinical trials. The dataset is a classical register; registration information (patient and diagnosis details) is held with no information on treatment and outcome details.

The dataset is used for the same purposes today as it was originally. The UKCCSG dataset also forms part of a larger NRCT dataset which is held by the Childhood Cancer Research Group (CCRG) in Oxford.

Funding

Since 1981, the Cancer Research Campaign (CRC) has been the main source of funding through 5-year grants to the UKCCSG. Additional support is received through donations from parents, friends and pharmaceutical companies.

Population covered

The group holds information on children entering clinical trials, but this is not included in the dataset. There is currently registration information for 23,639 children in the UK.

Since January 1995, the UKCCSG has also been registering those young people (15–24 years), treated by UKCCSG, to try to monitor cancer occurrences at the same standard as that of the younger age group. There are currently 772 young people registered.

The completeness of notifications from participating centres is believed to be virtually 100% for children up to the age of 15 years. For those aged 16–24 years it is thought that the figures will take the same path as the younger age group figures, where completeness started at 45% in 1997.

Process of data collection

There are currently approximately 350 members of UKCCSG (including clinicians, pathologists, epidemiologists and basic scientists), based in 22 paediatric oncology centres throughout the UK.

Any child up to the age of 15 years receiving treatment at one of the 22 centres in the UK will be registered on the UKCCSG dataset (as will the age group 16–24 years).

Data for the registry and for trials are collected at each centre by a part-time data manager who completes forms from the hospital notes and forwards them to the UKCCSG as and when each patient is treated. Once data are received at the

UKCCSG data centre, they are checked, coded and processed and any missing data are chased. A copy of the dataset is sent to the CCRG for inclusion in the NRCT. The information from UKCCSG forms 85% of this registry and those patient records not appearing on the UKCCSG dataset are collected from other sources by the CCRG.

Summary of data items collected
- patient details, including full name and date of birth
- administrative details, including clinical trials/studies in which the patient is participating
- diagnosis details, including pathology report (if possible) and the presence of any chronic diseases
- mother's details
- father's details
- familial disease/disorders.

A complete list of data items collected is given on pp. 251–2.

Coding schemes
The UKCCSG employs the following morphology coding schemes:

- ICDO (1st edition)
- ICDO (2nd edition) used for disease coding.

Continuity
There have been no reported significant disruptions or breaks in the collection, coding or processing of the data.

Completeness
The completeness for key data items is reported at 100%, as any missing data will be automatically requested from the centres. Some fields, including place of birth of parents or occupation of parents, are not readily available to the centres and are generally not chased up.

Accuracy
There is a continuing process of feedback to the clinicians and data managers via the UKCCSG Annual Scientific Report and also at the Annual Review Meeting held in January of each year. This is an opportunity for discussion on items of concern or particular interest. A yearly update meeting attended by the data managers is usually held in May. This is an opportunity for feedback on data collection aspects of the register.

Internal validation
The following validation checks are performed:

- Range checks preventing out-of-range data entry in certain areas.
- The UKCCSG requests pathology reports to accompany forms.
- Patient lists are sent annually to the centre data managers, allowing a check against the centre-held information.
- The UKCCSG dataset is compared with the Clinical Trials Database; details in both datasets are usually found to be exact duplicates.

External validation
The UKCCSG does not externally validate its database at present.

Future developments
The UKCCSG does not plan to discontinue the dataset at any point; however, it was planning to change the dataset by the end of 1998. There are, at the time of writing, two datasets in existence at the UKCCSG: the registry and another holding information on clinical trials. The plan is to merge the two datasets, eliminating duplication of patients' details. There are no plans to change the coding system of the dataset unless a specific request is made by CCRG.

Discussions have taken place on whether to introduce remote data entry from the treatment centres. This is seen as a long-term development.

Access
Information on the registry is provided by the CCRG and published each year in the UKCCSG Annual Scientific Report. This document is confidential and is not obtainable by outside researchers. Specific registry data can be released to researchers according to the formal procedure for release and access to data, which details all channels to be taken by a researcher to gather information. This document is now enshrined in the UKCCSG Code of Conduct for Clinical Trials. There is at present no charge for information.

Contact details
United Kingdom Children's Cancer Study Group
Department of Epidemiology and Public Health
University of Leicester
22–28 Princess Road West
Leicester
LE1 6TP
Tel.: 0116 252 3280
Fax: 0116 252 3281

Information sources
Information was extracted from an interview.

Publications and further information sources

UKCCSG Annual Scientific Report (produced for all members in December).
CCRG Annual Report.
UKCCSG publishes data in scientific journals.
A website was under construction at the time of writing this report, http://www.prw.le.ac.uk/ukccsg/.

UKCCSG data items

Patient details
Name
Address
Place of birth
Postcode
Country of residence at diagnosis
Sex
Date of birth
Is child a twin?
  If yes: same sex?
Ethnic group

Administrative details
Registering hospital
Treating hospital(s)
Hospital number
Consultant
Referring hospital and consultant
Patient was treated at the referring hospital?
Reason for referral to registering hospital
Is patient in a clinical trial or study?
  If yes, specify
  If no, comments

Diagnosis details
Diagnosis
Primary site
Side:
  Bilateral
  Right
  Left
  Midline
  Not applicable
Date of diagnosis
Age at diagnosis
Basis for diagnosis:
  Histology/bone marrow
  Haematology
  Biochemistry
  Radiology
  Clinical
  Other (specify)
  Unknown
Summary of histology/marrow report/other diagnostic investigations, copies attached?
Pathologist and hospital
Pathology lab. number
Stage
Highest pretreatment leucocyte count at diagnosis ($\times 10^9$)
Is this is a second cancer?
Congenital abnormality or genetic disorder in patient
Chronic disease in patient

continued

Mother's details			
Name (and maiden name)			
Date of birth			
Place of birth			
Occupation at diagnosis			
Father's details			
Name			
Date of birth			
Place of birth			
Occupation at diagnosis			
Familial disease/disorders			
Specify:	Father	Mother	Biological siblings (specify full/half)
Associated conditions			
Congenital abnormalities			
Malignancy			
Other conditions			

Scottish Cancer Registry (SCR)

General description

The SCR evolved from a scheme set up by the Radium Commission in 1936 to ascertain the outcomes of persons treated with radiation for cancer. Scottish national collection of cancer registrations did not start until 1947, and five regional registries (corresponding to the then five Regional Hospital Boards) were established in 1958. In 1997 the regional registries were disbanded and the collection of cancer notifications was centralised. Responsibility for the maintenance of the SCR is now the concern of the Scottish Cancer Intelligence Unit [Information and Statistics Division, NHS Scotland (ISD Scotland)].*

The aims of ISD Scotland are to:[1]

- define, collect and process high-quality and timely data on cancer risk factors, incidence, therapy and survival in Scotland
- analyse and interpret these data for the purposes of cancer control in Scotland
- work to ensure recognition as leading exponents of the collection and analysis of cancer data.

The SCR is routinely used for the following:

- clinical audit and health services research
- evaluation of the impact of interventions on the incidence and survival
- needs assessment, planning and commissioning cancer services
- public health surveillance
- epidemiological studies aimed at determining the cause of cancer.

Data have also been supplied to other studies/publications, including:

- Cancer Incidence in Five Continents
- EUROCIM database of cancer incidence and mortality in Europe
- EUROCARE Study (survival of cancer patients in Europe)
- ECLIS study (European Childhood Leukaemia/Lymphoma Study)
- EUROCLUS Study (Clustering of Childhood Leukaemia in Europe)
- Clinical Outcome Indicators
- Scottish Needs Assessment Programme (SNAP).

All cancer records can be linked with hospital inpatient data through SMR COPPISH records.

Population

Population estimates (mid-year 1997) show that SCR covers a total population of greater than 5.1 million. The SCR holds over 900,000 records of people receiving a malignant diagnosis or treatment for cancer and Scottish residents receiving diagnosis/treatment in hospitals out of Scotland.

Two studies have been conducted to ascertain the completeness of Scottish cancer registrations. For both studies the diagnosis year 1992 was analysed.

* Of which there are five main units: Information Systems; Cancer Registration; Cancer Surveillance; Scottish Cancer Therapy Network; Analytical Studies Research Group.

The first study, which compared pathology records against cancer registrations (Arran and Ayrshire), produced an overall estimate of completeness of ascertainment of 94.3%.[2] The second study, which used 14 separate sources of information to capture missed registrations in Tayside, resulted in an overall estimate of completeness of 96.5%.[2]

Process of data collection

Since September 1997, the process of data collection was significantly altered owing to both the centralisation of the SCR and the implementation of a new computer system: Scottish Open Cancer Registration and Tumour Enumeration System (SOCRATES*). The following is an account of the stages involved in the present process of data collection.

Stage 1: notifications

Notifications are obtained from the following sources:†

- hospital discharges: SMR1
- radiotherapy/oncology records
- pathology records
- death records (from the General Register Office, Scotland).

For notification sources not already collated centrally at ISD Scotland, a specific software package has been developed to extract a predefined set of data items. Each notification source throughout the country runs the extraction programme at an agreed interval of time, and sends the information to the SCR.

Stage 2: record linkage

For one patient, there can be a number of notifications from each of the sources. All new notifications are linked to provide a patient record by the probability method. This procedure eradicates duplication.

Stage 3: provisional registration

The SOCRATES computer system automatically creates the provisional patient registration record from all available notifications. In most cases the patient address is obtained from SMR1 (hospital inpatient data). However, for all other data items, the computer will select the most complete account.

Stage 4: post-provisional registration

Cancer registration officers are based in the majority of hospitals within Scotland. After a 6-month period, the officers obtain the clinical notes of persons provisionally registered in their area. In all cases the data items, abstracted from the clinical notes, are directly entered on to computer systems. Before the registration is confirmed, the computer will run a series of validation checks. The record will not be accepted until the validation checks are completed. Inconsistencies may be rectified by the officers rechecking the clinical notes. The registration officer will download batches of validated data to the SOCRATES computer system where a series of additional validation checks are undertaken.

The SCR uses Record Linkage to track and link tumours and source data to people. Information is also received from the NHSCR, which provides people's name changes.

Summary of data items collected

- person record, including person identifier, name and date of birth
- identification at diagnosis, including NHS and CHI numbers
- diagnosis details
- initial treatment
- system administration.

A more detailed list of data items collected is given on pp. 255–7.

Coding schemes

The SCR employs the following coding schemes:

- ICD-10 (although all pre-1997 records are coded with ICD-9 and show both ICD-10 and ICD-9)
- ICD-0(2)
- OPCS4.

Continuity

An extended set of data items was introduced in 1999. These additional items will be collected from all patients diagnosed on or after January 1997. The centralisation of the SCR has not affected the continuity of data collection.

Completeness

No information was available on the completeness of the dataset.

* SOCRATES data fields that are common with those collected by the SMR schemes conform to COPPISH formats.

† Since January 1997, Trust hospitals have ceased to submit SMR6 notifications.

Accuracy
Assessment of accuracy was performed using registrations for the year 1990, a random sample of 2200 registrations being generated and the (available) medical records reviewed. Serious discrepancies were judged to have occurred in 2.8% of cases.[4] Annual accuracy checks are planned, involving the reabstraction of data relating to a random sample of cancer registration.

Internal validation
Validation is performed at point of entry, and includes:

- validity checks on options; codes and typical values accepted
- logicality checks, e.g. is the date of death on or after the incidence date?
- plausibility checks, e.g. is a tumour site/type likely in a patient of this age?

The computer system will not allow a record to be confirmed unless it has been validated.

The Quality Assurance Team of ISD Scotland runs continuous training schemes for all cancer registration officers.

External validation
Comparative analyses are conducted with both the Breast Screening Registry and the SNLG on an annual basis.

The Cancer Surveillance Group has also written and performed data validation routines for various studies including:[5]

- Case Control Study of Oesophageal Cancer
- Childhood Cancer dataset
- Scottish Case Control Study of Childhood Leukaemia and Cancer.

Access
Charges are not normally made for medical research studies from the health service or medical schools. Charges may be made to other organisations to cover the costs of data processing and analyses.

If patient-identifiable data are requested, an application form along with a signed confidentiality agreement, obtained from ISD Scotland, must be submitted. Patient-identifiable data have been classified by ISD Scotland as:[6]

- surname
- CHI number
- hospital case reference number
- NHS number
- full postcode
- when a small number of cases are involved, other data items may also become identifiable items.

An application form does not have to be completed if patient-identifiable data are not requested. For further information or data requests, researchers should contact the Registry.

Contact details
Dr D Brewster
Director of Cancer Registration
Scottish Cancer Registry
Information and Statistics Division
Trinity Park House
South Trinity Road
Edinburgh
EH5 3SQ
Tel.: 0131 552 6255
Fax: 0131 551 1392
E-mail: david.brewster@isd.csa.scot.nhs.uk

Information sources
Information was extracted from an interview and the references cited.

Publications and further information sources
Annual report of the Scottish Cancer Intelligence Unit may be found on the 'Scottish Health on the Web' (Show) website: http://www.show.scot.nhs.uk

Cancer Registration Statistics Scotland has just been updated to include 1986–95 and is also available on the web.

Scottish Health Statistics: www.show.scot.nhs/isd/scottish_health_statistics/sciu/annual99.pdf

References
1. Scottish Cancer Intelligence Unit, 1999.
2. Brewster DH, Crichton J, Harvey JC, Dawson G, Nairn ER, 1996.
3. Brewster DH, Crichton J, Harvey JC, Dawson G, 1997.
4. Brewster DH, Crichton J, Muir C, 1994.
5. Scottish Cancer Intelligence Unit, 1997.
6. Scottish Cancer Intelligence Unit, 1996.

SCR data items[a]

Person record
Person identifier
Latest surname
Latest forename
Date of birth
Year of birth
Sex
Independent primary count
Date of emigration
Vital status:
Alive
Dead
Moved to England/Wales
Moved to Northern Ireland
Emigrated abroad
Immortal/not known
New data
Date registration changed
Lowest link weight
Active provisional
Person comments
Death details
Death record identifier
Date of death
Cause of death (primary) ICD-9 changing to ICD-10 after 1998
Cause of death (secondary) × 3 ICD-9 changing to ICD-10 after 1998
Death certificate initiated
Death certificate only
Identification at diagnosis
Address at diagnosis
Postcode at diagnosis
Marital status
Surname at diagnosis
Forenames at diagnosis
Previous surname
Sex at diagnosis
NHS number
CHI number
Ethnic group
GP practice code
Diagnosis details
Independent primary status
Date of registration
Incidence date
Hospital or GP of diagnosis
Hospital patient ID
Side (laterality):
Left
Right
Bilateral
Not known
Tumour site code:
ICD-9
ICD-10
ICD-O(2)
Tumour type code:
ICD-O
ICD-O(2)

continued

Behaviour code (5th digit of ICD-O morphology code, currently derived from ICD-9 site code):
- Benign
- Uncertain benign/malignant
- Carcinoma *in situ*
- Malignant primary site
- Malignant – metastatic site or secondary site
- Malignant – uncertain if primary or metastatic site

Grade classification:
- Nottingham (breast only)
- ICD-O/UICC
- Gleason score (prostate only)
- Other
- Not known

Grade or cell type:
- Grade I–IV
- B-cell
- Null cell
- Natural killer
- Not determined/known

Most valid basis of diagnosis:
- Clinical only
- Clinical investigation
- Exploratory surgery/endoscopy/autopsy (without concurrent/previous histology)
- Specific biochemistry and/or immunology
- Cytology
- Histology of metastasis
- Histology of primary
- Autopsy (with concurrent/previous histology)
- Not known
- Death certificate only

Histological verification (y/n)

Method of first detection:
- Screening
- Incidental finding
- Clinical presentation
- Incidental finding at autopsy
- Other
- Unknown

Clinical T stage (breast only):
- Primary tumour cannot be assessed
- ≤ 2 cm, without direct extension to chest wall or skin
- ≥ 2 cm, ≤ 5 cm, no extension
- ≥ 5 cm without extension
- Any size, with extension

Clinical N stage (breast only):
- Regional lymph nodes cannot be assessed
- No regional lymph node metastasis
- Metastasis to movable ipsilateral axillary nodes
- Metastasis to ipsilateral axillary node(s) fixed to one another or to other structures
- Metastasis to ipsilateral internal mammary lymph node(s)

Clinical M stage (breast only):
- Presence of distant metastases cannot be assessed
- No distant metastases
- Distant metastases

Dukes' stage (colorectal only):
- Limited to muscularis propria, regional lymph nodes negative
- Invades through muscularis propria into serosa/subserosa or through peritoneum, lymph nodes negative
- Regional lymph nodes positive, apical negative
- Regional lymph nodes positive, apical positive
- Regional lymph nodes positive (apical unknown/not stated)
- Distant metastases
- Not known

continued

Figo stage (cervix only):			
Strictly confined to cervix			
Beyond cervix/uterus, but not as far as pelvic wall or lower third vagina			
Extends to pelvic wall or lower third vagina			
Invaded beyond true pelvis, or has involved mucosa of bladder/rectum			
Not known			
Pathological tumour size (initially for breast)			
Nodes examined (breast):			
No			
Yes, a sample			
Yes, axillary node clearance			
Not known			
Number of nodes examined (breast)			
Pathological nodal status (breast) (+ve): (yes/no/not known)			
Number of nodes positive (breast)			
Oestrogen receptor status (breast):			
Negative			
Positive			
Not known			
Initial treatment			
Entered into clinical trial (yes/no/not known)			
Surgery:			
No			
Yes			
Planned			
Not known			
First surgery:			
Date			
Hospital/GP practice			
Radiotherapy:	Referred	Treated	
Yes			
No			
Planned			
Not known			
Radiotherapy to	Primary	Metastases	Other
Yes			
No			
Not known			
First radiotherapy			
Date			
Hospital			
Treatment	Chemotherapy	Hormone therapy	Other (specify)
No			
Yes			
Planned			
Not known			
Date of first			
Hospital/GP practice of first			
Therapy objectives:			
Curative intent			
Non-curative intent			
Not known			
System administration			
Quality check:			
In force			
Date			
Checked by			
Registration comments			

[a] This extended set of data items has recently been introduced; these additional items were collected from all patients diagnosed on or after January 1997.

Welsh Cancer Registry

Description

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) is responsible for the Welsh Cancer Registry. Officially established in 1962, information became computerised in 1972 under the direct management of the Welsh Office. WCISU took over the running of the Registry in April 1997 in an attempt to improve the completeness and accuracy of the Registry and to enable the Registry to be located in a host Trust.

Some of the current and planned uses of the Registry are as follows:

- registration and analysis of high-quality and timely data on cancers in Welsh residents
- epidemiological and public health research and surveillance
- planning and commissioning cancer services
- monitoring and evaluation of screening services
- facilitation of clinical research and trials, including supply of information to the Clinical Trials Network
- clinical management and audit
- resource management and planning
- cluster analyses
- education of professionals and public.

The Registry has not been used for any assessments of efficacy, efficiency or cost-effectiveness. There have been a small number of research projects carried out by PhD students. None subsequent to 1994 have been published, owing to issues around data validation.

The Welsh Registry forwards the Cancer Minimum Dataset to ONS for inclusion in the NCR.

Funding

The Registry is funded by the Welsh Office (covered by a 3-year service-level agreement).

Population covered

The Registry holds in excess of 411,000 individual patient-based records, containing data on the occurrence and characteristics of all malignant neoplasms and certain non-malignant tumours occurring in Welsh residents (wherever diagnosed in the UK) and non-Welsh residents diagnosed/treated in Welsh hospitals.

The registry follows the UK guidelines for validity, based on the average of the data for the last 3 years. At the completion of registration of incidence each year, comparative checks are undertaken to ensure completeness, and any shortfalls of incidence are investigated. The Registry has plans to improve the level of completeness for notifications that involve linking with pathology laboratories and external validation.

Process of data collection

Information for the Registry is collected from every Trust in Wales, and the sources of information are as follows:

- PEDW
- ONS mortality statistics
- death certificates
- NHSCR flagging and tracking
- regional Cancer Registries outside Wales*
- radiotherapy details (which include outpatient information)
- clinical coders in hospitals.

Clinical and morphology information is collected via the PEDW and is sent to the Registry continuously, as and when available. Once received, data are batched into site-specific groups.

The Registry employs a matching and merging system similar to the system used by the SCR. Data entry clerks with clinical coding backgrounds are employed, who carry out manual checks (e.g. whether patient details match, whether the neoplasm is correct). Ambiguities are referred to the initial source in the hospital. Once this information has been corrected, it is input manually on to the database. There are also peripatetic coders who carry out validations in various hospitals, checking with medical records.

Summary of data items collected

No list was available.

Coding schemes

The Registry was in 1999 still in the process of changing from ICD-9 to ICD-10 codes. OPCS4 codes are also used. Problems have been found in the coding for leukaemia, as the classification did not reflect current procedures.†

Continuity

The implementation of a new computer system and the movement of all files to the new system

* Returning details on Welsh residents diagnosed and treated elsewhere.

† The International Association of Cancer Registries has reported this information to the WHO.

meant that no registration information was entered for an 18-month period. The inputting of these data is currently under way. At the end of March 1999, 99% of cancer incidence for 1997 had been completed, and 25% of registration of 1998 incidence had been achieved.

Completeness

The level of completeness for data items is reported as >90%. Missing items are usually postcodes and occupation details, but the return of these is becoming more complete from year to year. These figures were produced recently from performance indicators for the UKACR. Initial information supplied to the Registry may sometimes have codes missing for morphology; these are completed at a later date. As the Registry extracts PEDW data, any missing clinical coding can be identified the next time a patient is treated, and the information added retrospectively.

Accuracy

The information sent to WCISU is reported to be fairly accurate as a whole.* There could be slight differences in addresses due to a patient being treated in a different hospital. There is an administration database for the whole of Wales, which holds demographic details for all patients living in Wales. This is used to check patients' details. The peripatetic clerks check information at each hospital. There are future plans to carry out a random sample of raw data in the hospitals. The accuracy of information entered into the central database is reported to be very high. Validation checks are carried out at WCISU to check on missing data, and ONS also sends back any information that is invalid.

Internal validation

The Registry follows the UK guidelines for validity, based on the average of the data for the last 3 years. WCISU uses a specifically written in-house internal validation software program, including checks for logicality, site type and postcodes. There are also mandatory data entry fields.

A Quality Assurance Manager is employed along with the peripatetic clerks, who assess the source records and carry out validations. Three statisticians and a senior advisor are also employed, who indicate anything that looks uncommon or incorrect.

The validity of the database is planned to increase, owing mainly to more thorough checks.

A research project entitled 'Cancer Registration through Online Pathology' (CROPS), examining direct links from pathology laboratories to the Cancer Registry, was undertaken during 1998–99.

External validation

The Registry currently compares with the following:

- The Childhood Cancer Group in Oxford – who will compare with WCISU for completeness and accuracy
- CANTORIS, a hospital-based cancer information system – who will collect all the minimum data collected by WCISU, plus their own additional information for use on local levels.
- Report of QS1 Data – this is compared with PEDW records on an aggregated basis, and details the percentage of records which have been clinically coded.

The Welsh Cancer Registry is also planning to externally validate with:

- Breast Test Wales
- The Information System for Clinical Oncology (ISCO), a hospital cancer information system.†

Future plans

Wales was in 2001 developing a cancer plan.

Access

WCISU have confidentiality guidelines that need to be agreed to and signed by a researcher for any information required.

For access to patient-identifiable patient records or anonymised data containing patient records, full ethical approval would need to be obtained. Aggregated data are available at district, regional and national levels after signing the confidentiality agreement.

Charges are made for the supply of data to bodies outside the NHS, and this depends on the amount of time involved. Requests for information should be addressed to Dr J Stewart (address below).

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* An investigation into medical records was carried out, which concluded that during 1987–88 significant errors were made in the coding process.

† In the final stages of development at the time of writing, it will contain all information for South-East Wales patients and other specialist oncologist information. This will be compared with the WCIU data on a data–data basis.

Contact details
Mrs S Reynolds
Registry Manager
Wales Cancer Intelligence and Surveillance Unit
14 Cathedral Road
Cardiff
CF1 9JL

E-mail: shelagh.reynolds@veludine-iv.wales.nhs.uk

Information sources
Data were extracted from an interview and NHS Wales (1998).

Publications and further information sources
Annual Reports.
Cancer Statistics Registrations.
Summary information is included in 'HealthShow'.
Cancer registration from online pathology systems (submitted for publication).

Northern Ireland Cancer Registry (NICR)

Description
The NICR was established in 1994 under the Department of Epidemiology and Public Health, Queen's University of Belfast.

Data were previously collected by the Department of Health and Social Services (DHSS) for Northern Ireland (1959–94). However, this relied on clinicians sending information in on patients they had treated, which led to an extremely incomplete registry with poor verification/validation. The situation was rectified by the establishment of a dedicated tumour-based cancer registry.*

The purpose of the NICR is "to provide accurate, timely information on cancers occurring in the population of Northern Ireland to enable research, planning and education so the burden of disease may be reduced", and has the following objectives (NICR website, 1999):

- collect, analyse and store accurate, timely and comprehensive data on cancer
- uphold patient and carer confidentiality
- promote a research agenda for cancer
- facilitate and undertake research into cancer causes, treatments and outcomes
- facilitate planning of cancer services for prevention, diagnosis, cure and care
- assist professionals in audit of treatments, outcomes, etc. (guidelines are available)
- promote professional and public education in cancer causes, prevention, treatment and outcomes
- publish scientific reports and papers relating to cancer in Northern Ireland
- link nationally and internationally to increase understanding and control of cancer
- review activities and programmes of the Registry regularly to ensure the provision of high-quality data on cancer
- provide appropriate information on cancer for *ad hoc* queries.

Funding
The Registry is funded mainly by the DHSS for Northern Ireland, with some research projects funded by the Ulster Cancer Foundation.

Population covered
NICR covers a population of almost 1.7 million and the Registry receives multiple notifications on 8500 annual registrations of cancer. These include non-melanoma skin cancers.

Completeness is high as deemed from validation against external sources and the mortality:incidence ratio. The number of DCO notifications was approximately 2% of registrations during 1993–95 (NICR, 1999).

Process of data collection
Data are collected electronically† on a quarterly basis for the whole of Northern Ireland from the following:

- pathology laboratories
- patient administration systems
- Registrar General's Office (death certificates)
- radiology sites
- Central Services Agency
- *ad hoc* registries (leukaemia, lymphoma melanoma and colorectal)
- hospices.

Data are validated and loaded on to the database system. Case note review is used for specific research projects and to quality assure the data.

Summary of data items collected
- patients' details, including community health index number, name and date of birth
- diagnosis/tumour details
- admission/surgical details
- death details.

* The card indexes of the original Registry are held within the new Registry.
† Except stage of diagnosis and grade of tumour, which are received via pathology reports.

The only treatment details collected are OPCS4 codings.

A more detailed list of data items collected is given on p. 262.

Coding schemes
The NICR uses ICD-10; previously ICD-9 was in use. OPCS4, ICDO-2 and SNOMED classification systems have been used since 1994.

Continuity
Although the 'new' Registry was established in 1994, new methods of data collection began in 1993. Since 1993 there have been no reported disruptions in the collection and processing of data; however, records prior to 1993 are unreliable.

Completeness
The level of completeness for data items varies; items including name and sex are reported to be 100%, whereas items such as address and OPCS4 procedure codes are around 80% complete.

Accuracy
Comparisons with other registries indicate a high level of accuracy. However, in the first report for 1993–95 problems were identified in the source data for bladder tumours and cervix, Cervical Intraepithelial Neoplasia II (CINII). These were validated by review of other records, including pathology reports and hospital records, and altered appropriately.

Internal validation
The NICR's computing software has built-in validation checks, assessing cross-validations (e.g. site/sex), formatting validations (e.g. dates) and temporal consistencies; problems are checked with the data source. Duplication checks for both tumour and patient are also run using a weighted probability system based on name, date of birth and other details. Identification of duplicates/matching multiple-source data should be solved when a Unique Patient Client Identifier is routinely adopted for use in Northern Ireland. Statistical analyses are performed and returned to the original data source for comment. Data are also compared with expected levels based on information derived from similar registries.

External validation
The dataset has been validated against other datasets such as Colorectal Registry and Malignant Melanoma.

Future developments
The Registry plans to collect more staging information on the spread of tumours. The planning of cancer services is likely to be affected by England's Cancer Plan.

Access
Clinicians may have access to their own patients' data. To obtain individual patient data (both identifiable and anonymised), a medical doctor is required to take clinical responsibility for the data and written permission must be received from the doctor with clinical charge of the patient; ethical approval may also be required. Aggregated data from the district level through to national level are freely available from NICR reports and the Internet.

Researchers may request specific data and should contact the Data Manager in the first instance. There are charges for the provision of data, relative to the time and resources involved. Data may be provided free to local clinicians and researchers.

Contact details
Dr R Middleton
Data Manager
Northern Ireland Cancer Registry
Mulhouse Building
Queen's University of Belfast
Royal Victoria Hospital
Belfast
BT12 6BJ
Tel.: 02890 972577
Email: Rjmiddleton@qub.ac.uk

Dr A Gavin
Director
Northern Ireland Cancer Registry
Mullhouse Building
Queen's University of Belfast
Royal Victoria Hospital
Belfast
BT12 6BJ
Tel.: 02890 975043
Email: A.Gavin@qub.ac.uk

Information sources
Data were extracted from a questionnaire and the references cited.

Publications and further information sources
The NICR publishes *ad hoc* reports and peer-reviewed papers.
NICR website: http://quis.qub.ac.uk/nicr/intro.htm

NICR data items

Patient details
Community health index number
Surname
Forename(s)
Maiden/previous name
Marital status
Address at diagnosis
Home postcode
Sex
Date of birth
Religion code
Patient occupation at diagnosis
Employment status
Social class indicator
District Health Authority/Board of Residence
Live/dead indicator
District Council
Registered GP:
  Code
  Name
Consultant:
  Code
  Name
  Specialty
Hospital of treatment code

Diagnosis/tumour details
Date of diagnosis
Primary ICD-9/ICD-10 site code
Subsidiary ICD-9/ICD-10 site code
Secondary ICD-9/ICD-10 site codes
SNOMED topography site code
SNOMED morphology code
Behaviour code
Basis of diagnosis
Pathology report number
Radiology diagnosis code
Date of radiological examination
Stage of diagnosis
Grade of tumour

Admission/surgical details
Date of admission (hospital spell)
Date of discharge (hospital spell)
Patient consultant – episode start date
Patient consultant – episode end date
Method of admission
Method of discharge
Primary OPCS4 surgical operation procedure code
Date of primary surgical operation
Secondary OPCS4 surgical procedure codes

Death details
Date of death
Cause of death (up to 4 causes)
Patient occupation at death
Institution or place of death
Certification type

Regional Cancer Registries

Description

The NHS established the United Kingdom Regional Cancer Registries during the period 1945–65. The Regional Registries' purpose was to evaluate the risk and survival of cancer. Following the 1996 NHSE letter [EL(96)7], a national core contract for England and Wales was issued. The aim was to produce and maintain a register of cancers that is:

- comprehensive
- accurate
- timely
- accessible.

Information is collected on all regional residents wherever diagnosed or treated and non-residents diagnosed or treated within the region. Ten (nine English and one Welsh) Regional Cancer Registries (*Table 21*) collect data stipulated by the Cancer Minimum Dataset and Registry-specific additional information.

The national Minimum Dataset is forwarded to the ONS/NCR for compilation of national statistics.

In addition to the NCR, information is also supplied to various sectors, including:

- purchasers
- provider Trusts
- clinicians
- researchers
- NHS Regional Offices
- WHO
- International Association of Cancer Registries
- International Agency for Research into Cancer (IARC)
- European Network of Cancer Registries.

The Regional Cancer Registries are members of the United Kingdom Association of Cancer Registries (established in 1992). Among other things, the Association represents cancer registries, promoting liaison and national initiatives and helping to agree policy (ONS, 1998).

Process of data collection

Cancer notification is mandatory for the NHS, and the Regional Registries collect information continuously from all (relevant) Trusts, hospitals and laboratories within their region. *Figure 1* is a summary of the data collection process and the interactions between participating units.

TABLE 21 *Regional Cancer Registries*

East Anglian Cancer Registry	South and West Cancer Intelligence Unit
Merseyside and Cheshire Cancer Registry	Thames Cancer Registry
North Western Cancer Registry	Trent Cancer Registry
Northern and Yorkshire Cancer Registry and Information Service	Wales Cancer Intelligence and Surveillance Unit
Oxford Cancer Intelligence Unit	West Midlands Cancer Intelligence Unit

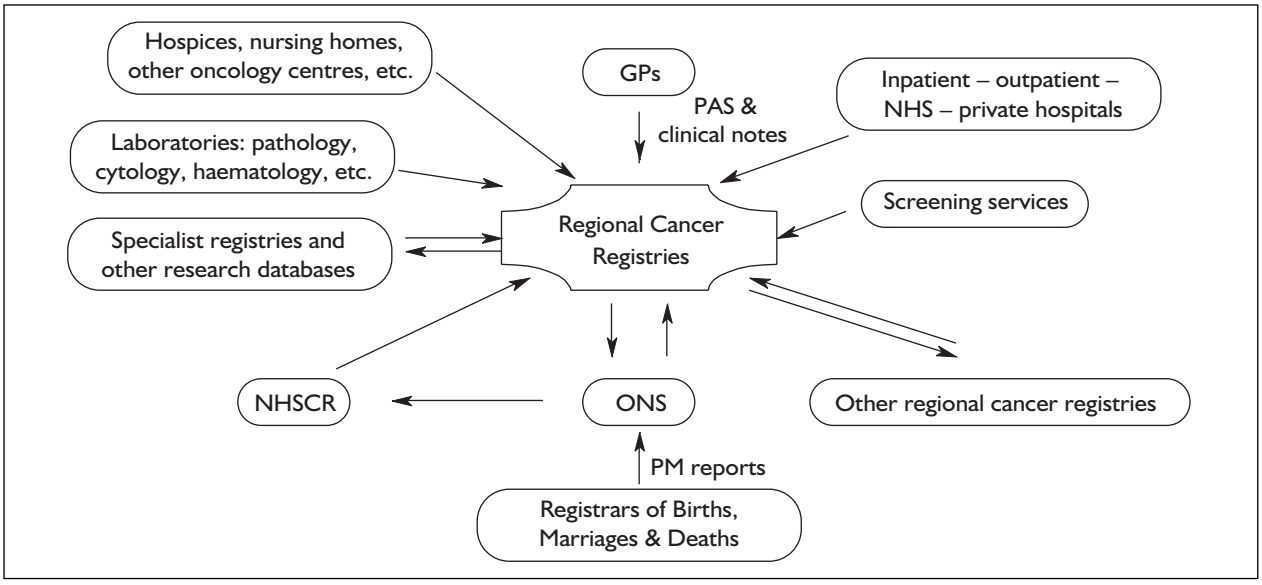

FIGURE 1 *Data collection process and interactions between participating units. Adapted from Northern and Yorkshire Cancer Registry and Information Service, Centre for Cancer Epidemiology (1998) and Office for National Statistics (1998).*

Access
A researcher should follow the guidelines below for the release of information.

Information required	Procedure
Patient-identifiable information	Request in writing Signed confidentiality form and copy of study protocol Approval by the Director of the Centre Written permission of each treating consultant In some cases: approval from each DHA Ethical Committee
Individual patient records with data items for record linkage	As above, although in some cases consultant and ethical permission is not required
Anonymised data with patient records	Request in writing Signed confidentiality form and copy of study protocol Approval by the Director of the Centre
Aggregated data at district level	If data are not routinely available, approval from the Director of the Centre and the Director of Public Health is required
Aggregated data at regional level	Request in writing
Aggregated data at national level	Request in writing When no 'off-the shelf' information is available, researchers are referred to ONS

Charges may be levied for source-intensive requests and for commercial organisations.

Contact details
Refer to the specific Regional Cancer Registry.

Information sources
Data were extracted from Bell,[1] interviews, completed questionnaires and the references cited.

Publications and further information sources
Annual reports.
ONS Cancer Statistics: Registration.
A wide range of publications on cancer registrations, both regional and national, is provided by ONS; for further details, refer to StatBase, UK National Statistics Online: http://www.statistics.gov.uk/statbase/mainmenu.asp

Reference

1. Bell C. Reducing risk: improving outcome in cancer. London: United Kingdom Association of Cancer Registries; 1998.

East Anglian Cancer Registry

Description
The East Anglian Cancer Registry was established in 1988 by the amalgamation of the original three cancer registries in East Anglia (dating from around 1960). The Registry is funded by the Cambridge and Huntingdon Health Authority on behalf of the NHS. Data are now collected with the Head Office in Cambridge and two sub-offices, collecting information from Norfolk, Suffolk, Bedfordshire and Cambridgeshire. The data collected from the original three registries are held within the East Anglian Cancer Registry.

Funding
The Registry has 15.46 whole-time employees who include directors, manager, IT, research and clerical staff.

Population covered
There are over 300,000 individual records on the database since 1971. The database covers a population of approximately 2,500,000, with over 16,000 registrations a year.

Process of data collection
When the Registry receives a notification, it checks to make sure that the patient or tumour is not already registered with it. This is put on to the system as a provisional registration: name and tumour. In the following 6 months to 1 year, information about the patient is entered little by little, each time a notification is received, until all information has been received, when a complete registration is carried out.

After at least 6 months from the original notification, Registry staff check clinical records, abstracting data on to a cancer registration form, which is coded and input on to the computer at the Registry. Clinical coders check coding before entry on to the database.

Summary of data items collected

- patients' details, including name, date of birth, address, patient ID and NHS number
- occupation details
- GP/hospital details
- tumour details
- treatment details
- other primaries
- follow-up and death information.

A more detailed list of data items collected is given on pp. 266–7.

Continuity

There have been no significant discontinuities in the collection or processing of data. Prior to 1988 there were different methods of validation and accuracy, and when the databases were merged there was a slight delay in the collection of data.

There was a change from the Paradox system to Oracle in April 1997, and a new in-house system was introduced. This did not cause any disruptions.

Completeness

See Review of cancer registration in England.[1]

Accuracy

See Review of cancer registration in England.[1]

Internal validation

ONS validation checks are made for data logicality and inconsistency.

Other types of validation include:

- visits from Registry staff to check information
- Registry Manager and Medical Director checks on staging
- manual checks for any discrepancies.

There have been no reported areas of weakness or areas that constantly suffer from miscoding. The validity of the data does not change from year to year, but during the takeover period in 1988–89 validity suffered and fewer cases were reported.

External validation

The Oxford Cancer Registry is compared with the East Anglian and the two Registries work closely together.

When any other database requests information from the Registry, they are asked to supply a list of all their cases to enable a comparison to be made.

The Registry regularly exchanges information with the Breast Screening Service, the Oxford Childhood Cancer Register and the Bone Marrow Transplant Database (Addenbrookes Hospital) and this is used on an *ad hoc* basis, particularly for leukaemia.

Future developments

See NCR (p. 243).

Contact details

East Anglian Cancer Registry
Box 193
Level 5 Oncology
Addenbrookes Hospital
Hills Road
Cambridge
CB2 2QQ
Tel.: 01223 316592
Fax: 01223 245636
Email: eacr@medschl.cam.ac.uk

East Anglian Cancer Intelligence Unit
University of Cambridge
Strangeways Research Laboratory
Wort's Causeway
Cambridge
CB1 8RN
Tel.: 01223 740273
Fax: 01223 411609
E-mail: sara.godward@srl.cam.ac.uk

Director
East Anglian Cancer Registry and Intelligence Unit
University of Cambridge
Institute of Public Health
University Forvie Site
Robinson Way
Cambridge
CB2 2SR
Tel.: 01223 330318
Fax: 01223 330330
E-mail: d10@medschl.cam.ac.uk

Publications and further information sources

Website: http://wwweb.org/eacr/

Reference

1. Gillis CR. Review of cancer registration in England. London: Department of Health; 2000.

East Anglian Cancer Registry data items[a]

Patient details
Registration number
Surname
Forename and initials
Maiden name/previous surname
Sex
Date of birth
NHS number – old
NHS number – new
Address
Postcode
Marital status
Area code
Country of birth

Occupation details

	Occupation	*Status*	*Industry*
Patient			
Head of household			

GP/hospital details
GP:
  Code
  Date of 1st attendance
Date of 1st hospital attendance

	Hospital	*Code*	*Number*	*Consultant*
Referring				
Diagnosis/treatment				
Radiotherapy				

Tumour details
Date of diagnosis
Primary site/main secondary
Tumour type
Grade
Lab. number
Staging details:
  Size
  Invasion
  Nodes
  Metastasis
  Scans
  etc.
Stage classification:
  Dukes
  Clarkes
  Breslow
Stage:
  T
  N
  M
ICD code
Laterality:
  Left
  Right
  Bilateral
  Not known
Screening (yes/no/not known)
Morphology code

continued

Basis of diagnosis:
- *Histology*
- *Cytology*
- *Other tests*
- Clinical
- *Not known*

Multiple tumour indicator

Treatment details

Surgery:
- *Date*
- *Hospital*
- *Procedure*
- *Code*

Radiotherapy:
- *Date*
- *Hospital*
- *Type*
- *Dose*

Chemotherapy:
- *Date*
- *Hospital*
- *Drugs*

Hormone:
- *Date*
- *Hospital*
- *Drugs*

Hormone ablation
- *Date*
- *Hospital*
- *Type*

Other:
- *Date*
- *Hospital*
- *Type*

Other primaries

Centre
Registration year
Registration number
Site

Follow-up and death information

DLA registration
Follow-up code
Patient:
- Date last known alive
- Comments
- Rec.

Date of death
Cause of death (Ia–Ic, II) and code
Place of death:
- Hospital
- Other
- Not known

Post-mortem (yes/no/not known)
Special:
- *DCO*
- PM only
- GP only
- PP

[a] Italics indicate items collected as part of the Cancer Minimum Dataset.

Merseyside and Cheshire Cancer Registry (MCCR)

Description

The MCCR was originally established in 1944,* collecting data on all cases of malignancy occurring in the area served by the Liverpool Radium Institute. It has extended coverage to surrounding areas.

Population covered

Since 1974 the MCCR has collected data on all cancers occurring within the region of Merseyside and Cheshire. The registry holds over 517,000 patient records, with around 550,000 tumours.

Process of data collection

Electronic transfer systems provide notifications from hospitals and pathology departments. The computer system uses a complex record matching and linkage process to check that the tumour has not already been registered and then automatically registers details on to the main registry database. Further information may be sought from the GP, hospital or nursing home. For the main hospitals in Merseyside and Cheshire, Registry staff visit and extract information from the hospital records.

Information concerning deaths from cancer is processed quickly. The minimum processing time for the data is 12–15 months as treatment information is collected for 1 year following diagnosis. Processing, however, often takes longer as delays in notifying sources occur. Incidence data are available earlier than treatment data as they are based on registrations, not hospital data.

Summary of data items collected

- administrative details
- notes and comments
- personal details, including name, address, date of birth, patient ID and NHS number
- death details
- GP details
- tumour information
- dates
- hospital information
- treatment information.

A more detailed list of data items collected is given on pp. 269–72.

* The database holds information on cancers diagnosed from 1951.

Continuity

There have been no significant breaks in the collection or processing of information. Changeover to a new computer system was smoothly implemented in 1994. The Registry is currently completing development of the second phase of this system (the automatic record matching/linkage process).

Completeness

See review of cancer registration in England.[1]

Accuracy

See review of cancer registration in England.[1]

Internal validation

The Registry database employs data-checking systems including a relational technology 'behind the screen' validation, audit logging and site and pathology cross-checks.

Software checks include:

- site, pathology and sex cross-checks
- complex cross-checks with conditional mandatory items
- restrictions on values entered
- full use of look-up tables to ensure correct codes selected.

Other checks include:

- use of record matching and linkage processes to highlight possible duplicates.

If the data are to be used, other checks are performed such as for District Health Authorities and postcodes, missing values, dates of birth of children under 1 year old and checks for unusual coding combinations.

The validity varies from year to year; earlier years were not subject to such stringent computer checking. Additional data items have also been incorporated into the database since its inception.

External validation

Standard ONS procedures apply.

Contact details

Merseyside and Cheshire Cancer Registry
2nd Floor
Muspratt Building
The University of Liverpool
Liverpool
L69 3BX
Tel.: 0151 794 5691
Fax: 0151 794 5700

Publications and further information sources

Data are published in 5-year incident reports. Bulletins on skin cancer, breast cancer, lung cancer.

Reference

1. Gillis CR. Review of cancer registration in England. London: Department of Health; 2000.

MCCR data items[a]

Administrative details			
Registration number			
Tumour number			
Multiple tumour indicator			
Notes and comments (including clinical trials)			
Personal details			
Surname			
Forenames			
Birth name			
Address			
Registry code			
Birth place			
Occupation:			
Patient			
Husband/father			
Socio-economic group			
Date of birth			
Sex			
Marital status			
NHS number			
Related factor:			
Trauma			
Smoking			
Alcohol			
Occupation			
Oral contraceptive pill/hormone replacement			
Pregnancy			
Pre-existing condition			
None			
Not known			
Family history			
Ethnic origin			
Death details			
Date of death			
Death cause			
Cause text			
Post-mortem:			
Yes, no new primary found			
Yes, new primary			
No post-mortem			
Not known			
Cancer activity at death:	T	N	M
Disease free			
Disease active			
Disease cause death			
Other			
Not known			
GP details			
Name			
Address			
Code			

continued

Tumour information
Diagnostic source:
- *Pathology*
- *Cytology*
- *Haematology*
- *Hospital records*
- *Other cancer registry*
- *ONS/death certificate*
- *DCO*
- *Not known*

Site
Side:
- *Right*
- *Left*
- *Bilateral*
- *Not relevant*
- *Not known*

Pathology
Grade:
- *Well*
- *Moderately*
- *Poorly*
- *Undifferentiated*
- *T cell*
- *B cell*
- *Null cell*
- *Not known*

Pathology reference number
Subsequent pathology reference
Proof of diagnosis:
- *Histology A*
- *Histology B*
- *Cytology*
- *Haematology*
- *Special test*
- *Imaging techniques*
- *Observation*
- *Clinical*
- *Not known*

Mode of presentation:
- *Screening*
- *Symptoms*
- *Incidental*
- *Post-mortem*
- *Previous Rx*
- *Not known*

Size
Stage:
- *T*
- *N*
- *M*

Treated:
- Complete
- No Rx
- No Rx info.
- PT Rx info.
- E.R. complete
- E.R. no Rx
- E.R. no Rx info.
- E.R. PT Rx I/C
- Not known

continued

Reason untreated:
- Post-mortem diagnosis
- General condition poor
- Patient refused
- Too advanced
- No treatment necessary
- Planned delay
- Not applicable
- Not known

Dates
Last screen
Diagnosis
GP referral
First seen
Registered

Hospital information
Hospital
Hospital PID
Clinician
Specialty
Date attended
Tumour management:
- Diagnosis
- Diagnosis and treatment
- Treated only
- Referred and not treated
- Other
- Not known

Treatment information
Surgery:
- *Description*
- *Code*
- *Date treated*
- *Hospital*
- *Clinician*

Chemotherapy:
- *Code*
- *Method:*
  - *Topical*
  - *Oral*
  - *Intravenous*
  - *Intrathecal*
  - *Subcutaneous*
  - *Intracavity*
  - *Intramuscular*
  - *Multiple*
  - *Not known*
- *Date*
- *Hospital*
- *Clinician*

Hormone ablation
- *Site:*
  - *Pituitary*
  - *Thyroid*
  - *Testes*
  - *Ovary*
  - *Adrenals*
  - *Ovary & adrenals*
  - *Testes & adrenals*
  - *Others*
  - *Not known*

continued

Method:
Surgery
Radiation only
Combination of methods
Chemotherapy
Not known
Date
Hospital
Clinician
Radiotherapy
Description:
Radical Rx
Palliative
Yes, details not known
Other
Not known
Date started
Hospital
Clinician

[a] Italics indicate items collected as part of the Cancer Minimum Dataset.

Northern and Yorkshire Cancer Registry and Information Service (NYCRIS)

Description

The NYCRIS replaced the separate Northern Cancer Registry and Yorkshire Cancer Registry on 1 April 1998.

Funding

The registry is funded through a 'service agreement' in which all the regional Health Authorities contribute, depending on their populations.

Population covered

The database covers a population of approximately 6.7 million with around 41,000 new registrations annually.

Notifications up to 1995 are reported to be complete. Notifications for 1996 and 1997 are reported to be 82% and 21%, respectively. The completeness of notifications is calculated by comparing the total number with the expected number. The expected number of notifications is based on the average of the past 3 years. At the time of reporting, the overall data item response had not been recently assessed.

Process of data collection

Once a notification has been obtained, an initial registration is made. After a 6-month period a clerk will attend the relevant hospital or hospice to abstract the dataset items from the patients' clinical notes. The 6-month waiting period is to allow for treatment data to accumulate. Once the dataset items have been retrieved, the information is transferred to the central computer system by a number of clerks. The NHSCR informs the Registry on a weekly basis of all deaths with previous notifications of cancer. Once informed of the death of a registered patient, the relevant GP is contacted and past treatment details are obtained. If a death notification is received for a person not already registered, a clerk will attend the place of treatment to abstract the clinical information. There are provisional plans to change the collection process by receiving pathology reports electronically.

Summary of data items collected

- administrative details
- patient details, including name, address, date of birth, ID and NHS number
- occupation details
- GP/hospital details
- date information
- tumour details
- treatment details
- further primary details
- death details.

A more detailed list of data items collected is given on pp. 274–5.

Continuity

There have been no significant breaks in the collection or processing of NYCRIS data.

Completeness
See Review of cancer registration in England.[1]

Accuracy
See Review of cancer registration in England.[1]

Internal validation
The following validation techniques are conducted:

- Computer packages are used to search for a range of logicalities and inconsistencies.
- A number of basic quality analyses are conducted to assess both the level of completeness of submitted data and their quality.
- A full-time quality assurance officer constantly assesses the accuracy of information input by the clerks. Before the mid-1980s, no quality assurance officer was employed, and the quality of data is reported to be less reliable.
- All information submitted to the registry is checked for data item response. If key information is found to be missing, the relevant source is re-contacted.
- The completeness and accuracy of data items used for researchers are assessed on a study-to-study basis.
- From 1998, 2% of all notifications were re-input on an annual basis.

External validation
External validation is conducted on an *ad hoc* basis with the ONS database and specialist local registries such as the local tumour registry and the local leukaemia research fund.

Future developments
There are existing plans to extend the amount of staging information recorded from the pathological staging forms. The extension of staging data items recorded has already begun in a few select sites. All occupation data items, which are optional in the Cancer Minimum Dataset, will cease to be collected owing to consistent incompleteness and poor quality.

Contact details
NYCRIS
Arthington House
Hospital Lane
Leeds
LS16 6QB
Tel.: 0113 392 4416
Fax: 0113 392 4132
E-mail: adms@yco.leeds.ac.uk

Publications and further information sources
General incidence and treatment data are published every 5 years.

Key sites currently comprising central nervous system, lung, melanoma and pancreas, with others (e.g. ovary, breast) to follow.

Website: http://www.nycris.org.uk/

A CD-ROM or disk 'Quick Data' is also produced, which allows for the customisation of the incidence, treatment and survival rates within the Yorkshire (up to 1996) and Northern (up to 94) regions.

All publications can be ordered from the website or by contacting the Registry.

Reference
1. Gillis CR. Review of cancer registration in England. London: Department of Health; 2000.

NYCRIS data items[a]

Administrative details
Source of document
Date CD sent
Cancer registry number

Patient details
Patient ID
NHS number
Surname
Forename and initials
Previous surname/maiden name
Address
Postcode
Sex
Marital status
Date of birth
Birthplace
Ethnic origin
Religion

Occupation details

	Occupation	Industry
Patient		
Husband		
Father		

GP/hospital details
GP:
Initials
Surname

Hospital	Unit no.	Consultant initials	Consultant surname

Date information
Date of:
1st symptom
GP referral
Hospital visit
Diagnosis
Treatment

Tumour details
Site
Laterality:
Right
Left
Bilateral
Not known
Type
Differentiation:
Well
Moderately
Poor
Undifferentiated
Not known
Grade
Basis of diagnosis:
History
Cytology
Observation
Clinical
Not known

continued

Regional nodes (yes/no/not known) *Metastasis (yes/no/not known)* *Site of metastases:* *Nodes* *Skin* *Bone* *Brain* *Lung* *Liver* *Per* *Med* *Spleen* *Other* *Screening (yes/no/not known)* Date of screening Assessment
Treatment details *Operation:* *Date* *Surgery* *Radiotherapy:* *Date* *Radiotherapy* *Other treatments* *Chemotherapy date* *Hormone therapy date* *Ablative therapy date*
Further primary details *Multi primary* *Other primaries:* *XR code* *Year* *Cancer registry number* *Site*
Death details *Date* Place: Hospital Home Hospice NH Post-mortem (yes/no) *Death certificate only (yes/no)* Cause of death (1a–1d) Comments
[a] Italics indicate items collected as part of the Cancer Minimum Dataset.

North Western Regional Cancer Registry (NWRCR)

Description

The NWRCR is run by the Centre for Cancer Epidemiology under a lead purchaser arrangement with West Pennine Health Authority. Originally established in 1962 as a national initiative, the Registry was managed by the Manchester Regional Hospital Board. Collection of treatment information commenced in 1993, when the minimum dataset was introduced. The NWRCR is a tumour-based registry, currently processing around 22,000 tumours per year, approximately 28,383 patients.

Population covered

Information is collected from Greater Manchester, Lancashire and a small part of Derbyshire. The

Registry also started collecting from South Cumbria in 1994. The total population covered by the Registry is 4.1 million.

In 1994, the Registry estimated that notifications were 99% complete, with 1995 being 93% complete. This is completeness of notifications, that is, the number of registrations compared with actual cancers.

Process of data collection
Clinical coders, who have been trained by the NWRCR, are responsible for extracting the relevant registration details at provider level and entering the details on a form. These forms are then sent to the NWRCR, where they are entered by a group of trained personnel on to the central database.

Training is carried out whenever necessary and new coders are trained as soon as their employment starts. Training is also provided to private hospitals within the region.

Data are received on a continuous basis from all Trusts and pathology laboratories. When information is received (i.e. death certificates, pathology reports), the computer system instigates a warning to enable the hospitals to be contacted for further information.

Information received at the Registry is processed chronologically. The annual information is usually available around 18 months later.

Summary of data items collected
- administrative details
- patient details, including name, address, date of birth, patient ID and NHS number
- occupational details
- diagnostic details
- treatment details
- death details.

A more detailed list of data items collected is given on pp. 277–8.

Continuity
There have been no significant discontinuities in the processing or collection of data.

Completeness
Regular staff assessments are carried out in the Registry to identify the quality of data. In January 1998, an assessment was carried out which identified that of the 21,300 cases, there was an approximate 6% error rate.

For standard indicators, see review of cancer registration in England.[1]

Accuracy
For standard indicators, see review of cancer registration in England.[1]

Internal validation
The Registry's computer package contains an IARC software system that carries out stringent validity checks and also performs patient linkage checks (i.e. double checking on date of birth, etc. – patient may have more than one tumour).

Other checks involve the clinical coders reporting any unusual findings to a supervisor at the Registry.

Primary site and behaviour of tumour have, in the past, been identified as areas of weakness.

External validation
Special registers are compared with the dataset, including the Childrens' Tumour Registry, Manchester Ovarian Tumour Panel and the Mesothelioma Registry. Information is also downloaded biannually to ONS for comparison.

Occasionally information is compared with a Trust's PAS to check that information is correct, and also to check that the clinical coders are entering all information required.

The Registry has carried out various analyses, including cluster analysis for children with retinoblastoma. The Director of Public Health was informed that there may be a cluster in the area, so the Registry was asked to investigate this in detail, take information from notes, compare with the childhood groups and so on. Data were compared with the Childhood Cancer Group to ensure that information matched. The outcome was that the Registry identified two more cases in total. No cluster was identified.

There are no immediate plans to use any other datasets for external validation.

Future developments
See NCR (p. 243).

Contact details
North Western Regional Cancer Registry (NWRCR)
Centre for Cancer Epidemiology
University of Manchester
Christie Hospital NHS Trust

Kinnaird Road
Withington
Manchester
M20 4QL
Tel.: 0161 446 3570
Fax: 0161 446 3578
Email: registry@cce.man.ac.uk

Publications and further information sources

Website: www.cce.man.ac.uk

Reference

1. Gillis CR. Review of cancer registration in England. London: Department of Health; 2000.

NWRCR data items[a]

Administrative details
Registering hospital
Hospital no.
GP:
- Name
- Address
- Postcode

Patient details
Surname
Previous surname
Forenames
Date of birth
Sex
Marital status
Address
Postcode
Birthplace
NHS number

Occupational details

	Occupation	Industry	Status
Patient			
Husband or father (if child)			

Diagnostic details
Date of first hospital attendance (for this malignancy)
Referred from another hospital (y/n)
- If yes specify hospital

Primary site:
- *Left*
- *Right*
- *Bilateral*
- *Not known*
- *Not applicable*

Main secondary if primary not known
Type of growth
Basis of diagnosis:
- *Histology*
- *Cytology*
- *Bone marrow investigation*
- *Radiology investigations*
- *Clinical*
- *Not known*
- *Other (specify)*

Histology:
- *Type*
- *Date*

continued

Stage: *Details* *Classification:* *TNM* *FIGO* *Dukes* *Other (specify)* *Details of any previous malignancy*
Treatment details Treatment at registering hospital (y/n) If no: PM diagnosis GC too poor Patient refused Too advanced Referred to other hospital (specify) Not known Other (specify) *Date* *Hospital* *Treatment/operative procedures* *Consultant* *Other consultants*
Death details *Date of death* PM (y/n/not known) PM histology (if available)
[a] Italics indicate items collected as part of the Cancer Minimum Dataset.

Oxford Cancer Intelligence Unit (OCIU)

Description

The OCIU was established in 1952. It is responsible for the collection and dissemination of the Oxford Cancer Registry with computerised information being held from 1967.

Funding

The database is funded by health authorities in the Oxford region.

Population covered

The Registry covers Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire (total population 1.3 million). The database currently holds over 350,000 tumour records, with 18,000 notifications annually.

Process of data collection

The Registry collects information continuously from all Trusts, hospitals and laboratories within the region. Death certificates are collected on a quarterly basis. All information is entered on to the central database, whether the patient's treatment has been completed or not. Data are processed in date order and, at the time of writing, the Registry was registering data from the last quarter of 1998. Once the backlog of information has been processed at the central office, the OCIU intends to process data on a quarterly basis.

Visits to the Trusts, hospitals and laboratories are carried out by Registry staff, who negotiate more effective ways of sending information to the Registry. Most information is now collected by electronic download although there are still some paper returns. Update meetings are then held on at least a yearly basis.

Summary of data items collected

- administrative details
- patient details, including name, address, patient ID, NHS number
- occupation details
- family history details
- date information
- tumour details
- links to other tumour details
- screening details
- breast staging details
- hospital/GP details
- treatment details

- miscellaneous details
- transaction audit details
- data used for OPCS processing
- death details.

A more detailed list of data items collected is given below.

Continuity
There have been no significant discontinuities in the collection or processing of data.

Completeness
See Review of cancer registration in England.[1]

Accuracy
See Review of cancer registration in England.[1]

External validation
The database is compared with other regional cancer registries and cancer registries worldwide. Comparison with other registries shows that OCIU data are of high quality. The Registry is always willing to consider validation with any other registry showing interest.

Future developments
See NCR (p. 243).

Contact details
Oxford Cancer Intelligence Unit
Institute of Health Sciences
Old Road
Headington
Oxford
OX3 7LF
Tel.: 01865 227040
Fax: 01865 226809
E-mail: ociu@compulink.co.uk

Publications and further information sources
Trends in cancer survival in Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire (1996).
Cervical cancer in Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire (1997).
Cancer incidence in Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire in 1994 (1997).
Cancer incidence and survival in Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire in 1995 (1998).

Reference
1. Gillis CR. Review of cancer registration in England. London: Department of Health: 2000.

OCIU data items[a]

Administrative details
Health Authority code
Ward code
Registration centre
Patient's number
Registration year serial
Patient details
Surname
First forename
Forename/initials
Soundex code
Birth/maiden name
Area of residence
Address
Postcode
Sex
Date of birth
Place of birth
NHS number
Marital status
Ethnic origin
Status of patient
Date of status of patient
Date of birth flag
Smoker

continued

Occupation details	Occupation	Employment status	Industry
Patient			
Head of household			

Family history details
Family history:
- Relative
- Site
- Surname
- Initial
- Registration number

Date information
Anniversary date
Date first attended hospital
Anniversary age
First symptom date
GP referral date
Diagnosis date
First treatment date
OPCS anniversary date

Tumour details
Primary code
Morphology
Laterality
Basis of diagnosis
Histological grading
Special registration
ICD version flag
Stage 1
Stage 2
Tumour size
Regional nodes
Metastases present
Metastases site 1
Metastases site 2
Metastases site 3

Links to other tumour details
Multiple tumour indicator
Previous centre code
Previous registration number
Next centre code
Next registration number

Screening details
Diagnosis from screening
Screening:
- Type
- Centre
- Number
- Classification
- Comments
- Date
- Result

Breast staging details
Regional nodes sampled
No. of nodes:
- Sampled
- Positive

continued

Hospital/GP details		
GP code		
Hospital code		
Hospital number		
Main consultant		
GP start date		
Treatment details		
Treatment type:	*Treatment/dose*	*Date*
Surgery		
Radiotherapy		
Chemotherapy		
Hormone		
Other		
No treatment flag		
Hospital sequence number		
Consultant specialty		
Treatment code		
Treatment comments		
Miscellaneous details		
Clinical trials		
Transaction audit details		
Initial registration date		
Transaction date		
Source document type		
Data used for OPCS processing		
Record type		
Death details		
Date of death		
Place of death		
Post-mortem		
Cause of death (1a–1c, 2)		

[a] Italics indicate items collected as part of the Cancer Minimum Dataset.

South and West Cancer Intelligence Unit (CIU)

Description

The CIU was formed in 1995 due to the merger between Wessex Cancer Intelligence Unit, South Western Cancer Registry and the Cancer Epidemiology Unit of the University of Bristol (South and West Cancer Intelligence Unit, 1998). Data have been collected from the area since 1973 when the Wessex Cancer Intelligence Unit separated from Thames.

Population covered

The CIU registers all cases of cancer within the geographical boundaries of the South and West region, and covers a population of 6.6 million (South and West Cancer Intelligence Unit, 1998). Over 200,000 hospital episodes are processed to register approximately 45,000 new tumours annually. It has over 400,000 patient records on its database.

An independent audit of three source locations in 1997, concerning the capture of 1994 notifications, reported a 95% capture rate.

Process of data collection

Data are mainly collected electronically with only the minimum received on paper. Electronic data are received from the various sources on diskettes that are transposed into a common format on-site ready for the registration process. Data may be received on a continual, *ad hoc*, weekly through to yearly basis depending on the supplier.

Summary of data items collected

It was not possible to obtain a list of the data items included, despite requests.

Completeness
See Review of cancer registration in England.[1]

Accuracy
See Review of cancer registration in England.[1]

Internal validation
ONS error/validation processes are fully supported by the Registry's computer system. In addition, internal validation is carried out by in-house developed software checking:

- format
- sense
- reference table validation
- intelligent cross-checks/multiple field relationships
- time management/date dependency.

All data received in electronic format are put through separate format, validation and time-based checks. Depending on the results, sources are asked to re-compile, re-run or re-send extracts.

The validity checks reveal inconsistency in reporting and completion of pathology reports, and incomplete reporting of NHS numbers and status within the health community. Postcode and use of local GP/consultant codes suffer from miscoding.

The overall validity of the dataset varies from year to year owing to:

- Changes in the NHS organisational boundaries disrupting the accurate and timely flow of data from the various sources.
- Changes in individual consultant practice can increase or decrease the identification and confirmation of specific cancer sites (e.g. bladder, prostate).

External validation
The Registry is externally validated annually. The validation indicates there may be problems with the level of pathological verification and the availability of staging data in pathological reports.

Future developments
See NCR (p. 243).

Contact details
South and West Cancer Intelligence Unit
Highcroft
Romsey Road
Winchester
SO22 5DH
Tel.: 01962 863511
Fax: 01962 878360

Grosvenor House
149 Whiteladies Road
Bristol
BS8 2RA
Tel.: 0117 9706474
Fax: 0117 9706481

Publications and further information sources
No list available.

Reference

1. Gillis CR. Review of cancer registration in England. London: Department of Health; 2000.

Thames Cancer Registry (TCR)

Description
The TCR was established in 1958.

Population covered
The TCR covers the London region, part of Eastern and South East regions, with a population of 14 million. The Registry receives between 67,000 and 70,000 registrations per year. In 1998 there were 1.7 million patient records and 1.8 million tumour records on the database.

The Registry states that 1997 data were 99% complete when compared with 1996 data. This figure was compiled by using an average of the 1996 and 1997 data as a baseline.

Process of data collection
With the exception of two Trusts which collect data electronically, most Trusts collect data manually. It takes the Registry approximately 3 months to code, process and validate data after they have been received.

Summary of data items collected
- administrative details
- identification details, including name, address, date of birth and NHS number
- GP details
- tumour details
- treatment details.

A more detailed list of data items collected is given on pp. 284–5.

Coding schemes
The Registry stores information in SNOMED and this information can be translated to ICD-9, IC-10

and ICD-0 as required. Surgical information is coded in OPCS4.

Continuity

Continuity of data collection was affected by boundary changes in 1985 when the Registry became responsible for the old North Thames region. Information collected for North Thames prior to 1985 was minimal and so information on North Thames residents is sparse prior to 1985.

Continuity of collection was also affected by an exercise undertaken in 1993, when the Registry actively traced death certificates. This had the effect of increasing the registrations in 1992, as death certificates were traced back for that year, and decreasing registrations for 1993. This exercise was not repeated until December 1997, when time tracing death certificates became part of routine practice.

In 1997, the Registry concentrated on 1996 data to the initial detriment of 1994 and 1995 data. At this time there was a $3^1/_2$-year backlog in registrations. As a result, in early 1998 there was a report published incorporating 1996 data but without 1994 and 1995 data. In 1998, the Registry attempted to collect information on 1994 and 1995, but ascertainment for these years is still lower than for any subsequent years.

Data collection has become more timely in recent years and as at July 1999 the Registry received around 60% of 1998 registrations. The target is 90% of a year's registration received by December of the next calendar year.

Completeness

United Kingdom Association of Cancer Research Quality and Performance Indicators 1999 show that although some data items are 100% complete (these include patient's name, address, date of birth), data items such as treatment codes for chemotherapy are only 28% complete.

For standard indicators, see Review of cancer registration in England.[1]

Accuracy

The Registry undertook a re-abstraction exercise of data collected in 1996 and identified that the data were 86% accurate. The Registry suggests that it is very difficult to identify the accuracy of information sent to it as it relies upon coding by Trust staff and staging by clinicians.

For standard indicators, see Review of cancer registration in England.[1]

Internal validation

A sample of each day's data entry is reviewed for accuracy and the Registry has taken measures to reduce the number of immortals and duplications on the database. All other validation checks are managed by the central database system; these include IARC and ONS checks. The computer package checks for inconsistencies such as validation between data values for diagnosis details and dates, and basic integrity of records.

External validation

From 1999, annual comparisons are to be carried out comparing prospective regional breast audit against data collected by the usual Registry methods. Annual comparisons have also been made for breast screening data, which are compared with the normal processes of registration and, for those Trusts which have only recently begun to send pathology, comparisons of registrations with the pathology diagnosis. External validation highlighted that the breast audit was more accurate in the collection of basic registrations than the routine method of collection. However, problems were seen in patients who had chemotherapy and radiotherapy. As a result, for some Trusts collection of breast audit data has become the means by which registrations are received.

Future developments

See NCR (p. 243).

Access

Most requests for information are free to health professionals and academic institutions within the boundaries covered by the TCR. However, there is a charge for information requests which take more than 1–3 days to complete.

Contact details

Dr E Davis
Director of Thames Cancer Registry
Division of Oncology
Guy's, King's and St Thomas' School of Medicine
Capital House
42 Weston Street
London
SE1 3QD
Tel.: 020 7378 7688
Fax: 020 7378 9510

Publications and further information sources
Millennium Report (published mid-2000).

Website: http://www.thames-cancer-reg.org.uk.
London Region Incidence Report, 19 October 1999.
South Eastern Reports 1997.
South Eastern Regional Reports 1997.

Reference

1. Gillis RD. Review of cancer registration in England. London: Department of Health; 2000.

TCR data items[a]

Administrative details
Old TCR number
New TCR number

Identification details
Surname
First forename
Address
Postcode
Date of birth
Birth/maiden name
Place of birth
Ethnic origin
NHS number
Sex
Marital status
Occupation

GP details
Practice
Code
Date GP referral letter written
Date GP referral letter received

Tumour details
Basis of diagnosis:
- *Clinical*
- *Cytology*
- *Death certificate*
- *X-ray*
- *Haematology*
- *Not known*
- *Scan*
- *Histology of metastases*
- *Exploratory*
- *Histology*
- *Marker*
- *Post-mortem*

Pathology report seen (y/n)
Date of diagnosis
Morphology of primary
Behaviour:
- *Benign*
- *Borderline*
- *In situ*
- *Invasive*
- *Not known*

continued

Differentiation:				
Well				
Moderate				
Poor				
Undifferentiated/anaplastic				
T cell				
B cell				
Null cell				
Not stated				
Primary:				
Site				
Laterality:				
Left				
Right				
Bilateral				
Not applicable				
Unknown				
Distant metastases (y/n)				
Location of secondary				
		T	N	M
Clinical				
Pathological				
Direct extension (y/n)				
Nodes sampled (y/n)				
If yes:				
How many				
If positive:				
How many				
Tumour size (mm)				
Stage/grade				
Other malignancy (y/n):				
If yes:				
Site				
Year				

Treatment details			
Surgery (y/n)			
If yes:			
Date			
Hospital			
Consultant			
Specialty			
Operation			
Treatment type:	*Date*	*Hospital*	*Consultant*
Radiotherapy			
Chemotherapy			
Hormone			
Notes			
All hospitals visited:			
Date			
Hospital			
Case note number			
Refer for:			
Date of birth			
Pathology report			
Address			
Grade/staging			
Treatment			
Side			
Full registration			

[a] Italics indicate items collected as part of the Cancer Minimum Dataset.

Trent Cancer Registry

Description

The Trent Cancer Registry was established in 1961 and was computerised in 1966.

Population covered

The Registry covers the whole of the Trent Region, excluding South Humber. The Registry covers a total population of around 4.8 million and currently hold records for over 650,000 patients with 750,000 tumours. There are over 25,000 new tumour registrations annually (Trent Cancer Registry, 1998).

Process of collection

Information is not collected from every Trust because non-acute and mental health trusts are not usually included. Only a small amount of information is received from private hospitals and GPs. If the Registry receives a death notification for which it has no registration, it tries to track diagnosis via the GPs who often refer it to the hospitals.

Information is provided to the Registry through clerks who carry out clinical coding for contracts. There is a PAS within the Trent Region that requires the coding clerk to make a notification to the Registry. Demographic data are used, along with specific additional data fields that are completed by the coding clerks. Information is downloaded every month and is sent to the Registry for processing.

Once data have been received at the Registry, they are loaded into the main database with automatic matching of registrations. There are small amounts of paper notifications, usually received from the smaller hospitals or hospices, which are entered manually at the Registry. Extra regional notifications and exchanges from other cancer registries are also received.

Information is received weekly for death notifications, monthly for PAS and on an *ad hoc* basis for data exchanges.

Summary of data items collected

- hospital details
- personal details, including name, address, patient ID and NHS number
- occupation details
- tumour details
- treatment indicators
- diagnostic details
- death details.

A more detailed list of data items collected is given on p. 287.

Continuity

There have been no significant discontinuities in the processing or collection of data.

Completeness

See Review of cancer registrations in England.[1]

Accuracy

See Review of cancer registration in England.[1]

Internal validation

Miscoding is known to apply to translating textual data, such as morphology, occupation, industry data, site and morphology combination. Thorough scrutinisation is carried out at the Registry for these items, to try to minimise these problems during the year.

External validation

The Registry uses ONS to compare data, along with other datasets (registries such as the NRCT) during the year.

Future plans

See NCR (p. 243).

Contact details

Trent Cancer Registry
Weston Park Hospital
Whitham Road
Sheffield
S10 2SJ
Tel.: 0114 226 5351
Fax: 0114 226 5501
E-mail: director@trentcancer.prestel.co.uk

Publications and other sources of information

Website: http://www.trentcancer.nhs.uk

Reference

1. Gillis CR. Review of cancer registration in England. London: Department of Health; 2000.

Trent Cancer Registry Data items[a]

Hospital details			
District Health Authority			
Hospital			
Consultant			
Patient unit number			
Radiotherapy treatment number			
Personal details			
NHS number			
Forenames			
Surname			
Name at birth (previous surname)			
Address at time of diagnosis			
Postcode			
Sex			
Marital status			
Ethnic origin			
Date of birth			
Country of birth			
Status (alive/dead)			
Registration at screening			
Occupation details	*Occupation*	*Employment status*	*Industry*
Patient			
Head of household[b]			
Diagnostic details			
Site of primary neoplasm[c]			
Morphology			
Laterality			
Stage of disease			
Grade of tumour			
Basis of diagnosis:			
Histology			
Cytology			
Haematology			
Clinical opinion			
Other tests			
Date of diagnosis			
Treatment indicators:			
Surgery			
Radiotherapy			
Chemotherapy			
Hormone therapy			
Other			
Death details			
Date of death			
Cause and place of death (from 1996)			
Post-mortem			

[a] Italics indicate items collected as part of the Cancer Minimum Dataset.
[b] Completed for females and children under 16.
[c] Or main presenting secondary if primary is not known.

West Midlands Cancer Intelligence Unit (WMCIU)

Description
The WMCIU has been population based since 1957.

Population covered
It registers just over 30,000 new cases of cancer per year, covering the resident population of the West Midlands health region, a population of about 5.3 million people.

Process of data collection
The Regional Cancer Registries report gives a generalised overview of the process throughout the registries. WMCIU is currently a paper-based registry and relies on Trusts and other data providers sending data to it. Most of the Trusts have specific contractual agreements with the regional purchasing authorities. However, the WMCIU does not receive any specific forms and has to rely on what information is sent to it.

Summary of data items collected
A list was not available.

Coding schemes
As Regional Cancer Registries.

Continuity
Unknown.

Completeness
See Review of cancer registration in England.[1]

Accuracy
See Review of cancer registration in England.[1]

Internal validation
Each year the WMCIU shares with the Trusts the information that they have sent, compared with the performance of other Trusts in the region. The Trusts are then asked to identify and complete any missing fields. The WMCIU database has many internal cross-checks embedded in it to ensure that data are correctly entered. Many of these reflect the ONS data validation checks.

External validation
Audit studies with local clinicians are undertaken each year. These compare the data held on the WMCIU database with external clinical systems.

Future developments
See NCR (p. 243).

Access
Data sheets are circulated annually to both Trusts and Health Authorities. The WMCIU is also compiling a web page.

Contact details
West Midlands Cancer Intelligence Unit
Public Health Building
The University of Birmingham
Birmingham
B15 2TT
Tel.: 0121 414 7711
Fax: 0121 414 7712

Publications and further information sources
No information available.

Reference

1. Gillis CR. Review of cancer registration in England. London: Department of Health; 2000.

Leukemia registers

We were able to obtain a description of one register (Oxford Region Leukaemia Register) and details of the contents of two others (Mersey Register and Clwyd District Leukaemia Register and West Midlands Leukaemia Register). Since these registers were, in 2002, in the process of being reorganised with their close relations, the cancer registers, we considered these descriptions sufficient to provide an indication of the main features of the Leukaemia Registers. Any more detailed account will, at a time of rapid change, be quickly out of date.

Mersey Region and Clwyd District Leukaemia Register[a]

Administrative details

Forename
Surname
Date of birth
Sex
Presentation date
Patient no.
Hospital
Consultant
Current address
Postcode
Length of residence
Previous address
Previous address postcode
Length of residence (previous address)
GP:
- Reference no.
- Name
- Address
- Postcode

Study no.

Diagnosis details

Acute lymphoblastic leukaemia (ALL)

- L (unknown)
- L1
- L2
- L3

Description	Morphology	ICD-9
Unknown	M9821/3	204
B Mature	M9821/3	204
Common	M9821/3	204
Common/Pre-b (Cyu not done)	M9821/3	204
Immunophenotype not done	M9821/3	204
Mixed phenotype	M9821/3	204
Null	M9821/3	204
Pre-B	M9821/3	204
T	M9821/3	204
Unusual/unclassified	M9821/3	204

Acute myeloid leukaemia (AML)

FAB	Description	Morphology	ICD-9
Unknown		M9861/3	205.0
M0	Minimal evidence myeloid differentiation	M9801/3	205.0
M1	Myeloblastic without maturation	M9861/3	205.0
M2	Myeloblastic with maturation	M9861/3	205.0
M3	Promyelocytic	M9866/3	205.0
M3v	Promyelocytic (variant)	M9866/3	205.0
M4	Mylomonocytic	M9861/3	205.0
M4Eo	Mylomonocytic eosinophilia	M9861/3	205.0
M5	Monocytic	M9891/3	206.0
M5a	Monoblastic without maturation	M9891/3	206.0
M5b	Monoblastic with maturation	M9891/3	206.0
M6	Erythroleukaemia	M9840/3	207.0
M7	Megakaryoblastic	M9910/3	207.2

Chronic myeloid leukaemia (CGL)

Description	Morphology	ICD-9
Ph+	M9863/3	205.1
Ph-	M9863/3	205.1
Karyotype unknown	M9863/3	205.1
Juvenile	M9863/3	205.1

continued

Karnofsky performance scale (status)
Status (at diagnosis):
- *Unable to care for self, requires equivalent of institutional/hospital care, disease may be progressing rapidly:*
  - Moribund, fatal process progressing rapidly
  - Very sick, hospitalisation is indicated although death is not imminent
  - Severely disabled, hospitalisation is indicated although death is not imminent
  - Disabled, requires special care and assistance
- *Unable to work, able to live at home, cares for most personal needs, varying amount of assistance needed*
  - Requires considerable assistance and frequent medical care
  - Requires occasional assistance and frequent medical care
  - Cares for self, unable to carry on normal activity or do active work
- *Able to carry on normal activity, no special care is needed*
  - Normal activity with effort, some signs or symptoms of disease
  - Able to carry on normal activity, minor signs or symptoms of disease
  - Normal, no complaints, no evidence of disease

Not known

Biochemical details
Presenting blood counts:
- Hb (pre-transfusion)
- WBC
- Plat
- Neur
- Lymp
- Mono
- Eos
- Baso
- Blas
- UNC

Karyotyping:
- Being done (y/n)
- Where being done
- Results if available

Treatment details
Treatment:
- Details
- Start date
- End date
- Included in MRC trial (y/n)
- Name of trial

Bone marrow transplant details
Date
Type:
- None
- Alogeneic
  - Sibling
  - Twin
  - MUD
  - Other
  - Unknown
- Autologous
  - BMT
  - LTBMC
  - PBSCT
  - Other
  - Unknown
- Other
- Type unknown

Other relevant details

continued

Previous malignancy history/family history		
Previous details		
Site of primary		
Year of diagnosis		
Previous:		
Chemotherapy		
Radiotherapy		
Blood disorder		
Family member with blood disorder/malignancy (details)		
Occupation details		
	Current	Previous
Occupation:		
Length of time		
Duties		
Exposure to radiation/chemicals in occupation		
Occupation of:		
Spouse:		
Parent		
Smoker:		
Unknown		
Never smoked		
	Current	Stopped
Cigarettes		
Light		
Trivial		
Moderate		
Heavy		
Very heavy		
Cigar		
Pipe		
Death details		
Date of death		
Cause of death		
Post-mortem details		

[a] Three different data forms are used for the three diagnoses: ALL, AML and CGL. The forms are identical except for the diagnosis details items which are collated here.

West Midlands Leukaemia Registry[a]

Administrative details
Forename
Surname
Date of birth
Sex
Presentation date
Patient no.
Hospital
Consultant
Current address
Postcode
Length of residence
Previous address
Previous address postcode
Length of residence (previous address)
GP:
Reference no.
Name
Address
Postcode
Study no.

continued

Diagnosis details

Acute lymphoblastic leukaemia (ALL)

L (unknown)
L1
L2
L3

Description	Morphology	ICD-9
Unknown	M9821/3	204
B Mature	M9821/3	204
Common	M9821/3	204
Common/Pre-b (Cyu not done)	M9821/3	204
Immunophenotype not done	M9821/3	204
Mixed phenotype	M9821/3	204
Null	M9821/3	204
Pre-B	M9821/3	204
T	M9821/3	204
Unusual/unclassified	M9821/3	204

Acute myeloid leukaemia (AML)

FAB	Description	Morphology	ICD-9
Unknown		M9861/3	205.0
M0	Minimal evidence myeloid differentiation	M9801/3	205.0
M1	Myeloblastic without maturation	M9861/3	205.0
M2	Myeloblastic with maturation	M9861/3	205.0
M3	Promyelocytic	M9866/3	205.0
M3v	Promyelocytic (variant)	M9866/3	205.0
M4	Mylomonocytic	M9861/3	205.0
M4Eo	Mylomonocytic eosinophilia	M9861/3	205.0
M5	Monocytic	M9891/3	206.0
M5a	Monoblastic without maturation	M9891/3	206.0
M5b	Monoblastic with maturation	M9891/3	206.0
M6	Erythroleukaemia	M9840/3	207.0
M7	Megakaryoblastic	M9910/3	207.2

Chronic myeloid leukaemia (CGL)

Description	Morphology	ICD-9
Ph+	M9863/3	205.1
Ph–	M9863/3	205.1
Karyotype unknown	M9863/3	205.1
Juvenile	M9863/3	205.1

Karnofsky performance scale (status)

Status (at diagnosis):

Unable to care for self, requires equivalent of institutional/hospital care, disease may be progressing rapidly
- Moribund, fatal process progressing rapidly
- Very sick, hospitalisation is indicated although death is not imminent
- Severely disabled, hospitalisation is indicated although death is not imminent
- Disabled, requires special care and assistance

Unable to work, able to live at home, cares for most personal needs, varying amount of assistance needed
- Requires considerable assistance and frequent medical care
- Requires occasional assistance and frequent medical care
- Cares for self, unable to carry on normal activity or do active work

Able to carry on normal activity, no special care is needed
- Normal activity with effort, some signs or symptoms of disease
- Able to carry on normal activity, minor signs or symptoms of disease
- Normal, no complaints, no evidence of disease
- Not known

continued

Biochemical details
Presenting blood counts:
- Hb (pre-transfusion)
- WBC
- Plat
- Neur
- Lymp
- Mono
- Eos
- Baso
- Blas
- UNC

Karyotyping:
- Being done (y/n)
- Where being done
- Results if available

Treatment details
Treatment:
- Details
- Start date
- End date
- Included in MRC trial (y/n)
- Name of trial

Bone marrow transplant details
Date
Type:
- None
- Alogeneic
  - Sibling
  - Twin
  - MUD
  - Other
  - Unknown
- Autologous
  - BMT
  - LTBMC
  - PBSCT
  - Other
  - Unknown
- Other
- Type unknown

Other relevant details

Previous malignancy history/family history
Previous details
Site of primary
Year of diagnosis
Previous:
- Chemotherapy
- Radiotherapy
- Blood disorder

Family member with blood disorder/malignancy (details)

Occupation details

	Current	Previous
Occupation:		
Length of time		
Duties		
Exposure to radiation/chemicals in occupation		

continued

Occupation of:		
Spouse:		
Parent		
Smoker:		
Unknown		
Never smoked		
	Current	Stopped
Cigarettes		
Light		
Trivial		
Moderate		
Heavy		
Very Heavy		
Cigar		
Pipe		
Death details		
Date of death		
Cause of death		
Post-mortem details		

[a] Three different data forms are used for the three diagnoses: ALL, AML and CGL. The forms are identical except for the diagnosis details items which are collated here.

Oxford Region Leukaemia Register

Description

The Registry was established in 1988, to examine the outcomes of patients with leukaemia owing to the Cancer Registry data being inaccurate and out of date.

Regarded as part registry and part clinical database, it can identify cohorts and request clinical notes. It has been used for the studies of patients who died early in the records, 1988–90 and 1988–93.

The Register produces survival data for patients with different kinds of leukaemia. Efficacy of treatment is also identified. There are no cost type data on the Register. The Register has not been used to assess the equity of a treatment, but can identify, for instance, that patients in a certain area have been referred to larger hospitals.

Process of data collection

Data are collected from all nine hospitals within the old Oxford Health Authority Region that treat leukaemia, covering Northamptonshire, Oxfordshire, Berkshire and Buckinghamshire. Each of the nine hospitals has a haematologist blood specialist who diagnoses and completes all forms for leukaemia.

Once a patient has been diagnosed as having leukaemia, a form is completed and sent to the Register. These forms are held at the Register until there is a large enough batch to enter the information into the computer. Data are received continuously, but this very variable.

The entering of information on to the computer takes around 5 minutes, but the information could be waiting for entry for up to 9 months, owing to the batching system. Validation is variable – some data can be validated as they are entered, as the computer holds a checking system – if all information is present this will be accepted. As information is entered by a haematologist, this is a double validation check in itself.

Completeness

The completeness of notification is reported to be around 30% at present, and has previously been 80–90%. Comparisons with other leukaemia registers have been made during the Register's peak period, and it was found to be as complete as the other registers. The completeness of data items is reported very high. The number of data items on each form has decreased over the years, and this has made it easier for haematologists to complete the forms. There have also been a number of changes to the forms to make them easier to complete. These have been made over the years, owing to forms being analysed and identifying that a section of the form was poorly completed.

Treatment data are no longer collected, as the answer to the best possible treatment for leukaemia comes from clinical trials rather than collecting data. Data on treatment, if needed, can

be produced by the Register with the help of the MRC to identify how many patients are in a medical trial. This has been carried out in the past in a study funded by the Leukaemia Research Fund, which took data from Oxford, Northern, North Western, Mersey and some other Registers' data, which were tied with MRC data to look at what proportion of patients were in a trial of leukaemia treatment. This was produced as a scientific paper and sent to *BMJ*, which turned it down. It was then rewritten for another journal.

Accuracy

The accuracy of information entered into the computer is reported to be very high, as this is carried out by only one person. There was previously a clerical person who carried out the data entry, and the accuracy at that time was not very good. This has since improved, owing to a new computer system and a different way of collecting and inputting the information.

The accuracy of information received is very high, as all data are put on to forms by consultants. Cross-checking is carried out with MRC clinical trial data (this may identify diagnosis changes).

External validation

Comparison with:

- Northern
- Northern Regional Leukaemia Register
- Mersey Regional Leukaemia Register.

This was a study funded by Leukaemia Research Fund which looked at survival for the different leukaemias in the different regions.

Some information from the Register is sent to the Regional Cancer Registry via disk. Specific haematologist information is not sent, as it is not of interest to the Cancer Registry. The Cancer Registry is used to a certain extent for comparison, but it is likely that the Leukaemia Register will always have better information: the Cancer Registry may be informed of a leukaemia at a later date, when the diagnosis has changed, so the Leukaemia Registry will have a different diagnosis. Information will sometimes differ as the Leukaemia Register does not collect from the new Regional Health Authority like the Cancer Registry, so its patient numbers are different.

Internal validation

The Register has a database program which has built-in checks for plausibility and illogicalities such as date of birth and date of death. There are some mandatory fields and some are optional (hospital, address, etc.). There is also a checking system which can identify any postcodes which do not exist. There is a program called Paradox for Windows, which can be used to find specific information, such as how many patients have a certain leukaemia.

A follow-up form is sent to the haematologists for clarification and validation. As haematologists are the only consultants dealing with the patient (i.e. diagnosis, treatment and follow-up), their information is very good.

The Director also carries out a yearly comparison, and then double checks with other haematologists within the hospitals.

No specific areas of weakness have been identified, other than some haematologists being more consistent than others in sending forms to the Register.

Coding schemes

The data form consists of tick boxes, haematologist's classification [French, American, British (FAB)] and description. No coding scheme is used, but it does state the equivalent ICD-10 code on the form. All information on the Register's database is in ICD-10, and was previously in ICD-9.

Continuity

Over the last 2 years, the number of forms received has dropped. Usually the Register would receive over 100 forms per year, but this has fallen to around 40. This is due to the holder of the Registry being busy with other duties, and not having time to chase consultants for forms. There have been no significant discontinuities in the processing of data.

Future plans

The Cancer Registry does not supply the Register with information. There are discussions currently under way with the Cancer Registry for it to send anonymised data to the Leukaemia Register.

The Register will also need to make a decision on whether to continue collecting information, or whether the Cancer Registry could provide it with sufficient information regarding leukaemia. As the Cancer Registry does not currently collect performance data (how fit the patient is at present), and the classification for leukaemia is not as refined as the Leukaemia Register, these areas

would need to be improved. The Cancer Registry is also some way behind in the collection of data compared with the Leukaemia Register, but is catching up.

An ideal solution would be for the Cancer Registry to collect the data and then send them back to the local haematologist for validation.

Access

An outside researcher would need to contact the Registry for any information. Aggregated data are available in the Annual Reports, which include information such as the number of patients reported by each hospital and each county and audit of early deaths in treatment at individual patient level. A study has been carried out for the Leukaemia Research Study, and there was also a comparison of four Leukaemia Registries. The Audit of Early Deaths is detailed in the 1995 Annual Report. There have also been presentations of posters at scientific meetings such as those of the British Society of Haematology, and these have been published in abstract form in scientific journals.

The Oxford Region Bone Marrow Transplant Registry is another dataset run by the Register, and was set up later using the same catchment area and collecting in the same way as the Leukaemia Registry. The Bone Marrow Transplant Registry collects data on bone marrow transplants – which has proved useful for the diffusion of treatments – monitoring how many are carried out, why they are done and for what conditions, and shows trends in an increase of a particular kind of procedure. This also contains cost information.

Appendix 3

Population-based single health technology databases

Contents

All the databases presented are Central Returns, with minimal variations by UK country.

The combining of the two cancer screening programmes and the various immunisation and vaccination programmes has been done by the authors to reduce the number of accounts. This was justified on the basis that each of these programmes has similar sets of returns.

Immunisation, vaccination and cancer screening returns

England: screening and immunisation programmes: KC50, KC51, KC53, KC61, KC62 and KC63

Description

The Department of Health immunisation and screening returns were established to monitor the effectiveness of programmes, ensure targets were being achieved and assess equity of access. The information is used to monitor progress towards the relevant targets. Aggregate data are collected under the following returns.

Childhood immunisation programme: KC50 and KC51

Childhood immunisation has traditionally been monitored by two returns, KC50 and KC51, both of which feed into an annual report, Immunisation Statistics. KC50 monitors immunisation programme activity. Data are mainly derived from child health registers held by the Trusts and GPs. Collection of data was established in 1988. Targets for immunisation in 1999 were 95% of children aged 2 years* to be immunised against diphtheria, tetanus, polio, pertussis, *Haemophilus influenzae* B (HIB), measles mumps and rubella (MMR). Stratified target payments are offered to immunisation providers to boost levels of pre-school childhood immunisation.

KC50 was merged in 1999 with COVER, run by the Public Health Laboratory Service, Communicable Disease Surveillance Centre (CDSC). COVER incorporates Return KC51 (Immunisation Status of District Residents) and provides more information than the KC50 system. COVER returns are carried out quarterly. Return KC50 was due to be merged with COVER by 2001, although the Department of Health will still carry out their returns on an annual basis (see the CDSC website listed in Contact details on p. 300).

Cervical screening programme: KC53 and KC61

All women between the ages of 20 and 64 years are eligible for a free cervical smear test every 3–5 years. Around 60% of Health Authorities invite women every 3 years and 15% have a mixed policy, inviting women every 3 or 5 years, depending on their age.

Health Authorities invite women who are registered with a GP, using a computerised call–recall system. This also keeps track of any follow-up investigation and, if all is well, recalls the woman for screening in 3 or 5 years' time. It is therefore important that all women ensure that their GP has their correct name and address details and inform them if these change.

Women who have not had a recent smear test may be offered one when they attend their GP or family planning clinic on another matter. Women should receive their first invitation for routine screening before their 25th birthday.

Cervical screening began in Britain in the mid-1960s. By the mid-1980s, although many women were having regular smear tests, there was concern that those at greatest risk were not being tested, and that those who had positive results were not being followed up and treated effectively. The NHS Cervical Screening Programme was set up in 1988 when the Department of Health instructed all health authorities to introduce computerised call–recall systems and to meet certain quality standards.

The Cervical Screening Service has been monitored by two returns, KC53 and KC61, with overall results reported in an annual report Cervical Screening Programme. Return KC53 collects data on the cervical call–recall system, monitoring progress in achieving the Government's target to reduce the incidence of invasive (most severe/abnormal) cervical cancer and ensuring that the screening programme is managed effectively. Information concerning cervical smears and biopsies examined by pathology laboratories is collected on return KC61 (which includes some information about both symptomatic and screening programme smears). KC61 monitors the standards of laboratories in examining smears in line with guidance provided by NHS Cervical Screening Programme. Both returns were revised for use in 1997–98. National policy recommends screening every 3–5 years for

* England currently has no formal targets for pre-school booster doses, unlike Scotland.

eligible women, with a target age group for invitation of 20–64 years. Stratified target payments (values) are offered to providers to boost levels of cervical screening. For more detailed information, see Department of Health Statistical Bulletin, Cervical Screening Programme, 2000.

Breast screening programme: KC62 and KC63
The NHS Breast Screening Programme provides free breast screening every 3 years for all women in the UK aged 50 years and over. Around 1.5 million women are screened in the UK each year. Women aged between 50 and 64 years are currently routinely invited for breast screening every 3 years, and work is being carried out to extend the programme to women up to and including the age of 70 years by 2004. Once women reach the upper age limit for routine invitations for breast screening, they are encouraged to make their own appointment.

The programme was set up by the Department of Health in 1988 in response to the recommendations of a working group, chaired by Professor Sir Patrick Forrest, which had been set up to consider whether or not to implement a population screening programme in the UK. The report Breast Cancer Screening was published in 1986, and became known as The Forrest Report. The NHS Breast Screening Programme was the first of its kind in the world. It began inviting women for screening in 1990, and national coverage was achieved by 1993.

There are over 90 breast screening units across the UK, each inviting an average population of around 45,000 women. Women are invited to a specialised screening unit, which can be mobile, hospital-based or permanently based in another convenient location such as a shopping centre.

The NHS Breast Screening Programme is nationally coordinated. It sets national standards for the quality of the programme which are monitored through a quality assurance network that covers each region in the NHS. For England, there is a national coordination office, based in Sheffield, and an advisory committee which oversees the programme and reports to government ministers.

The Breast Screening Programme is monitored by two central returns, KC62 and KC63, which provide data for an annual report, Breast Screening. KC62 collects data on the call–recall systems of breast screening centres, assessing performance and monitoring quality targets. Information about the programme population coverage is collected on return KC63. Data collection was established in 1994–95; information was collected prior to this but was considered of poor quality. The screening programme is open to eligible women aged 50–64 years routinely and those 65 years old and over on request.

In addition to the original objectives, the returns are used in conjunction with the public expenditure survey and NHS resource allocation. The Department of Health has also used the datasets to assess the equity of access.

Plans exist to change the process of collection to electronic data interchange (EDI). This would be carried out in sections starting with the largest, KC62, followed by KC53 and KC63.

Screening information is collected from the whole of England. There are no statistics available to assess the current completeness for notifications. Centres or Trusts failing to complete returns are followed up.

Data
Information is collected annually. Return KC50 is completed at the level of provider, mainly extracted from child health registers held by the Trusts and GPs. KC53 and 63 are returned at a Health Authority level extracted from the FHSA computerised systems. The cytopathology laboratories extract and complete return KC61. The breast screening service extracts information for return KC62. Quality assurance coordinators exist in each region who collate all the returns and validate them for their area before forwarding them to the Department of Health.

All information is either in paper form or printed on to paper when received at the Department of Health. Units are usually given 2 months in which to complete all information. Publications are usually completed within 6–9 months from the end of the year. Data items used by the immunisation programmes (KC50 and KC51), adult screening (KC53 and KC62) and pathology laboratories (KC61) are listed on pp. 301–6.

Coding systems
No information has been located on the coding schemes used in these databases.

Completeness and accuracy
Immunisation and screening information is collected from the whole of England. Coverage of target populations is reported. The level of

completeness for data items is estimated at 99%, as most returns are completed in full, particularly by those laboratories with computer systems. Out of the 180 laboratories, only 5–6 records are omitted each year.

The information entered into the dataset is thought to be accurate. Accuracy is assessed when the final tables are compared with previous years and input errors are found to be very rare. The level of accuracy for information received is thought to be consistent owing to various plausibility checks. Validity checking is built into the software that searches for internal inconsistencies.

Some incorrect information is inevitable, such as in cases where a woman has been recalled because she is between 60 and 64 years, but records show she was recalled for medical reasons. Plans to improve the validity of data include:

- the appointment of quality control coordinators
- increased use of computer systems
- systems updated and upgraded constantly
- increased awareness from Health Authorities and Centres.

Validation of information has been by external audits, which sometimes have revealed major problems in relation to the screening programmes.

Uses
The various returns are used to monitor the effectiveness of the systems.

Funding
Funding is by the NHS via the Health Authorities.

Access
There are no access restrictions on these data apart from the KC61 information. This is sensitive information concerning smear tests and will only be provided to certain bodies. All other information can be requested directly from the Department of Health. No charges are made unless considerable time is spent in preparation. Researchers should contact the Department of Health.

COVER/Korner statistics on immunisation coverage rates in the whole of the UK are published quarterly by the CDSC in the CDR Weekly (see the CDSC website listed below).

Contact details
Mr L Lancucki
Department of Health
Statistics Division 2B
Skipton House
80 London Road
London
SE1 6LH
Tel.: 020 7972 5533
E-mail: lesz.lancucki@doh.gsi.gov.uk

Department of Health immunisation programmes website: http://www.doh.gov.uk/public/imunstat.htm
CDSC Public Health Laboratory Service immunisation coverage website: http://www.phls.co.uk/facts/Vaccination/cover.htm

Cancer Screening Evaluation Unit
The Institute of Cancer Research
123 Old Brompton Road
London
SW7 3RP
Tel.: 020 7352 8133
Fax: 020 7370 5261
Website: http://www.icr.ac.uk/cseu/

Publications
Annual statistical bulletins focusing on each of the programmes are available from the Department of Health
P.O. Box 410,
Wetherby
LS23 7LN
Tel.: 0541 555455; Fax: 0990 210266 and the Department of Health website: http://www.doh.gov.uk/HPSSS/INDEX.HTM#sectiona

For immunisation programmes only, see:
NHS Immunisation Statistics, England: 1997–98. Bulletin. London: Department of Health; 1998.
See also the Department of Health website, http://www.doh.gov.uk/public/imunstat.htm and CDSC (Public Health Laboratory Service) immunisation coverage website: http://www.phls.co.uk/facts/Vaccination/cover.htm

For cancer screening programmes, see:
NHS website: http://www.cancerscreening.nhs.uk/
Cancer Screening Evaluation Unit publications: http://www.icr.ac.uk/cseu/

For cervical cancer screening, see:
NHS website: http://www.cancerscreening.nhs.uk/cervical/index.html
Department of Health Statistical Bulletin, Cervical Screening Programme, England 1999–2000, London: Department of Health; 2000
Department of Health statistical bulletin website: http://www.doh.gov.uk/pub/docs/doh/sb9932.pdf

For breast cancer screening, see:
NHS website: http://www.cancerscreening.nhs.uk/breastscreen/index.html
Department of Health Statistical Bulletin, Breast Screening Programme, England 1999–2000. London: Department of Health; 2001.

Department of Health Statistical Bulletin: http://www.doh.gov.uk/public/sb0110.htm
Department of Health website: http://www.cancerscreening.nhs.uk/breastscreen/statistics.html

Immunisation programmes: district activity: KC50 data items

District/NHST/SHA code and name

Primary courses completed in the year

Age (years):	Diphtheria	Tetanus	Pertussis	Polio	MMR
Under 1					
1					
2					
3					
4					
5					
6–7					
8–15					
16–19					
20 or over					
Total					

Booster/reinforcing doses given in the year

Age (years):	Diphtheria	Tetanus	Polio
Under 4			
4			
5			
6–7			
8–15			
16–19			
20 or over			
Total			

BCG tests/vaccinations in the year

Age (years):	Number of skin tests		Number of vaccinations
	Found positive	Found negative	
Under 1			
1–9			
10–13			
14–15			
16 or over			
Total			

Females vaccinated in the year with single antigen rubella (excluding that given by MMR)

Age (years):	
Under 10	
11	
12	
13	
14	
15	
16–19	
20 or over	
Total	

continued

***Haemophilus influenzae* B (HIB)**

	Primary (3-dose) courses completed	Single-dose courses
Age (years):		
Under 1		
1		
2		
3		
4		
5 or over		
Total		

Adult screening programmes: cervical cytology: KC53 data items

DHA code

Routine recall interval

Routine recall interval in use (years):
- 5
- 4
- 3
- 3 and 5 mixed
- Other (specify)

Status of district residents

	Residents	Recall ceased			No cytology record	Tested in last	
		Clinical	Age	Other reason		5 years	3 years
Age (years):							
Under 20							
20–24							
25–29							
to:							
65–69							
70–74							
75 and over							
Target age group (25–64)							
Total all ages							

Number of women invited

Reason:	Call	Routine recall	Repeat <3 years for reasons of:		
			Surveillance	Abnormality	Inadequate smear
Age groups:					
As above					

Number of women tested

Reason:	Call	Routine recall	Repeat advised	Repeat <3 years for reasons of:			While recall suspended	Opportunistic screen
				Surveillance	Abnormality	Inadequate smear		
Age groups								
As above								

Results of woman's most severe test in the year

	Negative	Borderline/Mild dyskaryosis	Moderate dyskaryosis	Severe dyskaryosis
Age groups:				
As above				

Pathology laboratories: cervical cytology and biopsies: KC61 data items

NHS Trust name
NHS Trust code
Pathology laboratory name
Pathological laboratory code

Number of smears examined by source of smear

Source of smear:	Results of test[a]	Total number examined
GP		
NHS Community Clinic		
GUM clinic		
NHS hospital		
Private		
Other		
Total GP and NHS Community Clinics		
Grand total		

Results of smears from GP and NHS Community Clinics only, by age group

Age group (years):	Results of test	Total number examined
<20		
20–24		
25–29		
30–34		
35–44		
45–54		
55–64		
65+		
Total 20–64		
Total		

Outcome by 31 March for women recommended for gynaecological referral during April–June

Outcome of referral:	Inadequate	Borderline changes	Mild dyskaryosis	Moderate dyskaryosis	Severe dyskaryosis
Cancer (including microinvasive)					
Adenocarcinoma *in situ*					
CIN3					
CIN2					
CIN1					
HPV only					
No CIN/no HPV					
Inadequate biopsy					
Colposcopy NAD, no biopsy taken					
Result not known					

Results of cervical biopsies (including hysterectomy specimens)

Age group:	<20	20–24	25–29	30–34	35–44	45–54	55–64	65+
Result:								
Negative								
CIN I								
CIN II								
CIN III								
Microinvasive squamous carcinoma								
Invasive squamous carcinoma								
Adencarcinoma								
Endometrial carcinoma								
Other malignant disease								
Total								

[a] Results of test: inadequate; negative; borderline changes; mild dyskaryosis; moderate dyskaryosis; severe dyskaryosis; severe dyskaryosis/?invasive carcinoma; ?glandular neoplasia.

Adult screening programmes: breast screening: KC62 data items

Breast screening unit code
Breast screening unit name

A1: invitations and outcomes

Age at first appointment:	<44	45–49	50–54	55–59	60–64	65+	Target group[a]	All ages
No. invited								
Lost to follow-up after technically inadequate screen								
No. screened (technically adequate)								
Outcome of initial screen:								
Not known								
Routine recall								
Early recall								
Referred for assessment or direct to histology								
Final outcome of assessment:								
DNA assessment or histology								
Outcome of assessment not known								
Routine recall								
Early recall								
Cancer								

A2: assessment

Age at first appointment:	<44	45–49	50–54	55–59	60–64	65+	Target group[a]	All ages
Cancer identified without cytology/biopsy								
Up to and including cytology and/or core biopsy:								
Total referred for cytology and/or core biopsy								
Not referred for open biopsy:								
No result recorded/inadequate result								
Routine recall								
Early recall								
Cancer								
Referred for open biopsy								
Up to and including open biopsy:								
Total referred for open biopsy								
No results/inadequate result								
Result benign/normal:								
Routine recall								
Early recall								

Cancers diagnosed by cytology and/or histology

Age at first appointment:	<44	45–49	50–54	55–59	60–64	65+	Target group[a]	All ages
Total number women with cancer								
Invasive status not known								
Non-invasive or possibly micro-invasive								
Definitely micro-invasive								
Invasive size:								
<10 mm								
≥ 10 mm & <15 mm								
≥ 15 mm & <20 mm								
≥ 20 & <50 mm								
≥ 50 mm								
Size not known								
Total invasive								

Outcome measures

	Target group	Total all ages
Uptake rate (% invited)		
Referral rate (% of screened)		
Non-invasive or microinvasive cancers (% of all cancers diagnosed)		
Benign biopsy rate (% of screened)		
Invasive cancer detection rate (per 1000 screened)		

continued

	Target group	Total all ages
Detection rate of invasive cancers <10 mm (per 1000 screened)		
Detection rate of invasive cancers <15 mm (per 1000 screened)		
Referral rate for cytology and/or core biopsy (% of screened)		
Referral rate for open biopsy (% of screened)		
Preoperative diagnosis rate (% of all cancers diagnosed)		
Malignant:benign ratio of all surgery		
Early recall rate following initial screen (% of screened)		
Early recall rate following assessment (% of screened)		

Data completeness indicators

	Target group	Total all ages
Assessment result not known (% of referred)		
Cytology and/or core biopsy result not known (% of referred)		
Open biopsy result not known (% of referred)		
Invasive status of cancer and/or size not known (% of all cancers diagnosed)		
Invasive status of cancer not known (% of all cancers diagnosed)		
Size not known (% of all invasive cancers)		

B: routine invitation to previous non-responders: 1 April–30 March
As above

C1: routine invitation to previous responders: last screen within 5 years: 1 April–30 March
As above

C2: routine invitation to previous responders: last screen >5 years: 1 April–30 March
As above

D: early recalls: women screened 1 April–30 March
As above

E: self- or GP referrals of women not previously screened: 1 April–30 March
As above

F1: self- or GP referrals of women previously screened: last screen <5 years: 1 April–30 March
As above

F2: self- or GP referrals of women previously screened: last screen >5 years: 1 April–30 March
As above

Cancers diagnosed at above screens

Age at first appointment:	<44	45–49	50–54	55–59	60–64	65+	All ages
Total no. of cancers							
Invasive status not known							
Non-invasive							
Microinvasive							
1–9 mm							
10–14 mm							
15–19 mm							
20–49 mm							
50 mm+							
Not known							
Total invasive							

Screening category[b]:	A	B	C1	C2	D	E	F1	F2
Total no. of cancers								
Invasive status not known								
Non-invasive								
Microinvasive								
1–9 mm								
10–14 mm								
15–19 mm								
20–49 mm								
50 mm+								
Not known								
Total invasive								

[a] Target group 50–64 years.
[b] Categories as above.

Adult screening programmes: breast screening: KC63 data items

Health Authority code								
Health Authority name								
Cross-section analysis of population coverage within period								
Age:	<45	45–49	50–54	55–59	60–64	65+	Target group (50–64)	Total
No. women resident at 31 March								
No. ineligible women								
Call/recall episodes:								
No. invited in period								
No. screened in period								
No. invited in last 3 years								
No. screened in last 3 years								
Early recall episodes:								
As above								
Self/GP referral episodes								
No. screened in period								
No. screened in last 3 years								
Women screened:								
No. screened in period								
No. screened in last 3 years								
Women with open episodes								
Number with open episodes:								
No invite								
Invited								
Time since most recent screen								
Age:	<45	45–49	50–54	55–59	60–64	65+	Target group (50–64)	Total
No. women resident at 31 March								
Never screened:								
No. women selected								
No. women never selected								
Time since last screen (from any source):								
≤ 12 months								
>12 – 24 months								
>24–36 months								
>36–39 months								
>39–48 months								
>48–60 months								
Over 60 months								
Total screened								

Scotland: screening and immunisation programmes: ISD(S) 13/1, 13/2, 13/3, 12/2 and ISD(D)1Q, 1A and 4

Description

The immunisation and cancer screening services are essentially the same in Scotland as in England and Wales.

Primary immunisation: ISD(S)13/1 and 13/2

The primary immunisation database was set up to provide information on the levels of immunity against childhood diseases, providing uptake rates at 12 and 24 months of age. ISD(S)13/1, which is a quarterly report, was established in 1995 and ISD(S), which is an annual report, was introduced in 1997.

Pre-school booster immunisations: ISD(S)13/3

Form ISD(S)13/3 was introduced in 1996 and collects information on pre-school booster immunisation.

BCG vaccination: ISD(S)12/2

Established in 1965, the Bacille Calmette–Guérin (BCG) vaccination database provides information on the coverage of BCG immunisations within specific age groups.

Cervical cytology screening: ISD(D)4
Form ISD(D)4 is used to monitor the cervical screening progress.

Cervical cytology: quarterly and annual laboratory reports: ISD(D)1Q and 1A
Collection of workload information on cytological tests (including results) carried out by NHSiS laboratories.

Data
Data on immunisations is collected from Health Boards and via Trusts with child health departments. ISD(S)13/1 is returned quarterly and ISD(S)12/2, 13/2 and 13/3 are reported annually.

Form ISD(D)4 processes data annually at Health Board level. ISD(D)1Q is processed quarterly and ISD(D)1A annually, with data being collected at laboratory level. Data items for immunisation and screening programmes are given on pp. 308–11.

Completeness and accuracy
No information has been located.

Uses
No information has been located.

Funding
Scottish Executive.

Access
Via contact details below.

Contact details
Information and Statistics Division
Common Services Agency
The National Health Service in Scotland
Trinity Park House
South Trinity Road
Edinburgh
EH5 3SQ
Tel.: 0131 551 8891
Fax: 0131 551 1392
ISD website: http://www.show.scot.nhs.uk/isd/

Immunisation statistics:
E Buist/B Cant
Tel.: 0131 551 8715/8558
Fax: 0131 551 1392

Screening:
Scottish Screening Programmes Central Coordinating Unit (CCU)
J Warner (ISD)
Tel.: 0131 551 8626
E-mail: webmaster@nsd.csa.scot.nhs.uk
Website: http://www.show.scot.nhs.uk/nsd/services/screening.htm

GP targets:
M Mackenzie
Tel.: 0131 551 8773

Laboratory work load:
S Young
Tel.: 0131 551 8208

Scottish Centre for Infection and Environmental Health (SCIEH)
Dr I Jones (Director)
Dr C Bramley (Epidemiologist)
Clifton House
Clifton Place
Glasgow
G3 7LN
Tel.: 0141 300 1100
Fax: 0141 300 1170
SCIEH website: http://www.show.scot.nhs.uk/scieh/

Publications
(ISD) Scottish Health Statistics, 2000; see website.
ISD website:
http://www.show.scot.nhs.uk/isd/Scottish_Health_Statistics/SHS2000/B1.pdf.

Immunisation programmes:
ISD website: http://www.show.scot.nhs.uk/isd/child_health/ch_immunisation/ch_immunisation.htm

Quarterly data are published in Scottish Centre for Infection and Environmental Health (SCIEH) Weekly Report: Immunisation Statistics.
SCIEH website: http://www.show.scot.nhs.uk/scieh/infectious/vaccine/infvaccine.html

Cervical cytology workload statistics (Quarterly Health Briefing).
Cervical cytology statistics (annual).
ISD website:
http://www.show.scot.nhs.uk/isd/cancer/screening/screening.htm

BCG vaccination: ISD(S)12/2 data items

Health Board		
	For each year of birth[a]	Total
Total no. children (i.e. target group)		
No. with scar present		
No. tuberlin tested		
Positive reactors		
Negative reactors		
Total no. school children vaccinated		
Comments (includes factors which may account for significant variations from previous years)		

[a] i.e. for returns in 1996, pre-1982, 1982, 1983 … , 1988 and post-1988.

Primary immunisations completed: ISD(S)13/1 and 13/2 data items

Health Board		
Number of children resident in the Health Board area on 31 March		
Number of children reaching their 1st birthday during the quarter and resident in the Health Board area		
Population source:		
SIRS/GIRS		
CHI		
Number of children reaching their 2nd birthday during the quarter and resident in the Health Board area		
Population source:		
SIRS/GIRS		
CHI		
Number of children (included in above population) completing a primary course		
Number of children (from above population) completing a primary course any time up to their 1st birthday		
	Total number	Percentage immunised
Diphtheria		
Pertussis		
Tetanus		
Polio		
HIB		
MMR		
As above, for children completing a primary course any time up to their 2nd birthday		

Pre-school booster immunisations: ISD(S)13/3 data items

Health Board		
Number of children resident in the Health Board area on 31 December		
Total number of children reaching their 6th birthday during the year and resident in the Health Board area		
Population source:		
SIRS/GIRS		
CHI		
Number of children included in above population receiving a pre-school booster immunisation		
Number of children (from above population) receiving a pre-school booster immunisation		
	Total number	Percentage immunised
Diphtheria		
Tetanus		
Polio		
MMR (2nd dose[a])		

[a] Introduced October 1996.

Cervical cytology: quarterly laboratory report: ISD(D)1Q data items

Laboratory
Examinations by result and source of smear
Total number of smears assessed by the following sources of smears:
Colposcopy
GP
Family planning/well women clinic
Gynaecological IP and OP
Department of genitourinary medicine
Hospital – other
Other(s) – specified
Number of unsatisfactory results by source of smear (see above for sources)
Number of negative smear results by source of smear (see above for sources)
Number of borderline changes by source of smear (see above for sources)
Number of mild dyskaryosis test results by age group (see above for sources)
Number of moderate dyskaryosis test results by source (see above for sources)
Number of severe dyskaryosis test results by source (see above for sources)
Number of severe dyskaryosis invasive squamous carcinoma results by source (see above for sources)
Number of glandular abnormalities by source (see above for sources)
Number of adenocarcinomas by source (see above for sources)
Number of other test results by source (see above for sources)

Number of tests by Health Board of residence	
Health Board of residence	Number of smears processed
Additionally: total (all areas)	

Reporting and processing time of examinations		
	Processing time (days)	Reporting time (days)
50th percentile		
90th percentile		
Average (mean)		

Cervical cytology: annual laboratory report: ISD(D)1A data items

Laboratory
Cytology: analyses by source
Total number of smears processed by the following sources of smears:
Colposcopy
Family planning
GP
Well women clinic
Gynaecological IP and OP
Department of genitourinary medicine
Hospital – other
Other(s) – specified
Number of unsatisfactory test results by source of smear (see above for sources)
Number of negative test results by source of smear (see above for sources)
Number of mild dyskaryosis test results by source of smear (see above for sources)
Number of moderate dyskaryosis test results by source of smear (see above for sources)
Number of severe dyskaryosis/invasive squamous carcinoma test results by source of smear (see above for sources)
Number of glandular abnormality test results by source of smear (see above for sources)
Number of adenocarcinoma test results by source of smear (see above for sources)
Number of other test results by source of smear (see above for sources)

continued

Cytology: analyses by age group
Total number of smears processed by the following age groups:
- Under 20
- 20–24
- 30–34
- 35–39
- 40–44
- 50–54
- 55–59
- 60–64
- 65 and over
- Not known

Number of unsatisfactory test results by age group (see above for age groups)
Number of negative test results by age group (see above for age groups)
Number of borderline changes test results by age group (see above for age groups)
Number of mild dyskaryosis test results by age group (see above for age groups)
Number of moderate dyskaryosis test results by age group (see above for age groups)
Number of severe dyskaryosis test results by age group (see above for age groups)
Number of severe dyskaryosis/invasive squamous carcinoma test results by age group (see above for age groups)
Number of glandular abnormality test results by age group (see above for age groups)
Number of adenocarcinoma test results by age group (see above for age groups)
Number of other test results by age group (see above for age groups)

Examination and results of histology (of all cervical biopsies)
Number of benign results by 5-year age groups
Number of CIN grade I results by 5-year age groups
Number of CIN grade II results by 5-year age groups
Number of CIN grade III results by 5-year age groups
Number of micro-invasive carcinoma of cervix results by 5-year age groups
Number of invasive squamous carcinoma of cervix results by 5-year age groups
Number of endocervical adenocarcinoma results by 5-year age groups
Number of other malignancies results by 5-year age groups

Cervical cytology screening: ISD(D)4 data items

Health Board

Cytology: number of women with a record of previous smear: by age group

Record of a smear:	Within previous 5.5 years	Within previous 3.5 years
Age:		
Under 20		
20–24		
30–34		
35–39		
40–44		
50–54		
55–59		
60–64		
65 and over		
Not known		
Total		

Cytology: number of women by age group
For above age groups:
- Female population on CHI
- Female population on cytology systems
- Number of females ineligible

continued

Cytology: age group of women with a record of a smear during year
For above age groups:
Number of women undergoing smear examination

Cytology: smear results of women with a record of a smear during year	
Result of cytology:	Number of women
Unsatisfactory	
Negative	
Borderline changes	
Mild dyskaryosis	
Moderate dyskaryosis	
Severe dyskaryosis	
Dyskaryosis/invasive squamous	
Glandular abnormality	
Adenocarcinoma	
Other	
Total	

Wales: screening and immunisation programmes: KC50, KC51, KC53 and KC61

Description

Run by the Welsh Office (Health and Statistics and Analysis Unit, HSA), screening information is collected for Wales on an annual basis using the following returns which are identical to those described above for England.

Immunisation and vaccination activity: KC50

KC50 collects aggregate information on immunisation and vaccination. The main source of information on immunisation and vaccination is the Child Health System which includes uptake rates for children for specific diseases. However, the KC50 database collects some additional information including adult treatments.

Immunisation status of district residents: KC51

KC51 forms part of the Child Health System (CHS refers).

Cervical cytology screening: KC53

KC53 records the cervical screening status of Health Authority residents in the previous 3 and 5 years.

Pathology laboratories: cervical cytology and biopsies: KC61

KC61 records aggregate data on cervical smears and biopsies performed in the Health Authority, examined by pathology laboratories.

Data

The data collected for each programme cover:

Immunisation and vaccination activity: KC50

- diphtheria, tetanus and polio booster/reinforcing doses, categorised by age.
- BCG (tuberculosis), skin test results and vaccination programmes, categorised by age.

Immunisation status of district residents: KC51

- Number of children vaccinated by first and second birthdays.

Cervical cytology screening: KC53

- routine recall interval in use in the Health Authority
- status of Health Authority residents, by age
- number of women invited and tested, by age
- result of test, by age.

Pathology laboratories: cervical cytology and biopsies: KC61

- number of smears examined by source of smear, by result
- results of smears examined from GP and NHS Community Clinics only, by age group of women
- outcome by end of financial year for women recommended for gynaecological referral during April to June of the previous year.

Coding systems

No information located.

Completeness and accuracy

No information located.

Uses

For monitoring the effectiveness of the various programmes.

Funding
Funding is by the Welsh Assembly.

Access
See publications and contact details listed below.

Contact details
HSA, Welsh Office
National Assembly for Wales
Cathays Park
Cardiff
CF1 3NQ

HSA enquiries/publications:
D Leigh
Tel.: 02920 825036

Statistics for Wales:
E-mail: Stats.Info.Desk@Wales.gsi.gov.uk
Website: http://www.wales.gov.uk/keypubstatisticsforwalesfigures/content/health/prevent_med.htm

Publications
Key Health Statistics For Wales, National Assembly For Wales, 2000, see Statistics for Wales website: http://www.wales.gov.uk/keypubstatisticsforwalesfigures/content/health/prevent_med.htm.
Key Statistical Indicators for Health in Wales.
Health Statistics: Wales.
Cervical Screening Programme Wales, Annual Statistical Brief, HSA, National Assembly for Wales, 2001.

Immunisation and vaccination activity: KC50 data items

Trust name

Diphtheria, tetanus and polio booster/reinforcing doses

No. of doses given in the year	Diphtheria	Tetanus	Polio
Age (years)			
Under 3			
3			
4			
5			
6–7			
8–15			
16–19			
20+			
Total			

BCG (tuberculosis)

Number in year:	Skin tests/vaccinations				No. of skin	No. of vaccinations
Age:	Positive	Negative	Planned programmes[a]	Other programmes[b]	tests in year	in year
Under 1						
1–9						
10–13						
14–15						
16+						
Total						

Comments

[a] Planned programmes for neonates and schoolchildren.
[b] Those for other programmes and opportunistic.

Immunisation status of district residents: KC51 data items

Information recorded by the KC51 form
Number of children vaccinated by first birthday against:
Diphtheria
Tetanus
Pertussis
Polio
HIB
MMR
Number of children vaccinated by second birthday against:
Diphtheria
Tetanus
Pertussis
Polio
HIB
MMR

Cervical cytology screening: KC53 data items

Health Authority								
Routine recall interval in use in the Health Authority								
5 years	4 years	3 years	3 and 5 years mixed	Other				
Status of Health Authority residents								
Age of woman at 31 March:								
<20	20–24	25–29	…	65–69	70–74	75+	Total[a] target	Total all ages:
Number resident on 31 March:								
With recall cases ceased for:								
Clinical reasons (no cervix)								
Age reasons								
Other reasons								
With no cytology record								
Tested in the last 5 years								
Tested in the last 3 years								
Number of women invited								
Age of woman at 31 March:								
<20	20–24	25–29	….	65–69	70–74	75+	Total[a] target	Total all ages:
Call								
Routine recall								
Repeat in <3 years for reasons of:								
Surveillance								
Abnormality								
Inadequate smear								
Number of women tested								
Age of woman at 31 March:								
<20	20–24	25–29	…	65–69	70–74	75+	Total[a] target	Total all ages:
Call								
Routine recall								
Repeat in <3 years for reasons of:								
Surveillance								
Abnormality								
Inadequate smear								
While recall suspended								
Opportunistic screening								

continued

Result of test								
Age of woman at 31 March:								
<20	20–24	25–29	…	65–69	70–74	75+	Total[a] target	Total all ages:
Result of woman's most severe test in financial year:								
Negative								
Abnormal:								
Borderline/mild dyskariosis								
Moderate dyskariosis								
Positive								
Comments								

[a] Total target age group (20–64 years).

Pathology laboratories: cervical cytology and biopsies: KC61 data items

Trust name
Laboratory name
Pathology laboratory code

Number of smears examined, by source of smear
Results of test
Inadequate
Negative
Borderline changes
Mild dyskaryosis
Moderate dyskaryosis
Severe dyskaryosis
Severe dyskaryosis/? invasive carcinoma
? Glandular neoplasia
Total number examined
Results of test (as above)
Source:
GP
NHS Community Clinic
GUM clinic
NHS hospital
Private
Other
Total of GP and NHS Community Clinics
Grand total

Results of smears examined from GP & NHS Community Clinics only, by age group of women								
Results of test (as above)								
Age of woman at 31 March:								
<20	20–24	25–29	…	65–69	70–74	75+	Total[a] target	Total all ages:

Outcome by end of financial year for women recommended for gynaecological referral during April–June previous year						
Most significant result:			Dyskaryosis			
	Inadequate	Borderline changes	Mild	Moderate	Severe	Total
Outcome of referral:						
Cancer (including microinvasive)						
Adenocarcinoma *in situ*						
CIN 3						
CIN 2						
CIN 1						
HPV only						
No CIN/no HPV						
Inadequate biopsy						
Colposcopy NAD – no biopsy taken						
Result not known:						
Positive predictive value						

[a] Total target age group (20–64 years).

Northern Ireland: screening and immunisation programmes: KC50, KC51, KC53, KC61, KC62 and KC63: group 1c

Description

The immunisation and cancer screening services are essentially the same in Northern Ireland as in England and Wales.

Child immunisation programme: KC50
KC50 collects information on vaccinations given by or on behalf of the Health Board.

Immunisation status of trust: KC51
KC51 collects data on children reaching the ages of 1 and 2 years immunised against diphtheria, tetanus, pertussis, polio, MMR and HIB. Information on girls reaching 14 years and immunised against rubella is also returned.

Adult screening programmes: cervical cytology: KC53
KC30 records the number of women invited, number screened and whether the results were negative, abnormal or positive for different age categories.

Pathology laboratories: cervical cytology and biopsies: KC61
KC61 records the number of smears examined by source and the results of cytology tests for different age categories.

First invitation for routine breast screening: KC62
KC62 provides a summary of invited and screened women and results of screening.

Adult screening programmes: breast cancer (Board): KC63 (suspended in 1999)
KC63 collects aggregate screening information concerning numbers of women resident, numbers screened and details of screening status call and recall status.

Data

Data is processed annually at Health Board level.

Immunisation programme: KC50
- number of primary courses and booster/reinforcing doses of diphtheria, tetanus, pertussis, polio and MMR, categorised by age
- number of BCG skin tests (by result) and vaccinations, categorised by age
- number of females vaccinated with single-antigen rubella (excluding that given by MMR), categorised by age.

Immunisation status of trust residents: KC51
- total number of children reaching 1st (and 2nd) birthdays
- total number of above children receiving vaccination, categorised by vaccine
- total number of girls reaching 14th birthday
- total number of girls above immunised against rubella.

Adult screening programme: cervical cytology: KC53
- number of women invited/screened and aggregated results, categorised by age
- smear status of Board residents, categorised by age.

Pathology laboratories: cervical cytology and biopsies: KC61
- results of cytology tests by source of smear
- results of cytology tests by age group of women from whom smears are taken.

First invitation for routine breast screening: KC62
- results of screen, categorised by screen type (e.g. first invitation, early recall) and age
- women with cancer diagnosed as a result of screening, categorised by age and type of screen
- outcome measures, categorised by type of screen.

Adult screening programmes: breast cancer (Board): KC63
- screening status of Board residents, categorised by age
- number of women with screening record, invited, screened, categorised by age
- screening coverage, categorised by age
- time since last screen, categorised by age.

Completeness and accuracy

No information has been located.

Uses

No information has been located.

Funding

No information has been located.

Access

See contacts below.

Contact details

RIB (Community Services)
DHSS
Annexe 2
Castle Buildings

Stormont
Belfast
BT4 3UD
Tel.: 02890 522800
E-mail: rib@dhsspsni.gov.uk
RIB website: http://www.dhsspsni.gov.uk/iau/order.html#community

Cancer screening:
Dr A Gavin (Director) or Miss B Torrans (Administrator)
Department of Epidemiology and Public Health
The Queen's University of Belfast
Mulhouse Building
Institute of Clinical Science
Grosvenor Road
Belfast
BT12 6BJ
Tel.: 02890 894614

Publications
Community Statistics Bulletin, 1999–2000, RIB, DHSS 2000 on RIB website: http://www.dhsspsni.gov.uk/iau/order.html#community

Immunisation programme: KC50 data items

Provider name											
Provider code											
Diphtheria, tetanus, pertussis, polio and MMR											
Number of primary courses completed											
Age:	<1	1	2	3	4	5	6–7	8–15	16–19	20+	Total
Course:											
Diphtheria											
Tetanus											
Pertussis											
Polio											
MMR											
HIB											
Number of booster/reinforcing doses											
Age:	<4	4		5	6–7		8–15		16–19	20+	Total
Course:											
Diphtheria											
Tetanus											
Polio											
BCG (tuberculosis)											
Age:	<1		1–9		10–13		14–15		16+		Total
Number of:											
Skin tests:											
Positive											
Negative											
Vaccinations											
Single-antigen rubella (excluding that given by MMR)											
Age:	<10	10	11	12	13	14	15	16–19	20+	Total	
Number of females											
Provider comment											

Immunisation status of Trust residents: KC51 data items

Provider name Provider code
Diphtheria, tetanus, pertussis, polio, measles, MMR and HIB Total number of children resident on 31 March, reaching their 1st birthday during the previous year Total number of those above immunised before their 1st birthday against: Diphtheria Tetanus Pertussis Polio MMR HIB As above for those reaching 2nd birthday during previous year
Rubella Total number of girls resident on 31 March, reaching their 14th birthday during previous year Total number of those above immunised before their 14th birthday Provider comments

Adult screening programmes: cervical cytology: KC53 data items

Provider name Provider code											
Number of women invited/screened											
Age at test:	<20	20–24	25–29	30–34	35–39	40–44	45–49	50–54	55–59	60–64	65+	Total
Numbers:												
Invited												
Screened												
Results of test:												
Negative												
Abnormal												
Positive												
Status of Board residents											
Age end of year:	<20	20–24	25–29	30–34	35–39	40–44	45–49	50–54	55–59	60–64	65+	Total
Numbers of women:												
Resident on 31 March												
No longer require screening												
Known to have had smear <5 years												
Provider comment												

Pathology laboratories: cervical cytology and biopsies: KC61 data items

Results of cytology tests by source of smear

	Total number examined	Source of smear			
		GP	Family planning clinics	Hospital	Other
Result of test:					
Inadequate sample					
Negative					
Abnormal					
Positive					

Results of cytology tests by age group of women from whom smears are taken

	Total all ages	Under 20	20–24	25–29	30–34	35–39	40–44	45–49	50–54	55–59	60–64	65+	Age not known
Result of test:													
Negative													
Abnormal													
Positive													
Inadequate sample													

First invitation for routine breast screening: KC62 data items

Provider name
Provider code

1st invitation for routine screening: women invited

Age at 1st appointment:	<44	45–49	50–54	55–59	60–64	65+	Total
Number:							
Women invited							
Lost to follow up-after inadequate screen							
Number screened: technically adequate							
Outcome of initial screen:							
Not known							
Routine recall							
Early recall							
Referred for assessment (or direct to histology)							
Final outcome of assessment							
Failed to attend for assessment/histology							
Not known							
Routine recall							
Early recall							
Cancer							

Age at 1st appointment:	<44	45–49	50–54	55–59	60–64	65+	Total
Number:							
Cancer diagnosed without cytology/histology							
Outcome of assessment up to and including cytology:							
Total referred for cytology							
Not referred for diagnostic histology:							
No result recorded							
Routine recall							
Early recall							
Cancer – not diagnostic histology							
Referred for diagnostic histology							
Outcome of assessment up to and including diagnostic histology							
Total referred for diagnostic histology							
No/inadequate result							
Benign/normal:							
Routine recall							
Early recall							
Cancer							

continued

Routine invitation to previous non-attenders: women invited
As above

Routine invitation to previous attenders: last screen <5 years: women invited
As above

Routine invitation to previous attenders: last screen >5 years: women invited
As above

Early recalls: women screened
As above

Self/GP referrals (women not previously screened): women screened
As above

Self/GP referrals (women previously screened): last screen <5 years: women screened
As above

Self/GP referrals (women previously screened): last screen >5 years: women screened
As above

Women with cancer diagnosed as a result of the screens detailed above

Age at 1st appointment:	<44	45–49	50–54	55–59	60–64	65+	Total
Number:							
Women with cancers							
Invasive status not known							
Non-invasive/possibly microinvasive							
Definite microinvasive							
Invasive size:							
<10 mm							
>10–<15 mm							
>15–<20 mm							
>20–<50 mm							
>50 mm							
Size not known							
Total invasive							
Numbers of cancers as diagnosed above, categorised by type of screen:							
1st invitation							
1st screen: previous non-responder							
Routine rescreen:							
<5 years							
>5 years							
Early recall							
Self/GP referral:							
No previous screen							
<5 years							
>5 years							

Outcome measures
Outcome measures, categorised by type of screen (as above):
- Uptake rate (% of invited)
- Referral rate (% of screened)
- Benign biopsy rate (% of screened)
- Benign diagnostic histology rate (% of screened)
- Invasive cancer detection rate
- Detection of invasive cancers (per 10,000 screened):
  - <10 mm
  - <15 mm
- Referral rate (% of screened):
  - Cytology
  - Diagnostic histology

continued

Malignant:benign ratio
Open biopsy
All diagnostic histology
Early recall rate following (% of screened):
Initial screen
Assessment
Results not known:
Assessment (% of referred)
Cytology (% of referred)
Histology (% of referred)
Invasive status of cancer and/or size (% of cancers)
Invasive status (% of cancers)
Size (% of cancers)
Provider comments

Adult screening programmes: breast cancer (Board): KC63 (currently suspended) data items

Provider name						
Provider code						
Status of Board residents						
Age at 31 March:	15–49	50–54	55–59	60–64	65+	Total
Number:						
Women resident						
Not screened in last 3.5 years (ceased/suspended)						
Known to have been screened in last 3.5 years						
Number of women with screening record, invited, screened						
Age at 31 March:	15–49	50–54	55–59	60–64	65+	
Number:						
Women resident						
With no screening record						
1st call for screening:						
Not invited (ceased/suspended)						
Invited						
Screened within 6 months of invitation						
Screening recall						
Not invited (ceased/suspended)						
Invited						
Screened within 6 months of invitation						
Screening coverage						
Age at 31 March:	15–49	50–54	55–59	60–64	65+	
Number:						
Women resident						
With no screening record						
1st call for screening:						
Not invited (ceased/suspended)						
Invited						
Screened within 6 months of invitation						
Screening recall						
Not invited (ceased/suspended)						
Invited						
Screened within 6 months of invitation						

continued

Time since last screen										
Age at 31 March:	15–39	40–44	45–49	50–54	55–59	60–64	50-64	65-69	70-74	75+
Number:										
Women resident										
Never screened										
Time since last screen:										
<12 months										
12–23 months										
24–35 months										
36–47 months										
48–59 months										
60 months+										
Provider comment										

Breast Test Wales (BTW)

General Description

BTW is a division of Velindre NHS Trust. The Breast Screening System (BSS) was implemented from 1989 (depending on the area of Wales), with the BTW Medical Office System established in 1995. The BTW databases hold administrative and clinical data, supporting the NHS breast screening programme in Wales. The databases are used for the administration of inviting, screening, recording diagnostic treatment and follow-up of screened women. They are also useful for quality assuring the breast screening programme in Wales, including audit, disseminating results and research on screening. The main aim is to reduce deaths from breast cancer.

The databases have been used to assess the following benefits of treatments:

- efficacy: multi-disciplinary review of cases treated but found negative at treatment
- diffusion: review of mastectomy versus conservation within Wales
- cost-effectiveness: economic review of screening costs in Wales
- equity: current study on use of programme by women over 64 (self-referring).

Funding

BTW is funded from a budget within Velindre NHS Trust, provided by the Welsh Assembly (formerly the Welsh Office). The approximate cost of maintaining the database is around £71,500, excluding PC and communication systems.

Population covered

Screening information is held on all women resident in Wales within the age range 50–64 years. Data are collected from all GPs and Health Authorities but not from every hospital in Wales, as only certain hospitals have links with the screening service, that is, a team of surgeons, radiologists and pathologists carrying out screening and hence treatments. The system currently holds information on around 700,000 screening episodes.

Process of data collection

The main screening database is held on the 'Oxford' system, a specifically designed national breast screening system. All women resident in Wales aged 50–64 years registered with a GP are invited for mammography screening every 3 years. Self-referring is allowed for women over 64 years. Batches of eligible women are identified on the computer system [Health Authority (Family Health Services)], batching those from the same practice. These details are checked by the GP and sent electronically to BTW, where appointments are created and scheduled. Self-referring women over 64 years provide their own demographic details by telephone or letter cross-checked with the Health Authority. Screening may be either at a static centre (one of three) or else at mobile units.

The radiographer and clerical officer enter screening data directly on to computer. Data are held on a central database (Unix system), with disk uploads from mobile units. The radiographer and medical staff produce assessment data and these are entered by medical secretaries. BTW then sends out the screening results to the women (usually within 14 working days).

If a possible abnormality is detected, an invitation to attend a specialty clinic is given. Treatment and follow-up data are collected from hospitals by letter and medical secretaries enter them on to the database. Death data are collected from Health Authority deduction lists and from ONS (via the NHSCR, flagged cancer cases only) and entered by clerical staff and medical secretaries.

The Oxford system is a relational system with client details records, allowing a separate record for each screening episode. The Oxford system allows only some standard reporting; to aid analysis, the data are downloaded to the Welsh custom-developed system (BTWMOS).

The sources of the information used for the dataset include:

- Health Authority systems: all Health Authorities in Wales
- treatment data from hospitals, from screening surgeons mainly by letter, operation sheet copies
- cytology and pathology reports and forms, screening pathologists
- follow-up data, letters from surgeons
- ONS death data for breast cancers only.

The data are received continuously; BTWMOS is updated about every 6 weeks. BTW reports on the screening year ending 31 March. Women are counted as 'screened' if they attend within 6 months of invitation. Hence results for the year cannot be finalised until 6 months after the end of the screening year. Detailed information is available 9–12 months following the year end; some aggregate information may be obtained in 7 months.

Summary of data items collected
- screening women, including name, postcode, date of birth and NHS number
- screening, diagnosis, treatment details
- death details
- quality assurance
- evaluation.

A more detailed list of data items collected is given on pp. 323–4.

Coding schemes
The BSS internal coding system has been employed throughout.

Continuity
There have been no disruptions or breaks in the continuity of data.

Completeness
Completeness of data items is not guaranteed as the data rely on Health Authority databases and self-referrals from the public. Validation has revealed that postcode data are not complete and there are electronic links to the Administrative Register to help this. Pathology data are good, but still improving.

A continuing programme of data audit using the BTWMOS error or anomaly flagging system should reduce these problems. The introduction of a full-time information officer, whose post includes data audit, has meant that the database has become more complete.

Accuracy
Improvements in software have increased accuracy. Audits of surgical data have improved initial data recording through feedback of previous audit remits.

Internal validation
BTWMOS checks the database for inconsistencies in:
- KC table allocation
- age at appointment
- screening year
- Health Authority code
- GP round
- cancer diagnostic methods
- node status
- tumour size
- missing histology
- missing or faulty notes on procedure records
- missing invasive sizes
- general 'problem' flag.

The system also follows up records over 15 months ago, with missing data items.

The databases are audited for completeness through the annual statistics report KC62 (breast screening) and annually through the British Association for Surgical Oncology (BASO) screening surgical audit. Internal audits are also performed as requested by quality assurance clinicians (e.g. treatment consistency, conservation surgery should be accompanied by radiotherapy unless patient is in a trial and randomised not to receive information or patient unsuitable) by checking patients' notes.

External validation
The following databases are used for external validation of BTWMOS:

- The BTW Incidence Database (includes ONS death data) is used for external validation of the database every 6 months (additionally if required). Problems highlighted by this include grade classification of tumour and missing death data.
- The NHS Administrative Register, Health Solutions Wales (formerly Welsh Health Information Services), is online and used when required.

- Electoral rolls are used in a research role only, to check possible inaccuracies in Health Authority population lists.
- The Information System for Clinical Oncology (ISCO) is used for initial investigation only, highlighting a lack of follow-up data, and provides some treatment data to the screening unit.

Future plans

Some links between Health Authorities and BSS are still in paper format, and it is intended to make these electronic eventually. Links to hospital data for follow-up treatment have been investigated briefly – these may become more feasible in the future.

Access

To access patient-identifiable data or individual patient records with data items necessary for record linkage, a request form would need to be completed, approved and signed by the BTW data custodian. If not medically qualified, a letter from a medically qualified person may be required. If data are required for research purposes, ethics committee approval may be required and also permission from the patient's clinician.

If anonymised data are required, from individual patient records through to regional aggregated levels, a request form is completed to be approved by the data custodian.

Aggregated data at the national level are published. Alternatively a request form may be completed, again to be approved by the data custodian.

Contact details

Dr D Brook
Information Manager
Breast Test Wales (Bron-Brawf Cymru)
Welsh Breast Screening Centre
18 Cathedral Road
Cardiff
CF1 9LJ
Tel.: 02920 373500
Fax: 02920 373511
E-mail: diane.brook@velindre-tr.wales.nhs.uk

Information sources

Data were extracted from an interview and the references cited.

Publications and further sources of information

Annual report, BTW.
Annual report, UK NHS Breast Screening Programme.
Health Statistics Wales.
Health Show.
Website: http://www.velindre.org.uk/btw

Breast Test Wales data items[a]

Screening women
Demographic details:
Name
Sex
Date of birth
Address
Postcode
NHS number
Various ID codes for trials, etc.
Client history:
Family history of breast cancer
GP and Health Authority details
Registration
Appointment details
Screening, diagnosis, treatment details
Screening film
Imaging assessment
Clinical examinations
Other mammogram records
Referral

continued

Fine needle aspiration (FNA) details Biopsy and treatment details Follow-up biopsy and treatment records Ultrasound Medical treatment records Radiotherapy Review Follow-up details Nursing details Support data files, e.g. BTW staff codes, screening officer and Health Authority codes Statistical items derived from the above External linked statistics (Health Authority) Programme plans
Death details Date Main cause Contributory cause
Quality assurance Radiology reading and recall details, interval cancers data, early recall data Surgery results Pathology results Nursing results Radiographic data Physics data Consumer satisfaction data Waiting times at appointments Result letters waiting times Hospital admission waiting times Complaints Comments form
Evaluation Breast cancer incidence and mortality data Interval cancers Research data (CROPS project, non-attenders projects)
Finance Expenditure Plans Budgets
Personnel Staffing Training
[a] BTW is a very detailed database, so field headings only are included except for patient identifiers and death details.

Community dental health services

Community dental health services, England: KC64

General description

Covering community dental health service activity, KC64 returns information on:

- screening programmes, oral health programme screening activity carried out on the dental health target populations
- preventive programmes, oral health programmes with a screening or promotion indicator of health promotion
- referral information
- patient care
- epidemiology.

Data are available from 1990–91:

- returning information on manpower, target populations, levels of activity, outcomes and further referrals in each programme
- ensuring value for money is achieved
- circulation to policy colleagues (Dental and

Optical Services Branch) and regional dental officers
- departmental accountability.

Process of data collection
Data are processed annually at Trust level.

Summary of data items collected
- screening programmes
- preventive programmes
- patient care
- epidemiology.

A more detailed list of data items collected is given below.

Contact details
S Lea
Department of Health
Skipton House
80 London Road
London
SE1 6LW
Tel.: 020 7972 5392
Fax: 020 7972 5661
E-mail: dnijjar@doh.gov.uk

Information sources
Data were extracted from return KC64.

Publication and other information details
Health and Personal Social Services Statistics.

Community dental health service: dental activity: KC64 data items

Health Authority code Health Authority name Trust code Trust name			
Screening programmes	Number screened	Number referred	Total
Children 0–4			
Children 5–15			
Patients 16–64			
Patients 65 or over			
Total			
Preventive programmes			
Hours worked in oral health promotion and other preventive programmes (total all grades)			
	Number of oral health and other preventive programmes		
Age groups as above			
Patient care			
	Hours worked		
Total (all grades)			
	Age groups (as above)		
Total episodes of care (initial contacts)			
Total individuals seen (first contacts in the financial year)			
	Age groups (as above)		
Source of referral:			
Episodes of care:			
CDS screening programme			
Other dentist			
Recall			
Self			
Other			
Total			
Episodes for which individuals were unable to obtain treatment within the GDS			
	Age groups (as above)		
Number of episodes of care which include:			
General anaesthesia			
Sedation			
Orthodontics			
Epidemiology			
	Total hours spent on survey work		
Dental officers			

Dental screening programme: KC64 (Wales)

Description

KC64 is a series of aggregate returns collecting details of total contact with and number of people seen by the dental screening programme. The community health service dental screening programme is maintained by the Welsh Office [(Health Statistics and Analysis Unit (HSA)].

The database is used to look at community dental service provision and treatments and also monitors activity and trends. Information is collected from all Welsh NHS Trusts that provide the service.

In 1999, a project was under way to identify the requirements of users of the Community Dental Service (CDS), providing an assessment and evaluation of the data process and to make recommendations for future collection, collation, analysis and presentation of CDS Wales information (Statistics Plan website, 2001).

Data

The information is collected annually, with the forms sent out by the HSA in March to all NHS Trusts providing the service. Following return of the forms, the HSA enters the data into either Microsoft Access or Excel. Key summary information for the previous financial year is usually available by the end of September (dependent on form return and timely resolution of queries). A detailed list of the data items collected is given on pp. 327–9.

Coding systems

No coding schemes have been documented.

Completeness and accuracy

The data are generally reasonably complete for the key summary and total fields, although estimates are sometimes required. However, there are concerns about the quality of some data (particularly detailed) and the extent to which Trusts return data on a consistent and comparable basis.

The number of disabled people treated is returned, but the determination of disability is dependent on the judgement of the dental officer concerned and therefore is not standardised and not comparable across the country.

The forms are under review at the time of writing, as it is thought that some Trusts do not find the forms easy to fill in and the details required are not readily available.

Queries are returned to Trusts or estimates are made and returned to the Trusts for comment. A basic check against Welsh Office Core Indicator data is performed. Welsh Office databases are subject to periodic review for the control of statistical surveys. The results of the review are submitted to the Survey Control Unit at the Office for National Statistics and to Ministers, and are also examined by the Information Requirements and Standards Sub-committee of the Information Policy Group of the Welsh Office Executive Committee

Uses

Data are used by the Welsh Office to monitor trends and activity. Summary data are useful to the Public Expenditure Survey.

Funding

Funding is by the Welsh Assembly.

Access

The information is held at aggregate level with no confidentiality restrictions. Information is freely available although it is normally accessed only by HSA – see contact details below.

Contact details

HSA, Welsh Office
National Assembly for Wales
Cathays Park
Cardiff
CF1 3NQ
E-mail: stats.info.desk@wales.gsi.gov.uk

Enquiries: D Leigh
Tel.: 02920 8825036

Statistician: C Roberts
Tel.: 02982 5825033

Project manager, statistics review primary health/dental review: G Thomas, National Assembly for Wales; see National statistics website: http://www.statistics.gov.uk/nsbase/about_ns/welsh/welsh_theme_health.aspl

Publications and further sources of information

Health and Personal Social Services Statistics, Department of Health, 1999.
Statistics Plan, Primary Care 2000–1 to 2002–3, National Assembly for Wales, 2001.
Statistics Plan (National Statistics) website: http://www.statistics.gov.uk/nsbase/about_ns/welsh/welsh_theme_health.asp
Statistics for Wales website: http://www.wales.gov.uk/keypubstatisticsforwales figures/content/health/comm_health.htm

Dental screening programme: KC64 (Wales) data items

NHS Trust

Screening programmes

Care group:	Population	Target numbers	Number screened	Number referred GDS	Number referred CDS	Number referred HDS	Hours worked: dental officers
Pre-school children							
Secondary school children							
Expectant & nursing mothers							
Elderly in residential accom.							
Others (specify)							
Total							

Preventive programmes

- Programme name
- Care group (as above)
- Type of programme
- Population
- Target numbers
- Number of contacts
- Hours worked by:
  - Dental officers
  - Therapists
  - Hygienists
  - Other CDS staff

Dental health promotion

As above

Treatment: referral, location and completion

Initial contacts: source of referral

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped
Source of referral						
Recall						
Screening (CDS)						
GDP						
Hospital						
Self-referral						
Other health professional						
Other						
Total initial contacts						

Initial contacts: reason for referral

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped
Reason for referral						
Unable to obtain treatment in GDS						
Emergency						
Orthodontic care						
Extractions under general anaesthesia						
Restorative treatment under general anaesthesia/sedation						

Total episodes completed or discontinued

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped
Completed episodes						
Discontinued episodes						
Total episodes						

First contact in financial year

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped

Total contacts by location (initial and subsequent contacts)

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped
Location:						
Health centre/clinic						
Mobile surgery						
Domiciliary						
Hospital						
Total contacts						

continued

Total contacts by staff grade (initial and subsequent contacts)

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped
Staff grade:						
Dental officers						
Dental therapists						
Dental hygienists						
Total contacts						

Interventions

Interventions: dental officers

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped
Interventions:						
Examination only						
Exam. leading to prevention/treatment						
Preventive counselling						
Topical fluoride						
Fissure sealants						
Gumshields/mouthguards						
Scaling and polishing						
Restorative treatment						
Extractions (non-orthodontic)						
Extractions (orthodontic)						
Orthodontics						
Prosthetics						
Periodontal treatment						
General anaesthesia						
Sedation						
X-rays						

Interventions: dental therapists

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped
Interventions:						
Preventive counselling						
Topical fluoride						
Fissure sealants						
Scaling and polishing						
Restorative treatment						
Extractions (non-orthodonitic)						
Extractions (orthodontic)						
Periodontal treatment						
X-rays						

Interventions: dental hygienists

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped
Interventions:						
Preventive counselling						
Topical fluoride						
Fissure sealants						
Scaling and polishing						
Periodontal treatment						
X-rays						

Episodes of care

Age groups:	0–4	5–15	16–64	65+	Total all ages	Of which handicapped
Number of episodes of care which include the following interventions:						
Examination only						
Exam. leading to prevention/treatment						
Preventive counselling						
Topical fluoride						
Fissure sealants						
Gumshields/mouthguards						
Scaling and polishing						
Restorative treatment						

continued

Extractions (non-orthodontic)						
Extractions (orthodontic)						
Orthodontics						
Prosthetics						
Periodontal treatment						
General anaesthesia						
Sedation						
X-rays						
Hours worked and travelled						
Dental personnel:	Officer	Therapists	Hygienists	Surgery assistants	Other staff	Total
Activity:						
Screening: work/travel						
Preventive programmes: work/travel						
Dental health promotion: work/travel						
Epidemiology: work/travel						
Treatment: work/travel						
Administration						
Education and training						
Audit						
Total						

Community dental service screening programme: Scotland: ISD(S)23

General description

ISD(S)23 collects data on the inspection and results of the dental screening programmes of pre-school and school children and adults with special needs. The information is held by the Information and Statistics Division (Edinburgh). In addition to allowing audit of the performance of the inspection programme, data on supplementary and other inspection programmes are also collected.

The dataset is used for the collection of local and national statistics on community dental screening in Scotland.

Process of data collection

Community Trusts and dental departments return paper forms quarterly which are checked and entered on to spreadsheets. Data are aggregated to Health Board and Scotland totals.

Summary of data items collected

Breakdown of the screening inspections and results.

A more detailed list of data items collected is given on p. 330.

Future developments

A proposed publication on community dental services would use information from these returns.

Contact details

Information and Statistics Division
Common Services Agency
The National Health Service in Scotland
Trinity Park House
South Trinity Road
Edinburgh
EH5 3SQ
Tel.: 0131 552 6255
Fax: 0131 551 1392

Dental services: G Thompson
Tel.: 0131 551 8049

Information sources

The information was extracted from return ISD(S)23 and ISD draft information.

Publications and further sources of information

Summary tables are published quarterly.
Annual summary tables are published in Scottish Health Statistics.

Community dental service screening programmes: ISD(S)23 data items

Trust/unit	Numbers: Estimated target population	Screened	Requiring referral	No. caries	Caries requiring treatment	Edentulous	Edentulous requiring treatment
Basic school inspections:							
Primary							
Secondary							
Total							
Supplementary school screening:							
Primary							
Secondary							
Total							
Other screening programmes:							
Pre-school							
Adults (special needs)							
Total							
Grand total:							

Appendix 4

Health technology only databases

Contents

The databases in this section are Central Returns and hence are the same for each country. For this reason, where it has proved difficult to locate details of a particular database in one of the smaller UK countries, it has been ignored.

Several other databases could plausibly be included in this group, notably radiology and nuclear medicine returns. These have been investigated and omitted on the grounds of the limited data that they provide (number of scans without any data on the patients, conditions or machines used).

Prescription funding databases

Prescription Pricing Authority: PPA (England)

Description

The PPA is a Special Health Authority with four main functions:

- to scrutinise pricing and authorising payment to contractors for dispensing of NHS prescriptions
- to provide prescribing and dispensing information to NHS (non-hospital dispensing)
- to manage the NHS low-income scheme
- to prevent prescribing and dispensing fraud within the NHS.

In 2000, the PPA processed over 500 million prescriptions and holds 2 years' data or over one billion records on its database. The database provides four sets of prescribing information:

- prescribing analysis and cost (PACT)
- electronic PACT (ePACT, ePACT.net and Toolkit)
- Itemised Prescribing Payment Report system (IPPR) and Prescribing Cost Analysis (PCA)
- Prescribing Monitoring Document System (PMDS), which replaced the Indicative Prescribing Scheme (IPS) in 2000.[1]

These systems were restructured in 1999–2000 to cover Primary Care Groups (PCGs) and the creation of unified budgets, including drugs expenditure which was cash limited for the first time.[1] Each system is summarised below.

Prescribing analysis and cost: PACT, ePACT ePACT.net and Toolkit

The origins of PACT datasets providing regular prescribing information to GPs go back to 1976.[2] Computerised information services commenced in 1986 with the Prescribing Dispensing Report 8 (PD8).[3] This was superseded in 1988 by PACT which was updated in 1994. The PPA has a range of on-line query services: FEPACT (on-line PACT, data), PACTline (allows local data analysis) and GPEP (electronic PACT for GPs).

PACT provides GPs with regular information on their prescribing habits and costs. Traditionally, PACT was used as a financial tool for setting and monitoring general practice prescribing budgets but increasingly became used for other purposes including audit and research, improved methods of funding high-cost drugs and for the development of practice formularies. Comparisons of rates and costs of prescribing in different practices or health authorities are available.[4,5]

The electronic PACT (ePACT) system allows access data to authorised NHS users to the following analyses:

- analysis of practice data to aggregated Health Authority data
- comparisons between practice types
- analysis of cost.

ePACT was enhanced in 1999 to provide Health Authorities with electronic access to prescribing information for 'their' PCGs. ePACT.net is a web-based prescribing analysis application for PCGs available to Community Trusts and Health Authorities. ePACT.net will be the basis for all future electronic prescribing analysis service developments at the prescriber level, including GPs.

Toolkit is another web-based product providing PCG/Trust comparative information in addition to providing additional performance indicators relating to GP practices at the PCG level, PCGs at the Health Authority level and Health Authorities at the Regional Office level.

ePACT, ePACT.net, PMDS reports and the IPPR system were all revised to cater for Primary Care Trusts (due to be online by 2001).[1]

Itemised Prescribing Payment Report system (IPPR) and Prescribing Cost Analysis (PCA)

The IPPR system attributes actual costs of prescribing back to Health Authorities. The PCA scheme, established as a stand-alone system in 1991, provides national drug information including analysis of drugs, pharmacies,

dispensing GPs and (more recently) PCGs to the Department of Health:

1. analysis of drug prices
2. forecasting information
3. monitoring data for:
   (a) new products
   (b) adverse drug reactions
   (c) *ad hoc* analysis
   (d) research potential
   (e) possible fraud indications or irregularities
   (f) potential income from the sale of information.

PCA reports are produced on a monthly, quarterly and annual basis covering:[6]

- drug analysis (e.g. costs, numbers dispensed, patient exemption category)
- pharmacy analysis (e.g. number, size, group, type of ownership, type of fees)
- dispensing doctor drug analysis (e.g. number, cost of prescriptions)
- miscellaneous analysis.

Prescribing Monitoring Document System (PMDS) [formerly the Indicative Prescribing Scheme: (IPS), 1990–2000]

This enables Health Authorities to charge the appropriate cost of PCG prescribing to their unified budgets and provide prescribing information to practices on a monthly basis. Its aims are to:

- make PGCs and GPs aware of and more accountable for cost of prescribed drugs
- monitor wasteful or unnecessarily expensive prescribing
- increase Health Authority involvement in monitoring prescribing habits
- encourage the development of formularies and repeat prescribing control systems
- return monthly and annual end-of-year prescribing statements to PCGs, GPs, Health Authorities, Regional Offices and the Department of Health.

Data

The database (paper-based until computerised in the 1990s) allows 600 million prescriptions to be processed annually.[7] The PPA collects information on all prescriptions issued by GPs that are dispensed by community pharmacists, dispensing GPs, PCGs or appliance contractors in England.[8] Prescriptions are submitted monthly, numbered, coded and keyed into Unix systems.[3] Pricing information is held within the computer and the computer system calculates the drug price. Data are collected on dispensing pharmacy, prescribing GP/PCG, drug details, including quantity dispensed, exemption details and prescription type.

Coding schemes

Since 1981, the PPA has used three structured coding systems for drugs.[2,3]

For drugs covered by the Drug Tariff price, a 'velocity drug code' of two to five digits (the more popular the drug, the shorter the code) is used and converted to a structured code designed for the pricing of drug items in accordance with the Drug Tariff. This is a nine-digit code which links all packs and presentations of the same drug together.

Category D drugs, which are not covered by the Drug Tariff price, have much longer input codes, which are different for each supplier and for each pack size.

The third coding system, the Primary Care Drug Information Database* (PCDID), reflects the BNF, grouping drugs for analysis purposes and enables all like drugs, or chemical substances, to be identifiable under the same therapeutic classification. All PPA information service reports on prescribing are based on this coding system and an agreement has been reached with the BNF to keep the two standards in step. The coding scheme can link to other schemes including BNF, WHO, Pharmaceutical Interface Produce Code (PIP), European Article Number (EAN) and National Supply Vocabulary (NSV).

The PCDID is a 15-digit code:

- Characters 1–7: BNF Therapeutic Classification.
- Characters 8 and 9 define the drug code or chemical substance.
- Characters 10–15 define the product, strength, form and the equivalent.

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* A comprehensive database of drug, appliance, chemical reagent and oxygen pricing information. The database holds details of 30,000 drug preparations and appliances, with main functions being: information is consistent with the Drug Tariff; reimbursement and remuneration procedure for NHS Pharmaceutical Services; links generic drugs to their proprietary equivalents; includes extensive information for each entry, manufacturer, unit of measurement, preparation class, pack size, date first prescribed, pricing information, etc.; historical entries on the database are retained, allowing the PPA to produce historical drug analyses as required.

The code forms the basis of the Prescribing Information Services provided by the PPA to itemise, aggregate, order and present drug-based information.

Completeness and accuracy

The level of notification completeness is thought to be high as pharmacy and dispensing doctor remuneration schedules are calculated through this system.

Staff receive specialised modular training to achieve set standards of accuracy and speed. Uniformity of interpretation and processing is maintained by the use of technical procedure manuals.

Controls built into the PPA databases provide validation of data capture. Checks may be made on individual prescription data where costs appear to be unusual. In-house quality control checks monitor accuracy and consistency of data capture. The Central Quality Assurance Division reprocesses randomly selected samples, investigating any errors found and suggesting remedial action if necessary. The National Prescription Research Centre also independently reprocesses samples of prescriptions. All PPA processes are subject to both internal and external audit.

In 1999–2000 there was an unprecedented rise in the number of Category D prescribing orders (traditionally 1%, peaked at 17% in 1999). As it takes longer to input the codes, by 2000 a 3-month backlog of processing Category D products amounting to 150 million prescriptions had built up. The PPA planned to clear the backlog by the end of 2001.[1]

Uses

The PPA database is used to monitor prescribing and dispensing. Prescribing data are used to inform NHS research and development, NICE and CHI. It can investigate variations and trends in prescribing costs[9] and examine the effective use of drugs for specific diseases such as use of low-level doses of bendrofluazide for hypertension.[1]

PPA data provide a narrow range of information and cannot be linked to demographic/clinical data. If a unique patient identifier (e.g. NHS number) were included on prescriptions, patient-based data and analyses would be available. Since 1990, the Medicines Monitoring Unit (Scotland) has been adding the NHS number to selected prescriptions.[10] Diagnostic data entered on to the prescription would allow prescribing for specific clinical conditions.

The PPA database has been widely used, including an assessment of the impact of on-site counsellors,[11] the quality of prescribing for asthma[12] and for audits of benzodiazepine[13] and antibiotic[14] prescribing. It has also been used to assess the diffusion of anti-psychotic drugs in schizophrenia[15] and for costing ulcer-healing drugs,[16] NSAIDs[17,18] asthma,[18] heart failure,[19] benzodiazepines,[20] antibiotics[21] and wound care.[22,23] Evaluations of the impact of fundholding on prescribing have also used PPA data.[24–27]

Funding

In 1999–2000 PPA expenditure was £53 million, funded mainly from the Department of Health.[1]

Access

Standard PACT report information is sent to each GP and PCGs every quarter (monthly information is available through ePACT.net), covering:

- PCG- or GP-level cost of all prescriptions for that quarter
- number of prescriptions
- the 20 leading cost drugs
- the top 40 BNF sections
- average cost per prescription.

These reports are also available at Health Authority, Regional Office and national level.

PACT prescribing catalogue reports are issued only at the request of the individual prescriber concerned. They contain a full inventory of the prescriptions issued during the relevant period (1–24 months). Prescriptions are grouped by product within each BNF therapeutic group. These reports are available at GP, practice, Health Authority, Regional Office and national level. One use of these reports is in the production of prescribing formularies by GPs, practices or Health Authorities.

PPA information is provided to prescribers, the Department of Health, RHAs, FHSAs, hospitals, Health Authorities, medical advisors, dispensers, police, auditors, Home Office and research groups;[2] *ad hoc* analysis is also available.

Contact details

PPA
Bridge House
152 Pilgrim Street
Newcastle upon Tyne

NE1 6SN
Tel.: 0191 232 5371
Fax: 0191 232 2480
E-mail: info@ppa.nhs.uk

PPA website: www.ppa.nhs.uk

Publications

PPA website listed above.
Annual reports are published – see website.

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PPA data items

Field name
Record type
Period
System code
Contractor
Form number
Item number
Process flag
Process sequence
Form type
Exemption group
Drug code
Velocity
Quantity dispensed
Broken bulk
Unit price
Contractor basic price
Oxygen band
Oxygen journeys
Prescriber type
Prescriber code
Practice code
Community unit
Prescriber basic price
Practice payment
Exemption category
Number of endorsements
Endorsement table
Endorsement code
Endorsement value

Pharmacy Practice Division: PPD (Scotland)

Description

Scottish prescribing data were established in 1985–86 to assess prescription pricing and to calculate the pharmacists' remuneration. The PPD (a Division of the Common Services Agency for the NHSiS) is responsible for the dataset. The aims of the PPD are:

- to process accurately all NHS prescriptions dispensed in Scotland*
- to authorise payments for NHSiS dispensing contractors
- through information services, directly and indirectly, to influence NHS prescribing in Scotland
- to provide services and resources to support pharmacists in developing their professional role
- to support policy development and implementation aimed at cost-effective delivery of NHS pharmaceutical and dispensing services in both primary and secondary care in Scotland.

The dataset also permits the routine analysis of prescribing and dispensing prescriptions and allows GP expenditure to be calculated for GP fund-holding initiatives.

In 1998–99, nearly 59 million prescription items were processed by PPD and analysed by the Primary Care Information Unit (Information and Statistics Division).

The Scottish prescribing system has incorporated the CHI number†, in addition to organisation codes, patient types, net ingredient costs (presently gross), prescription serial number and adjustments, although the impact of the CHI number depends on GPs completing the new prescription forms accurately. Use of the CHI number is seen as helping improve the system, allowing linkage to other datasets and reporting best practice and fraud detection.

Data

Prescriptions are used as the source of information for the database, and these are bundled and sent monthly to PPD from every dispensing unit in Scotland. They are then forwarded to one of the three PPD bureaux (based in Edinburgh, Glasgow and Aberdeen). The bureaux then sort the bundles for data entry (a manual data entry system is currently used) and checking, and the monthly prescription figures are consolidated. From this the business information department issues reports on production. The data are then archived as a database.

The data headings are similar to those in England (except for the inclusion of the CHI number): CHI number, prescription serial number, dispensing pharmacy, prescribing GP, drug details, including quantity dispensed, exemption details and prescription type. Reports are produced 2 months from completion of data entry.

* Includes hospital outpatient prescriptions but not inpatient prescriptions. Items personally supplied and administered by GPs are recorded separately as 'stock orders' via GP10E form submission.

† The Community Health Index Number (CHI number), a 10-digit number incorporating date of birth and sex, that is allocated to patients when they register with a GP in Scotland. The CHI number is used as a patient identifier in primary and secondary care. The Community Health Index is a computerised list of the CHI numbers of all GP-registered patients, together with names and addresses and registration details.

Coding schemes
In 1999, the PPD item code (a unique Scottish system comprising 11 characters) was changed to the 15-character PCDID code in order to keep Scotland in line with the English PPA.

Completeness and accuracy
The level of completeness for notifications and data items is 100%; every prescription dispensed is passed to the PPD. Contractor remuneration is dependent on this process. These values are for NHS prescriptions only; private prescriptions are not seen. In the prescription pricing department, everything is checked monthly; there are also checks at the bureaux to ensure that their data are complete and accurate, and various reporting/cross-checking is also carried out.

The Evadis software system is used for internal validity checks, comprising built-in validation in virtually every field. The computer checks that the default value is correct. The data input system has in-built checks, and the GP and contractor codes are checked for unusually large quantities being dispensed. The consistency of data is checked on a regular basis. All work carried out at PPD meets with ISO 9000 and external audits are processed annually. If any queries arise when entering data, the person entering the data contacts the dispensing pharmacist. The validity checks do not reveal consistent areas of weakness, and the overall validity does not vary from year to year. The GP reference number is sometimes omitted; the GP therefore cannot be contacted as the PPD office only has access to the pharmacist's name.

The Scottish Pharmacist General Council (SPGC) re-enters a random sample of prescriptions every month to ensure that the information is being entered correctly.

Uses
PPD data are used to price prescriptions, thereby calculating the pharmacist's remuneration. They are also used for financial planning, monitoring and forecasting, fraud detection, costs, policy development and monitoring, to provide a behaviour benchmark and for drug information.

Comparisons are made with similar datasets for England, Wales and Northern Ireland for cross-regional comparisons (website, Government Statistical Service, statbase, 2001) drawn from Regional Trends Datatset (RT35717).

Since 1990, the Medicines Monitoring Unit (MEMO) in Tayside has been adding the NHS number (formerly CHI) to all prescriptions for the Tayside region (400,000 people) and prescriptions for certain medicines in the whole of Scotland (5.5 million people), allowing accurate collection of drug records.[1] MEMO provides a service similar to that provided by GPRD (see p. 228) and DIN-LINK (see p. 239). The key data source in MEMO is the unique dispensed prescribing database, a GP-specific, person-specific record of prescribing in the population. Records of all prescriptions dispensed to Tayside residents in community pharmacies are forwarded to MEMO, and the information is entered into a database. This database has records of 15 million dispensed prescriptions, indexed by CHI number, with data on drug name, dose, amount dispensed, regimen, prescribing GP, the date the prescription was written and whether a generic or proprietary preparation was dispensed. Costs can be obtained for all drugs dispensed. This has generated a range of published studies.[2–9]

Funding
Funded by the Common Services Agency NHS Scotland. No detailed costing information is available.

Access
To access information at a patient level (including anonymised data), a researcher would need authorisation from the GP/pharmacist involved. The PPD must then be contacted, who may ask for a confidentiality form to be completed, or may in certain cases need to speak to the Health Board (Medical Prescribing Advisor). Access of information at a district and/or national level is also available. Regional areas are not dealt with at present.

There are facilities for researchers to request specific data. Charges for data requests are dependent on the information supplied, the use of disks/CDs and the staff time.

Contact details
Pharmacy Practice Division
Director, Mrs D Anderson; Administrative Secretary, Ms A McMillan
Elliot House
Hillside Crescent
Edinburgh
EH7 5EA
Tel.: 0131 557 3733
Fax: 0131 557 6883

Websites:
Scottish Health on the Net (SHOW): http://www.show.scot.nhs.uk/
PPD: http://www.show.scot.nhs.uk/psd

Data analysis:
Common Services Agency NHS Scotland
Primary Care Information Unit
Information and Statistics Division (ISD)
Trinity Park House
South Trinity Road
Edinburgh
EH5 3SQ
Tel.: 0131 551 8899
Fax: 0131 551 1392

Websites:
Common Services Agency (ISD):
http://www.show.scot.nhs.uk/isd
Primary Care Information Unit (ISD):
http://www.show.scot.nhs.uk/isd/primary_care/primary_care.htm

Government Statistical Service (Regional Trends):
http://www.statistics.gov.uk

Publications

Reports are summarised on the web and hard copies of reports/information are available from PPD (addresses are listed above).

Analyses of prescribing information are published by the Commons Services Agency in Scottish Health Care Statistics and Drugs Misuse Database Bulletin. See the Primary Care Information Unit (ISD) website (listed above). For cross-sectional analysis of prescriptions dispensed by region, see the Government Statistical Service/statbase website.

References

1. MacDonald TM, Parkinson J, Davey PG, Morris AD, McDevitt DG, McGilchrist MM. PACT data for dispensed drugs linked to NHA numbers are available now. *BMJ* 1998;**316**:1530–1.
2. MacDonald TM, McDevitt DG. The Tayside Medicines Monitoring Unit (MEMO). In Strom BL, editor. *Pharmacoepidemiology*. 2nd ed. Chichester: Wiley; 1994. pp. 245–55.
3. Evans JMM, McDevitt DG, MacDonald TM. The Tayside Medicines Monitoring Unit (MEMO): a record-linkage system for pharmacovigilance. *Pharm Med* 1995;**9**:177–84.
4. Evans JMM, Henderson LE, Goudie B, MacDonald TM, Davey PG. Demand for warfarin anticoagulant monitoring in Tayside. *Scot Health Bull (Edinb)* 1997;**55**:88–93.
5. MacDonald TM, Collins S, McGilchrist MM, Stevens J, McKendrick AD, McDevitt DG, *et al*. The utilisation and economic evaluation of antibiotics prescribed in primary care. *J Antimicrob Chemother* 1995;**35**:191–204.
6. Steinke DT, Seaton RA, Phillips G, MacDonald TM, Davey PG. Prior trimethoprim use and trimethoprim-resistant urinary tract infection: a nested case–control study with multivariate analysis for other risk factors. *J Antimicrob Chemother* 2001;**47**:781–7.
7. Steinke DT, Bain DJ, MacDonald TM, Davey PG. Practice factors that influence antibiotic prescribing in general practice in Tayside. *J Antimicrob Chemother* 2000;**46**:509–12.
8. Evans JM, MacDonald TM, Leese GP, Ruta DA, Morris AD. Impact of type 1 and type 2 diabetes on patterns and costs of drug prescribing: a population-based study. *Diabetes Care* 2000;**23**:770–4.
9. Barbone F, McMahon AD, Davey PG, MacDonald TM. Association of road-traffic accidents with benzodiazepine use. *Lancet* 1998;**352**:1331–6.

Prescription Pricing Services: PPS (Wales)

Description

The PPS is responsible for the prescribing and dispensing database for Wales, on behalf of the WHCSA, which is a special Health Authority within the NHS. The database includes details of all prescriptions dispensed in the community* and is used for the pricing and payment of community dispensing activity and the provision of information services, including:

- management of prescribing costs/drug budgets
- analysis of prescribing patterns, options and trends.

In 1999, 40 million prescriptions items were processed in Wales.[1] Information is exchanged with the PPA (Department of Health, England) for cross-border dispensing and regional comparisons (with England, Scotland and Northern Ireland).

Data

Following dispensing, prescriptions are sorted and batched by the pharmacies and forwarded to the PPS where the data are entered and verified as necessary. A 'priced items file' is produced that is passed to WHIS and used for the production of dispensing contractors' monthly payment schedules and information provision.

Other data required for production of monthly payment schedules (including fees, allowances, GP and pharmacy details) are held by WHIS or

* This is mainly GP prescribing but does include dentists, and NHS hospital prescriptions dispensed in the community, items dispensed by dispensing doctors and items personally administered by GPs.

obtained from other sources. See below for a detailed list of data items collected.

Coding schemes
Drug details are recorded using the PPA coding scheme (see p. 333).

Completeness and accuracy
Payments to dispensing contractors depend on provision of this information and therefore it is considered to be complete and of good quality. Prescribing allocation to specific GPs can be inaccurate if they do not use their own (personalised) prescription pads.

Uses
PPD data are used to price prescriptions, thereby calculating the pharmacist's remuneration. They are also used for financial planning, monitoring and forecasting, fraud detection, costs, policy development and monitoring, to provide a behaviour benchmark and for drug information.

Comparisons are made with similar datasets for England, Scotland and Northern Ireland for cross-regional comparisons[2] drawn from the Regional Trends Datatset (RT35717).

Funding
Funded by the WHCSA. No detailed costing is available.

Access
Ad hoc requests for data are considered, although agreement by the Welsh Office may be necessary. Data are not available at a practice level without the consent of the practice.

Contact details
Dr G Thomas
The National Assembly for Wales
2-002
Crown Building
Cathays Park
Cardiff
CF10 3NQ
Tel.: 02920 82511
E-mail: gwyneth.thomas@wales.gov.uk

Mr D Noon
Welsh Health Information Services
Welsh Health Common Services Agency
Crickhowell House
Pierhead Street
Capital Waterside
Cardiff
CF1 5XT

Publications
Paper reports (with some electronic versions*) of prescribing audit reports and catalogues (PARC), and *ad hoc* reports, etc., are available to GP practices, Health Authorities and the Welsh Office. Summary information is published in Health Statistics Wales and NHS Wales: Quarterly Statistics. See also the the Government Statistical Service website: http://www.statistics.gov.uk

For cross-sectional analysis of prescriptions dispensed by region see Government Statistical Service/statbase website.

References
1. Government Statistical Service, http://www.statistics.gov.uk; 1999.
2. Government Statistical Service. Health Statistics Wales 1998. Cardiff: Welsh Office; 1999.

Prescribing and dispensing information data items

Field name
Record type
Period
System code
Contractor
Form number
Item number
Process flag
Process sequence
Form type
Exemption group
Drug code
Velocity
Quantity dispensed
Broken bulk
Unit price
Contractor basic price
Oxygen band
Oxygen journeys
Prescriber type
Prescriber code
Practice code
Community unit
Prescriber basic price
Practice payment
Exemption category
Number of endorsements
Endorsement table
Endorsement code
Endorsement value

* PC-based with analysis tools, available from PPS at an annual charge covering system support.

Abortion notifications: HSA4, England and Wales

Description

HSA4 was established in 1968 after the 1967 Abortion Act required that details of all terminations of pregnancy be notified to the Chief Medical Officer (CMO). The Department of Health and the ONS maintain a database covering all legal abortions carried out in England and Wales regardless of the country of residence. The ONS on behalf of the CMO collate all the information and provide a fully anonymised (but including postcode) dataset. A Welsh copy of the dataset is extracted* and sent to the Welsh Office. The dataset holds information on 155,000–170,000 legal terminations reported annually in England and Wales.[1]

The database is used to monitor terminations occurring in England and Wales. The notification forms are also checked to ensure the abortion did not contravene the Abortion Act. The information is also used to answer Parliamentary Questions.

Proposed changes in the form were out to consultation in late 2000. Two main reasons were given for why a review of the HSA4 form was being undertaken. The first was that any changes, no matter how straightforward, in the layout or content of the form require amendment Regulations because the form is specified in the Abortion Regulations 1991. This was seen as unnecessarily complex and our intention is that the Regulations specify the content of the notice and other information but not the format in which it has to be given. The Department of Health proposed to continue to supply forms for registered medical practitioners to use, but as the form would not be included in the Regulations any future stylistic changes could easily be made. It was noted that about 4% of forms are incorrectly filled in and are returned to registered medical practitioners for completion. The options for electronic transfer of data were being considered.

The second reason for a review of the form was to ensure that the Regulations comply with the Human Rights Act 1998, which came into force on 2 October 2000. The Government considered the 1967 Abortion Act, as amended, to be in compliance with the Human Rights Convention (HRC) and the Human Rights Act 1998. The restriction in the Abortion Regulations that a woman can only see the HSA4 relating to her termination via a registered medical practitioner may not comply with Article 8 of the HRC and the Government intended to remove this restriction. As the Regulations need to be amended to give effect to this, it was seen as timely to examine the data items collected to consider if any can be removed and if any need to be added.

The Abortion Regulations 1991 also prescribe the wording and layout of the two forms in which medical practitioners certify their opinion that there are grounds for carrying out a termination (HSA1 and HSA2). These would also be amended.

An issue of particular interest was the feasibility of adopting the Caldicott recommendation on using the NHS number or other identifier instead of patient name and address. This could help improve patient confidentiality as an individual's details would not be available simply from sight of the form.

The Government was also considering extending the time for returning the form from 7 to 14 days after the termination, which was understood to help with administrative arrangements, as meeting this deadline can sometimes be a problem.

Data

Statutory regulations prescribe the information to be notified and its form HSA4 'Abortion Notifications' are returned continuously for each termination of pregnancy from all NHS hospitals and approved places. The doctor performing the termination is required to complete a notification of abortion form. Following checking, the forms are forwarded to the ONS where they are scrutinised for completeness and accuracy. The forms are anonymised, statistically coded and processed, within 2 weeks of receipt. No patient names are held on the database and the paper returns are destroyed after 3 years.

Data are collected under 11 headings, including practitioner, patient, gestation, grounds for termination, selective termination, method of termination, sterilisation, death details and details of antiprogesterone with prostaglandin treatments. A detailed list of data items is given on pp. 342–4.

* Details of all terminations performed in Wales and those performed on Welsh residents in England. The original database (disk copy) sent to the Welsh Office is kept under strict security procedures. The postcode information is removed from the computer copy held at the Welsh Office.[2]

Coding systems
ICD-10 has been used since 1995, replacing ICD-9.

Completeness and accuracy
Abortion data have been collected since 1968. Section 37 of the Human Fertilisation and Embryology Act 1990 changed the Abortion Act 1967, in turn changing some of the statistics collected before and after April 1991. In particular it affected the time limit for some of the statutory grounds for abortion and introduced a new statutory ground (website, statbase, June 2001). A summary of the changes is in the OPCS publication 'Abortion Statistics 1991' series AB, no. 18.

Completeness of notifications is thought to be high, owing to the legal requirement to notify all abortions. Any registered medical practitioner failing to notify is liable to prosecution. Various system checks are made for duplicate records and missing serial-numbered returns. These checks suggest a 2% error rate, with the main weakness being incomplete/inaccurate postcodes.

As noted above, about 4% of forms are returned incorrectly completed.

No external validation occurs, owing to restrictions on the release of data and confidentiality rules.

Uses
Data are available at regional health authority, district health authority and (from 1992) local authority area levels.

The database reports variations in service use by area, in ways similar to those on immunisation/vaccination and screening. A review of the effects of legalising abortion drew heavily on the abortion returns.[3]

Funding
Funded by the Department of Health and the National Assembly of Wales. No cost information available.

Access
Data are published quarterly about 6 months after the end of the quarter. Summary annual data are produced 7 months after the end of the year with final detailed data published 12 months after the end of the year. Patient-identifiable data or individual patient records with data items necessary for data linkage will not be released to outside researchers. Individual patient data (anonymised with no linkage data) may be released via the CMO for bona fide scientific research. Information aggregated at district levels and above is freely available and is published annually and quarterly. Researchers may request specific data from the CMO, with charges dependent on the complexity of the request.

Contact details
Morbidity Statistics Division
Office for National Statistics
Segensworth Road
Titchfield
Hampshire
PO15 5RR
Tel.: 01329 813618
Fax: 01329 813637
E-mail enquiries (publications):
lyn.watmore@ons.gov.uk
Website: http://www.statistics.gov.uk

C Roberts
Health Statistics and Analysis Unit
Welsh Office
Cathays Park
Cardiff
CF1 3NQ
E-mail: cath.roberts@wales.psi.gov.uk

Policy enquiries:
A Duncan
Health Promotion Division
Department of Health
Wellington House
113–135 Waterloo Road
London
SE1 8UG

Publications
Provisional quarterly and annual figures for abortion by age, area and gestation appear in Health Statistics Quarterly. Abortion statistics, Annual Reference Volume (final figures and a high level of detail) and Health Statistics Wales. The latest available data are for 1998 (website, June 2001).

Other key publications also draw on the HSA4 data (including Population Trends, Birth Statistics, On the State of the Public Health, Public Health Common Dataset, Health and Personal Social Statistics, Social Trends, Social Focus on Women and UN Demographic Year Book).

Uses of abortion statistics in health technology assessment include analysis of variations by Health Authority[4] and trends over time.[3]

Website: http://www.statistics.gov.uk

References

1. ONS. In: Wisniewski D, editor. Annual abstract of statistics: 1998. London: The Stationery Office; 1998.
2. NHS Wales. Review of national databases. Cardiff: NHS Wales; 1998.
3. Munday D, Francome C, Savage W. Twenty one years of legal abortion. *BMJ* 1989;**298**:1231–4.
4. Raleigh VS. Abortion rates in England in 1995: comparative study of data from district health authorities. *BMJ* 1998;**316**:1711–12.

Abortion notification: HSA4 data items

Practitioner terminating pregnancy
Name
Address
Signature
Date

Certification
In all non-emergency cases: particulars of practitioners who joined in giving Certificate A:

	1	2[a]
Name		
Permanent address		
Did practitioner named at:	1	2
Certify he saw/and examined pregnant woman before giving certificate?	y/n	y/n

Name and address of place of termination
Was patient NHS case terminated in an approved place under an agency agreement?

Patient details
Surname
Forenames
Address
Postcode
Country (if resident outside England and Wales)
Present address in England and Wales, including postcode
Date of birth
Marital status:
- Single
- Married
- Widowed
- Divorced
- Separated
- Not known

Parity:
- Livebirths
- Stillbirths
- Spontaneous miscarriages
- Legal terminations

Administrative termination details[b]
Admission date
Termination date
Discharge date
Was this a planned day case?

Gestation details

Pregnancy:	Has not exceeded 24th week	Has exceeded 24th week
Number of weeks gestation (estimated):		

Method(s) of estimation:
- LMP
- Ultrasound
- Other (specify)

continued

Grounds for termination

The certified ground(s) for terminating the pregnancy stated on Certificate A were:

A. that the continuance of the pregnancy would involve risk to the life of the pregnant woman greater than if the pregnancy were terminated: State main medical conditions(s)
B. that the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman: State main medical condition(s)
C. that the pregnancy has not exceeded its 24th week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman: State main medical condition(s)
D. that the pregnancy has not exceeded its 24th week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of any existing child(ren) of the pregnant woman: State number of children
E. that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped:
   State either:
      Diagnosis
      Method(s) of diagnosis:
         Aminocentesis
         Ultrasound
         Chorionic villus sampling
         Other (specify)
   Or
      Condition in pregnant woman causing suspected condition in fetus:
         Specify condition in woman
         Specify condition in fetus

Emergency only

Termination was immediately necessary, as stated on Certificate B:

   To save the life of the pregnant woman
      State main medical condition(s)
   To prevent grave permanent injury to the physical or mental health of the pregnant woman
      State main medical condition(s)

Over 24 weeks gestation

If the pregnancy was terminated after it had exceeded its 24th week, please give below a full statement of the medical condition of the pregnant woman/fetus

Selective termination

If selective termination:
   Original number of fetuses
   Number of fetuses reduced to

Method of termination

Cervical preparation?
Method of termination:
   Surgical termination:
      Vacuum aspiration
      Dilatation and evacuation
      Hysterotomy
      Hysterectomy
      Other surgical (specify)
   Medical termination:
      Prostaglandin only
      Prostaglandin with:
         Oxytocin
         Antiprogesterone
         Other medical agents (specify)
Complications:
   None
   Haemorrhage
   Uterine perforation
   Sepsis
   Other (specify)[c]

continued

Sterilisation		
Sterilisation performed (y/n)		
Death details		
In case of death:		
Date		
Cause		
Details of antiprogesterone with prostaglandin treatments		
Treatment:	Antiprogesterone	Progesterone
Date		
Name		
Address		
Date termination confirmed		
Patient an NHS case treated under an agency agreement? (y/n)		

[a] Unless operating practitioner joined in giving Certificate A.
[b] If antiprogesterone with prostaglandin termination without surgical termination, do not complete this section.
[c] Do not enter evacuation of retained products of conception as a complication.

Family planning

Family planning activities (England): KT31

Description

The Department of Health's annual return KT31 collects information on services provided in England by NHS family planning clinics, Brook Advisory Centres and other clinics funded wholly or partly by the NHS. Data are not collected on family planning services supplied by GPs, consultants in outpatient clinics or non-NHS-funded clinics. In 1998–99, data were collected on 1.2 million women and 80,000 men attending family planning clinics (bulletin, Department of Health website, 2001).

Changes in the return were reported to be under review as part of the National Sexual Health and HIV Strategy.[1]

Data

Data are collected annually at Trust level on number and type of contacts made (by age and gender) and methods of contraception supplied, including emergency contraception. See pp. 345–6 for full details of data collected.

Completeness and accuracy

It is estimated that the coverage of the KT31 return is limited to around one-fifth of the total number of women (aged 16–49 years) using family planning services. This is because the majority of women go to their GP for family planning services and, as described above, the KT31 return only covers NHS Trust-funded clinics (bulletin, Department of Health website, 2001).

In 1999–2000 (the most recent data available in 2001), all 176 NHS Trusts known to provide family planning clinic services in England made returns for 1998–99 except Epsom Healthcare, and all 14 Brook Advisory Centres submitted returns. Where a provider is unable to submit a return, data from the latest available year are used. Where parts of a return are missing, the corresponding parts from the latest available year are used, scaled as appropriate. A few returns were incomplete and estimates were made of the missing data using the provider's data from the latest available year (bulletin, Department of Health website, 2001).

Uses

KT31 returns provide the basis of the bulletins published annually by the Department of Health Statistics Division under the annual publications NHS Contraceptive Services, England.[2,3] KT31 annual returns are also used to monitor the Health of the Nation objective, to ensure the provision of effective family planning services for those who want them and evaluate progress in the Health of the Nation target D3 (prevention of pregnancies in females under 16). The data are used in the public expenditure survey negotiations and NHS resource allocation.

Some very limited data are available on GP and hospital family planning services and some data are available from the Department of Health's analysis of prescriptions. Other national data about the use of contraception are collected in the General Household Survey and in the Omnibus Survey, both run by the ONS and referred to in the annual bulletin reporting on KT31 returns to

provide an overview of family planning activity (bulletin, Department of Health website, 2001).

Funding

Funded by the Department of Health Statistics Division. No detailed costing information is available.

Publications

Annual bulletins: NHS Contraceptive Services, England. Copies of the bulletins are available from the Department of Health at the address below or the most recent bulletin report (in June 2001 the bulletin was for 1998–99). See Department of Health website: http://www.doh.gov.uk/public/sb9930.htm.

Contact details

L Lancucki
Statistics Division 2B
Department of Health
Skipton House
80 London Road
London
SE1 6LW
Tel.: 020 7972 5533
Fax: 020 7972 5662
E-mail: lesz.lancucki@doh.gsi.gov.uk

Copies of the bulletin are on the website or available from:
Department of Health
PO Box 777
London
SE1 6XH
Tel.: 0541 555455
Email: doh@prologistics.co.uk
Website: http://www.doh.gov.uk/public/sb9930.htm

References

1. National sexual health and HIV strategy, Progress Report 2000. London: Department of Health; 2000.
2. Bulletin: NHS contraceptive services, England: 1998–99. London: Department of Health; 1999 (Department of Health website, 2001).
3. Department of Health. NHS contraceptive services, England, 1999–2000. London: Department of Health; 2001.

Family planning activities (England): KT31 data items

Number of contacts	
Type of contact:	
Clinic attendance	
Domiciliary visit	
Total	
Number of clinic sessions for people aged under 20 years	
Type of contact:	
Clinic session	
Total contacts in young persons' clinics	
Number of first contacts in financial year – females	
By age groups:	Under 15/15/16–19/20–24/25–34/35+/total
Main method of contraception chosen:	
Combined preparation oral contraceptive	
Progestogen oral contraceptive	
IUD	
Cap, diaphragm	
Injectable contraceptive	
Other chemicals including sponge	
Male sheath/condom	
Female sheath/condom	
Rhythm method	
Female sterilisation	
Other methods	
No method provided	
Contact for reasons other than contraceptive	
Total	

continued

Post-coital contraceptives – females	
By age groups:	Under 15/15/16–19/20–24/25–34/35+/total
Type:	
Hormonal	
IUD	
Total	
Number of first contacts – male	
Type of contact:	
Vasectomy	
Male sheath/condom	
Other method	
No method provided	
Contact for reasons other than contraception	
Total	
Number of vasectomies	
Total number, all operations in family planning clinics, outpatient clinics or under contract	

Family planning services (Northern Ireland): KT31

Description

Aggregate information on family planning activities, including total contacts and method of contraception chosen at first contact. This return was under review in 2000.

Data

The process of data collection is quarterly at Trust level. Data are collected under three main headings (total contacts, by type of contact; first contacts: female, main method of contraception chosen, categorised by age; and first contacts: male, main method of contraception chosen). See below for details of data items collected.

Contact details

RIB (Community Services)
DHSS
Annexe 2
Castle Buildings
Stormont
Belfast
BT4 3UD
E-mail: rib.dhss@nics.gov.uk

Publications

Community Service Bulletins.

Family planning services (Northern Ireland): KT31 data items

Purchaser name									
Purchaser code									
Total contacts									
Type of contact:	Number of contacts								
Clinic attendance									
Domiciliary visit									
Total									
First contacts: female: main method of contraception chosen									
Age:	>16	16–19	20–24	25–29	30–34	35–39	40–44	45+	Total
No. of first contacts:									
Oral contraceptive:									
Combined preparation									
Progestogen									
IUD									
Cap, diaphragm, sponge									

continued

Sheath Chemicals Rhythm method Female sterilisation Implant Other methods No method provided Total
First contacts: male: main method of contraception chosen No. of first contacts: Vasectomy Sheath Other method No method provided Total
Provider comment:

Family planning: ISD (Scotland) 19–21

Description

The Family Planning dataset holds information on all family planning services provided by Health Boards in Scotland.

Returns are made in three categories:

- *ISD(S)19: Clinic Services*: Patients attending family planning clinics.
- *ISD(S)20: Domiciliary Services*: Patients visited in their homes to be given family planning advice.
- *ISDS(S)21: Contraceptive Services Provided by GMPs*: General medical practitioners providing contraceptive services, and the fees due for this service.

Data

Annual paper returns for ISD(S)19 and 20 and quarterly returns* for ISD(S)21 are completed at the Health Board level. A limited amount of information is also supplied by the Lothian Brook Advisory Centres. Returns are sent to ISD Scotland where they are checked, entered on a spreadsheet and used in the production of Scottish Health Statistics (website listed on p. 348).

Three forms are used to collect data [clinic services, ISD(S)19; domiciliary services, ISD(S)20; and contraceptive services provided by GPs, ISD(S)21]. See pp. 348–50 for a full list of the data items collected by each form.

Completeness and accuracy

In March 2001, the ISD(S)(19) form was revised to collect more data on clinic attendance; 2001–02 is viewed as a 'transition' period between the old dataset and the new dataset with usable data available in March 2002.

Information on prescribed contraception dispensed by community pharmacists became available in 2001 (website, Scottish Health Statistics, June 2001). Data on emergency contraception are not available.

Information on the contraceptive method chosen is only collected for patients attending Family Planning Clinic Services. ISD(S)19 and information on this topic therefore represent only part of the picture. It is possible that the patterns of contraception use among those using other types of family planning service differ from those reported (website, Scottish Health Statistics, June 2001).

Uses

Mainly administrative; there are no reported uses in health technology assessment.

Funding

Funded by the Scottish Executive Statistics Division. No detailed costing information is available.

* Although ISD(S)21 returns quarterly information, only the last quarter of the year is used.

Contact details

Information and Statistics Division
Common Services Agency
The National Health Service in Scotland
Trinity Park House
South Trinity Road
Edinburgh
EH5 3SQ
Tel.: 0131 552 6255
Fax: 0131 551 1392

Website: http://www.show.scot.nhs.uk/isd/Scottish_Health_Statistics/SHS2000/home.htm

Publications

Summary tables are published in Scottish Health Statistics. In June 2001, tables based on 1998–99 data were listed on the website (given above).

For more general information on sexual and reproductive health, see http://www.show.scot.nhs.uk/isd/index.htm

Family planning services: clinic services: ISD(S)19 data items

Health Board

Age of patient

Total number of patients, by age at first visit or attendance in the year

Age groups:	Male	Female	Total
Under 16			
16–19			
20–24			
25–34			
35 and over			
Total			
of which no. of new patients (in Health Board area)			

Parity[a] of patient

Total number of female patients at first visit or attendance of the year, by parity

Parity:	
0	
1–2	
3 and over	
Total	

Contraceptive method

Number of persons adopting each of the following contraceptive methods:

None	
Cap	
Condom	
IUD	
Oral combined pill	
Oral progestogen pill	
Injectable	
Female sterilisation (counselling)	
Vasectomy (counselling)	
Other	
Not known/not applicable	
Total	

Vasectomy

Number of male patients:

Age group:	Counselled	Operations performed
Under 25		
25–29		
30 and over		
Total		

Special services

Are separate sessions held by the Health Board's family planning clinics for psychosexual counselling?
Are separate sessions held by the Health Board's family planning clinics for subfertility counselling?

continued

Premises Type of premises in regular use for family planning sessions (as at the end of the year): Family planning clinics Hospital premises Health centres Other Total
Sessions and attendances: Total number: Sessions (all types) Patient attendances
Comments (including any factors which may account for significant variations from previous years)
[a] Number of pregnancies of duration beyond 28th week, includes those resulting in stillbirths but not abortions/miscarriages. Multiple births count as one.

Family planning services: domiciliary services: ISD(S)20 data items

Health Board			
Age of patient Total number of patients (old and new) visited by age at first visit in year			
Age	Male	Female	Total
Under 16			
16–19			
20–24			
25–34			
35 and over			
Total			
Number of visits to patients Type of visit			
Involving an FP[a] doctor (with or without a nurse or other FP worker)			
Not involving an FP doctor			
Unproductive visits			
Total			
Number of patients removed from the domiciliary list during the period Reason for removal from list			
Transfer to clinic/GP			
Vasectomy			
Female sterilisation			
Moved from area/lost trace			
Not followed up			
Other reasons			
Total			
Comments (including any factors which may account for significant variations from previous years)			
[a] FP, family practice.			

Family planning services: contraceptive services provided by general medical practitioners: ISD(S)21

Health Board ID		
Number of practitioners at first day of quarter		
Number of practitioners for whom the HB:	Was responsible	Was not responsible
Principles in contract with HB:		
To provide general medical services		
To provide contraceptive services		
To provide contraceptive services only to patients for whom they provide general medical services		
To whom payment will be due at the end of the quarter for the fitting of IUDs		
Number of fees due for payment at end of quarter[a]		
Number of fees:		
For provision of ordinary contraceptive services		
For provision to temporary residents		
For fitting of IUDs		
Comments (including any factors which may account for significant variations from previous years)		

[a] Current claims: i.e. claims received during each of the preceding four quarters which are still current (although this return is completed quarterly, it is the December quarter that is used).

Family planning activities (Wales): KT31

Description

The National Assembly for Wales compiles data on family planning services activities in NHS clinics, domiciliary services and non-NHS clinics funded by the Health Authority. This forms part of the series of returns which make up the 'Korner Returns – Community Health Service Activity'.

Data

Data are collected on the number of people seen in NHS family planning clinics and the method of contraception chosen, including emergency contraception. Data are collected each financial year and published annually. See p. 351 for full details of data items collected.

Completeness and accuracy

Information on GP family planning services is excluded, as are NHS hospital outpatient clinics and other agencies providing family planning services not funded by the NHS. The data cover Wales and are available for NHS Trusts. Some information dates back to 1990–91, although the details collected were restructured in 1995. In June 2001 the latest available data on KT31 returns was for 1996–97.

Uses

Analyses of the KT31 returns are used to produce the statistical brief on family planning services in Wales produced annually.[1]

Funding

Funded by the National Assembly for Wales, Statistical Directorate, Health Statistics and Analysis Unit. No detailed costing figures are available.

Contact details

Mrs D Leigh
Health Statistics and Analysis Unit
Welsh Office
Cathays Park
Cardiff
CF1 3NQ
Tel.: 02920 825036

Publications

Statistical brief produced annually. Summarises information over time about family planning services provided by the NHS in Wales (in June 2001 the analysis was based on KT31 returns for 1996–97). A summary of the brief is on the web at http://www.statistics.gov.uk/statbase/ but this does not provide detailed information.

Full details are available in hardcopy only[1] from the Welsh Office (see contact details).

Reference

1. Family planning service in Wales – Annual statistical brief. Cardiff: Health Statistics and Analysis Unit, Welsh Office; 2000 (hardcopy only).

Family planning activities (Wales): KT31 data items

Trust name Contact within Trust Telephone number Contact address
Number of first contacts in financial year – females By age groups: Under 15/15/16–19/20–24/25–34/35+/total Main method of contraception chosen: Combined preparation oral contraceptive Progestogen oral contraceptive IUD Cap, diaphragm Sponge Sheath Chemicals Rhythm method Female sterilisation Female sheath Injectable contraceptives Contact for reasons other than contraceptive Implants Other methods No method provided Total
Post-coital contraceptives – females By age groups: Under 15/15/16–19/20–24/25–34/35+/total Type: Hormonal IUD Total
Number of first contacts in the financial year – male Type of contact: Vasectomy Male sheath/condom Other method No method provided Contact for reasons other than contraception Total
Total contacts in the financial year Type of contact: Clinic attendance Domiciliary visit Total
Number of clinic sessions in the financial year for people aged under 20 Type of contact: Young persons' clinics
Time taken to complete form Notes Signed Position Dated

Appendix 5

Adverse events and confidential enquiries

Contents

Adverse event reporting

Adverse drug reaction databases: Yellow Card and HIV Adverse Drug Reactions Reporting Schemes

Description

The Yellow Card Scheme for spontaneous reporting of suspected adverse drug reactions (ADRs) was introduced in 1964 after the thalidomide tragedy. Since then, more than 400,000 reports of suspected ADRs have been submitted to the Committee on Safety of Medicines (CSM)/MCA on a voluntary basis by doctors, dentists, pharmacists and coroners, and by pharmaceutical companies under statutory obligations; around 18,000–20,000 yellow cards are submitted each year. The MCA acts as the agent of the licensing authority and handles all aspects of drug regulation, including post-marketing surveillance.

In September 2000, changes were made to the yellow card to facilitate reporting. The major alterations are changes to patient details (to strengthen patient confidentiality) and the inclusion of a patient identification number (MCA/Yellow Card website, 2001).

Since October 1997, the HIV Adverse Drug Reactions Reporting Scheme, a collaboration between the MCA, MRC HIV Clinical Trials Centre and CSM, has requested the reporting of suspected ADRs occurring in HIV-positive persons. Within the first 7 months of launching the scheme, 207 reports were received, of which 129 were through the HIV ADR Reporting Scheme and the remaining 78 via the Yellow Card Scheme.

Data

Suspected ADRs to any form of therapeutic agent including prescribed/self-medicated drugs, blood products, vaccines, X-ray contrast media, dental or surgical materials, intra-uterine devices (IUDs), herbal products and contact lens fluids. Reporters are requested to record on 'yellow cards' all suspected reactions to newer drugs (however minor) and all serious suspected reactions to established drugs and vaccines (even if the effect is well recognised).

Notifications of ADRs arrive on the yellow cards to the MCA usually by post, where they are sorted for system entry (fatal and serious reactions take priority). The timescale involved for the processing of all reports is:

- 90% of Fatal Reports are processed within 24 hours, the remainder within 72 hours.
- 95% of Serious Reports are processed within 72 hours, the remainder within 7 working days.
- 80% of Non-serious Reports are processed within 7 working days, the remainder within 10 working days.

Incomplete yellow cards are returned to originators requesting the information necessary to complete the report. Once completed, the data are entered in a three-stage process:

- transcription: basic data (patient and reporter details, drug and reaction details) entered
- classification: entered data checked for accuracy, and additional information such as history investigations entered
- assessment: of all data entered plus an assessment of whether or not the MCA needs to contact the reporter for further clarification before the report is committed to the database.

The Yellow Card Scheme includes the following:

- reporting doctor's details, including name
- patient's details, initials and age (prior to 2000, name and date of birth were collected)
- local patient identification number (since 2000)
- suspected drug details
- other drugs taken in the last 3 months, including self-medication
- additional relevant information.

HIV Adverse Drug Reactions Reporting Scheme:

- reporter's details, including name
- clinician's details (if not the reporter)
- patient's details, including local patient identification number, patient initials and age
- suspected drug
- other drugs taken in the last 3 months
- description of reaction
- additional information.

A more detailed list of data items collected is given on pp. 356–7.

Coding systems

The ADR database employs a unique coding scheme in the form of a Medical Dictionary and a Drug/Product Dictionary. The Medical Dictionary is hierarchical and multi-axial and incorporates the terms of the WHO ADR terminology, Coding Symbols for a Thesaurus of Adverse Reactions Terminology (COSTART), the International Classification of Diseases ICD-9 and ICD-9CM and the Royal College of General Practitioners (RCGP) dictionary. The Drug/Product Dictionary

includes information on all licensed UK products. Drug substances and products are linked into a four-level hierarchical classification based on the Nordic Anatomical, Therapeutic and Chemical (ATC) classification.

Completeness and accuracy

Changes to the data collected on the Yellow Card Scheme in 2000 do not impact on time series analyses (MCA Yellow Card website, June 2001) of the data.

In 1991, a new computer system, ADROIT, was introduced. ADR pre-1991 data are stored on a separate database and the information is reportedly less comprehensive and accurate than the records stored on the new ADROIT system. For important investigations requiring pre-1991 records, the data are re-entered from the original reports.

All incomplete yellow cards are followed up. At each stage of data entry, the accuracy of information entered into the database is verified. The ADROIT system has a number of in-built automatic quality control checks that alert the user to on-line errors. No information is available on external validation.

Uses

The Yellow Card Scheme provides a monitoring service for drug safety by:

- providing early warnings of previously unexpected ADRs
- comparing the ADR profiles of medicines within therapeutic classes
- allowing continuous safety monitoring of medicines throughout their usage
- eliciting factors predisposing patients to ADRs.

Funding

MCA is funded partly by the Department of Health and partly by charges to companies. MCA expenditure was £25 million in 2000. The costs of the ADR function are not distinguished.

Access

Health professionals may request information by contacting the Yellow Card Information Service or the MCA (non-healthcare professionals). Aggregated information [Drug Analysis Print (DAP)] listing all reactions suspected to be associated with a particular product is available on request. Anonymised details of cases of interest (from DAP) may also be released to health professionals on request. No charge is made.

Contact details

Yellow Card Adverse Drug Reactions Reporting Scheme
Medicines Control Agency
CSM FREEPOST
London
SW8 5BR

Yellow Card Information Service:
Tel.: 0800 7316789
E-mail: info@mca.gov.uk
Website: http://www.open.gov.uk/mca/ourwork/monitorsafequalmed/yellowcard/yellowcardscheme.htm

HIV Adverse Drug Reactions Reporting Scheme
FREEPOST
London
SW8 5BR
E-mail: info@mca.gov.uk
Website: http://www.open.gov.uk/mca/ourwork/monitorsafequalmed/adrschemes/hivadrscheme.htm

Publications

MCA Annual Report and Accounts 1999/2000, London, 2000 (see website).
Yellow Card Schemes and HIV ADR Reporting Scheme News (see websites).
MCA website: http://www.open.gov.uk/mca/
Yellow Card website: http://www.open.gov.uk/mca/ourwork/monitorsafequalmed/yellowcard/yellowcardscheme.htm
HIV ADR Reporting Scheme website: http://www.open.gov.uk/mca/ourwork/monitorsafequalmed/adrschemes/hivadrscheme.htm

Adverse drug reaction databases: Yellow Card and HIV Adverse Drug Reactions Reporting Schemes data items

Yellow Card Scheme

Reporting doctor's details Name Specialty Address Telephone number Signature
Patient's details Initials Age Sex Weight Hospital Patient identification number Consultant in charge/GP principal
Suspected drug Brand name Batch number Route Daily dose Date drug: Started Stopped Therapeutic indication
Suspected reactions Suspected reactions Yes/No Was patient hospitalised because of the reaction? Date reaction: Started Ended Outcome (e.g. fatal, recovered continuing)
Other drugs taken in the last 3 months, including self-medication Brand name Route Daily dose Date drug: Started Stopped Therapeutic indication
Additional relevant information Include medical history, allergies, suspected drug interactions If congenital abnormality reported, state all other drugs taken during pregnancy and the LMP
LMP, last menstrual period.

HIV Adverse Drug Reactions Reporting Scheme

Reporter's details Name Professional address Specialty Date Signature
Clinician's details (If not the reporter) As above Doctor's signature (nurse reports only)
Patient's details Patient identification number Weight Initials Sex Age Does the patient have AIDS? CD4 count (with date): Lowest ever Most recent Most recent HIV RNA viral load (copies/ml) (with date)
Suspected drug Brand name Batch number Route Daily dose Date drug: Started Stopped Therapeutic indication Causality: Likely Possible Uncertain
Other drugs taken in the last 3 months Brand name Route Daily dose Date drug: Started Stopped Therapeutic indication
Description of reaction Description Date reaction: Started Ended Outcome
Additional information Including medical history, allergies, investigations

The Medical Devices Agency (MDA): Adverse Incident Centre

Description

Established in 1994, the MDA is an Executive Agency of the Department of Health. It is the designated Competent Authority for the UK, which means that it has the responsibility for enforcement of the medical devices regulations across England, Scotland, Wales and Northern Ireland. The Adverse Incident Centre (AIC) receives and coordinates information on the adverse incidents concerning medical devices received by the MDA. However, the MDA is only responsible for adverse incident reporting and investigation within England. Each of the other countries has its own arrangements. The Device Technology and Safety Division (DTS) is responsible for the investigation of adverse incidents associated with medical devices. Following investigation into incidents, the MDA may issue device bulletins, hazard or safety notices concerning devices, to the UK health services.

The MDA received over 6860 adverse incident reports during 1999–2000, following an underlying trend of an increase in the reporting rate by 12–15% annually (MDA annual report, 2000).

Data

The MDA should be notified about adverse incidents as soon as possible, with serious cases reported by the fastest means possible. Printed forms are available on the Internet (MDA website, listed below).

The MDA incident notifications are entered on to the database and reported to the AIC, which refers to the appropriate device specialist for analysis and action recommendation. The following response methods are available:

- in-depth investigation by a technical expert for reports involving death or serious injury
- mid-tier investigation, which involves the collection of information allowing appropriate action to be taken (including later in-depth investigation)
- proforma investigations, which involve responsibility for resolving the situation lying with the manufacturer.

Reports and results are logged for subsequent analysis. Data are collected under three main headings: origin of report, details of medical device involved and the nature of incident or defect. A detailed list of data items collected is given on p. 359.

Coding systems

Internally, the MDA uses a Broad Heading/Specific Equipment (BH/SE) system, which was originally devised as a filing system. For exchange of information between Competent Authorities, the MDA uses the ECRI UMDNS (Universal Medical Device Nomenclature System).

Completeness and accuracy

The number of data fields on the database, completed as part of the incident-inputting procedure, varies depending on the device involved in the incident report, as not all of the fields are relevant to each type of medical device. Many of the reports received lack information owing either to not being completed by the reporter or to the information not being available at the time. The MDA encourages people to report incidents as soon as possible rather than delaying to find out further information.

There is no information available regarding the accuracy of the database. There is no internal validation. The information entered is reviewed as part of the assessment of the incident report in order to determine what action should be taken. There is no process of external validation.

Funding

The MDA is funded by the Department of Health under a 'gross cost' regime. Funding for 1999–2000 was £9.2 million (MDA annual report, 2000).

Access

Information can be obtained via the Internet. There is no charge for information; however, information released is anonymised and the MDA restricts what information is made available to whom.

Contact details

Medical Devices Agency
Hannibal House
Elephant and Castle
London
SE1 6TQ
Tel.: 020 7972 8000
Fax: 020 7972 8108

E-mail: mb-mda-aic@doh.gsi.gov.uk
MDA website: http://www.medical-devices.gov.uk/

Publications

MDA annual reports and other publications are listed on the MDA website: http://www.medical-devices.gov.uk/publicat.htm

Most recent annual report (July 2001): 1999–2000 Annual Report and Accounts, MDA 2000 (see website: http://www.medical-devices.gov.uk/annrep992000.pdf).

Device Bulletins (see http://www.medical-devices.gov.uk/de_bulls.htm).
Guidance information, MDA website: http://www.medical-devices.gov.uk/mda-aic.htm

MDA: Adverse Incident Centre[a] data items

Origin of report
Trust/hospital/unit
Contact details
Date and time of incident
Details of medical device involved
Generic type
Brand name
Model/size
Serial/product code number
Batch/lot number
Manufacturer/supplier
Contact details
Presence of 'CE' marking (y/n/nk)
Date of manufacture
Date put in use
Quantity defective
Location of device now
Nature of incident or defect
Was injury caused (y/n)
If yes:
To whom (patient/staff/other)
Nature of injuries and treatment
Consultant in charge
Details of incident or defect and local action taken
[a] This is the general adverse incidents reporting form; there are similar versions relating to devices including wheeled mobility equipment, ancillary items, external limb prostheses and pacemakers.

Confidential enquiries

Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI)

Description

The CESDI was established in 1992 (beginning data collection in 1993) to improve understanding of how the risks of death in late fetal life and infancy, from 20 weeks of pregnancy to 1 year after birth, might be reduced. CESDI attempts to identify risks which can be attributed to suboptimal clinical care.

In 1991, the Department of Health directed that the 14 'Regions' of England should undertake Perinatal Mortality Surveys. CESDI was subsequently organised on this regional basis with separate arrangements for Wales and Northern Ireland. Each region is autonomous and has a full-time coordinator together with varying numbers of support staff. The network of CESDI has remained despite organisational changes in the NHS during 1994–95 and 1998–99.

Originally funded directly by the Department of Health and supervised by a National Advisory Body (NAB), CESDI has been managed by the Maternal and Child Health Research Consortium (MCHRC) since 1996 with representatives from four Royal Colleges (Royal College of Obstetrics and Gynaecologists, Royal College of Paediatrics and Child Health, Royal College of Pathologists and Royal College of Midwives). Since 1999, NICE has had overall responsibility of CESDI.

CESDI has two main functions: an overview of the numbers and causes of stillbirth and infant deaths and an enquiry system in which detailed analysis can be made into specific sub-sets of these deaths (these sub-sets change annually).

The enquiry collects information on around 10,000 stillbirths and deaths in infancy per year occurring in England, Wales and Northern Ireland. Scotland has its own enquiry system, the Scottish Stillbirth and Infant Death Survey (SSBID) (see p. 364), and Wales also has the more detailed All Wales Perinatal Survey (AWPS) (see p. 381), which provide data to CESDI.

Incorporation of the NHS number (or the introduction of NHS birth numbers) is seen by CESDI as valuable for linkage studies, such as the 27–28 weeks gestation study, but was deemed not feasible with the present system.

Data
Rapid Report Forms (RRFs) are used to notify CESDI of a stillbirth/death in infancy. Since NICE took over responsibility, the use of RRFs has become compulsory. These data are used to generate aggregate information on the numbers and causes of death and also to indicate if a death is part of a sub-set to be investigated in further detail. Different years collect slightly different information. The structure of RRFs has changed over time with, for example, details on terminations of pregnancy added in 1995.

Notification of deaths
RRFs are completed by district coordinators based in each hospital unit, who complete the forms (the CESDI target is within 5 days of death) and forward the information to one of the 16 regional coordinators in England, Wales and Northern Ireland. After checking for inconsistencies or missing data, the information is forwarded (within 1 month) to CESDI for collation and analysis.

Further details
For stillbirths or infant deaths which CESDI wishes to examine in more detail, the regional coordinator collects and anonymises* medical records (e.g. hospital/case notes) relating to the particular case. Peer-reviewed meetings enquire into specific cases. A summary of the case and a standard CESDI form are completed (including any comments on sub-optimal care). CESDI collates all the case reviews, culminating in publication in its annual report, usually published about 18 months after the end of the collecting year.

Details of the RRF and the Confidential Enquiry Panel Report Form (1994–95) are given on pp. 361–3.

Coding systems
ICD-10 was introduced in RRFs in 1998, replacing the previous scheme, which incorporated an extended Wigglesworth classification, a 24-point fetal and neonatal classification and the 22-point obstetric (Aberdeen) classification.

Completeness and accuracy
Notification of death is around 99% when compared with official mortality data† collected by ONS (England and Wales) and the General Register Office (GRO, Northern Ireland).

Although many individual data items on the RRF have a completeness of over 99%, post-neonatal deaths are thought to be a common source of under-reporting to CESDI (around 9%) and this is currently being evaluated.

Regional CESDI officers check RRFs for completeness, referring back to the district officer if necessary. Computer software checks the CESDI data for illogicality.

The Enquiry is carried out on a regional basis. In a 1996 study to investigate regional differences, every fifth case was subjected to a second-pass panel review in a different region, which found differences in gradings. Recommendations were made which were to be implemented in the 1998–99 Confidential Enquiry Programme.

Numbers of death notifications have been checked with ONS/GRO, producing levels of completeness estimates.

Uses
The main uses of the database are to initiate enquiries and to publish an annual report.

Funding
Funding by NICE was £1.8 million in 1999.

Access
As noted above, although RRFs identify the mother, the further details standard enquiry form is anonymised by the district coordinator; any requests to receive individual patient records should be through the Director of CESDI, who would forward the request to the Executive Steering Group (ESG). This would be discussed and advice sought from one or both of CESDI's national bodies (Professional Steering Group and

* Anonymisation of all parties concerned, including the health professionals involved.
† Late fetal losses are not calculated as they are not covered by the statutory system of registration.

Professional Advisory Body). Access to data aggregated at a district level and above could be discussed with the regional coordinator. There is currently no charge for information, although this may come under review.

Contact details

CESDI
Chiltern Court
188 Baker Street
London
NW1 5SD
Tel.: 020 7486 1191
Fax: 020 7486 6543
E-mail: maryh@cesdi.org.co.uk
CESDI website: http://www.cesdi.org.uk/

Publications

CESDI publishes annual reports in June of each year, available in hardcopy from CESDI (address below) or from the CESDI website: http:/www.cesdi.com/

CESDI 6th Annual Report. Focusing on the '1 in 10' enquiries 1996–97; the '4 kg and over' enquiries 1997; perinatal pathology; record keeping and developing the enquiries. London: MCHRC; June 1999.

CESDI 7th Annual Report. Focusing on breech presentation at onset of labour, obstetrics anaesthesia – delays and complications, cardiotocograph education survey and sudden unexpected deaths in infancy – Pathology. London: MCHRC; June 2000.

CESDI data items

Rapid Reporting Form (1998)

Survey number
Case definition:
- Late fetal loss[a]
- Still birth[b]
- Early neonatal death[c]
- Late neonatal death[d]
- Post-neonatal death[e]
- Legal abortion

Mother's details
Full name
Hospital no.
Usual residential address and postcode at time of delivery/birth
Date of birth
Ethnic group
Parity (24+ weeks only)

This pregnancy details
First day of the last menstrual period (LMP)
Agreed working estimated date of delivery just before birth
Gestation at birth
Date and time of delivery/birth
Intended place/unit of delivery at booking
Actual place of delivery
Reason for change between planned and actual place of delivery:
- No change
- Change of address during pregnancy
- Before labour:
  - Clinical reasons
  - Other reasons
- After onset of labour:
  - Clinical reasons
  - Other reasons
  - Unintentionally
- Not known

Number of fetuses/babies this pregnancy
Birth order this fetus/baby if not singleton
Baby/infant
Surname, first name, hospital number
Baby's residential address at time of death if different from mother's, postcode
Sex of fetus/baby

continued

Presentation just prior to delivery:
- Cephalic
- Breech
- Other

Mode of delivery:
- Spontaneous vaginal
- Low forceps
- Other forceps
- Ventouse
- Assisted manual
- Emergency Caesarean section
- Planned Caesarean section
- Other

Baby/infant details

Full name
Hospital number
Residence and postcode at time of death if different from mother's
Region of residence
Sex
Birth weight
Place of death (live births only)
Date and time death first diagnosed (confirmed) (live births only)
Timing of death (stillbirths and late fetal losses only):
- Before admission:
  - Not in labour
  - Probably in labour
- After admission:
  - Before labour
  - During labour
- Not known

Signs/observations at birth, those observed in first hour after delivery:
- Audible cry
- Spontaneous breathing effort or active body movements
- Spontaneous heart beat
- No maceration, no signs of life
- Early maceration
- Advanced maceration
- Not known

Discharge home after birth or neonatal care (live births only):
Was baby ever discharged home after birth (y/n/nk)
If yes:
- Date and time of readmission to hospital

Cause of death: clinical details:
Fetus/infants:
- Main diseases or conditions
- Other diseases or conditions

Maternal:
- Main diseases or conditions
- Other diseases or conditions

Other relevant
Extended Wigglesworth classification
Fetal and infant classification
Obstetric classification
Post-mortem/autopsy:
- Held/being arranged
- Not requested
- Requested but consent not given
- Coroner's PM
- Parental consent but autopsy not done

Date CESDI form completed

[a] 20–23+ weeks.
[b] 24+ weeks.
[c] 0–6 days.
[d] 7–27 days.
[e] 28–364 days.

Confidential Enquiry Panel Report Form (1994–95)

Case details
Mother's name
Mother's hospital number
Baby's name
Baby's hospital number
Summary of case

Assessment details
Date completed
Assessed by:
- Individual assessor
- Panel
- Local enquiry meeting

Acting status of assessor/attenders at panel/meeting (staff and status)

Sub-optimal care
Evidence of sub-optimal care:
- Grade and comments for each

	Antepartum, outside hospital	Antepartum, inside hospital	Intrapartum	Postpartum
Nature of sub-optimal care:				
Clinical practice:				
Failure to recognise problem				
Failure to act appropriately following recognition of problem				
Communication failure				
Patient/family (e.g. advice ignored)				
Any lack of human resource				
Any lack of failure of equipment				
Other				
Staff contributing to sub-optimal care:				
GP/primary care team				
Community midwife				
Hospital midwife				
Obstetrician				
Paediatrician				
Anaesthetist				
Other				
Overall grade of sub-optimal care (nil to III)				

Maternal, obstetric and fetal or infant pathology
Maternal disease not specific to pregnancy
Obstetric complications specific to pregnancy
Fetal or infant pathology

Pathological investigation
Not requiring formal parental consent:
- Positive results
- Relevant negative results
- Requested but missing results

Placenta:
- Macroscopic
- Microscopic

Formal post-mortem (autopsy) report:
- Nil
- Full
- Partial

Histology reported (y/n)
Main findings
Did post-mortem pathology results modify/contradict any provisional clinical assessment?
- No/yes/specify

What additional pathological information would you like to have seen that was not available?
Obstetric classification
Fetal and neonatal classification
Non-perinatal infant cause

Scottish Stillbirth and Infant Death Survey (SSBID)

Description

The SSBID was initially established as a research project in 1977 and was taken over by ISD Scotland in 1983. It represents the Scottish equivalent of the CESDI. In 1997, the Scottish Programme for Clinical Effectiveness in Reproductive Health (SPCERH) was instituted* and jointly undertakes the survey with ISD Scotland. The original use was to allow monitoring of trends in perinatal mortality, highlighting and analysing problems. The dataset has undergone a series of expansions in terms of case collection;† currently, information is collected on late fetal deaths, stillbirths, neonatal deaths and postnatal deaths, including information on deaths up to 1 year of age. Detailed information is collected (via completed form) on stillbirths, neonatal deaths and late fetal losses. Data are received on around 800 deaths out of a total of 60,000 live and still births in Scotland (ISD Scotland, 1998).

Data

The General Register Office for Scotland [GRO(S)] notifies ISD of all stillbirths and infant deaths occurring in the first year of life on a continuous basis. SSBID then collects the following (ISD Scotland, 1998):

Stillbirths and neonatal deaths

- completed Scottish Stillbirth and Neonatal Death Enquiry forms (from hospital local clinical co-ordinators‡)
- SMR2 Maternal Discharge Summary/Discharge letter
- death certificates (see CESDI, p. 359)
- post-mortem reports
- paediatric summary/discharge letter
- perinatal meeting summaries
- chromosome reports.

Late fetal deaths

- SMR2 (some cases)
- Completed Scottish Stillbirth and Neonatal Death Enquiry forms (from hospital local clinical coordinators). As late fetal deaths are not registered by GRO(S), local coordinators complete forms for those recorded in SMR2 and any others known to them.

Postneonatal deaths§

- death certificates
- SMR2.

Information is received in a paper format and entered on to a PC-based database.

Patient-identifiable data are entered but are only kept for the current year and deleted at file closure, whereon the year's data are combined with the mainframe file, containing data acquired since 1985.

A more detailed list of data items collected is given on pp. 365–6.

Coding systems

Infant's cause of death and obstetric factors leading to death are categorised with the Scottish diagnostic classification and also coded to ICD-9. FIGO and Wigglesworth classifications are also used. Post-neonatal deaths are classified by the International Collaborative Effort system.

Completeness and accuracy

Information on all registered stillbirths and infant deaths is provided by the GRO(S), hence case ascertainment is complete.¶ Notification of late fetal deaths is likely to be incomplete as they are not registered with the GRO(S).

Uses

The database is used to initiate enquiries, to provide data to CESDI and for the annual report.

Funding

Funded by the Scottish NHS.

Access

Data tables are published; *ad hoc* analysis is provided on request – see Contact details.

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* Partnership between obstetricians, midwives, ISD and Scottish Department of Health.
† Until 1983: stillbirths and deaths in first week of life. 1984: late fetal deaths (500 g or 20 weeks) included (variation in their recording: pre-viable, non-registerable late miscarriage or premature live birth with almost immediate death. 1985: deaths in first month of life included (more active neonatal care postponed death until after first week).
‡ Obstetricians, paediatricians, midwives and supporting secretarial staff.
§ Not covered by the detailed survey.
¶ The number of unregistered stillbirths and infant deaths is likely to be very small (ISD Scotland, 1998).

Contact details

J Chalmers
Scottish Birth and Infant Death Survey
ISD Scotland
Common Services Agency
The National Health Service in Scotland
Trinity Park House
South Trinity Road
Edinburgh
EH5 3SQ
Tel.: 0131 551 8662
Fax: 0131 551 1392

Scottish Programme for Clinical Effectiveness in Reproductive Health
Programme Administrative Office
Department of Obstetrics and Gynaecology
University of Edinburgh
37 Chalmers Street
Edinburgh
EH3 9EW
Tel.: 0131 229 2575 (Ext. 2318)
Fax: 0131 229 2408

Publications

Scottish Stillbirth and Infant Death Report, 1999. Edinburgh: ISD Scotland; 2000.
See ISD website:
http://www.show.scot.nhs.uk/isd/news/News_archive_2000.htm#081200_ssbid_99_report
Scottish Health Statistics:
http://www.show.scot.nhs.uk/

SSBID data items

Mother's details
Name
Address
Case reference number
Date of birth
Marital status
Parity:
- Total
- Spontaneous abortion
- Therapeutic abortion

Number of births this pregnancy

Birth details
Hospital of birth
Delivery:
- Date
- Time

Delivered at hospital of booking (y/n/nk)
Transferred *in utero* (y/n/nk)
Transferred after delivery (y/n/nk)
Method of delivery
Birthweight
Sex
Best estimate of gestation
Birth order
Type of resuscitation:
- Nil
- Mask/IPP (no drugs)
- Mask/IPPV (with drugs)
- Intubation (no drugs)
- Intubation (drugs)
- Drugs only
- Other
- Not known

Death details
Neonatal deaths:
- Date
- Time

continued

If stillbirth:
  Death before labour
  Death during labour
If late abortion:
  Abortion under the Abortion Act
  Spontaneous
  Missed
  Incomplete abortion
Place of death if transferred
Obstetric classification
Paediatric classification
Whether or not a post-mortem was performed
Whether or not the chromosomes were checked

The National Confidential Enquiry into Perioperative Deaths (NCEPOD), England and Wales

Description

The NCEPOD was established in 1988 (data collected from 1989) following the report Confidential Enquiry into Perioperative Deaths, 1987, which covered three regions. Its aim is to review clinical practice and identify potentially remediable factors in the practice of anaesthesia, surgery and other invasive medical procedures. The objective is to look at the quality of the delivery of care and not specifically the causation of death.

NCEPOD is an independent body to which a corporate commitment has been made by the Royal Colleges, Faculties and Associations related to its activity. Each of these bodies nominates members of the Steering Group.

Since April 1999, NCEPOD has come under the aegis of NICE, which provides the majority of the organisation's funding. NCEPOD does not cover Scotland, which conducts its own enquiry, the Scottish Audit of Surgical Mortality (SASM).

The dataset collects 18,000–21,000 records annually on hospital deaths* occurring within 30 days of a surgical procedure† (excluding maternal deaths, which are reported to the Confidential Enquiry into Maternal Deaths), and from April 1998, other invasive procedures (including interventional radiology). The NCEPOD Steering Group annually determines a group of procedures (around 10–20% of the total) for which more detailed information is collected.

The commentary and recommendations for future practice made in the annual reports are based on peer review of the data, questionnaires and other records submitted to NCEPOD.

Data

Information is provided on a continuous‡ and voluntary basis from the following:

- all NHS and Defence Medical Services in England, Wales and Northern Ireland
- public hospitals in Guernsey, Jersey and the Isle of Man
- BUPA Hospitals Ltd
- General Healthcare Group plc (until April 1998)
- Nuffield Hospitals
- St Martins Hospitals Ltd
- Benenden Hospital
- The London Clinic.

Local reporters receive information on deaths occurring in their hospital(s) from the following sources:

- mortuary records
- patient administration systems/theatre systems
- death certificate records
- any clinical audit system
- manual trawl of patients' notes (for patients who have had surgery or died)
- bereavement officer's records
- surgeons reporting directly to the local reporter.

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* Some home deaths within the 30-day period are reported.[1]

† NCEPOD defines a surgical procedure as 'any procedure carried out by a surgeon or gynaecologist, with or without an anaesthetist, involving local, regional or general anaesthesia or sedation'.[1]

‡ NCEPOD has, in the past, conducted prospective surveys including defining the pattern of surgical activity over 24-hour periods (to evaluate out-of-hours surgery).[2]

The local reporter (being consultant, clinical audit staff or information staff) in each hospital or Trust notifies NCEPOD of the death via a Local Reporting Form. For those cases where the procedure is part of a sample for more detailed review, questionnaires are then sent to the consultant surgeons and anaesthetists involved, who provide more specific information, and copies of the relevant parts of the patients' notes. Identification is removed from the paperwork at this stage and the information is reviewed under the lead of the Clinical Coordinators, appointed by the Trustees on the recommendation of the Steering Group.

Once NCEPOD has received information from the reporters, data are entered into the system on a priority basis. The process of collection lasts from 1 week to 1 month, depending on workloads.

In addition to anonymisation of records, all paper records are shredded following publication of the report and all patient identifiers are removed from the computer database.

A detailed list of data items collected is given on pp. 368–74.

Coding systems

The NCEPOD dataset does not employ a coding system.

Completeness and accuracy

Up to 1999, the Enquiry relied on voluntary data contributions of both notification and follow-up. The completeness of notification is unknown; 75% of the follow-up questionnaires were returned to NCEPOD. The degree to which notifications will remain voluntary under NICE remains to be clarified.

NCEPOD uses a different definition of surgical procedure (only those procedures carried out by surgeons) to that of other datasets, including HES (OPCS4 system), making comparison of collected cases difficult.

NCEPOD employs a checking system, which identifies incorrect data; NCEPOD data entry staff are specially trained.

As the dataset is primarily used to identify remedial factors, internal validation checks are not of the highest priority to NCEPOD. However, the dataset is due to move on to Access 98, which will enable continual plausibility/validation checks to be carried out. Any queries identified at the NCEPOD Centre are immediately taken up with the appropriate surgeon or consultant for validation. No external validation is carried out.

Uses

The main use of NCEPOD's database is for its annual report and for enquiries, which it initiates.

Funding

NICE provides £440,000, most of the organisation's funding. Financial support is also provided by the Welsh Office, Health and Social Services Executive (Northern Ireland), States of Guernsey Board of Health, Jersey Group of Hospitals, Department of Health and Social Security (Isle of Man) and the independent hospital groups who also submit data to the Enquiry.

Access

Data are published in the Annual Report. From 1999 there has been a supplement to the data in the Annual Report containing additional data from anaesthetic and surgical questionnaires and copies of the questionnaires are available from the NCEPOD office (listed below). Direct access to the dataset is denied to any party other than NCEPOD staff.

Contact details

National Confidential Enquiry into Perioperative Deaths
35–43 Lincoln's Inn Fields
London
WC2A 3PE
Tel.: 020 7831 6430
Fax: 020 7430 2958
E-mail: info@ncepod.org.uk
NCEPOD website: http://www.ncepod.org.uk/

Publications

Annual Reports are published in November each year and are listed on the NCEPOD website: http://www.ncepod.org.uk. In 2001 the annual NCEPOD report will include a review of those patients who had cancer at the time of their operation. This report will use data collected during the period April 1999 to March 2000 (NCEPOD website, June 2001).

Then and now: the 2000 Report of the National Confidential Enquiry into Perioperative Deaths. London: NCEPOD; 2000.

Extremes of age: the 1999 Report of the National Confidential Enquiry into Perioperative Deaths. London: NCEPOD; 1999.

Key issues and recommendations of NCEPOD Reports. London: NCEPOD; 1998.

Other publications:
Interventional vascular and neurovascular radiology. London: NCEPOD; 2000.
Percutaneous transluminal coronary angioplasty (PTCA). London: NCEPOD; 2000.
Pryce and Coles. The National Confidential Enquiry into Perioperative Deaths (NCEPOD), an external evaluation by CASPE. 1998.

See also the two references below.

For a full publication list, see the NCEPOD website: http://www.ncepod.org.uk/99refs.pdf

References

1. Gray AJG, Hoile RW, Ingram GW, Sherry KM, Report of the National Confidential Enquiry into Perioperative Deaths, 1996/97. London: NCEPOD; 1998.
2. Campling EA, Devlin HB, Hoile RW, Ingram GW, Lunn JN, Who operates when? A report by the National Confidential Enquiry into Perioperative Deaths. London: NCEPOD; 1997.

NCEPOD data items

Local reporting form

Administrative details
Form number
NHS Trust
NHS Region
Other Authority
Patient details
First name
Surname
Sex
Date of birth
Date of death
Hospital number
Surgery details
Name of hospital
Date of last operation before death
Surgical procedures performed
Name of consultant surgeon
Name of anaesthetist

Surgical questionnaire

Patient details
Date of birth
Sex
Date of final operation
Diagnosis at time of referral to surgeon/admission to surgical ward
Special care areas
Availability and staffing of:
Theatre recovery
Adult ICU
Adult HDU
Hospital where final operation took place
Type
Dates
Admission type
Referral/transfer details

continued

Perioperative care
Area type
Working diagnosis
Operation proposed
ASA status
Co-existing problems
Previous operations
Anticipated risk of death
Preoperative preparation
Precautions/therapeutic manoeuvres
Operation
Operation classification
Times
Operation undertaken
Diagnoses established at operation
Unanticipated intra-operative problems
Local anaesthetic/sedation by surgeon:
Physiology monitored
Staffing details
Specialty of surgeon, etc.
Time in post
Training/career grades
Staff attending post-mortem
Postoperative care
IDU/HDU/coronary care unit details
Discharge/transfer/readmittance details
Postoperative complications
Death details
Date
Time
Place
CPR details
Clinical cause of death
Cause of death:
Direct
Leading to
Contributing to
Death reported to Coroner
Post-mortem details:
Findings including histology
Pathological details confirm clinical impression?
Audit
Considered at audit/quality control meeting?
Availability of information

Surgical questionnaire (deaths)

Type of hospital in which final operation took place
Whether a theatre recovery area is available where final operation took place
Whether adult intensive care unit was available where final operation took place
Whether adult high-dependency unit was available where final operation took place
Patient's date of birth
Date of final operation
Patient's sex
Diagnosis recorded in notes at the time of referral to surgeon or admission to surgical ward

continued

Date patient admitted to hospital
Admission type
Pathway for admission
Type of referring hospital if patient was referred
Reasons why the patient was transferred
Explanation when patient's condition deteriorated during transfer from other hospital
Whether it was considered to transfer the patient to another hospital
Reasons why a desirable transfer to another hospital was not undertaken
Whether the patient was originally admitted under the care of surgeon carrying out operation
Original source of referral if not this hospital
Date of initial referral (i.e. date on referral letter)
Date and time of transfer from other service to surgeon (24-hour clock)
Date of first consultation following referral
Date and time of decision to operate
Date patient was placed on waiting list
Date and time of admission
Details of any undesirable delays occurring between decision to operate and date of surgery
Reasons why a patient's admission had been previously cancelled by the surgical service
Whether delays affected the outcome of surgery
Area where patient was first admitted
Details if admission area was not the most appropriate place for patient
Specialty of consultant surgeon in charge at time of final operation
Details of care undertaken on a formal shared basis
Grade of the most senior surgeon consulted before operation
Grade and working diagnosis of most senior surgeon making diagnosis
Grade of most senior surgeon and details of operation proposed
Grade of most senior surgeon taking consent from patient
Whether surgeon who took consent was present at operation
Details of the immediate indication for the proposed operation
Patient ASA status prior to final operation
Co-existing problems at time of operation
Precautions or therapeutic manoeuvres taken to improve patient's preoperative condition
Whether the hospital has a protocol based on THRIFT for thromboembolic prophylaxis
Risk group for patient with thromboembolic risk
Precautions taken to prevent thromboembolism
Use of prophylaxis
Explanation of why patient's medication (excluding premedication) was relevant to the outcome
Details, date and surgeon of previous operations with any possible connection to the final operation
Anticipated risk of death relating to the proposed operation
Anticipated benefit of operation when death was expected
Operation undertaken
Why operation was different to that proposed
Diagnosis established at operation
Unanticipated intra-operative problems
Details of any details (other than clinical) occurring between admission and surgery
Classification of operation
Time of start of operation (not including anaesthetic time) – 24-hour clock
Duration of operation (excluding anaesthetic time)
Day operation took place
Whether operation took place on a public or hospital holiday
Surgeons present during operation
Grade of most senior surgeon carrying out operation
Year of primary medical qualification of operation surgeon
Year of first full-time higher specialist training post for surgeon operating
Higher diploma(s) held by surgeon operating
Amount of time operating surgeon has spent at present grade and specialty
Number of similar procedures performed by operating surgeon in the last 12 months
Whether or not a more senior surgeon was immediately available to the surgeon operating
Grade and location of senior surgeon at close proximity to operation
Whether procedure was performed solely under local anaesthetic/sedation administered by surgeon
Details of drugs and dosages used when local anaesthetic/sedation given
Recording during or immediately after procedure

continued

When local anaesthetic/sedation performed, whether resuscitation immediately available
Area where patient was admitted immediately leaving the recovery suite
Whether a special nurse was employed to care solely for patient – if patient admitted to general ward
If admitted to general ward, whether transfer was required at any stage during postoperative period
Area to which patient was transferred after admission to general ward during postoperative period
Number of days postoperatively transfer required
Reasons for discharge from ICU/HDU/CCU
Reasons why patient was readmitted to an ICU/HDU/CCU
Reasons why patient could not be transferred to ICU/HDU in hospital where operation took place
Postoperative complications
Whether there was a shortage of personnel
Shortage of personnel
Date and time of death
Place of death
Whether cardiopulmonary resuscitation was attempted
Immediate clinical cause of death
Cause of death
Whether death was reported to the Coroner
Whether a Coroner's post-mortem examination was ordered and performed
Whether a hospital post-mortem was undertaken if Coroner did not perform one
Reasons why no hospital post-mortem undertaken
Whether the surgical team were informed of the date of post-mortem
Member(s) of team attending the post-mortem examination
Reason why surgeon did not attend post-mortem
Whether surgical team received copy of post-mortem
Date of receipt of post-mortem by surgical team
Relevant findings of post-mortem (including histology)
Whether post-mortem findings confirmed the clinical impression
Additional unexpected findings from post-mortem if findings confirmed clinical impression
Differences found when post-mortem did not reflect clinical impression
Whether death has/will be considered at local audit/quality assurance meeting
Time taken in obtaining patient's notes, if problems arose in receiving them
Inadequate/unavailable patient's notes were available from surgical team
Grade of surgeon completing questionnaire
Whether consultant surgeon has seen and agreed the questionnaire
Date questionnaire completed
Free text

Anaesthetic questionnaire (deaths)

Free text
Position of person completing questionnaire (if not involved with case)
Special care areas/rooms in hospital where operation took place
Whether hospital has scheduled daytime emergency lists of urgent general surgical cases
Usual anaesthetic cover available for urgent general surgical cases from emergency lists
Whether hospital has daytime emergency lists for urgent trauma or orthopaedic cases
Usual anaesthetic cover available from emergency lists for trauma/orthopaedic cases
Patient's date of birth
Date of admission to hospital in which final operation took place
Time of admission to hospital in which final operation took place
Primary preoperative surgical diagnosis
Co-existing medical diagnosis when final operation involved respiration
Co-existing medical diagnosis when final operation involved cardiac treatment
Co-existing medical diagnosis when final operation involved sepsis
Co-existing medical diagnosis when final operation involved neurological treatment
Co-existing medical diagnosis when final operation involved endocrine treatment
Co-existing medical diagnosis when final operation involved alimentary treatment
Co-existing medical diagnosis when final operation involved renal treatment
Co-existing medical diagnosis when final operation involved hepatic treatment

continued

Co-existing medical diagnosis when final operation involved musculoskeletal treatment
Co-existing medical diagnosis when final operation involved haematological treatment
Co-existing medical diagnosis when final operation involved other treatment (please specify)
Management of diabetes mellitus in relation to surgical operation
Latest preoperative blood sugar for patient who is diabetic
Whether the blood sugar was measured/estimated during surgery of patient with diabetes
Measured/estimated blood sugar for patient with diabetes
Whether insulin was given to diabetic patient during surgery
Whether insulin was prescribed postoperatively to diabetic patient
Method of prescribing insulin to diabetic patient during the first 48 hours
Person principally supervising the diabetic management postoperatively
Position of the person principally supervising the diabetic management postoperatively
Patient's ASA status prior to the final operation
Weight of patient before operation – if available
Estimated weight of patient before operation – if record not available
Whether a record of the patient's blood pressure was available before operation
Record of drugs being received by patient on a regular basis at the time of operation
Whether patient received intravenous fluid therapy in the 12 hours before induction
Whether it was necessary to delay anaesthetic to improve the patient's state before the operation
Systems needing attention when a delay in the anaesthetic was necessary
Reasons for delay in anaesthetic to improve patient's state before operation
Whether surgery was delayed for reasons other than the patient's state
Reasons why anaesthetic was delayed other than that of the patient's state
Whether premedication drugs were prescribed
Premedication drugs given to patient
Investigations carried out before anaesthetic
Date of final operation
Classification of final operation (NCEPOD codes)
Procedure(s) performed at final operation
Related surgical procedures carried out prior to final operation (including date)
Whether an anaesthetist was consulted by the surgeon (as distinct from informed)
Reason why anaesthetist did not visit patient before final operation
Whether anaesthetist visited patient before final operation
Area where anaesthetist visited patient before final operation
Whether anaesthetist who visited patient was present at start of final operation
Grade of the most senior anaesthetist present at the start of anaesthetic
Whether the anaesthetist was a locum appointment
Year of primary medical qualification for most senior anaesthetist at the start of the procedure
Country primary medical qualification was awarded to most senior anaesthetist at start of operation
Year of first full time anaesthetic training post for most senior anaesthetist at start of operation
Higher diploma(s) and year awarded to most senior anaesthetist at time of operation
Where consultant help was available if most senior anaesthetist was not a consultant
Grade and years of training if an assisting anaesthetist present at start of anaesthetic
Grade and years of training if assisting anaesthetist was a locum appointment
Whether advice was sought at any time from another anaesthetist not present during the operation
Grade of anaesthetist who gave advice but was not present during operation
Timing of advice from another anaesthetist
Time of start of anaesthetic
Time of start of surgery following anaesthetic
Time of transfer out of operating room (e.g. to recovery room, ICU)
Duration of operation from start of anaesthetic to time of transfer
Grade of the most senior surgeon in the operating room
Whether a preoperative assessment and anaesthetic record exists in patient's notes for operation
Full account of anaesthetic if not noted in patient's records
Whether patient received intravenous fluids during the operation
Crystalloid intravenous fluids used during the operation
Colloid (and other) intravenous fluids given to patient during operation
Blood intravenous fluids given to patient during operation
Measured blood loss in ml during the operation
Estimated blood loss in ml during the operation
Whether anaesthetic room was used for the induction of anaesthesia
Monitoring devices already in place before induction of anaesthetic

continued

Monitoring devices used during induction of anaesthetic
Monitoring devices used during operation
Reasons for any hindrance in full monitoring of the operation
Details of lack of monitoring equipment
Measures taken (before, during and after operation) to prevent venous thrombosis
Measures taken to maintain body temperature before, during or after operation
Type of anaesthesia used
How airway was established during general anaesthesia
Problems with airway maintenance/ventilation during general anaesthesia
Whether patient was ventilated mechanically during general anaesthesia
Muscle relaxants used during general anaesthetic
Maintenance of general anaesthesia
Method used during regional anaesthesia
Agent (including drugs and dosage) used during regional anaesthesia
Drugs given for sedation (excluding premedication)
Reason for using oxygen during operation
Place the patient went on leaving the operating room
Reasons why, if patient could not be transferred to a ICU/HDU, etc.
Details of any monitoring devices or investigations carried out in the recovery room
Time of transfer from recovery area
Place patient went after recovery room
Whether controlled ventilation was used postoperatively
Reason why controlled ventilation was used postoperatively
Events occurring during anaesthesia or during the first few hours after operation
Account of critical events
Details of any mechanical failure of equipment during anaesthesia or recovery
Complications or events after operation including descriptions
Account of any adverse events after operation
Description of any inotropes given in first 48 hours after operation
Whether the hospital that carried out operation has an acute pain service
Details of hospital pain team including how many sessions attended
Availability of acute pain service
Nursing staff who have training in epidural/PCA analgesia
Whether patient operated on had a pain assessment chart
Whether drugs were given for pain in the 48 hours following operation
Drug types given for pain following operation
Route in which pain relief drugs were administered following operation
Whether complications occurred as a result of analgesic pain relief methods
Details of any complications occurring as a result of analgesic pain relief methods
Details of any other sedative/hypnotic/drugs given in conjunction with pain relief
Date of patient's death
Time of patient's death
Place of patient's death
Cause of patient's death
Whether morbidity/mortality review meetings are held in hospital department
Whether this particular case has been/will be discussed at a department meeting (if held)
Agreement of consultant anaesthetist to questionnaire
Initials and surname if consultant is completing questionnaire

Anaesthetic questionnaire

Patient details
Date of birth
Date and time of admission
Primary preoperative surgical diagnosis
Co-existing medical diagnosis
ASA status

Diabetes mellitus
Current anaesthetic management in relation to surgical operations

continued

Staffing Grade/year of training Grade
Hospital details Cover and list details Special care areas
Preoperative preparation Premedication drugs Other drugs Weight and availability Investigations
Operation Date Classification Procedure Related surgical procedures prior to this operation Intravenous fluids Monitoring devices Prevention of venous thrombosis Maintenance of body temperature
Anaesthetic details Type, maintenance Regional details Establishment of airway Muscle relaxants
Sedation Drugs Oxygen
Postoperative care Site Transfer Complications
Recovery room Monitoring Transfer Times Controlled ventilation
Critical events during anaesthesia or recovery Complications
Management of pain Drugs Complications
Death details Date Time Place Cause

Paediatric surgical questionnaire
This is similar to the adult version, with paediatric facilities and paediatric trained staff highlighted.

Paediatric anaesthetic questionnaire
This is similar to the adult version, with paediatric facilities and paediatric trained staff highlighted.

Scottish Audit of Surgical Mortality (SASM)

Description

Established in 1994, the SASM developed from two previous audits which amalgamated. The Scottish Mortality Study covered parts of Edinburgh and a few other hospitals from

1989–90. The Glasgow Audit of Surgical Deaths was established shortly afterwards, covering the Greater Glasgow Health Board area. Both audits were amalgamated at the end of 1993. SASM receives around 4500 mortality cases per year (Annual Report, 1999). SASM has a current total of 20,000 records on its database. SASM investigates all surgical mortalities, in contrast to the Confidential Enquiry into Perioperative Deaths (CEPOD) (England, Wales and Northern Ireland), which investigates only a selection.

The aim of SASM was to combine the two pre-existing databases to allow an audit of all deaths occurring under the care of a surgeon in all hospitals in Scotland.

Data

Information is collected continuously and voluntarily from all hospitals in Scotland where surgery is performed. Four SASM staff are responsible for the collection of data: two in Glasgow, one in Edinburgh and Aberdeen. Mortuaries are contacted weekly to find out what deaths have taken place. Some mortuaries fax a list to the relevant office. Following determination of a surgical death, staff enter available information on to SASM proformas, which are then forwarded to the relevant consultant surgeon. The surgeon completes the proformas and passes the anaesthetic proforma to the relevant anaesthetist. These forms are returned individually to the SASM office where they are anonymised. The forms are coded for diagnosis, operations, cause of death, adverse factors and comments, before entering on to the database.

Information sources are mainly hospital mortuaries, but additional data come from:

- hospital wards
- ward secretaries
- consultants' offices
- medical records offices
- pathology departments.

Forms are sent to a peer reviewer in the relevant specialty who completes a surgical assessment form and comments. The assessment forms are returned to SASM, which collates data and provides feedback to consultants on each individual case. Individual hospital data are also collated, and these (along with national average values) are reported back to the originating department and hospital.

If a peer reviewer identifies adverse factors in any case, a case note review can be requested and anonymity removed. This request is sent to the SASM office, where a surgical and anaesthetic coordinator reviews all aspects of the case, deciding if the reviewer has fair reason for requesting a case note review. The most common reasons for refusal for this are sub-optimal reasons or insufficient information is supplied.

Once authority has been given, a case note reviewer will be allocated to investigate the case. All identifiers are destroyed once the investigation has been completed.

Each individual case is coded and processed as and when received, so data are accessible from then. SASM produces an Annual Report, after information from hospitals has been obtained. This report collates all data in each specialty and is sent back to all participants. Completed data collection usually takes around 1 year. Data are collected using four forms: Surgical Proforma, Anaesthetic Proforma, Surgical Assessor's Form and Anaesthetic Assessor's Form.

A more detailed list of data items collected is given on pp. 376–9.

Coding systems

The Read 3 coding scheme has been used since the establishment of the database. An in-house list of adverse factors has been built into the database, which can be updated at any time. The two databases which preceded SASM used locally developed codes.

Completeness and accuracy

The level of compliance for returning proformas is documented as being above 95% (Annual Report, 1999). The current level of completeness for data items has not been assessed. On occasions when the forms have not been fully completed, they are sent back to the appropriate consultant for completion. No checks are made on the accuracy of information sent to the SASM. However, checks are made if the assessors suspect discrepancies or if a case note review is initiated.

Validation checks are made on the data entered into the central database. Some fields require mandatory data items to be input before any more information can be entered.

Different aspects of patient death are investigated in detail each year. In 1997, SASM received the American Society of Anesthetists (ASA) grades of the patients (the level of sickness before surgery, on a scale of 1–5). Forty-seven patients classified as

being ASA1 or -2 were considered as being wrongly classified by the anaesthetic assessor. A key point raised by this investigation was that correct classification is important (Annual Report, 1997).

No routine external validation checks are carried out. If SASM had to incorporate denominators into the database, then links would be required with some other dataset.

A project is exploring the potential value of comparing SASM and two mortality datasets, to see whether there are any useful data which can be compared.

Uses
In addition to audit, the dataset is currently used for the following purposes:

- improvement of patient care and the number of patients who die
- identifying adverse factors pertaining to the deaths, including specialties and anaesthetic deaths
- provision of a peer review for each case identified
- to enable reports to be produced (Annual Reports, DNG and Quality Health Care).

Funding
SASM was originally funded by the Scottish Office through the Health Boards via the Colleges. Since 1997, it has been funded directly by the Scottish Health Department through the National Projects Committee, with each Health Board contributing a proportion of the overall cost.

Access
No patient-identifiable data are available to a researcher or to a consultant. The SASM works to a protocol of confidentiality. All consultants are asked to sign a consent form before participation in the audit, and also to make their case notes available as and when required.

Anonymised data are available to consultants or researchers. Most commonly, consultants may require information to assist with report writing on specific aspects of care. Researchers request information on specific types of care. No charging system has been quoted. Researchers should contact SASM.

Contact details
Scottish Audit of Surgical Mortality
The Royal College of Physicians and Surgeons
232–242 St Vincent Street
Glasgow
G2 5RJ
Tel.: 0141 221 6072
Fax: 0141 204 5830
E-mail: helen.burton@repsglasg.ac.uk
SASM website: http://www.show.scot.nhs.uk/sasm/

Publications
The Scottish Audit of Surgical Mortality Annual Report 1999. Glasgow: SASM; 2000.
For previous annual reports, see the SASM website: http://www.show.scot.nhs.uk/sasm/

SASM data items[a]
Surgical proforma

Identifying/administrative details
Study number
Patient name
Date of birth
Hospital
Hospital unit number
Date:
Admission
First operation
Last operation
Death
Specialty of case
Staffing details
Names of consultant surgeon, additional surgeons/trainees
Name of anaesthetist(s)
Status of surgeon completing form
Specialty of consultant surgeon in charge of patient

continued

Preoperation and patient status
Type of admission
Patient transfer
Preoperative use of ITU and/or HDU
Main surgical diagnosis on admission (after initial assessment)
Confirmed main surgical diagnosis (after test results/operation/post-mortem, etc.)
Details of death
Final cause of death (including all information)
Significant co-existing factors increasing risk of death
Description of course to death
Was a decision made to limit treatment?
Operative/postoperative details
Surgeon's view (before and after any surgery) of overall risk of death
Operation description[b]
Staffing surgeon and anaesthetist
Timing:
Post-operative use of ITU and/or HDU
Areas where management could have been improved
Conclusions
Was there a failure in the continuity of care?
Was a post-mortem performed?
Statement describing the management of the case:
There were no adverse events in management
There were adverse events but they made no difference to the eventual outcome
There were adverse events which made a significant contribution to the patient's death
There were adverse events which caused death in this patient who would have been expected to survive
Comments
In retrospect would you have done anything differently?
[a] A summary of information collected is shown; proformas are produced yearly with specific questions reflecting the direction of the audit.
[b] Including radiological, endoscopic or thrombolytic interventions.

Anaesthetic proforma

Identifying/administrative details
Study number
Patient name
Date of birth
Hospital
Hospital unit number
Date:
Admission
First operation
Last operation
Death
Staffing details
Names of consultant surgeon
Name of anaesthetist(s) and additional anaesthetist(s)
Status of anaesthetist completing form
Specialty of consultant surgeon in charge of patient
Preoperation and patient status
Operation days and timings
Could preoperative management/preparation have been improved?
Preoperative use of ITU and/or HDU
ASA grades for operations (1–3)
Significant co-existing factors increasing risk of death
continued

Anaesthetic details
Type of anaesthetic
Regional anaesthesia details
Do you think the regional technique contributed to the eventual outcome?
Anaesthetist(s) at operation
Assistance available during anaesthesia
Quality of assistance satisfactory?
Monitor details:
  Description of technique, monitoring and untoward events during anaesthetic and recovery
Anaesthesia-related complications

Recovery and postoperative care
Recovery facilities
Postoperative use of ITU and/or HDU
Could postoperative care have been improved?

Conclusions
Statement describing the management of the case:
  There were no adverse events in management
  There were adverse events but they made no difference to the eventual outcome
  There were adverse events which made a significant contribution to the patient's death
  There were adverse events which caused death in this patient who would have been expected to survive
  Comments
In retrospect, would you have done anything differently?

Surgical assessor's form

Study number

Conclusions
Was there enough information to obtain conclusion?
If no:
  What information was lacking?
Should case go for case note review?
If yes:
  Which aspects to be looked at in more detail?
  Leave rest of form blank, return to SASM

Operation and management details
If no operation performed, should one have been performed?
If yes:
  What and why?
If an operation was performed, were there any adverse factors (specify)?
Preoperative management/preparation
  Decision to operate
  Choice of operation
  Timing of operation
  Intra-operative/technical management of surgery
  Grade/experience of surgeon deciding
  Grade/experience of surgeon operating
  Postoperative care

Assessor's view of overall risk of death:	Before surgery	After surgery
Minimal		
Small		
Moderate		
Considerable		
Expected		

If ITU used: was ITU care adequate?
If ITU not used, would patient have benefited from use?
If HDU used: was HDU care adequate?
If HDU not used, would patient have benefited from use?

continued

Was decision on use of DVT prophylaxis appropriate?
Was failure of continuity of care a factor?
If case notes were reviewed were they adequate?
Statement describing the management of the case:
- There were no adverse events in management
- There were adverse events but they made no difference to the eventual outcome
- There were adverse events which made a significant contribution to the patient's death
- There were adverse events which caused death in this patient who would have been expected to survive
- Comments

Were there adverse events in management that may have:
- Contributed to death
- Caused death
- No

Details of adverse events in management and adverse factors
Brief explanatory comments to be related to the clinician if adverse factors identified

Anaesthetic assessor's form

Study number

Conclusions
Was there enough information to obtain conclusion?
If no:
- What information was lacking?

Should case go for case note review?
If yes:
- Which aspects to be looked at in more detail?
- Leave rest of form blank, return to SASM

Anaesthetic and management details
Was type of anaesthetic appropriate?
If regional technique used, did it contribute to mortality?
Was grade/experience of the anaesthetist appropriate?
Was adequate assistance available for the anaesthetist?
Was monitoring appropriate?
Was overall conduct of the anaesthetic satisfactory?
If ITU used: was ITU care adequate?
If ITU not used, would patient have benefited from use?
If HDU used: was HDU care adequate?
If HDU not used, would patient have benefited from use?
If case notes were reviewed, were anaesthetic records adequate?
Statement describing the management of the case:
- There were no adverse events in management
- There were adverse events but they made no difference to the eventual outcome
- There were adverse events which made a significant contribution to the patient's death
- There were adverse events which caused death in this patient who would have been expected to survive
- Comments

Details of adverse events in management in order of significance
Brief explanation of adverse factors to be supplied to the clinician

Confidential Enquiries into Maternal Deaths (CEMD), UK

Description

CEMD were established in England and Wales in 1952, Northern Ireland in 1956 and Scotland in 1965 to audit and formalise information collection on maternal deaths, reasons for death and recommendations. Since 1985, CEMD have dealt with the whole of the UK within one report. CEMD cover all maternal deaths occurring directly due to pregnancy ('Direct'), those due to pre-existing disease, aggravated by pregnancy ('Indirect'), those in which the cause was unrelated to pregnancy ('Fortuitous') and those occurring after the internationally defined time limit of 6 weeks but before 1 year from delivery ('Late deaths') (CEMD 1998; website, June 2001).

The aims and objectives of the Enquiries are:

- assessment of the main causes of* and trends in maternal deaths; identification of avoidable or substandard factors; communication of findings to all relevant healthcare professionals
- reduction of maternal mortality and morbidity rates including those due to substandard care
- production of recommendations concerning improvement of clinical care and service provision (including local audit) to purchasers and healthcare professionals involved in maternity services
- suggestions for areas of research and audit (local and national)
- production of a triennial report for the four CMOs of the UK.

CEMD are a collaboration between the Department of Health, Welsh Office, Scottish Office Department of Health and the Department of Health and Social Services, Northern Ireland. Since 1999 NICE has had overall responsibility for CEMD.

The CEMD report for 1998 analyses 1994–96 data. For that period, there were 134 Direct, 134 Indirect, 36 Fortuitous and 72 Late deaths, giving a total of 376 deaths known to the Enquiry. Owing to increased case ascertainment, a new baseline maternal mortality rate has been set. By using a newly developed computer search by the ONS for secondary codings on death certificates that may be related to pregnancy related conditions, 67 additional deaths were reported. Ten were Direct, all but one from pulmonary embolism, 40 Indirect due to a number of underlying medical conditions and 17 were Late. These extra cases have increased the maternal mortality rate from conditions directly due to pregnancy (Direct deaths) to 6.1 per 100,000 maternities compared with 5.5 deaths per 100,000 maternities for 1991–93. Maternal mortality rates from medical conditions indirectly influenced by pregnancy have also risen to 6.1 compared with 4.5 per 100,000 maternities for the period of the last report. Exclusion of the additional cases identified by ONS would have given identical rates to those in the last report for both of these categories.

The new UK baseline maternal mortality rate, against which future reports will be judged, calculated from the 268 Direct and Indirect deaths, was 12.2 per 100,000 maternities (CEMD, 1998; website June 2001).

Data

Sources of notifications of maternal deaths are death certificates† and from health professionals, in particular the local supervisor of midwives or the Director of Public Health (DPH).

Data collection is continuous and there are slight inter-country variations in the process:

England and Wales

An enquiry into maternal death is initiated by the DPH of the district in which the woman lived. The Enquiry form MDR(UK)1 (previously MCW97) is forwarded from the central secretariat to the DPH, who arranges its completion by GPs, midwives, health visitors, consultant obstetricians and other relevant staff involved in the care of the woman. Details of the post-mortem or relevant pathological investigations are also obtained. The DPHs forward the information to the Regional Obstetric Assessor (England) or the Welsh Obstetric Assessor. Other Assessors available to CEMD for review of relevant cases include anaesthetics, midwifery and pathology. The assessors comment on the possible cause(s) of death.

The information is then sent to the central coordinators, acting on behalf of the two CMOs, where the cases are anonymised. The central assessors (by specialty as required) review all data and assess the case. Cases are reviewed thoroughly, taking into account all information including history and pathological examinations, before classifying the case to a particular cause of death and report chapter.

Scotland

A certificate of maternal death is sent from the GRO to the Scottish Office Department of Health (SODH), which in turn sends an enquiry form [MDR(UK1)] (previously MD1) to the DPH of the Health Board where the woman lived. As with the other countries, the DPH is responsible for organising the completion of the enquiry form by all the professional staff involved in the case. ISD

* The Enquiry classifies the case to a particular cause of death and report chapter (e.g. direct deaths associated with anaesthesia/embolism or indirect deaths due to cardiac disease).

† Around 40% of death certificates issued concerning women within the CEMD criteria do not have a pregnancy-related condition recorded.

Scotland provides additional statistical information, such as hospital discharge data collected by general and maternity hospitals. The remaining process of enquiry is similar to that in England and Wales, although a single panel of assessors considers all cases.

Northern Ireland
Maternal deaths are reported to the DPH of the Health and Social Services Board of residence. The DPH commences completion of MDR(UK)1 (previously MCW2 Rev. 2) by all the professional staff involved. Completed forms are forwarded to the Department of Health and Social Services. The remaining process of enquiry is similar to that in England and Wales except that, as with Scotland, one panel of assessors deals with all cases.

Information is held under strict confidentiality conditions and cases are anonymised before compilation of the Report. The database held is destroyed before the book is produced, so records are only available for the currently investigated time period. The timescale of the enquiry for each case is about 9 months, from notification of death to finalisation.

Coding systems
ICD-9 is currently employed, with plans to convert to ICD-10.

Completeness and accuracy
The level of completeness of notifications is reported to be around 99% [compared with official mortality data* collected by ONS (England and Wales) and the GRO (Northern Ireland)].

Each form is seen by four people before the case is assessed. Any serious inconsistencies are sent back to the reporters before the forms are anonymised. The dataset is not externally validated.

Uses
The database is used for the aims specified above and is the basis of the triennial reports.

Funding
Funded by NICE; the cost of this enquiry is not known.

* Late fetal losses are not calculated as they are not covered by the statutory system of registration.

Access
No direct access to the data is allowed for research. See Publications, Contact details and CEMD website, listed below.

Contact details
Dr G Lewis
Department of Health
520 Wellington House
133–155 Waterloo Road
London
SE1 8UG
Tel.: 020 7972 4344
Fax: 020 7972 4348
E-mail: glewis@doh.gsi.uk
CEMD website: http://www.doh.gov.uk/cmo/mdeaths.htm

Publications
Lewis G, Drife J, Why mothers die, report on confidential enquiries into maternal deaths in the United Kingdom 1994–1996. Department of Health. London: The Stationery Office; 1998.

CEMD website: http://www.doh.gov.uk/cmo/mdeaths.htm

All Wales Perinatal Survey (AWPS)
Description
The AWPS reports on deaths of babies (All Wales Perinatal Survey, 1998):

- fetal losses of 20 weeks' gestation or more (including therapeutic abortion)
- stillbirths
- early and late neonatal deaths
- postneonatal deaths.

The survey was established in 1993 and includes all deaths of babies whose mother is usually resident in Wales, regardless of place of birth or death, resulting in around 500 reports annually (All Wales Perinatal Survey, 1998). The database is maintained by the Perinatal Survey Office, Department of Child Health, University of Wales College of Medicine, co-holding the data with the Health Authorities and hospitals. The AWPS reports an extract of its data to CESDI.

The survey is used for surveillance of perinatal and infant mortality in Wales, allowing inter-regional and inter-district differences in mortality rates and unrecognised variations in the cause of death to be identified.

Data
Notification of deaths is dependent on a network

of unit-based local conveners and district co-ordinators appointed by the Director of Public Health Medicine in each District Health Authority. The local and district staff complete a paper form with help from the clinical staff (AWPS, 1998). The form is forwarded to the regional coordinating team with a clinical summary and post-mortem report if applicable. The Child Health System identifies deaths not reported through this system and forwards information to the survey office within 8 weeks of the death. Regional paediatric pathologists, coroners or other regional coordinators also report a small number of deaths. If the mother was resident outside Wales, the death is reported to the CESDI secretariat but not entered on to the AWPS database.

Once received by the regional coordinating team, the form is checked and entered on to the database. Deaths forming part of the confidential enquiry (CESDI) are then identified. Data are collected under six main headings (mother's details, including name, address and date of birth, obstetric history, current pregnancy, labour/delivery details, baby details, including name and date of birth, and death details).

A more detailed list of data items collected is given on pp. 383–5.

Coding systems
The obstetric (Aberdeen) and modified extended clinico-pathological (Wigglesworth) classification systems are used.

Completeness and accuracy
The survey office believes the data to be 'generally good', particularly for core fields such as gestation and birthweight.

The form is checked for completeness, resolving ambiguities and missing data items by the regional coordinating team. Gestational age is particularly checked and the address and postcode are checked on the Post Office Address File. Other internal validation checks include cross-checking and tabulating details.

The Child Health System may be used for cross-checking of data. The Cardiff Birth Survey data may be used as a proxy for maternity information.

Uses
The database is used to initiate enquiries, to provide data to CESDI and for the annual report.

Funding
Funded by NHS Wales.

Access
The regional coordinator acts as a data custodian ensuring protection of confidentiality. Named data would generally only be available to those who already have access to it (e.g. contributing hospitals and Health Authorities and national CESDI coordinators). Aggregate information is published in the annual report.

Contact details
The All Wales Perinatal Survey Office
Department of Child Health
University of Wales College of Medicine
Heath Park
Cardiff
CF4 4XN
Tel.: 02920 747747

Publications
All Wales Perinatal Survey and Confidential Enquiry into Stillbirths and Deaths in Infancy, Annual Report, 1997. Cardiff: All Wales Perinatal Survey; 1998.
See also http://www.gwent-ha.wales.nhs.uk/publications/phmreport/chapter6.pdf
Health statistics: http://www.dyfpws-ha.wales.nhs.uk/Compendium2000/page6.html

AWPS data items

Survey number		
Mother's details		
Surname		
Forename		
Address		
Postcode		
Date of birth		
Country of birth		
Ethnic group		
Hospital number		
Marital status		
Stable relationship		
Parents' occupation		
Father's current employment		
Obstetric history		
Previous infertility (y/n/nk)		
Date of first antenatal assessment		
	Number	Details of gestation, birthweight and cause of death (if applicable)
Livebirths		
Stillbirths		
Miscarriages, ectopics and moles		
Therapeutic abortions		
Neonatal deaths		
Post-neonatal deaths		
Number of previous deliveries of 24 or more weeks		
Maternal height		
Maternal weight at booking		
Current pregnancy		
Complications (y/n):		
Hypertension		
APH		
Polyhydramnios		
Oligohydramnios		
Diabetes mellitus		
If yes:		
Was the onset in pregnancy		
Was it insulin treated		
Haemolytic disease		
Amniocentesis		
Chorionic villus sampling		
Cordocentesis		
Drug or alcohol abuse		
Other problems		
Number of babies/fetuses this pregnancy		
Maternal smoking:		
None		
Less than 10/day		
10 or more/day		
Not known		
LMP		
Intended place of delivery (at booking)		
Type of care at booking:		
Consultant		
GP and midwife		
Midwife		
No care		
Not known		

continued

Labour/delivery details
Antenatal steroid treatment within 10 days of delivery:
- None
- For 24 hours or more
- For less than 24 hours
- Not known

Working EDD just before delivery
Type of care at delivery:
- Consultant
- GP and midwife
- Midwife
- No care

Reason for change in place of delivery:
- No change
- During pregnancy
  - Change of address
  - Clinical reasons
  - Other reasons
- During labour
  - Clinical reasons
  - Other reasons
  - Unintentionally
- Not known

Labour:
- Spontaneous onset/no induction
- Induced
- No labour/no induction/Caesarean section
- Not known

Induction before onset of labour (y/n/nk):
- Oxytocin
- Surgical
- Prostaglandin

Augmentation after onset of labour:
- As above

Membrane rupture:
- Date
- Time

Delivery:
- Spontaneous cephalic
- Forceps:
  - Low
  - Mid-cavity
- Ventouse
- Breech
- Breech extraction
- Destructive operation
- Elective Caesarean section
- Emergency Caesarean section
- Not known

Baby details
Baby's surname
Baby's forename
Mother's surname
Father's surname
Hospital number
Birth/delivery:
- Time
- Date

Sex
Birthweight
Clinical assessment of gestation

continued

Apgar score (1 and 5 min) Neonatal resuscitation (y/n): Oxygen Mask ventilation Intubation Cardiac massage Drugs (specify) Transfer to another hospital for neonatal care Clinical management Use of surfactant Outcome: Liveborn Spontaneous abortion Therapeutic abortion Stillbirth: Antenatal macerated Antenatal fresh In labour
Death details Date Time Place of death: Hospital Home In transit Elsewhere Autopsy: Yes Not requested Not permitted Requested: not done Not known Post-mortem number Autopsy findings Diagnosis Clinico-pathological classification Aberdeen classification (deaths up to 4 weeks only) Evidence of antepartum that may have contributed to death (y/n/nk/specify)

National Confidential Inquiry into Suicide and Homicide by People with Mental Illness, UK

Description

The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness was established at the University of Manchester in 1996, having previously been based in London. It was funded by the Department of Health in England. From 1997, additional funding was provided by the Scottish Office, the Welsh Office and the HSS Executive, Northern Ireland. In 1999, NICE was given administrative responsibility for all confidential enquiries. The Inquiry is conducted in association with the Royal College of Psychiatrists. Its main aims are:

- to collect detailed clinical data on people who die by suicide or commit homicide and who have been in contact with mental health services
- to make recommendations on clinical practice and policy that will reduce the risk of suicide and homicide by people under mental health care.

The Inquiry is particularly interested in the circumstances of suicide and homicide in specific 'priority groups' for whom recommendations are most needed. These are people who are known to be at higher risk or to have greater treatment needs, or who are likely to experience difficulty in maintaining contact with services. The priority groups are patients who:

- were inpatients at the time of the incident
- were discharged from inpatient care less than 3 months earlier
- were subject to the Care Programme Approach at a level requiring regular multidisciplinary review

- were not compliant with treatment
- had missed their final appointment with services
- were from an ethnic minority
- were homeless.

For each year (1996–2000) this represents around 1500 cases of suicide and probable suicide and 55 cases of perpetrators of homicide.[1]

Data

There are three stages to both the suicide and homicide components of the Inquiry. The first stage is the collection of a comprehensive national sample, irrespective of mental health history. The second stage is the identification of individuals within the sample who have been in contact with mental health services. The third stage is the collection of clinical data about these individuals.

Suicide

Information on people who die by suicide or who receive an open verdict at a coroner's inquest is obtained from the ONS for England and Wales and the GROs in Scotland and Northern Ireland. The majority of open verdicts are suicides and it is conventional to include some or all open verdicts in studies of suicide. In the Inquiry, all open verdicts are included unless it is clear that suicide was not considered at inquest, for example, in deaths in which a clear medical cause cannot be found but which were not self-inflicted. As a result, the Inquiry suicide sample consists of suicides and probable suicides but all cases are referred to as suicides in this report.

The Inquiry next determines which suicides were in contact with mental health services in the year before death with the help of hospital and community Trusts in each person's area of residence. This includes the Trust in the person's health district and any other Trusts to which patients in that district are frequently referred. When Trust records show that contact occurred in the 12 months before suicide the person becomes an 'Inquiry case' and the responsible consultant psychiatrist is contacted. The consultant is then sent a questionnaire and asked to complete it in consultation with other members of the mental health team. The questionnaire consists of sections covering the following 10 headings:

- identification of priority groups
- demographic details
- clinical history
- details of suicide
- details of care in inpatient suicides
- details of care in community suicides
- details of final contact with services
- events leading to suicide
- respondents' views on prevention
- additional information.

Individual reporting arrangements have been made for patients under the care of most regional and national units, including regional secure units.

Homicide

In England and Wales, people convicted of homicide – murder, manslaughter or infanticide – are notified to the Inquiry by the Home Office, which routinely collects this information in the Homicide Index. In Scotland and Northern Ireland it is the Crown Office and the Belfast Crown Court, respectively, which notify the Inquiry of homicide convictions. Data collection then proceeds in two ways. First, psychiatric reports and records of previous offences are sought on all homicides, whether or not they have ever had contact with mental health services. Psychiatric reports are usually prepared prior to a trial for homicide and may subsequently be retained in court files. We have sought reports from the following sources: courts, the Crown Prosecution Service, solicitors, prisons, secure units and hospitals, individual psychiatrists and the Home Office itself. Lists of previous offences have been obtained from the Police National Computer and court files.

Second, the Inquiry proceeds as in the Suicide Inquiry, in that individuals who have been in contact with mental health services are identified with the help of Trusts in the local district and in many cases several surrounding districts, and questionnaires are sent to the consultants whose teams provided care. However, there is not a 1-year limit for contact with services, as there is in the Suicide Inquiry, and people who are known to have had contact with services at any time become Inquiry cases. Those with contact in the last year are an identifiable sub-group and information on them rather than on the whole sample is more suitable for some analyses.

The psychiatric reports provide information on psychiatric and social history and mental state at the time of the offence. The questionnaires are similar to those used in cases of suicide but there are additional items on previous violence.

Coding systems

No details are available.

Completeness and accuracy
An assessment of the accuracy of checks by Trusts, carried out in 16 Trusts in the north-west, showed that 95% of eligible cases were identified. Most omissions arose because of minor inaccuracies in Trust records or in personal information notified to the Inquiry, such as mis-spellings of names. As a result, a checking protocol was developed and recommended to Trusts.

Uses
The Inquiry does not collect equivalent information on 'controls', individuals who have been in contact with mental health services but who have not committed suicide or homicide. This means that it cannot yet identify the causes of suicide or homicide by psychiatric patients or say with certainty how people who commit suicide or homicide differ from other patients. However, the Inquiry has begun case–control studies of suicide by inpatients and recently discharged patients. Findings will be published in future reports.

Currently, the Inquiry collects detailed information on the activities of clinical services prior to suicide and homicide and on patterns of events leading to these incidents. As a result, it can say how often certain kinds of problems occur prior to suicide and link these to service responses. For example, the Inquiry can tell us how often patients lose contact with services before suicide or homicide, and what actions services take. It can also carry out comparisons within the sample of patients committing suicide (their number being much larger than the number committing homicide), highlighting the features of suicides in different settings, such as inpatient suicides versus suicides in the community. Some of these findings will reflect differences between patients in these settings in general, whether or not they commit suicide; others will show particular problems of providing safe care.[1]

Funding
Funding by NICE in 1999 was £440,000. (Previously funded by the Department of Health at around £1.15 million over the first 5 years; additional funding from the Scottish Office, Welsh Office and the Department of Health and Social Services, Northern Ireland.)

Access
See website and contact details listed below.

Contact details
Professor L Appleby
PO Box 86
Manchester
M20 2EF
Tel.: 0161 291 4751/4752
Fax: 0161 291 4358
E-mail: confid@fsl.with.man.ac.uk
Website: http://www.confidentialinquiry.man.ac.uk/

Reports
Safety first. Five year report of the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness. London: Department of Health; 2001 (http://www.doh.gov.uk/mentalhealth/safetyfirst).
Safer services. Five year report of the National Confidential Inquiry, May 1999 (http://tap.ccta.gov.uk/doh/point.nsf).

Publications
Appleby L, Shaw J, Amos T. Confidential Inquiry into Suicide and Homicide by People with Mental Illness. *Br J Psychiatry* 1997;**171**:391.
Appleby L, Shaw J, Amos T, *et al*. Suicide within 12 months of contact with mental health services: national clinical survey. *BMJ* 1999;**318**:1235–9.
Shaw J, Appleby L, Amos T, *et al*. Mental disorder and clinical care in people convicted of homicide: national clinical survey. *BMJ* 1999; 318:1240–4.

Related publications
Appleby L. New confidential inquiry established into homicide and suicide by mentally ill people [letter]. *BMJ* 1996;**313**:234.
Appleby L, Shaw J, Amos T, Dennehy J. Global burden of disease. *Lancet* 1997;**350**:143.
Appleby L, Shaw J, Amos T. Homicide enquiries. *J Forensic Psychiatry* 1997;**8**:458–9.
Appleby L. Assessment of suicide risk. *Psychiatric Bull* 1997;**21**:193–4.
Appleby L, Shaw J, Amos T. Inquiry into homicide by psychiatry patients [correspondence]. *BMJ* 1997;**314**:375.
Amos T, Appleby L, Shaw J. National Confidential Inquiry into Suicide and Homicide by People with Mental Illness: recent developments. *Int J Psychiatry Clin Practice* 1997;**1**:69–71.
Publications website: http://www.confidentialinquiry.man.ac.uk/

Reference
1. Safety first. Five year report of the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness. London: Department of Health; 2001.

Appendix 6

Disease-specific registers without data on health technologies

Contents

The lists in this section relate to the largest registers located. A number of smaller databases were located for rare diseases, about which relatively few details were publicly available. These tended to be run by the relevant patient and clinician groups. Full details are available from the authors on request.

The account of the registers of blind or partially sighted, of physically handicapped and of deaf or hard of hearing have been combined into a single section owing to the similarity between these registers.

Asbestosis and Mesothelioma Registers

Description

The Health and Safety Executive* compiles the Asbestosis and Mesothelioma Registers to determine the nature and scale of deaths from asbestos-related diseases. The Registers cover Great Britain with around 200–300 cases per year. It has been completed since 1968, although computerised data are only available from 1978. Figures are updated and published annually; at the time of writing, the latest available were for 1996.

Data

Data are collected from the ONS and the GRO for Scotland through death drafts mentioning 'asbestosis'. Data are available for sex and age. Mentions of lung cancer and mesothelioma on the death draft are also collated. For death certificates mentioning mesothelioma, the following are collected: site of mesothelioma (pleura, peritoneum, both and unspecified) and occupation.

Data on mesothelioma are available since 1976 for standard regions, counties and county districts. Cancer registrations are used to monitor the completeness of the main data source.

Lists of data items collected are given on p. 391.

Uses

The data are used in the Health and Safety Executive's annual report and statistics.

Funding

Funded by the Health and Safety Executive.

Access

See publications, website address and contact details.

Contact details

J Jones
Health and Safety Executive
EMSU
Magdalene House
Stanley Precinct
Bootle
Merseyside
L20 7HE
Tel.: 0151 951 3819
Fax: 0151 951 4703
E-mail: point.publicenquiry@hse.gov.uk

Publications

Health and Safety Executive Annual Report, 1999–2000: http://www.hseni.gov.uk/Annual%20Report%20pdfs/Appendix1to4.pdf.

See also: Health and Safety Executive statistics website: http://www.hse.gov.uk/hsestats.htm
National statistics website: http://www.statistics.gov.uk/statbase/source.asp?vlnk=26Information Sources

* The Health and Safety Executive runs 11 databases, of which the two most relevant to health have been selected here. The others refer to injuries, enforcement statistics, workplace accidents, enforced premises, comparative injury statistics, industrial injuries scheme, work-related chest disease, records of lead work blood levels and investigations (see the Health and Safety Executive website).

Asbestosis Register data items

Patient details
Name
Date of birth
Sex
Country of usual residence
Regional, country and county district codes
Postcode
Job title and classification code
Husband's job title and classification code
Asbestosis details
Death registration details
Date of registration
Date of death
Other causes of death recorded[a]
[a] Mesothelioma or lung cancer coded.

Mesothelioma Register data items

Patient details
Surname and forename
Date of birth
Sex
Country and regional code
County and county district code
Job title (husband's occupation recorded for deaths registered prior to 1993 if 'own' occupation not recorded)
OPCS occupation classification code (husband's occupation classification code recorded as above)
Mesothelioma details
Site of mesothelioma
Death registration details
Date of registration
Final underlying cause of death
Cancer anniversary date

Chromosome Abnormality Database (CAD)

Description

The CAD is operated by the Oxford Medical Genetics Laboratories on behalf of the UK Association of Clinical Cytogeneticists. The database was established in 1991 and holds in excess of 123,000 records representing virtually all chromosome abnormalities detected by NHS cytogenetics laboratories in the UK since 1991 (many of the datasets go back much further). The database is divided into two separate registers. The first is the Constitutional Register that holds just constitutional abnormalities, and the second, the Acquired Register, holds abnormalities that are acquired as a result of an illness.

The database was established as a central UK resource of chromosome abnormality information for both research and clinical use. The primary objectives are (Chromosome Abnormality Database, 1999):

1. maintenance of a UK-wide database of chromosome abnormalities
2. provision of chromosome abnormality data facilitating:
   (a) cytogenetic diagnosis, prognosis, risk assessment and clinical counselling
   (b) cytogenetic research
   (c) human genetic, molecular cytogenetic and molecular diagnostic research
   (d) promotion of storage of permanent cell lines
   (e) collaboration with other national collections of cytogenetic data
3. provision of national data for collaborative scientific investigations.

The CAD provides a central UK source of reference for the prenatal detection of

karyotypically abnormal babies (approximately 2250 detected prenatally in the UK each year), postnatal diagnosis of constitutional chromosome anomalies (around 4500 people diagnosed annually) and abnormalities detected in malignant conditions (especially leukaemia and paediatric tumours). The database also provides data to cytogeneticists and clinicians, aiding understanding of clinical significance of unusual cytogenetic abnormalities. Gene mapping, diagnostic and prognostic correlations and similar research are carried out on data provided by the database. In addition, CAD carries out research on information held by the database, but this is severely limited by the situation of short-term funding.

Specific applications of the database include (Chromosome Abnormality Database, 1999):

- centralised source of reference for counselling and risk assessment of chromosome abnormalities
- provision of information regarding the diagnostic and prognostic implications of karyotypic abnormalities
- data management allowing correlation of incidences of abnormalities with diagnostic strategies and policies
- listing of recurrent chromosomal breakpoints and associated anomalies, aiding mapping of genes associated with malignancy, congenital malformations and other clinical conditions (contributing to the Human Genome Project).

In 1999, discussions concerning the merging of CAD with the National Down Syndrome Cytogenetic Register (NDSCR) were in progress. There are no additional plans to alter the types of data items collected or discontinue the dataset (unless funding ceases – see Funding section below).

There have also been discussions about forming a network of European cytogenetics databases, including the already established Human Cytogenetics Forum, based in Grenoble, to provide an even more comprehensive resource of chromosome abnormality information. EU funding will be sought for this venture.

Data

Data are received on an *ad hoc* basis* from the UK cytogenetics laboratories. Many laboratories contribute directly in electronic format although the database manager will visit the laboratories to collect data if necessary. The aim is to establish a regular cycle for collection of all data electronically:

- patient details, including identification number and date of birth
- laboratory administrative details
- abnormality details.

A full list of data items collected is given on p. 393.

Coding systems

The CAD uses the participating laboratories' data coding schemes. There is no national chromosome abnormality coding scheme, although the database would welcome one.

Completeness and accuracy

Data are received from 45 UK cytogenetics laboratories, which represent over 70% of laboratories performing routine cytogenetic services within the UK. The completeness of notifications from the laboratories that contribute data is 100%. The database is trying to encourage the handful of non-contributing laboratories to participate.

There have been disruptions in both collection and processing of data. These have been due to short-term funding leading to breaks between grants.

The level of completeness for the data items is 100% owing to the database's automatic data collection systems.

As most of the information is forwarded electronically to the database, the accuracy is determined by data entry at source.

There are no internal validation checks or data processing, except for exclusion of duplicate or incomplete data.

Uses

The database collaborates with projects undertaken by the UK Cancer Cytogenetics Group and shares data with the NDSCR and with the cytogenetics databases for the MRC Leukaemia Trials (e.g. CML, AML and ALL) and Paediatric Tumour Trials (e.g. neuroblastoma). The CAD has also provided data for national epidemiological monitoring studies.

Funding

The database was initially funded (1991–94) by the MRC with 1999–2000 funding† provided for 1 year by the NHSE South East.

* Regular collections are inhibited because of the short-term funding status of the database.
† Prior to this, funding was intermittent and the database is dependent on short-term funding.

Access

The CAD website provides access to limited data and general information about the database: http://www.hgmp.mrc.ac.uk/local-data/Cad_Start.html (under reconstruction, July 2001). Patient identity is known only to the laboratory that contributes the data. All data held on the central database are anonymous. Ethical approval and patient consent would be needed by the host laboratory to provide patient-identifiable data. Access to individual patient records through to national aggregated data requires contact with the Database Manager.

Contact details

C Scott
Database Manager
The Chromosome Abnormality Database
Oxford Medical Genetics Laboratories
Churchill Hospital
Headington
Oxford
OX3 7LJ
Tel.: 01865 226003
Fax: 01865 226006
E-mail: cscottcad@hotmail.com

Publications

Half-yearly newsletters are circulated to contributing laboratories and users of the CAD.

Chromosome Abnormality Database: centralised database for chromosome abnormalities: data collection, analysis and utilisation for diagnostic and research purposes. Chromosome Abnormality Database Report, 1999.

Brewer C, Holloway S, Zawalnyski P, Schinzel A, Fitzpatrick D. A chromosomal deletion map of human malformations. *Am J Hum Genet* 1998;**63**:1153–9.

Bueno JL, Watson A, Dainton MG, Hughes DM, Killick S, Treleaven JG, *et al*. Monosomy X as the sole cytogenetic abnormality in acute lymphoblastic leukaemia. A report of two new patients. *Leuk Lymphoma* 1999;**32**:381–4.

CAD: data Items

Patient details
Identification number
Date of birth
Sex
Pedigree number (constitutional register only)
Laboratory administrative details
Sample identification number
Laboratory name
Date of receipt of sample
Site at which stored materials are kept
Abnormality details
Tissue type
Karyotype
Number of cells analysed for each karyotype (acquired register only)
Primary reason for referral
Coded disease or phenotypic features

Craniofacial Anomalies Register (CARE)

Description

The CARE collects data on patients seen by Cleft Lip and Palate Teams in England [previously called the Cleft Lip and Palate Database, based in the Leeds Dental Institute (1998–99)]. CARE in 2001 was based at the Perinatal Institute, located in Birmingham Health Authority.

CARE has the following aims:

- ensure an up-to-date register of all cleft cases
- promote agreed standards in management
- audit and report on the quality of care
- monitor the frequency and incidence of clefting
- support research and focused studies, run educational meetings supporting the work of CARE
- host projects commissioned by the Cleft Levy Board
- maintain links with the Craniofacial Society and other anomaly registers.

Over 13,000 patients are registered on the database and approximately 1000 new cases are added each year. CARE is run by the Cleft Levy Board, which is made up of representatives of the NHS who commission cleft lip and palate care. They are largely medical and dental practitioners with a public health role (CARE website, July 2001).

Data

CARE is phasing out its paper-based system of data collection and has an on-line database and website called CAREnet on the NHSnet (http://www.cfsgb.org.uk). Each Cleft Team has a data coordinator, usually called a cleft coordinator, responsible for data input. Dedicated central support staff consisting of two part-time clerical assistants provide a point of contact for Cleft Teams throughout the week. The data collection form is on CAREnet.

The on-line form has six main headings (cleft team; patient information; type of cleft and additional clinical information; investigations and measurements; audit and outcome; and details of interventions). However, the headings on outcomes and intervention were yet to become operational at the time of writing (CARE website, July 2001). It aims to cover the minimum records required by the Eurocleft/BiomedII programme (Eurocleft website listed below). See pp. 395–6 for list of data items collected (CAREnet, 2001).

Each Cleft Team is expected to have a cleft coordinator who is responsible for completing the on-line data entry forms and updating this information. Meetings are held with the cleft coordinators of each Team to obtain feedback on data quality and operational problems. In addition, Clinical Directors of Cleft Teams meet to discuss projects, data input and reporting.

Coding systems

The database uses the Kiernahan Modified Pitch Fork code and the LASHAL code, both specific to cleft lip.

Completeness and accuracy

Data matching has shown poor correlation between data produced by CARE and those of the ONS. Protocols are in place to match data on a regular basis between a number of national and regional databases to improve ascertainment (CARE website, July 2001). HSC 1998/238 Cleft Lip and Palate Services[1] suggested that all centres should use recognised audit/outcome measures. These measures need validating over time to ensure consistency across different teams. Regional Specialised Commissioning Groups (RSCGs) will set targets for Cleft Teams in the future. To set these targets they will need comparative data. Use will be made of outcome measures such as CAPS and GOSLON/5 year yardstick.[1]

Uses

The dataset facilitates audit nationally and internationally (Eurocleft) (CARE website, July 2001). The (former) Cleft Lip and Palate Registry was used by the Clinical Standards Advisory Group[2] as part of a national audit of the treatment and outcome of patients with cleft lip; the database identified patients with cleft lip from whom additional data were collected. Published papers have mainly described the database.

Funding

CARE is NHS funded through the Cleft Levy Board, which is responsible for the management of CARE.

Access

CAREnet has a restricted and an unrestricted section. The restricted section contains patient data and only users certified by the Clinical Director of a Cleft Team have access to the on-line database and reports. Cleft Team users only have access to their own Team's data. The unrestricted section is open to all NHSnet users and contains information on cleft lip and palate, CARE and some aggregated anonymised data reports.

See also the Eurocleft website: http://natqa.uas.se/swedecleft/eng/projects/eng_eurocleft/eng_eurocleft.html

Contact details

M Hammond
Director
Consultant Orthodontist
Department of Orthodontics
Dudley Group of Hospitals NHS Trust
Corbett Hospital
Vicarage Road
Stourbridge
West Midlands
DY8 4JB
Tel.: 01384 244719
Fax: 01384 244798
E-mail: care@cfsgb.org.uk

CARE website: http://www.cfsgb.org.uk/care/CARE/CARENET/CARE.htm
Eurocleft website: http://natqa.uas.se/swedecleft/eng/projects/eng_eurocleft/eng_eurocleft.html

Publications

Details of the Annual Report and other publications are listed on the CARE website: http://www.cfsgb.org.uk/care/CARE/CARENET/FRAMESET.htm

Hammond M, Stassen L. Do you CARE? A National Register for cleft lip and palate patients (editorial). *Br J Oral Maxillofac Surg*; reprinted in *Br J Orthodont, Br J Plast Surg* April 1999.

CARE statistics: http://www.cfsgb.org.uk/care/CARE/CARENET/STATISTICS.htm

See also the references below.

References

1. Cleft Lip and Palate Services. HSC 1998/238.
2. Clinical Standards Advisory Group report (CSAG report): cleft lip and/or palate. London: The Stationery Office; 1998.

CARE data items[1]

Craniofacial Anomalies Register ~ C A R E ~			or nww.caredb.wmids.nhs.uk
1. TEAM	Cleft Team		Care ID
	Hub1 Hospital Name		Hub1 Hospital Unit No.
	Hub2 Hospital Name		Hub2 Hospital Unit No.
	Primary Cleft Surgeon		

Place a sticker from the patient's notes if possible

2. PATIENT	Eligible for NHS Treatment			Y	N	Patients NHS No.																		
	Date of Birth									Dae Deceased														
	Present Surname									Surname at Birth														
	First names																							
	House number/name					Postcode											Sex			M	F			
	Hospital of Birth or referral to if home birth														Pre-natal Diagnosis					Y	N			
	P'code 1st Trimester									Geneticist														
	Family History of Clefts		Y	N	GU		Y	N		Limb defects		Y	N	CVS		Y	N							

3. CLEFT		Patient's Right								Patient's Left														
	Simonart's Bands	Y				I = Incomplete								Y										
	Lip		C	I		C = Complete						I	C											
	Alveolus			C	I						I	C												
	Hard Palate					I	C																	
	Soft Palate					I	C																	
	Cleft Description																							

4. RECORD COLLECTION	enter dates	models	ceph	photos	speech	Audiometry/ tympanometry	satisfac																	
	Primary surgery	✓		✓																				
	3 yrs				✓	✓																		
	5/6 yrs	✓		✓	✓	✓																		
	10 yrs	✓	✓	✓	✓	✓																		
	15/16 yrs	✓	✓	✓	✓	✓	✓																	
	18 yrs			✓			✓																	
	VPI Surgery				✓																			
	ABG		occlusal	✓																				
	Orthognathic	✓	✓																					
	see notes. ✓ = suggested record, Enter dates over the ✓. VPI Surgery ~ pre-op & 1 year post-op. Orthognathic Surgery ~ pre-op & 1 year post op. ABG ~ pre-op, 6 months post-op, and when canine fully.																							

5. AUDIT/OUTCOME	5 YR INDEX	GOSLON	CAPS+
+ R= red, A = amber G = green			

continued

6. SURGERY							
	Primary Procedures						enter dates
	Primary Lip1			Primary Palate 1			
	Primary Lip2			Primary Palate 2			
	Secondary Procedures						enter dates
	Pre-Surg Ortho	Y	N	Pharyngoplasty		ABG1	
	Lip Revision			Palatal Fistula		ABG2	
	Nasal Revision			Palate Re-Repair		Osteotomy	
	Grommets			Cleft Rhinoplasty			
	Other procedures – please specify						enter dates

[1] This information is collected as part of the patient's treatment records. Data are held in accordance with recommendations of the Data Protection Act. White copy to Dr M Hammond, Consultant Orthodontist, Department of Orthodontics, Corbett Hospital, Stourbridge, West Midlands DY8 4JB.

HIV/AIDS A(C)A1–3

Description

These central returns enable the NHSE and regions to monitor and review progress. Reports are prepared under the AIDS (Control) Act 1987 and consist of three returns:*

- Reported AIDS Cases and Deaths: A(C)A1
- Newly Reported HIV Infected Persons (In Year): A(C)A2
- Newly Reported HIV Infected Persons (Cumulative): A(C)A3.

This information is collected by the Public Health Laboratory Service (PHLS) CDSC and CDSC Wales. It is linked to other CDSC databases: Notification of Infectious Diseases (NOIDS) (see p. 434) and Sexually Transmitted Diseases: New Cases Seen at GUM Clinics (KC60) (see p. 437).

Data

Data are processed annually at Health Authority level.

Reported AIDS Cases and Deaths: A(C)A1

- Within financial year, number of people with AIDS reported and died.
- Cumulative to end of financial year, number of people with AIDS reported and died.

Newly reported HIV Infected Persons (In Year): A(C)A2

- Suspected viral acquisition details, categorised by sex.

Newly reported HIV Infected Persons (Cumulative): A(C)A3

- As A(C)A2.

A more detailed list of data items collected is given on p. 397.

Uses

Data used by the PHLS CDSC: HIV and AIDS Report Section and Unlinked Anonymous Prevalence Monitoring Programme (PHLS website, 2001).
See also sections on NOIDS (p. 434) and Korner Return: Sexually Transmitted Diseases: New Cases Seen at GUM Clinics (KC60) (p. 437). The KC60 data allow high-risk behaviour to be related to HIV trends.

Access

See the PHLS website and CDSC monthly reviews (listed below).

Contact details

Dr B Evans
PHLS Communicable Disease Surveillance Centre
61 Collingdale Avenue
Collingdale
London
NW9 5EQ
Tel.: 020 8200 6868

* Originally four returns; AIDS Fund Monitoring Statement Summary, A(C)A4, was withdrawn in 1999.

Ms L Johnson-Laird
HP3
Skipton House
80 London Road
London
SE1 6LH
Tel.: 020 7972 4397
PHLS website: http://www.phls.co.uk/facts/HIV/HivDataSources.htm

Publications
CDSC, AIDS and HIV infection in the United Kingdom: monthly reports, PHLS.
http://www.phls.co.uk/publications/cdrelectronic/cdr%20weekly/cdr%20weekly/archive/hiv0401.html
PHLS website: http://www.phls.co.uk/facts/HIV/HivDataSources.htm

HIV/AIDS: A(C)A1–3 data items
Reported AIDS Cases and Deaths: A(C)A1

Health Authority		
In financial year		
No. of people with AIDS:	First reported from HA	Known to be resident in HA
Reported to and accepted by CDSC		
Numbers known by 31 March to have died		
Cumulative to end of financial year		
As above		

Newly Reported HIV Infected Persons (In Year): A(C)A2

Health Authority				
Suspected viral acquisition details				
How virus probably acquired:	Male	Female	Not known	Total
Sexual intercourse between:				
Men				
Men and women				
Injecting drug use (IDU)				
IDU and sexual intercourse between men				
Blood factor (e.g. haemophiliacs)				
Blood tissue transfer (e.g. transmission)				
Mother to child infected				
Mother to child indeterminate[a]				
Other/undetermined				
Total				

[a] Children less than 18 months when last tested positive for HIV-1 antibody and without evidence of HIV-1 infection.

Newly Reported HIV Infected Persons (Cumulative): A(C)A3
As A(C)A2.

National Amputee Statistical Database (NASDAB)

Description
The NASDAB was established in April 1997 and is maintained by the Information and Statistics Division of the CSA. The aims of the database are to permit common reporting procedures from each prosthetic service centre and to re-establish a national reporting system. The database is used to gauge the aetiology of amputees and provide comparison with centres of similar sizes highlighting differing practices in different centres. The database holds 5896 patient records for the year 1997–98 and 5665 records for 1998–99.

Data
Every prosthetic service centre in the UK (around 50 sites) submits an electronic file (extracted from the referral system) quarterly to ISD Scotland, where it is checked for quality and appended to the national file. Following receipt of data it takes

approximately 1 week to code, process and validate the data. The four main data headings cover: administrative details, patient details, left and right upper limb amputation details and left and right lower limb amputation details. A more detailed list of data items collected is given on pp. 399–400.

Coding systems
Coding lists as agreed by the Steering Group and centre consultants have been used throughout.

Completeness and accuracy
The level of completeness for notifications is 100% for centres providing data.* Data items are around 85% complete. There are plans to increase the level of completeness for data items; the database is new and through continued pressure from the Steering Group the completeness and quality are improving.

Internal validation is undertaken and completed fields and erroneous values are checked by SPSS. Each centre is given a quarterly report of its data that it checks against its own values. Analysis is also performed to check consistency with the previous year.

The internal validation reveals weaknesses in the coding of aetiology, although it is difficult to assess whether fields are being completed correctly without a full audit taking place. The database is not externally validated.

Uses
The database is used to produce an annual statistical report which provides demographic, diagnostic, activity information on new amputations referred to UK prosthetic services.

Funding
Funding for the database is provided by the UK Prosthetic Service at £17,000 per annum to ISD Scotland.

Access
All data requests should be directed to ISD Scotland, which will pass them on, or to the Steering Group for authorisation. Statistical data are available on website: http://www.statistics.gov.uk

Contact details
Dr R Swain
Centre Manager
Nottingham City Hospital Mobility Centre
City Hospital
Hucknall Road
Nottingham
NG5 1PJ
Tel.: 0115 962 8044
Fax: 0115 962 8052

Dr S Baird
Database Manager
Information and Statistics Division
The National Health Service in Scotland
Trinity Park House
South Trinity Road
Edinburgh
EH5 3SQ
Tel.: 0131 551 8952
Fax: 0131 551 1392
E-mail: stuart.baird@isd.csa.scot.nhs.uk

Publications
Amputee Statistical Database for the United Kingdom, 1998/99 Report. Edinburgh: ISD Scotland; 2000.
See websites: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3890
http://www.show.scot.nhs.uk

* For the first year of data collection not all centres contributed full datasets, although this has now been rectified (ISD Scotland on behalf of NASDAB, 1999).

NASDAB data items

Administrative details
Purchaser code
Centre code

Patient details
Patient number
Date of birth
Gender
New amputee (y/n)
Ethnic origin

Left upper limb amputation details
Date of referral following a left upper limb amputation
Date of amputation
Level of amputation:
- Forequarter
- Shoulder disarticulation
- Trans-humeral
- Elbow disarticulation
- Trans-radial
- Wrist disarticulation
- Partial hand
- Digits

Cause of amputation (aetiology):
- Trauma:
  - No additional details
  - Mechanical
  - Electrical
  - Thermal
  - Chemical
- Dysvascularity:
  - No additional detail
  - Diabetes mellitus
  - Non-diabetic arteriosclerosis
  - Embolism
  - Vasospatic conditions (including Raynaud's)
  - Disseminated intravascular coagulation
  - Endovascular chemical trauma
  - Buerger's disease
  - Iatrogenic vascular trauma
  - Arthritis (including rheumatoid arthritis, autoimmune disease)
  - Venous disease
- Infection:
  - No additional detail
  - Acute
  - Chronic
- Neurological disorder:
  - No additional details
  - Diabetic neuropathy
  - Infective (including leprosy, Madura foot)
  - Spina bifida
  - Poliomyelitis
  - Peripheral nerve injury

Neoplasia
- No additional details
- Benign
- Malignant:
  - Primary
  - Secondary

Congenital absence:
- No additional detail

Other:
- No additional detail

continued

Right upper limb amputation details As left upper limb
Left lower limb amputation details As left upper limb, except: Level of amputation: Hemi-pelvectomy Hip disarticulation Trans-femoral Knee disarticulation Trans-tibial Ankle disarticulation (SYMES) Partial foot Digits
Right lower limb amputation details As left lower limb

ONS National Congenital Anomaly System (NCAS)

Description

The ONS (previously OPCS) is responsible for the NCAS. The database was established in 1964, in the wake of problems associated with thalidomide,* to monitor sudden increases in specific malformations. For 1997, ONS received 5505 notifications of birth defects, a rate of 85.3 per 10,000 total births (ONS, 1999). Records from 1990 onwards are contained within the database and earlier records are archived.

NCAS has links with both the British Isles Network of Congenital Anomalies Register (BINOCAR) and the European Registration of Congenital Anomalies and Twins (EUROCAT) (listed in Contact details below).

Data

Data are collected continuously on a voluntary basis from Health Authorities in England and Wales. Health Authorities notify ONS monthly of malformations in live or stillbirths resident in their district.

Prior to 1990, all anomalies were reportable, however minor. Since 1991, exclusion criteria allow minor malformations to be omitted unless occurring in combination with major anomalies. 'Minor' anomalies include clicking hip, single umbilical artery and minor/unspecified anomaly of nose/auricle. A complete list of the exclusion criteria is given on pp. 403–4.

Prior to 1995, only those detected at or within 10 days of birth were included, but this time limit has been abolished. Statutory birth notification† is the most common source (99%) of information, although hospital discharge data, death certificates and paediatric notifications are also used.

Health Authorities notify ONS of malformations on paper forms (SD56). ONS analyses monthly returns, checking for significant changes in any of the 52 monitored classes or groups. Health Authorities are informed‡ within 12 weeks of notification (6 weeks for notifications to be received and 6 weeks at ONS for processing and analysis) of any increases.

Data are collected under four main headings: identification number of child; mother's details, including address and date of birth; occupational details; and child's details, including date of birth, first three letters of first and family name, details of malformation.

A more detailed list of data items collected is given on pp. 402–3.

* A (now withdrawn) sedative, which if administered during the first trimester of pregnancy causes defects ranging from minor ear malformations to a reduction of all limbs.

† Completed by those in attendance at the birth and returned to the Health Authority within 36 hours. The form asks if an abnormality is present, with specification if yes.

‡ Care is taken in interpreting 'increased' incidences, as this may be an increase in notifications.

Coding systems
Congenital malformations have been coded using ICD-10 since 1995. Social class (determined by occupation) is coded using the Registrar General's coding scheme.

Completeness and accuracy
Although the system is primarily for monitoring changes in the frequency of reporting anomalies, it does provide the most extensive data on the prevalence levels available in England and Wales. However, the major disadvantage of using the monitoring system to measure prevalence arises from the deficiencies in its coverage.[1] The BINOCAR was established in 1996 to help address promote reporting on congenital anomalies (National Statistics website, 2001).

In 1998, two regional congenital anomaly registers, the Trent Congenital Anomaly Register (CAR) (see p. 423) and the Welsh Congenital Anomaly Register and Information Service (CARIS) (see p. 404) began to provide notifications to the NCAS. In the Trent Region, CAR took over the responsibility of forwarding SD56 forms completed by NHS Trusts to ONS. CARIS provided data on congenital anomalies for all live and stillbirths to mothers resident in Wales.

Since 1999, data from CAR and CARIS for all live births and stillbirths with congenital anomalies have been exchanged electronically with ONS.[2] This is reported to be improving the quality and coverage of the data from these regions.[3]

The completeness for notifications is higher for major congenital anomalies, but less complete for those minor anomalies identified on p. 403. Lack of data on terminations of pregnancy for fetal abnormality limits the completeness of the system.

Completeness of data items also varies: birth weight is 95%, but parental occupation is poor at 60%.[1]

The accuracy of the data received at the Centre has never been assessed. All data that look incorrect or incomplete are sent back to the participating Trust. ONS plan to incorporate the NHS number to facilitate record linkage and reduce duplication. Linking the database with the births and deaths register has been considered, as has more complete information on parental occupation through linkage with other relevant datasets (e.g. CARE, see p. 393).

Data inputters are fully trained ONS clinical coders, who also input data on other datasets. A double-entry system is used; an in-house system checks the correct postcode and date of birth. Summarised information is sent back to the Health Authorities.

Comparison is made on an *ad hoc* basis with the National Down Syndrome Cytogenetic Register (NDSCR) (see p. 430), which receives its information from cytogenetic laboratories. As reported above, studies comparing the national data with local registers and with specific defect registers including Down syndrome and neural tube defects, have reported the national register to be less complete than the more specialised/regional systems.[1]

Access
Aggregated information at a district level and above is available to researchers by request to the ONS. More specific information projects would require formal application and ethical committee approval.

Health Authorities are not charged for information; researchers are charged depending on the amount of work carried out.

Uses
The database is used for national malformation surveillance and has investigated various possible 'clusters' of increased incidence of particular malformations, including:

- reported increase in congenital dislocation of the hip;[4] resulted from the introduction of a neonatal screening system
- limb reduction defects in certain coastal areas;[5] reported no association with residence
- anophthalmia incidences due to local, large-scale pesticide introduction; no changes in trends were observed.[6]

The dataset can be used to monitor the effects of preventive measures, such as maternal periconceptional dietary folic acid for the prevention of neural tube defects, and rubella immunisation programmes for the prevention of rubella embryopathology.[1]

Funding
Funded by the Department of Health.

Access
Statistics of notifications of congenital anomalies for England and Wales available for each year

from ONS. More specific information would require formal application and ethical committee approval. Health Authorities are not charged for information; researchers are charged depending on the amount of work carried out.

Contact details
ONS National Congenital Anomaly System (NCAS)
Room B6/10
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5641
E-mail: ncas@ons.gov.uk
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3115

British Isles Network of Congenital Anomalies Register (BINOCAR)
B Botting
ONS
E-mail: bev.botting@ons.gov.uk
Website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp

European Registration of Congenital Anomalies and Twins (EUROCAT) website: http://www.oecd.org/els/health/sources/Morbidity.htm

Publications
Payne JN. Limitations of the OPCS Congenital Malformation Notifications Scheme illustrated by the examination of congenital malformations of the cardiovascular system in Districts within the Trent Region. *Public Health* 1992;**106**:437–48.

See also the references below.

References

1. OPCS. The OPCS Monitoring Scheme for Congenital Malformations. A review by the Working Group of the Registrar General's Medical Advisory Committee. Occasional Paper No. 43. London: HMSO; 1995.
2. Botting B. The impact of more complete data from Wales on the National Congenital Anomaly System, *Health Stat Q* 2000; 7–9. http://www.statistics.gov.uk/themes/health_care/downloads/HSQ5Book.pdf
3. Congenital anomaly statistics notifications: a statistical review of notifications of congenital anomalies received as part of the England and Wales Congenital Anomaly System, 1999: Series MB3. London: Office for National Statistics, 2000; 14, 14603934. http://www.statistics.gov.uk/downloads/theme_health/MB3_14_Book_v4.pdf
4. Weatherall JAC. Congenital malformations: surveillance and reporting. *Popul Trends* 1978;**11**:27–9.
5. Botting B. Limb reduction defects and costal areas. *Lancet* 1994;**343**:1033–4.
6. Gilbert R. Clusters of anophthalmia. *BMJ* 1993; **307**:340–1.

NCAS SD56 data items

Identification number
Status of informant:
- Doctor
- Midwife
- Other (specify)

Mother's details
District Health Authority (usual address)
Home address and postcode
Date of birth (if not known, state age)
Number and outcome of previous pregnancies resulting in:
- Live births
- Stillbirths
- Others

Occupational details
Parents' occupation (just before or early in mother's pregnancy)
- Mother
- Father

continued

Child's details
First three letters of first and family name
District Health Authority in which baby was born
Place of birth:
- Home
- NHS hospital
- Other (specify)

Date of birth
Sex:
- Male
- Female
- Indeterminate

Whether live or stillbirth
- Live
- Born alive, died within 7 days
- Still

Whether single or multiple birth (if multiple, state number born)
Date of LMP (if not known, state estimated gestation)
Birthweight
Congenital malformations reported

Exclusions of minor anomalies and conditions not considered to be malformations

Minor anomalies given below are excluded

Spina bifida occulata – uncomplicated
Stenosis or stricture of lacrimal duct
Anomalies of ear – minor or unspecified
Anomalies of face – minor or unspecified
Deformity of face – minor or unspecified
Anomalies of nipple – minor, e.g. accessory or ectopic nipple
Congenital:
- Umbilical hernia
- Inguinal hernia
- Para umbilical hernia

Undescended testicle
Ectopic testicle
Congenital hydrocoele or hydrocoele of testis
Glandular hypospadias – if meatus lies before coronary sulcus
Abnormal palmar crease
Skin anomaly – surface less than 4 cm^2: skin tag naevus, angioma, haemangioma, glomus tumour, lymphangioma, birthmark
Clicking hip – unless confirmed as dislocatable
Clubfoot of positional origin
Anomalies of toes – minor or unspecified, e.g. hallux valgus, hallux varus or 'orteuil marteau'
Cardiac murmur – functional or unspecified
Anomaly of umbilical artery – absence or hypoplasia, single umbilical artery

Conditions not considered to be malformations

Abdominal distention
Abnormality – blood group
Acidaemia – organic
Atelectasis
Australian antigen
Bruising splenic region
Cephalhaematoma
Cerebral palsy

continued

Cyst on cord
Deafness congenital
Dystocia shoulder
Haematoma
Haematoma umbilical cord
Hyaline membrane disease
Hyperventilating
Inter-uterine growth retardation
Meconium liquor
Meconium peritonitis
Necrotising enterocolitis
Palsy facial nerve – traumatic
Perforated gut
Phimosis
Pleural effusions
Polycythemia
Respiratory distress syndrome
Rhesus affected baby
Rhesus antibodies
Ruptured bowel
Sclerema
Two teeth or congenital teeth
Umbilical granuloma
Weak femoral pulses

Congenital Anomaly Register and Information Service (CARIS) Wales

Description

The CARIS dataset was established in 1997 following recommendations of the review of congenital malformation monitoring (OPCS, 1995). The data are collected by the West Wales Centre for Public Health.

CARIS aims to collect data that can be used to describe the pattern of congenital anomalies across Wales. This should help:

- investigate suspected clusters of anomalies and association with possible causes
- assess the effectiveness of programmes to reduce birth anomalies (e.g. folic acid)
- assess the effectiveness of programmes which detect anomalies antenatally, both locally and nationally
- ensure that (anonymised) data are reported to the ONS into the NCAS as part of the British surveillance programme (see NCAS, p. 400).

In addition to the direct link to NCAS, CARIS is also a member of BINOCAR and EUROCAT (listed in Contact details below).

Data

Information supplied to CARIS includes all anomalies:

- detected in a child born to a mother resident in Wales at time of birth
- present at the time of birth whether first detected antenatally, at birth or other termination of pregnancy or during the first year of life*
- involving a structural, metabolic, endocrine or genetic defect in the child/fetus.†

Reporting sources include:

- direct reporting from professionals in General Trusts (such as obstetricians, midwives)
- specialist sources (e.g. clinical biochemistry, paediatric pathology)
- electronic data sources in General Trusts (e.g. maternity systems, PEDW data sources)
- ONS birth and death notification systems
- Trusts outside Wales serving Welsh residents
- other specialist information systems collecting data relating to congenital malformations (e.g. neighbouring congenital anomaly registers and the GP Morbidity Database).

* The collection of data on anomalies first detected in children older than 1 year will be addressed as CARIS develops.
† In line with ONS NCAS, CARIS excludes certain minor defects (e.g. clicking hips, tongue-tie) from registration (see NCAS, p. 400).

Data collection mechanisms have been established in most Trusts in Wales and are being expanded for the other Trusts. The information is received on a continuous basis and covers the whole of Wales.

It is intended that notifications to CARIS be made as soon as possible following anomaly detection. As many anomalies are detected antenatally, a 'warning card' system has also been introduced, allowing basic identifiers and details of a suspected anomaly to be reported (see p. 408).

The CARIS Main Registration Form (see pp. 406–7) is used to collect the data.

Coding systems

CARIS uses ICD-10 codes with Royal College of Paediatrics extensions. Read 4 is used for any items not covered by ICD-10.

Completeness and accuracy

A formal review was carried out in January 1999 with the coordinator in each Trust liaising with CARIS with regard to improving the system. This reported that there had been an increase in the number of notifications as a result of using multiple sources for notifications.[1]

Uses

The CARIS database can be used to assess the efficacy and effectiveness of treatments and screening services and perhaps for the diffusion of any treatments.[1]

Funding

Funded by the Welsh Office.

Access

A procedure of disclosure of information has been produced by CARIS. Researchers will not have access to any patient-identifiable information; this is strictly limited to the patients themselves or NHS staff for audit purposes, following written request.

Researchers requiring information on case notes must obtain the consent of the treating physician or GP, unless blanket approval has been obtained from the Medical Director of the Trust or the Chairman of the appropriate Consultant's Committee. Evidence of approval by an appropriate Ethics Committee must also be obtained.

Contact details

D Tucker
Congenital Anomaly Register & Information Service (CARIS)
c/o Level 3 – West Wing
Singleton Hospital
Swansea
SA2 8QA
Tel.: 01792 285241
Fax: 01792 285242
E-mail: dave.tucker@swansea-tr.wales.nhs.uk
CARIS website: http://www.lshtm.ac.uk/php/eeu/eurocat/caris/caris3.htm

ONS National Congenital Anomaly System (NCAS)
Room B6/10
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5641
E-mail: ncas@ons.gov.uk
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3115

British Isles Network of Congenital Anomalies Register (BINOCAR)
B Botting
ONS
E-mail: bev.botting@ons.gov.uk
Website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp
European Registration of Congenital Anomalies and Twins (EUROCAT) website: http://www.oecd.org/els/health/sources/Morbidity.htm

Publications

Congenital anomaly statistics notifications: a statistical review of notifications of congenital anomalies received as part of the England and Wales Congenital Anomaly System, 1999: Series MB3. London: Office for National Statistics; 2000; 14: 14603934. http://www.statistics.gov.uk/downloads/theme_health/MB3_14_Book_v4.pdf
BINOCAR, National Statistics website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp

Reference

1. Botting B. The impact of more complete data from Wales on the National Congenital Anomaly System. *Health Stat Q* 2000; 7–9. http://www.statistics.gov.uk/themes/health_care/downloads/HSQ5Book.pdf

CARIS data items
Main registration form

Mother's details
Surname
Forenames
Address
Postcode
GP practice
Hospital at which pregnancy ended
Hospital no.
NHS no.
Occupation
Date of birth
Ethnic origin

Father's details
Surname
Forename
Occupation
Age (years)

Family history
Anomalies mother's side (y/n/nk)
Anomalies father's side (y/n/nk)
Consanguinity (y/n/nk)
Details

Mother's obstetric history
Number of previous:
- Livebirths
- Stillbirths
- Spontaneous abortions
- Induced abortions

History of anomalies in previous pregnancy (y/n/nk)
- If yes, details and dates

Details of current pregnancy
Last menstrual period
Estimated date of delivery
No. of fetuses
Assisted conception (y/n/nk)
- If yes, give details

Maternal risk factors
Smoker:
- No
- Less than 10
- 10 or more
- Not known

Folic acid details (y/n/nk)	If yes, dates and details
Prescribed drugs (y/n/nk)	If yes, dates and details
Alcohol abuse (y/n/nk)	If yes, dates and details
Drug abuse (y/n/nk)	If yes, dates and details
Diabetes (y/n/nk)	If yes, dates and details
Epilepsy (y/n/nk)	If yes, dates and details
Previous radiation/chemotherapy (y/n/nk)	If yes, dates and details
Other significant maternal illness/exposures (y/n/nk)	If yes, dates and details

continued

Fetus/infant details
Outcome of pregnancy:
- Spontaneous fetal loss
- Therapeutic termination
- Stillborn
- Live born

If baby/fetus dead:
- Date of death
- Cause of death

Date end pregnancy
Place of delivery
Sex: M/F/indeterminate/not known
Birthweight (g)
Birth order
Surname
Forenames
Delivery unit number
NHS number
Address and postcode (if different to mother)

Details of congenital anomalies
Diagnostic techniques used to detect anomaly:

	Date anomaly first detected	Details of result
Antenatal ultrasound		
Serum screening		
Karyotype:		
Amniocentesis		
CVS		
Cordocentesis		
Infant blood		
Examination of newborn		
Heel prick test		
X-ray		
Cardiac studies		
Postnatal ultrasound scan (USS)		
Other (specify)		

Post-mortem:
- Yes
- Not requested
- Not permitted
- Requested, not done
- Not known

Report attached:
- Yes
- No
- To follow
- Not available

Anomalies/abnormalities found in infant/fetus (×8):
- Details of anomaly(ies)
- Diagnosis suspected or confirmed?
- Are any of the abnormalities thought to be part of a syndrome? (y/n/nk)
  - If yes, give details
- Space for further description/drawing of anomaly

Administrative details
Consultant from whom further details may be available:
- Obstetrician
- Paediatrician
- Other (specify)

Warning card

Mother's details Surname Forenames Address Postcode NHS number Hospital Hospital number Date of birth Total number of fetuses this pregnancy Expected delivery date Pregnancy status at time of notification: Continuing pregnancy TOP IUD Delivered
Baby's details (if liveborn) Surname Forenames Address Postcode NHS number Hospital number Date of birth
Details of anomaly and diagnosis Details
Staffing details Obstetrician Paediatrician Other and title

Glasgow Register of Congenital Anomalies (GRCA)

Description

The GRCA was set up by the Social Paediatric and Obstetric Research Unit in 1972. The Greater Glasgow Health Board took responsibility for the register in 1974. All anatomical, metabolic and genetic congenital anomalies (except minor defects), resulting in live births, stillbirths and therapeutic terminations, are included in the scheme. Approximately 8000 individual patient records are held in the database.

The aims of the database are:

- to monitor trends in the frequency of malformed births (and terminations)
- to detect epidemics
- to generate baseline rates of prevalence
- epidemiological investigation of malformations
- to study cohort survivors including: diagnostic, educational, employment and service needs
- the evaluation of preventive and therapeutic services.

The Register joined EUROCAT as a founder member in 1979.

It is also a founder member of BINOCAR and is linked to a number of other databases, including the ONS (listed in Contact details below).

Data

Multiple sources of ascertainment are used with no time limit for registration. Possible cases for registration are notified on a continuous basis from all maternity units in the Greater Glasgow Health Board area (around 13,000 births per year). All births and induced abortions following prenatal diagnosis are included in the surveillance. Notifications are received from:

- paediatric discharge letters, usually from ICUs
- SMR 1 with lists of provisional incidences of congenital anomalies printed every 3 months
- health visitor records
- pathology laboratory records
- neonatal screening laboratories

- outpatient clinics, e.g. paediatric cardiology clinics
- medical genetics service
- stillbirth and neonatal death reports
- stillbirth and infant death records at the Registrar General for Scotland
- routine hospital discharge forms SMR1, -2 and -11.

Provisional cases are notified to a central office located in the Greater Glasgow Health Board where a specially trained clerical officer examines the notifications, records the details, identifies the clinical record and requests this to be sent from the appropriate records office. At intervals, the officer visits the record offices to examine case records relating to the notifications. Checks are made to ensure that the diagnosis matches, and if the diagnosis has been confirmed by clinical or laboratory investigation.

This validation check is used to complete a new form which is initiated once accepted for registration, and information about the mother and child is recorded, including:

- birth weight
- gestational age
- evidence of antenatal screening
- prenatal diagnosis
- additional congenital anomalies.

If a case is still listed as a 'suspected' anomaly, no form is completed and the officer enters the information into a 'pending' file indefinitely until confirmation is received. The officer translates the diagnosis into ICD codes, and enters information into the database. Anonymised electronic data are shared with the EUROCAT Central Registry.

Data analysis is scheduled to meet annual deadlines. Individual notification details can be analysed more quickly if requested, taking around 6 months from the notification to complete.

A standard EUROCAT registration form is used, which collects data under six main headings: infant details; mother's details, father's details; diagnosis: time and techniques; diagnosis of malformations; and family history of anomaly. A detailed list of data items collected is given on pp. 410–12.

Coding systems

The Registry uses a combination of ICD-10 and occasionally the British Paediatric Association system (a five-digit system) for more detailed diagnostics.

Completeness and accuracy

The level of completeness for notification is reported as above 80%. Repeated comparisons with specialised databases put completeness at 89–100%. The completeness for specific data items is variable, between 50 and 100%; 100% is reported for basic demographic and clinical information and 50% for ethnicity, cigarette and alcohol consumption in pregnancy, drug use and radiation exposure.

The accuracy of information entered into the Central Database is reported as good and is expected to improve over time. Accuracy has been assessed in the past, for concordance of information compared with source information, including the SMR system. The last assessment was carried out in the early 1980s, and since that time the procedures have been reviewed with a view to improving accuracy. Validation checks also pick up accuracy problems.

The Register has a continuous process of looking for databases that can be used for validation purposes. Validations are carried out on an *ad hoc* basis. Often the Registry is approached by other databases to request comparison. Databases that the Registry has or is planning to use for validation are as follows:

- genetic register: NDSCR
- Scottish Trisomy Register: cross-validations
- Cardiology Department at the Children's Hospital.

Systematic validation is also carried out which critically analyses the information sent to it by the Registry. All coding is checked and any items of uncertainty are sent back to Glasgow for investigation.

Uses

The database is mainly used for epidemiological surveillance and research purposes. By integrating the Congenital Malformation Register with the child health record system, it has been possible to conduct prospective studies of children with specific anomalies. This exercise proved feasible with spina bifida. Follow-up studies have been carried out for Down syndrome, congenital heart disease and tracheo-oesophageal fistual/oesophageal atresia.

The database has been used for:

- assessment of the effectiveness of antenatal screening on the prevalence of congenital

anomalies (mainly neural tube defects and Down syndrome)
- assessment of the equity uptake of prenatal diagnosis in different age groups, different parts of the city and different social status
- assessment of the equity of a treatment of neural tube defects.

Access

No patient-identifiable information is made available to researchers. Anonymised information has to be requested from the Registry along with an outline of the proposal. This would be passed to the Director of Public Health in Glasgow for authorisation.

Aggregated data can be obtained from the Greater Glasgow Health Board, Director of Public Health, or from the Registry. Tabulation and trends are produced for all Registries under the EUROCAT group.

Contact details

Dr D Stone
Glasgow Register of Congenital Anomalies/BINOCAR/EUROCAT
Paediatric Epidemiology and Community Health
Yorkhill Hospital
Glasgow
G3 8SJ
Tel.: 0141 201 0171
Fax: 0141 201 0837
Email: d.h.stone@clinmed.gla.ac.uk

ONS National Congenital Anomaly System (NCAS)
Room B6/10
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5641
E-mail: ncas@ons.gov.uk
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3115

British Isles Network of Congenital Anomalies Register (BINOCAR)
B Botting
ONS
E-mail: bev.botting@ons.gov.uk
BINOCAR website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp

European Registration of Congenital Anomalies and Twins EUROCAT website: http://www.oecd.org/els/health/sources/Morbidity.htm

Publications

Scottish Health Statistics: http://www.show.scot.nhs.uk/isd/Scottish_health_statistics/SHS2000/B3.pdf
EUROCAT publications: http://www.iph.fgov.be/eurocat/6.htm

GRCA data items

Centre number
Infant details
Local ID number
Date of birth
Place of birth
Sex
No. of babies delivered
Birth order (in multiple set)
No. malformed (in multiple sets)
Type of birth
Live
Still
Spontaneous abortion
Induced abortion
Not known
Birth weight
Date of LMP and certainty
Length of gestation
Date of death
Survival beyond 1 week of age (y/n/nk)
Sources of information

continued

Mother's details
Residence code
Date of birth
Age at delivery
Reproductive history, number of previous:
  Spontaneous abortions
  Induced abortions
  Live birth(s)
  Stillbirth(s)
Total number of previous pregnancies
Occupation
Social status
Racial type
Assisted conception
Illness before pregnancy
Illness during pregnancy (specify)
Habitual exposures (specify)
Unusual exposures (specify)
Drugs – in the first trimester (specify)

Father's details
Date of birth
Age at delivery
Occupation
Social status
Racial type
Chronic illness

Diagnosis: time and techniques
Date of delivery
When discovered
If prenatally diagnosed, gestational age at discovery
Condition at delivery:
  Alive
  Dead
  Not known

Prenatal diagnosis:	Positive	Result not known	Not done	Negative	Failed	Not known
Amniocentesis						
Ultrasound						
Chorionic villi sampling						
Other techniques (specify)						

Karyotype of infant/fetus:
  Done, result known
  Done, result not known
  Not done
  Result negative
  Failed
  Not known
Post-mortem examination:
  Done, result known
  Done, result not known
  Not done
  Macerated fetus
  Not known

Diagnosis of malformations
Syndrome
Malformations present (×8)
McKusick code/type of Mendelian inheritance
Mode of transmission for single gene or chromosomal disorders:
  Familial
  De novo
  Not known

continued

Consanguinity Previous siblings notified to EUROCAT Local code number Confirmation of diagnosis Additional malformations or comments
Family history of anomaly Siblings with anomaly (specify) Mother's family (specify) Father's family (specify)

North Thames (West) Congenital Malformation Register

Description

The North Thames (West) Congenital Malformation Register was established in January 1990 to collect information about all fetuses and babies born, miscarried or terminated in the North West Thames Region who had or were thought to have a congenital malformation. The Register forms part of the North Thames Perinatal Public Health Department and receives data from all of the 17 contributing hospitals. The Register's aims are to:

- audit pre-natal screening and diagnostic programmes
- provide a database for epidemiological research
- contribute to surveillance being done to detect spatial or temporal clusters of malformation.

The Register collects data on approximately 1000 cases per annum and holds a total of over 8000 records.

The Register is a member of BINOCAR and EUROCAT (listed in Contact details below) and is linked to a number of other databases, including the ONS NCAS.

The Register provides information about malformations causing or contributing to deaths of fetuses/babies notified to the CESDI. They, in turn, notify the Register if a malformed baby dies subsequent to discharge from the hospital of delivery. The NDSCR, SMMIS and CESDI datasets are also used for external validation checks (see section on Completeness and accuracy below).

Data

Data are collected on malformations identified on ultrasound. All babies and fetuses with chromosome abnormalities are registered, including unbalanced karyotype and those with apparently balanced *de novo* translocations and also all with significant structural malformations (the list of exclusions is similar to the EUROCAT list*). Fetuses and babies with inborn errors of metabolism, haemoglobinopathies or other conditions resulting from gene defects are not registered unless the condition caused a structural malformation such as achondroplasia.

Data are obtained on a continuous basis from the following sources by colour-coded self-completion form (private maternity units are not included):

- cytogenetic laboratories (Kennedy Galton Centre, St Mary's Hospital Medical School, Queen Charlotte's and Chelsea Hospital)
- ultrasound departments
- fetal medicine units
- delivery wards
- paediatricians
- computer printouts
- postnatal wards
- pathologists
- CESDI
- special care baby units
- genetics clinics.

Data from the notification forms are entered on to the Register. The data are then checked for accuracy and completeness, reviewed and other information is gathered or flagged for future reference; for example, a prenatal diagnosis would be tracked to assess the pregnancy outcome or if a baby has died or been terminated post-mortem information would be requested. Information is collected under the following headings; the mother; antenatal investigations; the pregnancy; the baby/fetus.

A more detailed list of data items collected is given on pp. 414–17.

* Abnormalities not registered include talipes, hypospadias, polydactyly, syndactyly and single gene disorders such as sickle cell disease, thalassaemia and cystic fibrosis.

Coding systems
Prior to 1997, ICD-9 was used for coding but since then the data have been transferred to ICD-10.

Completeness and accuracy
There have been no discontinuities in the data except for the period of transition (1997) from the old to the present coding scheme. Multiple reporting ensures that the data collected are comprehensive and complete, although no specific figures are available.

Internal checks are carried out to validate data when they are received. Cross-checks are conducted to prevent duplications as data relating to an individual case are collected from multiple sources. Checks are also carried out against the monthly computer printouts received from the contributing hospitals' obstetrics records.

Data are validated against CESDI, the NDSCR and SMMIS. Comparison of numbers of cases of specified abnormalities reported to the Register, to the NCAS and the NDSCR enables estimations for completeness of coverage and the ability to detect potential ascertainment problems.

Uses
With its links to other databases (such as NCAS and CESDI), the Register has been used for research projects including:

- evaluating the effectiveness of different prenatal diagnosis programmes
- research into spatial temporal clusters of mothers living close to hazardous waste sites to assess incidence of babies with malformations.

The Register is used by the Core Blood Bank to help ensure that core blood from a baby with a serious abnormality is not used for bone marrow transplant. It also assists with the monitoring of serum screening for Down syndrome by providing information about Down syndrome pregnancies not screened or those with false-negative results on screening and by providing pregnancy outcome information when needed.

Funding
The Register is funded by the Regional Genetics Purchasing Forum at an approximate cost of £25,000 per annum.

Access
See contact details below.

Contact details
Ms L Abramsky
Register Coordinator
Congenital Malformation Register Office
Northwick Park and St Mark's Hospital NHS Trust
Watford Road
Harrow
Middlesex
HA1 3UJ
Tel.: 020 8869 3527
Fax: 020 8869 3387
E-mail: l.abramsky@ic.ac.uk

ONS National Congenital Anomaly System (NCAS)
Room B6/10
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5641
E-mail: ncas@ons.gov.uk
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3115

British Isles Network of Congenital Anomalies Register (BINOCAR)
B Botting
ONS
E-mail: bev.botting@ons.gov.uk
BINOCAR website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp

European Registration of Congenital Anomalies and Twins (EUROCAT) website: http://www.oecd.org/els/health/sources/Morbidity.htm

CESDI
Chiltern Court
188 Baker Street
London
NW1 5SD
Tel.: 020 7486 1191
Fax: 020 7486 6543
E-mail: maryh@cesdi.org.co.uk
CESDI website: http://www.cesdi.org.uk/

Publications
Periodic progress reports are issued (1993, 1995, 1997) together with regular newsletters available from the Register.

North Thames (West) Congenital Malformation Register data items

	Booking	Delivery
Administrative details		
Case number		
Infant number		
District Health Authority		
Hospital		
Number		
Booking obstetrician		
Mother's details		
Surname		
Forename and initials		
Postcode		
Date of birth		
LMP		
Estimated LMP		
Age at EDD		
Estimated age		
Pregnancy outcome		
Number of fetuses		
Previous:		
Live births		
Stillbirths		
Terminations		
Miscarriages		
Infant's details		
Surname		
Forename		
Carstairs quintile		
Carstairs Score		
Date of birth		
Date of birth estimated		
Gestation at delivery		
Delivery method		
Birth weight		
Postnatal diagnosis date		
Age at postnatal diagnosis		
Live-born infant died		
Infant date of death		
Sex		
Ultrasound details		
Date		
Gestation:		
LMP		
Scan		
Place of scan		
Reason for scan		
Ultrasound markers seen		
More markers seen (y/n)		
Extra markers seen		
Ultrasound diagnosis obstacle		
Screening details		
Screened		
Test type		
Date		
Nuchal translucency:		
Screening result		
Measurement		
Down's risk		

continued

Serum screening:
- Down's result
  - Risk of Down's
- NT result
  - Risk of NTD
- AFP MoM
- Total hCG MoM
- Free b-hCG MoM
- UE3 MoM
- Marker name
- Marker MoM

Karyotype details
Date of sample
Laboratory
Type of test
Prenatal test:
- Main reason
- Other reason
- Gestation

Postnatal test:
- Reason
- Age
- Reason not prenatal

Karyotype description
Mosaic
Culture failed

Pathology details
Post-mortem performed
Date of post-mortem
Post-mortem laboratory
Altered diagnosis
Reason for change

Risk factor details
Family history this disorder
Mother/sister/grandmother/aunt/female first cousin/other relation/male equivalents
Similar family history (and details)
Parents consanguinity
Parental relationship
Maternal race
Other race
Folic acid
Other multivitamins
Assisted conception
Assisted details
Antenatal invasive test
Invasive test details
Alcohol
Illegal drugs
Pre-pregnancy medication
Medication in pregnancy
Maternal occupational exposure
Paternal occupational exposure
Smoking
Chronic condition
Pregnancy-induced condition
Infection in pregnancy
Other hazard

continued

Final diagnosis
Result
ICD code
ICD description
When diagnosed
How diagnosed
Diagnosis confirmed
Final diagnosis
Syndrome code
Scan-only condition
Scan condition
Terminated false-positive

Notice of a suspected fetal malformation identified ultrasonically

Mother's details
Surname
First name
Hospital number
Date of birth
LMP
Hospital where mother booked
Consultant obstetrician

Scanning history
Hospital where ultrasound done
Dates of previous scans in this pregnancy
Date of scan
Gestational age by ultrasound
Purpose of scan:
- Dating
- Routine anomaly
- High-risk anomaly
- Raised AFP
- Suspicion of IUGR
- Presentation
- Viability
- Other (specify)

Nature of abnormality seen on this scan
- Anticipated further action:
- Karyotyping
- High-risk scan locally
- TOP
- High-risk scan elsewhere (specify)
- Other (specify)

Other comments

Notice of malformation noted at termination, delivery or in neonatal period

Mother's details
Surname
First name
Date of birth
Date of LMP

Hospital details
Hospital number
Consultant obstetrician
Hospital delivered
Hospital where booked (if different)

Baby/fetus details
Sex
Outcome:
- Live birth
- Stillbirth
- Termination
- Miscarriage

Date of outcome
Diagnosis or description of abnormality
Anticipated further action
Any further comments

Notice of congenital malformation or abnormality diagnosed before child's first birthday

Child's details
Surname
Child
Date of birth
Gestational age at delivery
Address
Hospital born
Abnormality diagnosed
Date diagnosed
Hospital/clinic diagnosed
Hospital/clinic number
Consultant paediatrician
Anticipated further action
Other comments

Mother's details
Surname
Name
Date of birth
Hospital number (for delivery)
Consultant obstetrician

North West (Merseyside and Cheshire) Congenital Anomaly Survey

Description

The Mersey Perinatal Epidemiology Unit (MPEU) is responsible for the Regional Congenital Anomaly survey, in addition to the CESDI. As from 2000, the MPEU has taken over coordination of the ONS NCAS SD56 forms, which notify the ONS of a congenital anomaly within the district.

The Register is a member of BINOCAR and EUROCAT (listed in Contact details below) and is also linked to the ONS NCAS.

Data

The data are collected under four main headings: details of the mother; pregnancy; baby; and death. A detailed list of data items is given on pp. 419–20.

Coding systems

ICD-10 codes are used.

Uses

The survey links to other databases (CESDI and NCAS) and is used in annual reports – MPEU and Liverpool Health Authority.

Funding

Funded by Liverpool Health Authority and various research grants.

Access

See contact details below.

Contact details

Merseyside and Cheshire Congenital Anomaly Survey
Grace Edwards Perinatal Surveys
Manager/Regional CESDI Coordinator
MPEU, 1st Floor
Liverpool Women's Hospital
University of Liverpool
Crown Street
Liverpool
L8 7SS
Tel.: 0151 702 4105
Fax: 0151 702 4242
E-mail: grace@liverpool.ac.uk

ONS National Congenital Anomaly System (NCAS)
Room B6/10
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5641
E-mail: ncas@ons.gov.uk
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3115

British Isles Network of Congenital Anomalies Register (BINOCAR)
B Botting
ONS
E-mail: bev.botting@ons.gov.uk
BINOCAR website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp

European Registration of Congenital Anomalies and Twins (EUROCAT) website: http://www.oecd.org/els/health/sources/Morbidity.htm

CESDI

Chiltern Court
188 Baker Street
London
NW1 5SD
Tel.: 020 7486 1191
Fax: 020 7486 6543
E-mail: maryh@cesdi.org.co
CESDI website: http://www.cesdi.org.uk/

Publications

Mersey Perinatal Epidemiology Unit Annual Report 1999/2000. Liverpool: MPEU; 2000.
Liverpool Health Authority Annual Report 1999/2000.
LHA website: http://www.liverpool-ha.org.uk/about/annrep20/2.pdf

North West (Merseyside and Cheshire) Congenital Anomaly Survey data items

Case definition:
- TOP
- Late fetal loss (<24 weeks)
- Stillbirth (24+ weeks)
- Early neonatal death (0–6 days)
- Late neonatal death (7–27 days)
- Post-neonatal death (28 days to <1 year)
- Alive

Mother's details
Surname
First name
Hospital no.
Usual residential address at time of delivery
Postcode
Date of birth
Ethnic group
Parity
Height
Weight (mid-pregnancy)

This pregnancy details
Working estimated date of delivery just before birth
EDD based on:
- LMP
- USS (<24 weeks)
- Both
- Other
- Not known

Clinical estimation of gestation just after delivery
Date and time of delivery/birth
Place of first booking for this pregnancy:
- Confirm if home planned

Type of care first booked:
Consultant
- GP and midwife
- Midwife only
- Never booked
- Not known

Place delivery/birth took place:
- Unit/place
- Home
- In transit

Number of fetuses/babies in this pregnancy
Birth order
History of maternal infection in this pregnancy:
- Yes:
  - Microbiological/serological confirmation
  - Clinical diagnosis only
  - Both
- No
- Not known

Baby/infant details[a]
Surname
First name
Hospital number
Baby's residential address at time of birth
Postcode
Sex
Birth

continued

Screening tests and results:
- AFP only
- AFP and HCG
- Triple test
- Other

Date diagnosis first suspected
Basis for suspicion:
- Clinical
- USS
- Serum
- Previous history
- Family history
- Other
- Antenatal diagnosis
- Postnatal diagnosis

Reason for USS:
- Routine dating
- Routine anomaly
- High-risk anomaly
- Other
- Markers seen

Date of final confirmation
Final diagnosis based on:
- USS
- X-ray
- Clinical
- Laboratory (specify)
- Autopsy
- Surgery
- Catheter studies
- Other (specify)
- Karyotype:
  - CVS
  - Amnio
  - FBS
  - Post-delivery

Date of death
Diagnosis
Post-mortem/autopsy:
- Held/being arranged
- Not sought
- No permission
- Coroner's post-mortem
- Permission granted, not done

Has post-mortem changed outcome (y/n/nk)
Obstetrician
Paediatrician
Other specialists

[a] Stillborn/died within 1 year: form is forwarded to CESDI along with CESDI death notification.

Oxford Congenital Malformation Registry (OCMR)

Description

The OCMR was established in 1991 with an initial grant of £800 from the Oxford District Clinical Quality and Audit Group (OCQA) and has remained unfunded ever since. The main aims and objectives of the Register are to:

- evaluate the effectiveness of prenatal diagnosis of congenital malformations through ultrasound scanning (USS) and invasive prenatal procedures such as chorion villus sampling, amniocentesis and fetal blood sampling
- evaluate and monitor new invasive and non-invasive prenatal tests such as first trimester

nuchal thickness scans for chromosome abnormality, coelocentesis
- evaluation of new screening programmes such as the triple test
- provision of data for healthcare policies and planning
- provision of data for the investigation of clusters of abnormalities
- investigation of putative teratogens
- provide access for research on aetiology of particular malformations.

The Registry aims to provide an audit of prenatal diagnosis, to evaluate screening programmes and to facilitate research. With currently 2243 cases on file, the Registry collects information on between 5550 and 6000 babies per year. It provides a full record of the increase in numbers of 'markers' diagnosed and on their effectiveness in detecting serious underlying pathology in the unselected local Oxford population.

The Registry is a member of BINOCAR and EUROCAT (listed in Contact details below). See also the ONS NCAS (p. 400).

Data

The process of data collection begins if an abnormality during pregnancy is detected on USS. A form is completed to enter details on to the dataset. Once forms have been entered into the dataset, one person is responsible for keeping and sorting them by order of expected delivery and checking if abnormalities were present at birth. It is the responsibility of the paediatricians to complete forms if a baby has been born with an unexpected abnormality.

Lists are also produced by the phytogenetics laboratory on chromosome abnormalities by the paediatric pathologists re post-mortem abnormalities, and the doctor in charge of the Down syndrome service. These forms are passed to the Registry or a genetic counselling representative who will enter all information on to the dataset.

The main sources of information are:

- the ultrasound department
- the prenatal diagnosis department
- neonatal paediatricians
- paediatric pathologists
- the genetics laboratory
- the Down syndrome service
- cytogenetic laboratory
- community paediatricians.

Information is received on a continuous basis from all units in the Oxford area, plus any referrals from other areas. Most information is from the John Radcliffe Hospital. For a detailed list of data items collected, see pp. 422–3.

Coding systems

The NHS ICD-9 coding scheme is used.

Completeness and accuracy

The Registry reports that the level of notifications is around 98% of prenatal cases. The current level of completeness for data items is estimated at around 98% and is based on the fact that the Registry always double checks and chases any missing information.[1]

There are currently no validation checks within the computer system. However, other validation checks are carried out:

- comparison carried out with the NDSCR
- comparison carried out with laboratory listings
- clinical notes are reviewed on an *ad hoc* basis.

The Registry is compared with a number of systems, which include:

- a local hospital system which is coded using ICD-9
- the ONS NCAS
- the Special Care Baby Unit, which holds a list of cases.

The Registry is involved in a European study on congenital malformation using congenital malformation registers (EUROCAT system). The study is entitled Evaluation of Prenatal Diagnosis of Congenital Anomalies by Foetal Ultrasound and is a European collaborative project funded by the EEC (not yet published, 2001).

Uses

An audit of the first 6 years has recently been completed which evaluated prenatal diagnosis in Oxford. With the initial uses still in force, the Registry is also used for information on specific cases. Current uses of the Register are to:

- evaluate the effectiveness of USS and other prenatal diagnostic tests in the detection of congenital malformations in women with an OX postcode, booked at the Oxford Radcliffe Women's Centre for delivery
- evaluate the effectiveness of certain ultrasound 'markers' in the detection of congenital malformations in women with an OX postcode,

booked at the Oxford Radcliffe Women's Centre for delivery
- study the natural history of certain congenital malformations detected prenatally.

Scope exists for the Registry to extend to the whole of Oxfordshire and possibly the four counties that make up the Oxford region.

Access

Information is available to researchers with appropriate ethical permission. The Registry does not have a very efficient method for the supply of information as this is not one of their main concerns. The Director would usually make a decision on whether information could be supplied, but would occasionally request permission from the local Ethics Committee. There are currently no charges for the supply of information.

Contact details

Dr P Boyd, Director
Oxford Congenital Malformation Registry
Prenatal Diagnosis Unit
Level 2, Women's Centre
Oxford Radcliffe Hospital
Headington
Oxford
OX3 9DU
Tel.: 01865 221716
Fax: 01865 221164
E-mail: patricia.boyd@urh.nhs.uk

ONS National Congenital Anomaly System (NCAS)
Room B6/10
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5641
E-mail: ncas@ons.gov.uk
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3115

British Isles Network of Congenital Anomalies Register (BINOCAR)
B Botting
ONS
E-mail: bev.botting@ons.gov.uk
BINOCAR website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp
European Registration of Congenital Anomalies and Twins (EUROCAT) website: http://www.oecd.org/els/health/sources/Morbidity.htm

Reference

1. Boyd P. An audit of the prenatal diagnosis of congenital malformations in Oxford, 1991–1996. Oxford: OCMR; 1997.

OCMR data items

Administrative details
Survey number
Old survey number
Mother's details
Name
Hospital number
Address
Postcode
Date of birth
Age
Consultant
Ethnic origin
Pregnancy details
LMP
Diagnosis suspected prenatally (y/n)
Date of diagnosis
Gestation at diagnosis
Prenatal investigations, e.g.
CVS
Amniocentesis

continued

Fetal blood sample Scan Serum screening DNA test Single or multiple pregnancy
Baby details Name Place of birth Date of birth Gestation at delivery Place at delivery Sex Birth weight Outcome of pregnancy Live born normal Live abnormal confirmed NND Later death Stillborn Spontaneous abortion Intrauterine death Termination
Abnormalities Abnormalities suspected Final diagnosis Confirmation of diagnosis Clinical Laboratory Post-mortem Comments Were the prenatal diagnoses confirmed? Possible teratogens Codes (ICD-9 BPA up to 5 different codes) Notified by Date of notification

Trent Congenital Anomalies Register (CAR)

Description

The Trent CAR was established in January 1997 as part of the Trent Infant Mortality and Morbidity Studies (TIMMS). By the end of June 1998, 2250 babies born, or having an estimated date of delivery in 1997, had been notified to Trent CAR with a suspected or confirmed anomaly (Annual Report, 1998).

CAR is directly linked to the NCAS (see p. 401) and is a member of BINOCAR and EUROCAT (listed in Contact details below).

Data

Every maternity unit in the region together with paediatric surgery, genetics and neonatal screening departments contribute. Data are collected by notification form on a continuous basis. A detailed list of data items collected is given on pp. 424–5.

Completeness and accuracy

Comparison with the ONS national anomaly system statistics for 1995–96 suggests that the existence of CAR has resulted in a vastly improved dataset for Trent, in terms of both quality and quantity. No figures are available (Annual Report, 1998).

Uses

Linked to NCAS (see p. 400).

Access

No details available.

Contact details

Dr JLS Budd, CAR Coordinator
Congenital Anomalies Register

Department of Epidemiology and Public Health
University of Leicester
22–28 Princess Road West
Leicester
LE1 6TP
Tel.: 0116 252 3210
Fax: 0116 252 3272
E-mail: jlsb1@le.ac.uk
CAR website: http://www.prw.le.ac.uk/research/timms/car/index.html

ONS National Congenital Anomaly System (NCAS)
Room B6/10
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5641
E-mail: ncas@ons.gov.uk
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3115

British Isles Network of Congenital Anomalies Register (BINOCAR)
B Botting, ONS
E-mail: bev.botting@ons.gov.uk
BINOCAR website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp

European Registration of Congenital Anomalies and Twins (EUROCAT) website: http://www.oecd.org/els/health/sources/Morbidity.htm

Publications

First Annual Report 1998. University of Leicester: Trent Congenital Anomalies Register; 1998.
Summary report on CAR website: http://www.prw.le.ac.uk/research/timms/car/report.html
OPCS. The OPCS Monitoring Scheme for Congenital Malformations. A review by the working group of the Registrar General's Medical Advisory Committee. Occasional Paper No. 43, London: HMSO; 1995.
Payne JN. Limitations of the OPSCS Congenital Malformation Notifications Scheme illustrated by the examination of congenital malformations of the cardiovascular system in Districts within the Trent Region. *Public Health* 1992;**106**:437–48.

Trent CAR data items

Mother's details
Surname
First name
Address
Postcode
Hospital number
NHS number
Date of birth
Ethnic group
Estimated date of delivery
Fetus/baby/child
Surname
First name
Address
Postcode
Hospital number
NHS number
Date of birth/delivery
Number of fetuses/babies this pregnancy
Birth order
Sex
Date of death (if applicable)
Details of anomalies
Description:
Suspected
Confirmed
Resolved

continued

How anomaly(ies) suspected or confirmed:
Clinical examination
Ultrasound
Previous history
Family history
X-ray
Surgery
Laboratory (specify)
Catheter studies
Post-mortem
AFP
Karyotype:
CVS
Amniocentesis
FBS
Post-delivery
Other (specify)
Date of diagnosis[a]
Status at time of notification:
Continuing pregnancy
TOP
Fetal loss
Stillbirth
Alive
Died
Source or department of notification
Hospital

[a] If paediatric diagnosis, also date of initial presentation.

Wessex Clinical Genetics Service Register of Antenatally Diagnosed Congenital Malformations

Description

In 1993, the Health Commissions of Basingstoke, Dorchester, Portsmouth, Poole and Winchester agreed to fund a continuing register of antenatally detected congenital abnormalities and in January 1994 surveillance began. In 1994, Salisbury enrolled, followed in December 1996 by the Isle of Wight.

The Register was set up because paediatricians, surgeons and obstetricians wanted to discuss the management of abnormalities diagnosed on scanning. By 2000, the Register covered the whole of Wessex and held details on all patients. In the period 1983–94, there were 850 patient records on the dataset, but that has grown to 2800.

The Register is a member of BINOCAR and EUROCAT (listed in Contact details below). It is also linked to the ONS NCAS (see p. 400) and to the CESDI (see p. 359).

Process of collection

The main sources of information for the Register are:

- ultrasonographies
- paediatricians
- paediatric cardiologists
- paediatric surgeons
- obstetricians
- paediatric pathologists (who provide autopsy information)
- cytogenetic laboratories (which provide information on chromosome abnormalities, CVS and postnatal)
- nurses on wards/ward clerks (who provide a ward log for double checking)
- monthly meetings in Southampton
- cardiac information
- comparison with CESDI.

Most centres provide information on a continuous basis and discuss the cases at their 3-monthly meeting. The Southampton meetings are held every month, so information is brought to the meeting for discussion. Attendees are usually paediatricians, obstetricians and surgeons.

Most centres complete a form for each relevant patient and others use their own format, listing all their patients' details, and these are provided to the Register on a monthly basis. Any information which has been missed at the time of scan is

identified through the discussions at the meetings, and cardiac cases are double checked. Once all the information has been received at the Register, it is entered into the central database.

Follow-up data are received routinely from most centres. At the end of the year, the Register prints out all those cases which do not identify an outcome, and case notes are chased up.

Once information has been received at the Register, the processing and validation of information are carried out within 1 month.

Coding systems

The Register has developed its own text hierarchy coding system and is currently exploring the use of ICD-10.

Completeness and accuracy

The Register covers the old Wessex Health Authority area, including Wessex, Portsmouth, Bournemouth, Poole, Dorchester, Winchester, Basingstoke, with Salisbury and the Isle of Wight joining at a later date. The level of completeness for notifications is reported to be very high for antenatal cases, with postnatal information only reaching 60–70%. This information is often supplied at a later date.

The level of completeness for crucial data items is reported to be very high, with items such as addresses being far more variable. Maternal data are not easily available, but are usually not relevant. Overall, the data are thought to be around 90% complete, and the Register chases any missing data.

The accuracy of the information entered into the central database is reported to be very good. When duplicate notifications are received, this gives the opportunity to double check information. If information is not known or available, the fields are usually left blank.

The computer system has a built-in check which will not allow a date to be entered if it appears incorrect. There are no other current checks built into the system. As an additional check, Register representatives visit the relevant centre and print out a list of patients – these patients are then discussed at the meeting and any adjustments to the information can be completed on the forms. These are primarily clinical validation checks. No consistent areas of weakness are identified from these discussions.

The overall validity of the database is not thought to have changed since 1994, before which some cases may be missing as they were diagnosed in earlier years. It is thought that the validity improves slightly each year, owing to the various centres building relationships with the Register.

Data are compared with CESDI every 6 months. The two registries exchange all the cases they have for the preceding 6 months. A group in Bristol, part of CESDI, are considering extending their information to include postnatal data to form a congenital malformation defect register. This information may be used by the Register in the future to compare the information collected.

Cytogenetics laboratories compared data for 1994, 1995 and 1996 with the Register to identify any differences.

Discussions have been held regarding the collaboration of the dataset with the Oxford and West Midlands Congenital Malformation Registers (see pp. 420 and 428, respectively). This could involve merging data and following up information to aid the management of particular conditions such as the Dandy–Walker syndrome and for epidemiological research.

Uses

Outcome information is included in the Annual Reports (i.e. number of terminations/miscarriages/post-mortems). Each Annual Report has a section on a certain area (gastroschisis), and also contains percentage rates of pregnancy and abnormalities. From this information, the effectiveness of screenings can be assessed.

The Register identifies cohorts of patients for which various studies can be carried out. The Register researched wolfen-embryoscopy (when two fetuses are born), which led to changes in clinical practice. Other studies include a 2-year cohort of pyelectasis using the Register to follow up, and a study into the increase of gastroschisis.

Through EUROCAT, the Register is part of a 2-year European directive examining registries, and is linked with Strasbourg. This ongoing project involves pooling the data and results.

Access

The Annual Report is distributed locally and to other Registries.

For patient-identifiable data, a researcher would need to contact the Register to discuss the project

and the Ethics Committee would need to give approval. This would also apply for patient records necessary for record linkage.

Anonymised and aggregated data would be available by contacting the Register. Charges would be levied for any research which involved a lot of manpower or extensive use of the dataset.

Contact details

Dr D Wellesley
The Wessex Institute for Health Research and Development
University of Southampton
Bio-Medical Sciences Building
Southampton
SO15 7PX
Tel.: 02380 595543
E-mail: dgw@sotn.ac.uk

ONS National Congenital Anomaly System (NCAS)
Room B6/10
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5641
E-mail: ncas@ons.gov.uk
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3115

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ONS
E-mail: bev.botting@ons.gov.uk
BINOCAR website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp

European Registration of Congenital Anomalies and Twins EUROCAT website: http://www.oecd.org/els/health/sources/Morbidity.htm

CESDI
Chiltern Court
188 Baker Street
London
NW1 5SD
Tel.: 020 7486 1191
Fax: 020 7486 6543
E-mail: maryh@cesdi.org.co.uk
CESDI website: http://www.cesdi.org.uk/

Wessex Antenatally Detected Anomalies Register data items

Maternal details					
Name					
Address					
Postcode					
Date of birth					
Hospital					
Hospital number					
Obstetrician					
GP					
Pregnancy details					
LMP					
EDD					
Single/multiple birth					
Prenatal risk factors (if yes, specify)					
Prenatal investigation:	Test	Date	Gestation	Hospital	Report
Ultrasound					
Amniocentesis					
CVS					
AFP/triple					
Fetal blood					
Biochemistry					
Outcome:					
TOP					
Spontaneous abortion					
Stillbirth					
Neonatal death					
Live birth					

continued

Counselled prenatally (y/n) If yes: by whom
Baby details Name Date of birth Sex Hospital no. Birth weight Gestation False antenatal diagnosis Paediatrician Other specialist Additional info. NHS number PM (y/n) If yes: where Congenital anomalies (and code) ×8

West Midlands Congenital Anomaly Register (CAR)

Description

The West Midlands CAR was set up in July 1994 and is administered by the West Midlands Perinatal Institute. The Register aims to collect information from conception to the first 2 years of life on the occurrence of suspected and confirmed congenital anomalies. It includes deliveries in any West Midlands maternity unit from residents in any region or deaths from congenital anomalies.

A number of minor anomalies are excluded from the register (see ONS NCAS, p. 403).

The Register is a member of the BINOCAR and EUROCAT (listed in Contact details below). It is also linked to the ONS NCAS (see p. 400).

Data

Notifications are received by two methods. The first is a notification card, usually completed by the Ultrasound Department. This notifies the Register of suspected anomalies and includes details of the type of anomaly seen on USS and the estimated date of delivery. The second method is a notification form that contains much of the dataset used for the CESDI (see p. 359). This form has additional details relating to the date when the anomaly was first suspected and includes the final diagnosis.

The notification forms are completed by midwives, obstetricians and paediatricians. The Register is maintained on the same database as the CESDI notifications of fetal and infant deaths and, in this way, the prevalence of fetal anomalies in perinatal deaths can be validated. Additional information is received from cytogenetics laboratories and Departments of Public Health (form SD56 used by NCAS), and on inpatient activity of infants with anomalies from hospital information departments. These extra data are matched with the existing notifications to give estimates of ascertainment, and additional clinical information is added in some cases.

See p. 429 for the detailed list of data items collected.

Coding systems

All anomalies are coded using ICD-10.

Contact details

A Tonks
West Midlands Congenital Anomalies Register
West Midlands Perinatal Institute
St Chad's Court
213 Hagley Road
Edgbaston
Birmingham
B16 9RG
Tel.: 0121 695 2447
E-mail: tonks@wmpi.net
Website: http://www.wmpi.net/wmpi/car/index_car.htm

ONS National Congenital Anomaly System (NCAS)
Room B6/10
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5641
E-mail: ncas@ons.gov.uk
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=3115

British Isles Network of Congenital Anomalies Register (BINOCAR)
B Botting, ONS
E-mail: bev.botting@ons.gov.uk
BINOCAR website: http://www.statistics.gov.uk/themes/health_care/Articles/binocar.asp

European Registration of Congenital Anomalies and Twins (EUROCAT) website: http://www.oecd.org/els/health/sources/Morbidity.htm

CESDI
Chiltern Court
188 Baker Street
London
NW1 5SD
Tel.: 020 74861191
Fax: 020 74866543
E-mail: maryh@cesdi.org.co
CESDI website: http://www.cesdi.org.uk/

West Midlands CAR data items

Mother's details
Surname
First name
Hospital no.
Usual residential address at time of delivery/birth
Post-code
Date of birth
Ethnic group
Parity
Height
Weight (mid-pregnancy)
Last date of the menstrual period (LMP)
Final working estimated date of delivery just before birth
On what was final EDD based
Unit of first booking for this pregnancy
Type of care first booked
Where delivery/birth actually took place
Type of care at delivery
Reason/timing for difference
Number of fetuses/babies this pregnancy
Maternal insulin or impaired glucose tolerance this pregnancy
Onset of labour
Pre-delivery syntocinon
Presentation just prior to delivery
Mode of delivery
Obstetrician
Infant details
Surname
First name
Hospital no.
Residential address at time of death if different from mother's
Postcode
Date and time of delivery/birth
Gestation at birth
Birth order
Sex
Birth weight
Diagnosis details
Screening test
Date diagnosis first suspected
Basis for suspicion
Date of final confirmation
Final diagnosis based on
All diagnoses
Post-mortem/autopsy (if baby died)
Paediatrician
Other specialists

National Down Syndrome Cytogenetic Register (NDSCR)

Description

The NDSCR is a population-based database for England and Wales on cytogenetically detected cases of karyotype trisomy 21 or related anomalies since 1989. The aim of the database is to examine the aetiology of trisomy 21 and to monitor changes in prenatal diagnosis. All karyotypes which could result in a diagnosis of Down's syndrome are obtained voluntarily from regional (NHS and private) cytogenetic laboratories within England and Wales. NDSCR holds over 14,000 anonymous records (NDSCR website, July 2001).

Data

Data are collected from the genetic centres of the Regional Health Authorities in England and Wales. For each laboratory diagnosis of trisomy 21, a three-copy form is completed, which includes the chromosome analysis and some information on the mother and child. This includes details such as area of residence, mother's age, gestation details, the reason for referring to the laboratory and the methods used.

One copy is sent to the Register. The second copy is usually sent to the referring clinician requesting any additional or missing information (although some laboratories will collect this information themselves) and this copy is either sent straight to the Register or to the laboratories where the complete dataset is forwarded at agreed intervals. The bottom copy is retained by the laboratory.

Personal identification details such as name and address are not documented, although data items such as date of birth, sex and postcode are included to exclude duplicate registrations and allowing linkage with other datasets where appropriate. Data entry and analysis are performed using SPSS PC+ v.5.0.

A detailed list of data items collected is given on pp. 431–4.

Coding systems

The coding schemes used for the majority of information are specific to the Register, although OPCS/ONS codes are used wherever possible.

Completeness and accuracy

The level of completeness of notifications was assessed for the cases registered between 1989 and 1993 where the data were compared with other ONS datasets (ONS Congenital Anomaly System and some of the Regional Congenital Anomaly Registers). The outcome of this comparison was 94% completeness (for live births). Collaboration with the Chromosome Abnormality Database indicated that only a few anomalies were omitted from initial registrations.

Since 1989 there have been a number of additions to the information collected (e.g. mother's hospital number and postcode, type of maternal serum test and serum risk denominator). However, in most cases, the new items of data collected were added to all of the years by backtracking over old data and implementing the new types of information collected.

The pregnancy outcome of prenatal diagnoses is requested and is documented for 91% of cases. Maternal ages (an indication of level of risk) are known for 92–98% of registrations.

The Statistical Package for the Social Sciences (SPSS) carries out logicality searches. Internal checks on data entry are performed for duplicates, miscodings and so on. Clinicians may check data on the copies of the form they fill in. Annual lists of records are returned to the laboratories for detail and completeness checks.

As mentioned above, NDSCR compares its data externally with those of the ONS (matching with region and date of birth). NDSCR is estimated to be more complete (for full cytogenetic Down's syndrome diagnoses), with less than 50% of Down's syndrome live births/terminations reported to the ONS (1990–93).* This is a similar figure to that estimated by matching the ONS form SD56 (notification of birth with congenital anomalies).

Uses

Data from the NDSCR have contributed to both the Public Health Common Data Set (since 1995), and to the Confidential Enquiry into Counselling for Genetic Disorders. See also the publications listed below.

Funding

NHS R&D Eastern have funded the Register (1999–2002). The project was funded initially by

* Under-reporting to the ONS is partly due to (a) postnatal notification was limited to diagnoses made less than 10 days after birth (pre 1995), capturing 94% of cases, (b) termination details to the ONS may diagnose chromosomal anomaly rather than specifically trisomy 21, or 'damage to maternal health' rather than chromosomal anomaly.

the MRC and from 1995 to May 1999 by the North and South Thames Regional Health Authority.

Access

See website http://www.mds.qmw.ac.uk/wolfson/ndscr/ and contact details below.

Contact details

The National Down Syndrome Cytogenetic Register
The Wolfson Institute of Preventive Medicine
St Bartholomew's and London Hospitals Medical College
Charterhouse Square
London
EC1M 6BQ
Tel.: 020 7882 6217/6220
Fax: 020 7882 6221
E-mail: d.e.mutton@mds.qmw.ac.uk
Website: http://www.mds.qmw.ac.uk/wolfson/ndscr/

Publications

Huang T, Watt HC, Wald NJ, Morris JK, Mutton D, Alberman E. Reliability of statistics in Down's syndrome notifications. *J Med Screen* 1997;**4**:95–7.
Morris JK, Alberman ED, Mutton DE. Is there evidence of clustering in Down syndrome? *Int J Epidemiol* 1998;**27**:495–8.
Mutton DE, Ide R, Alberman ED. Trends in prenatal screening for and diagnosis of Down's syndrome: England and Wales 1989–1997. *BMJ* 1998;**317**:922–3.
Huang T, Watt H, Wald N, Morris J, Mutton D, Alberman E, *et al*. Birth prevalence of Down's syndrome in England and Wales 1990 to 1997. *J Med Screen* 1998:**5**:213–14.
Morris JK, Wald NJ, Watt HC. Fetal loss in Down's syndrome pregnancies. *Prenat Diagn* 1999;**19**:142–5.
Hook EB, Cross PK, Mutton DE. Female predominance (low sex ratio) in 47,+21 mosaics. *Am J Med Genet* 1999;**84**:316–19.
Vrijheid M, Dolk H, Stone D, Abramsky L, Alberman E, Scott JES. Socio-economic inequalities in risk of congenital anomaly. *Arch Dis Child* 2000;**82**:349–52.
Publications listed on NDSCR website, http://www.mds.qmw.ac.uk/wolfson/ndscr/

NDSCR data items

Administrative details
NDSCR case number
Laboratory number
Laboratory case number
Hospital code number
Hospital name
Name and hospital code for obstetrician
Name and hospital code for paediatrician
Name and postcode of GP
Hospital of diagnosis
Regional Health Authority for hospital of diagnosis
Health Authority and NHS area for hospital of TOP or birth
District Health Authority area code for hospital of term/birth
ONS identifying code
Case matched with ONS report
Referral details
1st reason for referral
2nd reason for referral
Maternal serum test details
Date
Gestation (weeks)
Gestation (weeks) by sample/outcome
Test type:
1 Biochemical
2 Biochemical
Triple test
Quad test

continued

Serum risk ratio:
Afp, +Afp or +ve
1:1 – 1:<10
1:10 – 1:<50
1:50 – 1:<100
1:100 – 1:<200
1:200 – 1:<300
1:300 – 1<500
1:500 – 1:<1000
1:1000+
–ve NOR
Screening test group
Test centre reference
Biochemical test centre

Diagnosis details
Result of ultrasound scan
Prenatal test indicator:
<24 weeks pregnancy continued
>24 weeks pregnancy continued
Prenatal test normal
Prenatal test failed
Test offered but refused
Serum test not done
IVF pregnancy
GIFT pregnancy
Parents request, test denied
Karyotype
Karyotype code and sub-code
Karyotype confirmation
Confirmation of previous diagnosis
Clinician's report indicator
Stage at diagnosis:
Prenatal
Postnatal (including stillborn, neonatal death)
Miscarriage, spontaneous abortion, intrauterine death
Confirmation (2nd lab.)
Tissue sample for diagnosis:
CVS
Amniotic fluid
Fetal blood
Blood
Skin
Other (specify)
Date of sample
Gestation (weeks)
Diagnosis lag (days)
Parental origin:
Not known
Known
Maternal mosaicism
Testicular neoplasm
Parental origin of +21:
Maternal
Paternal
De novo
Unknown
NTAT (nuchal translucency all trisomy) risk code:
High risk
1:1 – 1:<10
1:10 – 1:<50
1:50 – 1:<100

continued

1:100 – 1:<200
1:200 – 1:<300
Low risk
Nuchal translucency (mm)

Pregnancy details
Date of LMP
Conception week number
Date of term/birth
If multiple pregnancy:
Number:
Outcome:
Outcome of pregnancy:
Waiting outcome
Live birth
Neonatal death
Stillbirth
Miscarriage, natural, spontaneous abortion, intrauterine death
Miscarriage, iatrogenic, spontaneous abortion, intrauterine death
Termination of pregnancy
If stillbirth, neonatal death, miscarriage: (specify)
Intrauterine death
Miscarriage
Neonatal death
Spontaneous abortion
Stillbirth

Previous pregnancy details
Number of previous births:
Live births
Stillbirths
Total
Number of previous abortions:
Therapeutic
Spontaneous
Total

Mother's details
Date of birth
Age
Hospital number
First 3 characters of mother's surname
Initial of mother's first forename
District Health Authority code for area of residence
Town of residence
Regional Health Authority for area of residence
Health Authority area of residence
NHS area of residence
Postcode at term/birth

Father's details
Date of birth
Age

Infant's details
Birthweight
Gestation (weeks) at outcome
Clinical sex of child
Infant's hospital number
Ethnicity
Pedigree reference

continued

If dead:
- Mortality status:
  - Live birth – died within 7 days
  - Died 8–28 days
  - Died 29 days –1 year
  - Died 1–5 years
  - Died 5 years+
  - Died, survival period unknown
- Date of death
- Survival (weeks)

Contact indicator:
- Baby adopted
- Baby in care
- Do not contact parents
- Fostered

Additional details

Leukaemia/blood disorders
Notes on condition of infant, previous family history, etc.
EUROHAZCON
CHD study
OP1–SD56 Match 1
OP2–SD56 Match 2
Childhood Cancer Registry match:
- Match
- No match
- Probable match

Childhood Cancer Registry index no.
CESDI case match
CESDI index no.

Data entry details

Batch entry:
- 1st quarter
- 2nd quarter
- 3rd quarter
- 4th quarter
- After following February
- After NDSCR request
- After general request

Notification of Infectious Diseases (NOIDS)

Description

The PHLS CDSC is responsible for the NOIDS database.

NOIDS was established in 1889 for the detection of outbreaks and epidemics of infectious diseases by comparing estimated numbers of cases with actual numbers within an area. The statutory requirement of notification of certain infectious diseases was established at the end of the 19th century, when cholera, diphtheria, smallpox and typhoid had to be reported in London from 1891, and the rest of England and Wales from 1899 (PHLS website, 2001). The list of notifiable diseases has increased to around 30 (listed below).

The prime importance of the NOIDS system is in the speed of detecting possible outbreaks and epidemic. Accuracy of diagnosis is of secondary importance, hence since 1968 clinical suspicion of an infection is all that is required. If the diagnosis is later proven incorrect, the record may be altered.

The following is the list of infectious diseases notifiable under the Public Health (Infectious Diseases) Regulations 1988 (PHLS, website, 2001):

Acute encephalitis
Acute poliomyelitis
Anthrax
Cholera
Diphtheria
Dysentery
Food poisoning

Hepatitis A
Hepatitis B
Leptospirosis
Malaria
Measles
Meningitis
Meningococcal meningitis
Meningococcal septicaemia
Mumps
Ophthalmia neonatorum
Paratyphoid fever
Plague
Rabies
Relapsing fever
Rubella
Scarlet fever
Smallpox
Tetanus
Tuberculosis
Typhoid fever
Typhus fever
Viral haemorrhagic fever
Viral hepatitis
Whooping cough
Yellow fever

The database contains over 2 million notifications of cases of infectious diseases (PHLS website, 2001).

PHLS CDSC Wales also collates different data on infectious diseases through 'GP spotter practice surveillance' in which volunteer* general practices report weekly to PHLS CDSC numbers of cases of selected infection† by age and sex. The system allows early warning of epidemics, gives an indication of trends in incidence and is very useful for infections including influenza not covered by the NOIDS database (NHS Wales, 2001).

The NOIDS database is linked to other CDSC databases: HIV/AIDS A(C)A1–3 (see p. 396) and Sexually Transmitted Diseases: New Cases Seen at GUM Clinics: KC60 (see p. 437).

Data

Doctors in England and Wales‡ complete statutory notifications of infectious diseases, sending them to the Proper Officer§ of the Local Authority, which anonymises the forms and forwards to CDSC on a weekly basis. Data are then entered on to the NOIDS database. Corrections to previous notifications of suspected diagnosis are submitted this way.

Six main data headings are collected for the above list of notifiable diseases:

- case number
- notification date and week
- disease name and code
- specific description for some diseases (meningitis, tuberculosis and food poisoning)
- age (years, months if under 1 year)
- sex.

Completeness and accuracy

There have been no reported breaks in the collection or processing of data, although changes were introduced in 1982, including more information for specific diseases. Throughout the lifetime of the database, infectious diseases have been added to the list of notifiable diseases.

Uses

The data are used by CDSC to report on infectious diseases. Information is made available in weekly, monthly, quarterly and annual bulletins. See also HIV/AIDS A(C) A1–3 (p. 396) and Sexually Transmitted Diseases: New Cases Seen at GUM Clinics: KC60 (p. 437).

Access

Anonymised data through to aggregated data at the national level from 1982 are held at CDSC. Researchers may request specific data.
PHLS CDSC website: http://www.phls.co.uk/facts/NOIDS/1999/noids99q3/noidsq399tabs.htm

Contact details

D Harding
PHLS Communicable Disease Surveillance Centre
61 Colindale Avenue
London
NW9 5EQ
Tel.: 020 8200 6868
Fax: 020 8200 7868
PHLS website: http://www.phls.co.uk

* In 1996, 34 practices (over 200,000 patients) were involved.
† The infections reported vary, generally including measles, rubella, chicken pox, shingles, mumps, whooping cough and influenza.
‡ Welsh information is also held in Wales in a separate database.
§ Under the Public Health Acts and Infectious Disease Regulations.

Publications
NOIDS Annual Totals 1991–2000, CDSC, PHLS, 2001. http://www.phls.co.uk/facts/NOIDS/anntot9100.htm
Communicable Disease Report (CDR) Weekly (national and county level aggregate information).
NOIDS Quarterly Supplement to CDR (as weekly with age/sex tables at the national level).
NOIDS Annual Review (until 1996).
CDSC Annual Review (from 1997).
PHLS website: http://www.phls.co.uk
NHS Wales (1998). Review of National Databases, National Assembly of Wales. Website: http://www.statistics.gov.uk/nsbase/about_ns/welsh/welsh_data_qual.asp

Registers of Deaf or Hard of Hearing (SSDA 910), Blind and Partially Sighted People (SSDA 902) and Physically Disabled (SSDA 911)

Description
Data are compiled on the numbers of people registered with Local Authorities as:

- deaf or hard of hearing
- blind or partially sighted
- physically disabled (general classes – excluding people on the blind register).

The Local Authority Social Services Departments under Section 29 of the National Assistance Act 1948 complete the returns on a rotating annual basis (hence each disability is returned triennially). Registration is voluntary and levels may be underestimated. The register covers England. Data on new registrations of children under 16 years are collected on an annual basis.

Data
Registered Deaf or Hard of Hearing (SSDA 910)

- Number of people on the register, deaf and hard of hearing, by age.

Registered Blind and Partially Sighted People (SSDA 902)
- Blind persons and partially sighted persons: numbers on the register and new registrations, by age.
- Blind persons registered at end of financial year with additional disability, by age.

Registers of Physically Disabled People (SSDA 911)
- Number of persons on the register of the general classes, by age.

A detailed list of data items is given on p. 437.

Uses
No use in HT assessment located.

Funding
Funded by the Department of Health.

Access
See publications and contact details below.

Contact details
Department of Health
Skipton House
80 London Road
London
SE1 6LH

Physical disabilities
D Treacy
Tel.: 020 7972 5589
Fax: 020 7972 5662
E-mail: david.treacy@doh.gsi.gov.uk

Deaf/hard of hearing and blind/partially sighted
T Kilbey/G Smith
SD3B
Department of Health
Room 456C
Skipton House
80 London Road
London
SE1 6LH
Tel.: 020 7972 5582
Fax: 020 7972 5662
E-mail: tracie.kilbey@doh.gsi.gov.uk
gerry.smith@doh.gsi.gov.uk
Website: http://www.doh.gov.uk/public/ssda910.htm

Publications
Registered Blind and Partially Sighted People Year Ending 31 March 2000, England 2001.
Registers of the Deaf and Hard of Hearing Year Ending 1998, England 1999.
Registers of Physically Disabled Persons (General Classes Year Ending 1993, England 1994).
Information was not collected in 1996 on physically disabled persons (general classes) pending a review of register information requirements.

Department of Health website: http://www.doh.gov.uk/

People registered as disabled data items

Registered Deaf or Hard of Hearing (SSDA 910)

LA name and code					
Number of people on the Register at end of financial year					
Age:	0–17	18–64	65–74	75+	Total
Deaf					
Hard of hearing					

Registered Blind and Partially Sighted People (SSDA 902)

LA name and code							
Blind persons and partially sighted person: numbers on the register and new registrations							
Age:	0–4	5–17	18–49	50–64	65–74	75+	Total
Persons registered at end of financial year:							
Blind							
Partially sighted							
New registrations in year							
Blind							
Partially sighted							

Blind persons registered at end of financial year with additional disability					
Age:	<5	5–17	18–64	65+	Total
Additional disability:					
Mentally ill people only					
Learning disabilities only					
Physical disabilities only					
Deaf without speech only					
Deaf with speech only					
Hard of hearing people only					
Mentally ill people with other physical, sensory or speech disabilities					
Learning disabilities and sensory or speech disabilities					
Physical disabilities, with other physical, sensory or speech disabilities					
Total					

Registers of Physically Disabled People (SSDA 911)

LA name and code					
Number of persons on the register of the general classes					
Age:	0–17	18–64	65–74	75+	Total
Very severely handicapped					
Severely or appreciably handicapped					
Other classified persons					
Total					

Sexually Transmitted Diseases: New Cases Seen at GUM Clinics (KC60)

Description

Aggregate quarterly information based on statistical returns (KC60) from genitourinary medicine (GUM) clinics provide data on new cases of sexually transmitted diseases (STDs). This information is collected by the PHLS CDSC and CDSC Wales. It is linked to other CDSC databases: NOIDS (p. 434) and HIV/AIDS A(C)A1–3 (see p. 396).

Data

Data collected include the following STDs: gonorrhoea, genital chlamydial infection, syphilis and HIV/AIDS.

Uses
Data are used by the PHLS CDSC (see publications listed below).
See also NOIDS (p. 434) and HIV/AIDS A(C)A1–3 (p. 396).

Access
Selected data are incorporated into the CDR weekly bulletins produced by the PHLS CDSC.
http://www.phls.co.uk/publications/cdrelectronic/cdr%20weekly/cdr%20weekly/archive/hiv1201.html
See also publications and contact details below.

Contact details
I Simms
STD Section
PHLS, Communicable Disease Surveillance Centre
61 Colindale Avenue
London
NW9 5EQ
Tel.: 020 8200 6868
PHLS CDSC website: http://www.phls.co.uk/facts/STI/sti_uk_data.htm

Publications
PHLS, DHSS&PS and the Scottish ISD(D)5 Collaborative Group. Trends in sexually transmitted infections in the United Kingdom, 1990–1999. London: Public Health Laboratory Service; 2000.
PHLS website: http://www.phls.co.uk/facts/STI/sti_uk_data.htm
Selected data are incorporated into the monthly bulletins produced by the PHLS CDSC.

Korner Return: Sexually Transmitted Diseases: New Cases Seen at GUM Clinics: KC60 data items

	Males	Homosexually acquired	Females
Condition:			
Primary and secondary infectious syphilis			
Early latent syphilis			
Other acquired syphilis			
Congenital syphilis aged under 2 years			
Congenital syphilis aged 2 years or over			
Epidemiological treatment of suspected syphilis			
Uncomplicated gonorrhoea			
Gonococcal ophthalmia neonatorum			
Epidemiological treatment of suspected gonorrhoea			
Gonococcal complications			
Chancroid/donovanosis/LGV			
Uncomplicated chlamydial infection			
Complicated chlamydial infection			
Chlamydia ophthalmia neonatorum			
Epidemiological treatment of suspected chlamydia			
Uncomplicated non-gonococcal/non-specific urethritis in males			
Epidemiological treatment of NSGI			
Complicated non-gonococcal/non-specific infection			
Trichomoniasis			
Anaerobic/bacterial vaginosis and male infection			
Other vaginosis/vaginitis/balanitis			
Anogenital candidosis			
Epidemiological treatment of vaginosis/vaginitis/balanitis, anogenital candidosis			
Scabies/pediculosis pubis			
Anogenital herpes simplex – first attack			
Anogenital herpes simplex – recurrence			
Anogenital warts – first attack			
Anogenital warts – recurrence			
Anogenital warts – registered cases			
Molluscum contagiosum			
Antigen positive hepatitis B			

continued

	Males	Homosexually acquired	Females
Other viral hepatitis			
Urinary tract infection			
Other conditions requiring treatment at GUM clinic			
Other episodes not requiring treatment			
Asymptomatic HIV infection – first presentation			
Asymptomatic HIV infection – subsequent presentation			
HIV infection with symptoms, not AIDS, first presentation			
HIV infection with symptoms, not AIDS, subsequent presentation			
AIDS – first presentation			
AIDS – subsequent presentation			
HIV antibody counselling with testing			
HIV antibody counselling without testing			
Hepatitis B vaccination			
Family planning			
Cervical cytology – minor abnormality			
Cervical cytology – major abnormality			
Total initial contacts			

Initial contacts in the year for selected conditions by age group and sex

Age groups:	Under 15	15	16–19	20–24	25–34	35–44	45–64	65+	Not known	All ages
Condition:										
Primary and secondary infectious syphilis										
Uncomplicated gonorrhoea										
Gonococcal ophthalmia neonatorum										
Uncomplicated gonorrhoea – homosexually acquired										
Uncomplicated chlamydial infection										
Anogenital herpes simplex – first attack										
Anogenital warts – first attack										
HIV antibody counselling – with testing										

New attendances in the year	
Total attendances in the year	
Incoming telephone calls for clinical advice/results	

Appendix 7

Health surveys, England 2000

Contents

Adult Dental Health Survey (UK)

Description

The Adult Dental Health Survey is part of a series of decennial national surveys in England and Wales since 1968 and across the UK since 1978. It is sponsored by the four UK Health Departments and carried out by the Social Survey Division of the OPCS/ONS in collaboration with the dental schools and the Central Survey Unit of the Northern Ireland Statistics and Research Agency.

The aims are to produce data on the condition of adults' teeth and oral health in the UK and also to compare the results of previous surveys. The last published survey was carried out in 1998, and consisted of an interview with 6204 adults and 3817 dental examinations.[1]

Data

The survey has a sample size 4960 (Great Britain) and 580 (Northern Ireland). There are two elements to the survey: a face-to-face interview to collect information on the respondent's oral health behaviour, attitudes and opinions, and, for respondents with some natural teeth, a home dental examination.

Completeness and accuracy

The survey covers both Great Britain and Northern Ireland. The response rate to the survey is reported to be 74% for interviews and 72% for dental examination (National Statistics website, 2001).

Uses

See aims under 'Description' above.

Funding

Commissioned by the four Health Departments in the UK.

Access

See publications, website addresses and contact details. A symposium discussing the results of the survey was held in November 2001. For details, see http//www.dundee.ac.uk/dhsru/adhs

Contact details

A Walker/M Kelly
Office for National Statistics
1 Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5413/5308
E-mail: alison.walker@ons.gov.uk
maureen.kelly@ons.gov.uk

A Roberts
Department of Health
453C
Skipton House
80 London Road
London
SE1 6LH
Tel.: 020 7972 5571
Fax: 020 7972 5662

Publications

Adult dental health survey: oral health in the UK 1998. Department of Health Bulletin. London: ONS, 2000. http://www.statistics.gov.uk/nsbase/downloads/theme_health/DHBulletinNew.pdf

Further details may be obtained from:
UK Data Archive website: http://www.data-archive.ac.uk/

National Statistics website:
http://www.statistics.gov.uk/themes/health_care/surveys/survey_of_adhs.asp

Reference

1. Kelly M, *et al*., Adult dental health survey: oral health in the United Kingdom in 1998. London: TSO; 2000. See Department of Health Website: http://www.doh.gov.uk/pub/docs/doh/survey5.pdf

Children's Dental Health in the United Kingdom

Description

The Children's Dental Health survey in the United Kingdom was established in 1973, with subsequent surveys carried out every 10 years (the last in 1993) by the Social Survey Division of the then OPCS, now the ONS, on behalf of the Department of Health. The 1973 survey established baseline information on dental health of children (5–15 years) in England and Wales; Scotland and Northern Ireland were included when it was repeated in 1983 and 1993. The aims of the surveys are to establish the current state of dental health in UK children and to monitor changes since the earlier surveys.

Dental examinations are carried out on the sampled children in schools (20,000 for 1993).

Data

The dental examination collects information on dental decay and erosion, enamel defects, dental trauma, treatment, care of teeth, periodontal and orthodontic health with background data on dental attendance and home background.

Uses
The data are used to report on the current state of children's dental health and to monitor changes by comparing data with previous surveys.

Funding
Commissioned by the Department of Health.

Access
See contact details below.

Contact details
A Walker/M Kelly
Office for National Statistics
1 Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5413/5308
E-mail: alison.walker@ons.gov.uk
maureen.kelly@ons.gov.uk

Children's Dental Health:
W Burns
Department of Health
Skipton House
80 London Road
London
SE1 6LH
Tel.: 020 7972 5389

1993 Survey:
S Lea
Department of Health
Skipton House
80 London Road
London
SE1 6LH
Tel.: 020 7972 5392
Fax: 020 7972 5661
E-mail: dnijjar@doh.gov.uk

Publications
Children's dental health in the United Kingdom, 1993. London: HMSO; 1994. See Department of Health website: http://www.doh.gov.uk/pub/docs/doh/survey5.pdf

Gregory JR, Bates CJ, Thane CW, Prentice A, Delves HT, Gregory J. National diet and nutrition Survey: young people aged 4 to 18 years. Volume 1: Report of the diet and nutrition survey. London: TSO; 2000.

O'Brien, M. Children's dental health in the United Kingdom 1993. London: HMSO; 1994.

Government Statistical Service website: http://www.statistics.gov.uk/statbase/mainmenu.asp

Department of Health website: http://www.doh.gov.uk/public/surveys.htm

General Household Survey (GHS)

Description
The GHS is conducted by the Social Survey Division of the ONS. This annual survey is based on a sample of around 10,000 private households in Great Britain. Interviews are conducted with everyone aged over 16 years in the household (around 18,000 adults). The GHS began in 1971 and data are available from 1973 onwards.

The topics covered to date are listed each year in the GHS Annual Report: *Living in Britain: results from the GHS*. The main aim of the survey is to collect data on a range of topics such as housing, employment, education, health and household formation. The survey is used to provide background information for decisions on resource allocation, developing household projection techniques and national population projections.

Data
Fieldwork for the GHS has been carried out almost continuously since 1971. Until 2000, the questionnaire changed at the beginning of each financial year, but it now has a continuous section which will remain unchanged for 5 years (see Continuity and accuracy below).

Data are collected under five main headings: household details, ethnicity, employment and education, finance and health. Trailers are included on an *ad hoc* basis. Methodological work has been done on developing new questions on cohabitation histories, on the sample design (around 13,000 households each year) and on methods of data collection.

A detailed list of data items collected is given on p. 444.

Continuity and accuracy
The survey has been carried out continuously since 1971, except for breaks in 1997–98 and 1999–2000. The break in 1999–2000 was the result of a review of the GHS in 1997 carried out by the ONS. This review concluded that the survey should be relaunched with a different design. The new survey began in April 2000 and consists of a continuous section that will remain unchanged for 5 years. Processing systems have also been reviewed to enable data to be available more speedily and in a more user-friendly form.

Uses

The GHS is widely used by sponsoring departments and academic researchers. It includes a broad range of questions and its continuity over almost 25 years allows trends over time to be explored particularly for policy-related research. Health-related examples include use of contraception, hearing impairment and private health insurance.

Funding

The survey is sponsored by the Socio-Economic Division of the ONS and by several other Government Departments.

Access

MIMAS provides online access to the data for academic research or teaching, by arrangement with the UK Data Archive.

Contact details

N Bullen
MIMAS, Manchester Computing
University of Manchester
Oxford Road
Manchester
M13 9PL
Tel.: 0161 275 6109
Fax: 0161 275 6040

MIMAS Helpdesk:
Tel.: 0161 275 6109
MIMAS E-mail: info@mimas.ac.uk
MIMAS website:
http://www.mimas.ac.uk/surveys/ghs/

GB General Household Survey Enquiries
Office for National Statistics
1 Drummond Gate
London
SW1V 2QQ
Tel. (UK callers only): 0845 6013034
E-mail: steve.jeeves@ons.gov.uk
GHS/ONS website: http://www.statistics.gov.uk

Publications

Tabulated results are published by ONS in the *Living in Britain* series. For the latest available report, see Living in Britain, results from the 1998 General Household Survey, ONS. London: HMSO; 2000. Data from the GHS are widely used in other publications, e.g. Social Trends and Regional Trends; see also the following websites:
Manchester Information and Associated Services (MIMAS) website: http://www.mimas.ac.uk/surveys/ghs/
ONS website: http://www.statistics.gov.uk
Data Archive website:
http://www.data-archive.ac.uk/

GHS core data items[a]

Household details Accommodation Household relationships, family information Appliances Vehicles Ownership details Housing benefits
Ethnic Migration and ethnic details
Employment and education Employment Education
Finance Income Benefits Pensions Inheritance
Health Overall and illnesses GP/hospital/casualty visits Child health Dental health Private medical insurance
Additional modules as required

[a] A summary of field headings, a complete listing of a specific year's questionnaire can be found at the back of the report for that year.

Health Education Monitoring Survey (HEMS)

Description

The HEMS has been carried out annually since 1995 for the Health Education Authority in England. The purpose of the HEMS surveys has been to monitor a set of health promotion indicators for health-related knowledge, attitudes and behaviours. The 1998 questionnaire continued this monitoring role and was extended to investigate the links between social inequality and social capital and health and health-related behaviours.

Data

The 1998 HEMS interviewed 5800 adults from private households in England in May and June 1998, a response rate of 71%. A probability sample of addresses was selected from the Postcode Address file. The interview was conducted using computer-assisted interviewing. Adults aged 16–54 years were eligible for the self-completion module on sexual health. The majority of these respondents keyed in the answers themselves on to laptops, as part of the self-completion module.

Core data headings in 1998 and previous HEMS covered:

- smoking
- drinking
- nutrition
- physical activity
- sexual health
- behaviour in the sun.

Additional data headings were included for the first time in 1998:

- social support
- community involvement
- neighbourhood characteristics
- activities of daily living for older people.

The 1998 HEMS was also extended to include older people, aged 75 years and over.

Uses

The most recent report, Health in England 1998: investigating the links between social inequalities and health, investigates the links between health inequalities and health behaviours and attitudes.

Funding

Funded by the Department of Health.

Access

See publications and contact details below.

Contact details

ONS Social Statistics Division Project Support Branch
1 Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5500
E-mail: ssdpsb@ons.gov.uk
National Statistics website: http://www.statistics.gov.uk

Publications

The published results on the Health Education Monitoring Survey are included in the following reports:

Bridgwood A, Malbon G, Lader D, Matheson J. Health in England 1995: what people know, what people think, what people do. London: HMSO; 1996.

Hansbro J, Bridgwood A, Morgan A, Hickman M. Health in England 1996: what people know, what people think, what people do. London: HMSO; 1997.

Bridgwood A, Rainford L, Walker A, Hickman M, Morgan A. All change? The health education monitoring survey one year on. London: The Stationery Office; 1998.

Rainford L, Mason V, Hickman M, Morgan A. Health in England 1998: investigating the links between social inequalities and health. London: The Stationery Office; 2000.

Health Survey For England (HSE)

Description

The HSE, established in 1991, is part of a wide programme of surveys commissioned by the Department of Health, designed to monitor trends in the nation's health. The annual survey concentrates on core questions and measurements and different health issues in different years, including cardiovascular and atopic diseases. The aims of the Health Survey series are to:

- provide annual data about the nation's health
- estimate the proportion with specified health conditions
- estimate the prevalence of risk factors associated with these conditions
- examine differences between population subgroups
- assess the frequency with which combinations of risk factors occur
- monitor progress towards two Health of the

Nation targets relating to blood pressure and obesity
- measure the height of children (since 1995) (aged 2 years and over) at different ages, replacing the National Study of Health and Growth.

The survey was carried out in 1991–93 by the OPCS, which is now part of the ONS. From 1994 the survey has been carried out by the Joint Survey Unit of the National Centre of Social Research and the Department of Epidemiology and Public Health at University College London.

Data
A set of core questions and measurements, including blood pressure, analysis of blood/saliva samples and anthropometric measurements, are asked each year with a series of non-core questions that vary from year to year. Children aged 2–15 years were included in the survey for the first time in 1995 and have been surveyed every year since. About 16,000 adults and 4000 children resident in 9000 households are interviewed each year.

Core questions in the survey include obesity, blood pressure, smoking, alcohol consumption and general health. The period 1991–94 focused on cardiovascular disease, 1995–96 on atopic diseases, accidents and disabilities, 1997 on respiratory conditions, lung function, non-fatal accidents, physical exercise and eating habits, 1998 on cardiovascular diseases, 1999 on ethnic groups and 2000 on older people and social exclusion. Plans for future years include the following: 2001, disability and asthma attacks; 2002, children and young adults and maternal health; and 2003, ethnic groups. Over 1000 data headings were included in the 1998 survey.

Coverage and accuracy
In 1998, 13,680 addresses were sampled and 9208 private households cooperated (74% of the sampled eligible households). In those cooperating households there were 17,240 adults aged 16 years and over. Of adults in cooperating households, 92% were successfully interviewed, 79% were visited by a nurse, 77% had their blood pressure taken, 77% gave a saliva sample and 62% gave a blood sample.

Uses
The surveys are used for the aims specified above and are the basis of the annual reports (see Publications).

Funding
Funded by the Department of Health at a cost of around £2 million or just over £100 per record.

Access
Annual reports provide results. Anonymised patient-level records are available for research purposes via the data archive (website listed below).

Contact details
P Tucker
Department of Health
Skipton House
80 London Road
London
SE1 6LH
Tel.: 020 7972 5718
Fax: 020 7972 5662
E-mail: patrick.tucker@doh.gsi.gov.uk
Department of Health website:
http://www.doh.gov.uk/public/summary.htm

Publications
Breeze E, *et al*. Health survey for England 1992. London: HMSO; 1994.
Bennett N, *et al*. Health survey for England 1993. London: HMSO; 1995.
Colhoun H, Prescott-Clarke, editors. Health survey for England 1994. Vols I and II. London: HMSO; 1996.
Prescott-Clarke P, Primatesta P, editors. Health survey for England 1995. Vols I and II. London: HMSO; 1997.
Prescott-Clarke P, Primatesta, P, editors. Health survey for England 1996. Vols I and II. London: HMSO; 1998.
Prescott-Clarke P, Primatesta P, editors. Health survey for England: the health of young people '95–97. Vols I and II. London: The Stationery Office; 1998.
Erens B, Primatesta P, editors. Health survey for England: cardiovascular disease '98. Vols I and II. London: The Stationery Office; 1999.
Erens B, Primatesta P, Prior G, editors. Health survey for England: the health of minority ethnic groups 1999. Vols I and II. London: The Stationery Office; 2000.

For further information on publications see:

Department of Health website:
http://www.doh.gov.uk/public/summary.htm
Data Archive website: http://www.data-archive.ac.uk/findingData/snDescription.asp?sn=3316/
Statbase: http://www.statistics.gov.uk
Manchester Information and Associated Services website: http://www.mimas.ac.uk/surveys

National Surveys of NHS Patients

Description

The White Paper *The New NHS Modern Dependable* committed the Government to carry out an annual national survey that would allow systematic comparisons of the experience of patients and their carers over time and between different parts of the country. It will be used to help monitor the delivery of quality standards locally, in line with the framework set out in *A First Class Service*.

The surveys programme consists of a core survey to collect information about patients' experience of primary care services, which started with general practice (1998), and a rolling programme to look in-depth at patients' experience in selected areas, which started with a survey of coronary heart disease patients (1999).

Data

General Practice Survey 1998

A 20-page postal questionnaire was sent in October 1998 to 100,000 adults selected at random from the Electoral Registers. The survey focused on patients' experience of General Practice. The survey covered a wide range of issues including access, communications, patients' views of GPs and practice nurses, quality and range of services including out-of-hours care and referrals by GPs to hospital.

A response rate of 64.5% was achieved after discounting ineligible addresses. The results were based on 61,426 completed questionnaires (Department of Health website, 2001).

Coronary Heart Disease 1999

The overall purpose of this survey was to assess the quality of NHS patient care as seen by hospital patients, both inpatients and day patients, who had been treated for CHD. The questionnaire comprised 20 sides (100 questions). It was sent out during mid-1999 to 112,000 patients who had been discharged in 1998, after being diagnosed as suffering from CHD. Fieldwork took place during 1999.

The results were based on a total of 84,300 questionnaires returned, a response rate of 74%, after discounting ineligible addresses. The numbers of questionnaires received from patients from individual hospitals ranged from 100 to in excess of 1500. The average number per hospital was 435. The survey was designed to feed back results to each participating Trust, and also to provide a national overview of CHD patients' opinions of their treatment (Department of Health website, 2001).

Uses

The data will be used by local managers and health professionals to take direct account of users' views in improving services. The surveys also provide data to inform the patient and user dimension of the Performance Assessment Framework.

Funding

Funded by the Department of Health. The surveys have been carried out by a consortium of independent research organisations: the National Centre for Social Research (formerly SCPR), the Picker Institute Europe and Imperial College School of Science, Technology and Medicine.

Access

For detailed results of surveys, see the Department of Health website: http://www.doh.gov.uk/public/nhssurveyrs.htm

Individual Trust reports on the survey of CHD patients were published in 2000 and are available on the Department of Health's website (www.doh.gov.uk/nhspatients/chdsurvey2a.htm). These reports set out in detail the results from the patients surveyed in the particular Trust in the context of national results.

See also Publications and Contact details below.

Contact details

Department of Health website:
http://www.doh.gov.uk/public/nhssurvey.htm

Publications

The National Surveys of NHS patients general practice 1998. London: NHS Executive; 1999.

The survey of CHD patients, results of the National Survey of NHS patients 1999. London: NHS Executive; 2000.

National Statistics website: http://www.statistics.gov.uk

Department of Health website:
http://www.doh.gov.uk/public/nhssurvey.htm

ONS Omnibus Survey: GB

Description

The Omnibus Surveys were established in October 1990 and have been carried out roughly monthly in Great Britain, initially by OPCS and then ONS. The Omnibus Survey is a multi-purpose survey based on interviews with a sample of about 1900 adults per survey month with one adult selected from each household. The Survey is a vehicle

providing quick results from relatively short and simple sets of questions. Questions on particular topics can be added for 1 month or for longer as required.

Over 100 topics have been included to date, covering a very wide range including contraception, unused medicines, mortgage arrears, organ transplants, retirement income, fire safety, daycare for the under-fives, sunburn and time use. The Omnibus Survey has facilities for questions to be asked on behalf of paying customers.

Data
The topics covered are very diverse – see the Data Archive or Government Statistical Service websites (listed in Contact details below).

Uses
Used for the following health topics: back pain prevalence, contraception, smoking, alcohol consumption (1993, 1996, 1998).

Access
Standard tables and data are available to customers within 4 weeks of the completion of fieldwork (8 weeks after the final date for commissioning).

Contact details
J Bowman
Omnibus Survey Queries
Office for National Statistics
1 Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5310
E-mail: june.bowman@ons.gov.uk

Publications
Further information and publications may be obtained from:
Data Archive website: http://www.data-archive.ac.uk/
Government Statistical Service website: http://www.statistics.gov.uk
Department of Health website: http://www.doh.gov.uk/public/omnibus.htm

Survey of Health and Well-being of Adults

Description
The survey is part of a Department of Health programme of research on the health and well-being of adults living in Great Britain. The survey undertaken in 2000 repeats and extends the 1994 Survey of Psychiatric Morbidity.

The main purposes of these surveys are to find out:

- how many people throughout the country experience mental, nervous or emotional problems as a result of the stresses and strains of everyday life
- what things make people nervous, anxious or depressed
- what people do for help or support when they need it.

Data
The sample for the survey in 2000 was drawn randomly from the Postcode Address File [a comprehensive list of all delivery points (postal addresses) in Great Britain]. One person per household was randomly selected and asked to take part in the survey.

There are two elements to the survey:

- A face-to-face interview using Computer Assisted Personal Interviewing (CAPI). It included some self-completion sections which were entered into the computer by the respondent themselves using Computer Assisted Self Interviewing (CASI).
- A small sub-group of respondents took part in a second interview which covered one or two topics in more detail.

The interviews covered a range of mental health problems, such as anxiety and depression, alcohol and drug dependence, psychosis and personality disorder. Questions were also asked about general health problems, use of health services and the social support people have available to them, and background information such as educational qualifications, income, housing conditions and key life events.

Uses
The data are used by the Department of Health to inform the development of policies aimed at providing services, help and support to people experiencing mental problems/depression caused by stress.

Funding
Funded by the Department of Health, the Scottish Executive and the Office of the National Assembly for Wales.

Access
The results of the survey were due to be published in late 2001. See National Statistics website: http://www.statistics.gov.uk

Contact details
Social Survey Division ONS
Project Support Branch
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5500
E-mail: ssdpsb@ons.gov.uk

Survey of Smoking, Drinking and Drug Use Among Secondary School Children (and) Young Teenagers

Description
Every 2 years since 1982, ONS (formerly OPCS) has conducted a secondary school-based survey focusing on smoking and drinking among secondary school children (since 1996 England and Scotland only). The 1998 survey was extended to include questions about drug use.

Data
Fieldwork for the 1998 survey was carried out in September–November 1998. A total of 4750 secondary school children aged 11–15 years in England and about 3500 aged 12–15 years in Scotland completed paper questionnaires at school, but under the supervision of Social Survey Division (SSD) interviewers. The response rate was 62% in England and 71% in Scotland.

Children were also asked to complete a diary in which they were asked to record all cigarettes smoked during the previous 7 days. Saliva samples were collected from all pupils in half the sample of schools, in order to measure for traces of nicotine. Pupils put a small dental roll in their mouths for about 20 minutes.

Alcohol and drug use were also surveyed as part of the Young Teenagers and Alcohol Survey but were not the main thrust of the survey. In 1990, estimates of consumption of different types of drink were included and in 1996 modified further to include alcoholic lemonades and the like.

Other data collected included attitudes to drug use and health education at school.

Completeness and accuracy
From 1982 to 1995 the survey covered Great Britain, and since 1996 England and Scotland only. The primary focus of the surveys is to provide estimates for the proportion of pupils smoking and their smoking behaviour. Data collection on alcohol consumption began in 1988 and on drug use in 1998, but is more limited in scope than data collected on smoking.

Uses
As described above, the surveys are used to report on the extent of smoking among secondary children and, to a lesser extent, on drinking and drug use. Continuing surveys allow trend analysis to be performed.

Funding
Funded by the Department of Health and the Scottish Office Department of Health.

Access
See publications, website addresses and contact details below.

Contact details
Social Survey Division ONS
Project Support Branch
Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5500
E-mail: ssdpsb@statistics.gov.uk

Smoking:
A Boucher
Department of Health
453C
Skipton House
80 London Road
London
SE1 6LH
Tel.: 020 7972 5389

Alcohol:
E Goddard
Office for National Statistics
D1/19
1 Drummond Gate
London
SW1V 2QQ
Tel.: 020 7533 5331

Publications
Goddard E, Higgins V. Smoking, drinking and drug use among young teenagers in 1998. Vol. 1. England. London: TSO; 1999.

Goddard E, Higgins V. Smoking, drinking and drug use among young teenagers in 1998. Vol. 2. Scotland. London: TSO; 1999.
For further information on ONS (SSD) related surveys and publications see:
National Statistics website:
http://www.statistics.gov.uk
See also:
Department of Health website:
http://www.doh.gov.uk/public/surveys.htm
Data Archive website: http://www.data-archive.ac.uk/

Welsh Health Survey

Description

The Welsh Health Survey first took place in 1995 and was repeated in 1998. A postal survey, it was designed to provide a picture of the health of the people of Wales, the way in which the NHS is used and areas for improvement.

The main aim of the survey was to collect aggregate information on representative samples of the population with a range of illnesses and disabilities and information on comparable groups of healthy people – without using any medical records. The survey provides baseline data for a range of health targets set for the NHS in Wales.

In 1995, questionnaires were sent out to 50,000 people living in Wales and over 28,000 were completed and returned. This resulted in large enough numbers of people with the targeted illnesses and disabilities for the data to be statistically reliable. To be sure of getting enough people with a learning disability, a separate survey was carried out using a slightly modified questionnaire and a sample drawn directly from Social Services Departments' Client Record Systems.

No plans have been located for the future.

Data

The questions which were asked covered people's views of the NHS and the areas they would most like to see improved, illnesses that had been diagnosed by a doctor, their own assessment of any disability and how they go about their everyday lives. There were also questions about their circumstances and lifestyle. The questionnaire included the Short Form 36 (SF-36), a standard set of health status questions. The ward code of respondents was recorded to enable results to be analysed by Health Authority and Unitary Authority areas.

A more detailed list of data items collected is given below.

Completeness and accuracy

The data have been weighted (by age and sex) to minimise bias due to differing response rates from differing cross-sections of the population. Recent research has shown that the answers can be combined to give two summary scores which have been interpreted as the physical and mental dimensions of health status.

Uses

The survey provides baseline data for a range of health targets set for NHS Wales.

Funding

Funded by the National Assembly of Wales.

Access

See contact details and data archive:
http://biron.essex.ac.uk/cgi-bin/doc?userguide=&study=4176Publications

Contact details

Health Statistics Analysis Unit
Welsh Office
Cathays Park
Cardiff
CF1 3NQ
Tel.: 02920 468600

Publications

Welsh Health Survey 1995.
Welsh Health Survey 1998.
Surveys are reported on the website:
http://qb.soc.surrey.ac.uk/surveys/whs/whsintro.htm
Summary information is included in Health Statistics Wales.
Website: http://www.statistics.gov.uk/statbase/Product.asp?vlnk=1471

Welsh Health Survey data items

Part 1: The NHS and Other Services
This section relates to the respondent's experiences of NHS services such as GP, hospital or casualty visits. Included are numbers and frequencies of visits and also satisfaction of services received.

Part 2: Dentists
Establishes the respondent's feelings towards dental visits, the frequency of visits and their dental status (number of own teeth, fillings, caps, etc.).

Part 3: Medicines
This section defines medicine as anything that is taken or put on the skin such as tablets, powders, creams and sprays to treat a medical condition. The survey asks for frequency of purchases, method (prescription, over the counter, etc.) and where purchased [local pharmacists, large chain (Boots, Superdrug, etc.), supermarket].

Part 4: General Health
This section asks questions about the respondent's views about their own health, how they feel and how well they are able to do their usual activities as at now and compared with 1 year ago. In addition to physical activities and exercise (walking, running, lifting and sport), emotional issues and their effects on lifestyle are covered.

Part 5: Illnesses
Establishes physical and emotional illnesses and disabilities that have been treated by a doctor. The headings include:

- heart diseases
- chest and breathing
- diabetes
- physical or mental disability
- cancer
- mental or nervous illness
- accident, injury or poisoning.

Part 6: Alcohol and Smoking
Reviews frequency and volume and timing of alcohol intake and smoking habits.

Part 7: General Questions
Establishes the respondent's age, sex, ethnicity, height, weight, marital status, employment status and living accommodation.

Feedback

The HTA Programme and the authors would like to know your views about this report.

The Correspondence Page on the HTA website (http://www.ncchta.org) is a convenient way to publish your comments. If you prefer, you can send your comments to the address below, telling us whether you would like us to transfer them to the website.

We look forward to hearing from you.

The National Coordinating Centre for Health Technology Assessment,
Mailpoint 728, Boldrewood,
University of Southampton,
Southampton, SO16 7PX, UK.
Fax: +44 (0) 23 8059 5639 Email: hta@soton.ac.uk
http://www.ncchta.org

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