The Costs, Outcomes and Satisfaction for Inpatient Child and Adolescent Psychiatric Services (COSI-CAPS) study

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)

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Contents

1 Introduction	n and	context for the study	8
1.1	Introdu	uction	8
1.2	The stu	udy questions	8
1.3	The po	licy context for inpatient CAMHS	10
	1.3.1	The NHS Plan and National Service Framework	10
	1.3.2	Mental health legislation and age-appropriate care	11
	1.3.3	Clinical practice guidelines	11
	1.3.4	Mechanisms to support policy implementation	12
	1.3.5	The Quality Network for Inpatient CAMHS (QNIC)	13
1.4	Provisi	on of inpatient CAMHS	13
	1.4.1	Number of units and beds in England	13
	1.4.2	The distribution of inpatient CAMHS	13
	1.4.3	Change in provision over the past 7 years	14
	1.4.4	The growing role of the independent sector	14
1.5	The ty	pes of disorder treated by inpatient CAMHS	14
	1.5.1	Young people with an eating disorder	15
1.6	The eff	fectiveness of inpatient CAMHS	16
	1.6.1	Effectiveness of inpatient care for specific disorders	19
	1.6.2	Studies that have examined mixed groups	19
	1.6.3	Negative aspects of inpatient care	20
	1.6.4	Patient satisfaction with inpatient CAMHS	21
1.7	Factors	s that influence the outcome of CAMHS inpatient care	22
	1.7.1	Type and severity of the disorder	22
	1.7.2	The family context	22
	1.7.3	Length of stay	22
	1.7.4	The organisation of care	22
	1.7.5	Treatment climate and ward atmosphere	23
1.8	Measu	rement approaches relevant to this study	24
	1.8.1	General measures of clinical severity	24
	1.8.2	Measures commonly used for eating disorders	27
	1.8.3	Measurement of treatment climate/ward atmosphere	28
	1.8.4	Measurement of patient dependency	31
	1.8.5	Measurement of service user experience	32
2 Methods			35
2.1		ew	
2.2		and research governance approvals	

	2.2.1	Original assumptions35
	2.2.2	The changes to research ethics and governance35
	2.2.3	MREC approval36
	2.2.4	Impact of the ethics and research governance process36
2.3	Study	advisory group37
2.4	Recruit	tment of units into the study38
2.5	Compo	onent 1: description of the units38
	2.5.1	Design38
	2.5.2	The data38
	2.5.3	Data collection39
	2.5.4	Data management and analysis39
	2.5.5	Estimating costs per day in inpatient wards39
2.6	Compo	nent 2: study of admissions40
	2.6.1	Design40
	2.6.2	The cohort of young people40
	2.6.3	Information and consent40
	2.6.4	The data collection tools (DCT)40
	2.6.5	Procedure for collecting data at admission and discharge42
	2.6.6	Procedure for collecting data post-discharge42
	2.6.7	Data management and analysis43
2.7	Compo CAMHS	onent 3: population based study of admissions to non- 5 wards43
2.8	Compo satisfa	nent 4: young peoples' and parents experiences of and ction with inpatient CAMHS care44
	2.8.1	Design44
	2.8.2	Development of the semi-structured interview schedule
	2.8.3	Sampling and recruitment45
	2.8.4	Data collection46
	2.8.5	Data management and analysis46
2 PECH TO		47
3.1		mpleteness of the data for units and patients47
5.1	3.1.1	The cohort of units and overall rates of data return47
	3.1.2	Completeness of patient data
	3.1.3	Implications for the data analysis50
3.2		cteristics of the units50
5.2	3.2.1	Availability of beds and unit admission practices50
	3.2.2	Physical environment, activities and contact with
	0.2.2	other services52
	3.2.3	Staffing of units55
3.3		Atmosphere58
	3.3.1	Ward Atmosphere Scale (WAS)58

		3.3.2	Ward Atmosphere Measure (WAM)	.59
	3.4	Inpatie	nt cost data	.59
		3.4.1	Management of the missing costs data	.59
		3.4.2	Costs per day and inpatient treatment costs	.61
		3.4.3	Comparing NHS and independent sector units	.64
		3.4.4	The costs of treating eating disorders	.64
	3.5	Charact	eristics of the patients at admission	.65
		3.5.1	Characteristics of the whole cohort and comparisons between those admitted to an NHS unit and those admitted to an independent unit	65
		3.5.2	Characteristics of those with an eating disorder and comparison between those admitted to a GAU and those admitted to an EDU	.68
		3.5.3	Characteristics of those with a diagnosis other than an eating disorder and comparisons between those admitted to an NHS unit and those admitted to an independent unit	.71
	3.6	Patient	levels of dependency	.74
		3.6.1	CAMHS-AID by unit type	.74
		3.6.2	CAMHS-AID by diagnosis	.74
	3.7	Length	of stay and clinical outcomes	.75
		3.7.1	Length of stay	.75
		3.7.2	Clinical outcomes	.75
	3.8	Predicto	ors of outcome	.77
		3.8.1	Predictors of outcome for the whole cohort	.77
	3.9	Costs a	nd outcomes	.79
	3.10	Service	satisfaction	.81
		3.10.1	Participants	.81
		3.10.2	Overall satisfaction as measured by CAMHSSS	.81
			Differences between NHS and independent sector units	.82
			Themes emerging from qualitative interviews with young people and parents	
	3.11		ive case studies	87
		3.11.1	Young person admitted to a specialist eating disorder service	.87
			Young person with schizophrenia admitted to independently managed unit	.88
		3.11.3	Young person with a mood disorder admitted to an NHS managed service	.88
4 Discus				
	4.1		ons of the study	
			tudy design	
	4.2		ompleteness of data	.89
	4.2	hypothe	ent to which the findings address the research	.90
	4.3		ndings	
			-	

		4.3.1.	Clinical severity and treatment outcome	92
		4.3.2 I	Factors associated with better outcome	92
		4.3.3 I	Differences between NHS and independent units	92
		4.3.4 I	Differences between eating disorder and general units	93
		4.3.5	The costs of CAMHS inpatient care	93
E Toolis	- 4 :			0.5
2 Tublica	5.1		conclusionsations for policy	
	5.1	5.1.1	Research governance and ethics	
		5.1.2	A continuing role for CAMHS inpatient units in England?	
		5.1.3	The role of the independent sector	
		5.1.4	The role of specialist eating disorder units	
	5.2	Implica	ations for practice	
		5.2.1	The impact of treatment climate on outcomes	96
		5.2.2	The potential value of routine outcomes measurement	97
	5.3	Implica	ations for future research	97
		5.3.1	The need for better understanding of what influences treatment climate in inpatient CAMHS	97
		5.3.2	The sustainability of outcomes post-discharge	97
		5.3.3	The effectiveness of alternatives to inpatient care in preventing admission and/or reducing length of stay	97
		5.3.4	The pros and cons of specialist eating disorder units	98
Referenc	es			. 99
_				
			npatient units participating in the COSI-	442
	CAPS	stuay	(incl. age range)	112
Appendix	k 2 D	etailed	d clinical data for each diagnostic group	
	by ur		e	115
	2.1	adoles	inical outcomes of patients admitted to either a general scent or specialist service	115
	2.2	Non-Ea Diagno	ating Disorder Population (Clinical Outcomes – osis and unit wise)	
		2.2.1	Independent Units	122
Appendix	x 3 5!	5kg Pa	aper Mountain article	128
		_		
Appendix	x 4 C	OSI-C	APS Research Pack	136

Appendix 5 6-Month post-discharge data collection tool 186
Appendix 6 Unit Questionnaire194
Appendix 7 General Information Sheet 212
Appendix 8 Semi Structured interviews - Parents and Carers 214
Appendix 9 Semi Structured interviews – Young People 219
Appendix 10 Young People CAMHSSS Questionnaire 223
Appendix 11 Adult CAMHSSS Questionnaire 225
Appendix 12 Ward Atmosphere measure 227
Appendix 13 Ward Atmosphere scale 229

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None

The Report

1 Introduction and context for the study

1.1Introduction

Inpatient services are the most highly specialised and most costly form of child and adolescent mental health service (CAMHS) provision and cater for young people with the most severe mental disorders (Gowers and Rowlands, 2005). However, until recently, surprisingly little was known about the type of inpatient care provided let alone its effectiveness.

Recent studies have mapped service provision in England and Wales (NICAPS, 2001), described the characteristics of young people admitted to these units (O'Herlihy et al., 2004), studied the outcomes of care achieved via a small sample of units (CHYPIE, 2004) and tracked the care paths of young people who were assessed but not admitted for inpatient care (CAMHS Inpatient Referral Study; O'Herlihy et al., 2007).

The Costs, Outcomes and Satisfaction for Inpatient Child and Adolescent Psychiatric Services (COSI-CAPS) study is part of a programme of research about CAMHS inpatient care conducted by the Royal College of Psychiatrists' Research and Training Unit (CRTU). The CRTU also manages the Quality Network for Inpatient CAMHS (QNIC) that engages with more than 80% of UK CAMHS units (Shingleton-Smith et al., 2006).

1.2 The study questions

The questions specified by the NHS SDO in the research brief were:

- A. Which types of CAMHS inpatient care produce better clinical and social outcomes?
- B. Which types of service offering acute treatment and care are preferred?
- C. What is the cost effectiveness of adolescent units, paediatric wards and adult acute inpatient wards?

The grant proposal described a set of research hypotheses that considered aspects of these three questions. In its application to SDO, the research team focused on acute treatment and care provided in inpatient settings as opposed to non-inpatient acute care as might have been permitted as part of question B. Also, in order to maximise sample sizes, its proposed comparisons categorised units by major divisions – those managed by the NHS vs those managed by the independent sector and specialist eating disorder units vs general adolescent units.

Hypothesis 1 (which considered aspects of questions A and C):

That, after allowing for differences in casemix, there are no differences in clinical and social outcomes or cost of care:

- 1.1 for patients treated in NHS vs independent sector units.
- 1.2 for young people admitted to adult psychiatric wards or paediatric wards vs adolescent units.

Hypothesis 2 (which considered aspects of questions A, B and C):

That for those admitted for the treatment of an eating disorder:

- 2.1 after allowing for any differences at admission, clinical and social outcomes are no better for those admitted to a specialist vs a general unit.
- 2.2 young people and their families are no more satisfied with the care provided by specialist units than with care provided by general units.
- 2.3 there is no difference in the total cost of care for those admitted to a specialist vs a general unit.

Hypothesis 3 (which considered aspects of question B):

That the qualities of the physical, social and therapeutic environment that young people value:

3.1 are no better provided by CAMHS inpatient units than by adult psychiatric units or paediatric wards.

1.3 The policy context for inpatient CAMHS

1.3.1 The NHS Plan and National Service Framework

The NHS plan for England (Department of Health, 2000), which applies to all forms of healthcare, outlined a ten-year strategy to:

- increase funding
- 'redress' geographical inequalities
- improve standards of care and patient choice

Every Child Matters (Department of Education and Skills, 2003) is specific to children and young people and describes the Government's policy to improve the wellbeing of all children and young people. For CAMHS, a Public Service Agreement target was set to provide a comprehensive service by 2006 (Department of Health, 2002). A commitment was made in the NHS planning and priority framework, to increase provision annually by 10% between 2003 and 2006 (Department of Health, 2002).

The National Service Framework for Children, Young People and Maternity Services (otherwise known as the Children's NSF), published in 2004, defines the standards of care that young people can expect from services, and by which the quality of care provided by trusts is assessed. Standard nine relates to mental health and psychological wellbeing:

"All children and young people, from birth to their eighteenth birthday, who have mental health problems and disorders [should] have access to timely, integrated, high quality, multidisciplinary mental health services to ensure effective assessment, treatment and support, for them and their families." (Standard nine in the Children's NSF)

The Children's NSF specifies that young people with mental health problems should expect:

- access to mental health care that is 'based on the best available evidence and provided by staff with an appropriate range of skills and competences';
- access to 'timely, integrated, high quality, multidisciplinary mental health services to ensure effective assessment, treatment and support';
- services that are provided in an equitable manner, particularly for vulnerable young people (16-17 yr olds; those with mental health and learning disabilities or pervasive developmental disorder);

- continuity of care when they are discharged from inpatient CAMHS or transferred to an adult community mental health team (one vehicle for this is the use of the 'care programme approach');
- admission to settings which are appropriate for their age and developmental needs.

1.3.2 Mental health legislation and age-appropriate care

The Mental Health Act 2007 contains a provision (section 31) to ensure that patients aged under 18 are treated in a hospital environment which is suitable to their age and needs.

The act places a duty on hospital managers to provide an age appropriate environment, and to consult a person with expertise and knowledge of working with children and young people in deciding whether such an environment is age appropriate. The person will usually be a Tier 3 or Tier 4 CAMHS professional. Discrete accommodation with an adult mental health ward is permissible, but only if appropriate CAMHS support, safeguarding measures and age appropriate facilities are made available.

The recent allocation by the Government of £31 million funding to increase bed capacity and improve facilities in CAMHS across England is designed to facilitate this process. Although the full range of provisions affecting children and young people will not commence until April 2010, it is hoped that the additional funding will bolster inpatient CAMHS provision.

1.3.3 Clinical practice guidelines

The National Institute for Health and Clinical Excellence (NICE) has published several guidelines on mental disorders that affect young people. These include: Eating Disorders, 2004; Self-Harm 2004; Post-Traumatic Stress Disorder 2005; Depression in Children 2005; Obsessive-Compulsive Disorder 2005; and Bipolar Disorder, 2006 (www.nice.org.uk). Several additional guidelines which include children in their scope are currently being developed.

As well as informing clinical practice, NICE guidelines make recommendations about the service provision required to meet the needs of children and young people.

Depression in children

The guideline adapts the Health Advisory Service four-tier model of services (HAS, 1995) to present a stepped-care model of intervention (NICE, 2005, p136). The guideline is explicit about the organisation and delivery of inpatient care for young people with depression (NICE, 2005, p141). It specifies:

1. The criteria that should be met for admission - inpatient care "should only be considered when the patient is at significant risk of self-harm

- and/or needs intensive treatment or supervision not available elsewhere".
- 2. Issues that should influence decisions to admit "when considering admission for a child or young person with depression, the benefits of inpatient treatment need to be balanced against potential detrimental effects, for example loss of family and community support."
- 3. The range of interventions that should be provided. These should include "medication, individual and group psychological therapies and family support".
- 4. The qualities required of the inpatient environment "age appropriate and culturally enriching, with the capacity to provide appropriate educational and recreational activities."
- 5. The skills and competencies required of staff which include training in "issues of consent and capacity, the use of current mental health legislation and the use of childcare laws, as they apply to this group of patients."
- 6. The responsibilities of commissioners and strategic health authorities to "ensure that inpatient treatment is available within reasonable travelling distance to enable the involvement of families and maintain social links" and to ensure that "inpatient services are able to admit a young person within an appropriate timescale, including immediate admission if necessary."

Eating disorders

The NICE guideline for Eating Disorders states that "admission of children and adolescents with anorexia nervosa should be to age-appropriate facilities (with the potential for separate children and adolescent services), which have the capacity to provide appropriate educational and related activities" (NICE, 2004, p68).

Bipolar disorder

The diagnosis and monitoring of children and adolescents with bipolar disorder should be made by a clinician with specialist training in child and adolescent mental health. Inpatient admission or intensive home based services should be considered for children and young people with bipolar disorder who present a significant risk of harm to themselves or others.

1.3.4 Mechanisms to support policy implementation

The report on the Implementation of standard 9 of the Children's NSF (DH, 2006, p7) states that service planners are to "offer a coordinated response to the totality of NICE guidance." This requirement is reflected in the Department of Health's Standards for Better Health (Department of Health,

2004 & 2006) which are monitored as part of the Healthcare Commission's annual review.

1.3.5 The Quality Network for Inpatient CAMHS (QNIC)

QNIC was developed from the National Inpatient Child and Adolescent Psychiatry Study (NICAPS) in 2001. The network aims to demonstrate and improve the quality of inpatient child and adolescent psychiatric care through a system of review against the QNIC service standards (Shingleton-Smith et al., 2006). This process follows a clinical audit cycle with self-review and peer-review. QNIC reviews are not an inspection or accreditation test, nor a drive to uniformity. It is a supportive network with the emphasis on facilitating change. The QNIC standards are mapped onto the Healthcare Commission's Better Standards for Health. 72 of the 93 units in England participated in QNIC in 2007.

1.4 Provision of inpatient CAMHS

1.4.1 Number of units and beds in England

The CAMHS Mapping Exercise (www.dur.ac.uk/camhmapping), established in 2001 to monitor and audit NHS CAMHS provision, does not include beds managed by the independent sector. A follow-up to the NICAP study has provided fuller information (O'Herlihy et al., 2007). This found that in 2006 there were 91 units providing 1128 beds.

1.4.2 The distribution of inpatient CAMHS

The National Service Framework sets standards and milestones for achieving an equitable service (Department of Health, 2004) and increased funding has been made available (Department of Health, 2002). As table 1.1 shows CAMHS inpatient units in England were unevenly distributed in 1999. Furthermore, although 19 more units and 284 more beds were created between 1999 and 2006, if anything the inequity of has become more marked.

Table 1.1 Total CAMHS and general beds numbers per million population in English regions (from O'Herlihy et al., 2007)

Pogion ²	Beds per milli	on population; to	tal (general) ¹
Region ²	1999	2006	% change
North East	27.8 (11.9)	36.2 (12.7)	30% (7%)
London	26.5 (19.5)	44.2 (28.6)	67% (47%)
East Midlands	24.9 (9.7)	29.7 (10.2)	19% (5%)
South East	23.2 (18.6)	25.5 (20.9)	10% (12%)

East of England	11.9 (10.0)	12.6 (10.8)	6% (8%)
Yorkshire/Humber	11.3 (11.3)	9.1 (9.1)	-19% (-19%)
South West	11.1 (8.1)	12.8 (10.5)	15% (30%)
West Midlands	10.4 (10.4)	25.8 (12.5)	148% (20%)
North West	9.8 (8.3)	12.0 (10.5)	22% (27%)
ALL ENGLAND	17.2 (12.6)	23.0 (15)	34% (19%)

¹ Units that admit children and adolescents with a wide range of diagnoses and problems are categorised as 'general'.

1.4.3 Change in provision over the past 7 years

The independent sector accounts for 69% of the increase in bed numbers between 1999 and 2006. By 2006, the independent sector provided 36% of all beds, up from 25% in 1999 (O'Herlihy et al., 2007). The independent sector is also a major cause of the inequity of distribution because much of its provision is a concentrated in London and in the south-east of England.

1.4.4 The growing role of the independent sector

Until recently there has been a lack of separate and emergency provision in the UK for adolescents presenting with urgent need and acute psychiatric disturbance or life-threatening behaviour (Cotgrove, 1997). Young people requiring emergency admission have frequently been inappropriately admitted to adult and paediatric wards (O'Herlihy et al., 2001, Mental Health Act Commission, 2001; 2004; Worrall et al., 2004; Gowers et al., 2001).

Although the number of adolescent psychiatric units with dedicated emergency admission beds has increased in recent years, many young people who require immediate admission still cannot be admitted within one working day (Cotgrove et al., 2007). The majority of units (56%) never admit 'out-of hours'. The authors of this survey suggest this unmet need may best be addressed by the development of specialist acute admission units.

1.5 The types of disorder treated by inpatient CAMHS

Table 1.2 lists the diagnoses of young people resident in 71 general psychiatric or specialist eating disorder units on the census day (19th October 1999) for the NICAP Study (O'Herlihy et al., 2001).

² English regions are based on boundaries set in 2003.

Table 1.2 The principle diagnosis of 537 young people resident in services participating in the NICAPS study

services participating in the NICAPS study	NICAPS (%)
Eating disorder	125 (23.3)
Schizophrenia, delusional or psychotic disorder	103 (19.2)
Mood (affective) disorder	80 (14.9)
Mental and behavioural disorders due to psychoactive substance use	6 (1.1)
Anxiety disorders	28 (5.2)
Other neurotic, stress-related and somatoform disorders	7 (1.3)
Disorders of adult personality and behaviour	12 (2.2)
Hyperkinetic disorders	18 (3.4)
Conduct disorder (including mixed CED)	37 (6.9)
Organic, including symptomatic, mental disorders	9 (1.7)
Behavioural syndromes associated with physiological disturbances	5 (0.9)
Disorders of psychological development	9 (1.7)
Other (including learning difficulties and OCD)	88 (16.4)
Diagnosis unknown	10 (1.9)

1.5.1 Young people with an eating disorder

As Table 1.2 shows, eating disorder is the most common diagnosis for young people resident in CAMHS inpatient units. Anorexia nervosa, which has a peak age of onset of between 14 and 15 years (Strober et al., 1997), has the highest mortality rate of any psychiatric disorder (Sullivan, 1995). Despite the recommendation from NICE that "people with anorexia nervosa requiring inpatient treatment should be admitted to a setting that can provide the skilled implementation of refeeding with careful physical monitoring (particularly in the first few days of refeeding) in combination with psychosocial interventions" (NICE, 2004, p4), NICAPS found that as many young people with an eating disorder were admitted to a general unit as were admitted to a specialist eating disorder unit.

COSI-CAPS will compare outcomes for young people treated for an eating disorder in a general adolescent unit with those for young people treated in a specialist eating disorder unit.

1.6 The effectiveness of inpatient CAMHS

We have identified six reviews of outcome studies of inpatient CAMHS (Pfeiffer & Strzelecki, 1990; Curry, 1991; Pottick et al., 1993; Blanz & Schmidt, 2000; Meads et al., 2001; Jacobs et al., 2004). These all conclude that inpatient care is effective. However, most studies included in the reviews have small samples and few have used standardised outcome measures.

Evidence for the effectiveness of inpatient CAMHS comes from two broad types of study – those that examine outcomes of admission for young people with a specific type of disorder and those that examine outcomes for a heterogeneous group of young people admitted for inpatient care. Table 1.3 lists the published studies that have been conducted in the UK since 1990.

Table 1.3 Summa	ry of inpatient CAMHS	Table 1.3 Summary of inpatient CAMHS outcome studies conducted in the UK since 1990	n the UK since 1990	
Reference	Type of study	Patient group(s)	Unit type(s)	Broad conclusion
Crisp, Norton & Gowers, et al., 1991	Randomised Control Trial	Adolescents with an Eating disorder (n=90)	Four groups: Inpatient, out- patient groups (x2) and assessment only	All three treatment groups were effective across a range of outcomes. No significant differences in outcomes between in- and out-patient groups
Wells & Faragher, 1993	Prospective cohort study	Consecutive admissions of adolescents (13-18 yrs) with emotional or conduct disorders (n=165)	General adolescent unit	Significant overall improvement at discharge and 2 years post discharge
Rothery et al., 1995	Prospective multi- centre cohort study	Consecutive admissions of adolescents (12-20 yrs) with a range of diagnoses (n=276)	Four NHS general adolescent units	Substantial improvement across a range of treatment goals
Jaffa & Stott, 1999	Prospective cohort study	Consecutive admissions of adolescents (12-18 yrs) with a range of diagnoses (n=50)	General adolescent unit	Inpatient treatment can be effective and acceptable
Gowers et al., 2000	Mixed method; retrospective (case note) and prospective cohort study	Adolescents with an eating disorder (n=72)	Community and inpatient setting	Patients accessing inpatient care had a significantly worse outcome than those not admitted
Green et al., 2001	Prospective cohort study	Consecutive admissions of children and adolescents (n=55)	Two inpatient child and adolescent units	Significant health gain during hospitalisation, sustained to follow-up

Corrigal & Mitchell, 2002	Prospective cohort study	Consecutive admissions of children and adolescents (n=118)	Acute General Adolescent Unit	Substantial health improvements
Green et al., 2007	Prospective multi- centre cohort study	Children and Adolescents (n=150)	8 units; 4 children's and 4 adolescent units	Significant and clinically meaningful improvement at discharge, sustained at 1 year follow-up, across a range of diagnoses
Gowers et al., 2007	Multi-centre Randomised Control Trial	Children and Adolescents (n=167)	Inpatient, specialist out-patient or general CAMHS treatment	Each group made considerable health gain at 1 year, with further improvement by 2 years. Full recovery rates were poor. Neither inpatient nor specialist out-patient treatment demonstrated advantages over general CAMHS treatment

1.6.1 Effectiveness of inpatient care for specific disorders

Eating disorder

Randomised controlled trials (RCTs) show few if any advantages of inpatient care over community-based care for adolescents with anorexia nervosa (Crisp et al., 1991; Gowers et al., 2007). Likewise, there is little evidence concerning the relative effectiveness of different type of inpatient unit such as specialist adolescent eating disorder units, all-age eating disorder units or generic units (Fonagy et al., 2002). As a result, there is an unresolved debate about the value of inpatient treatment for young people with anorexia nervosa (Green, 2002). Inpatient treatment of an eating disorder is expensive and some conclude that it may not be effective in the long-term (Lock, 1999; Gowers et al., 2000).

Mood disorder

Although it is unusual for a young person with depression alone to be admitted, depression is often a comorbid diagnosis (Green and Jacobs, 1998). The NICE guideline group undertook a systematic review of the treatment of depression in children and adolescents (NICE, 2005). They found no recent RCTs that examined at admission as a treatment modality for depression.

Psychosis

There is a lack of research comparing admission with alternative forms of treatment for young people with psychosis. However, studies of early intervention, many of which include young people under the age of 18, report that intensive care in the community can be at least as effective as admission (Spencer et al., 2001).

1.6.2 Studies that have examined mixed groups

General CAMHS units

A number of studies have examined the benefits of admission to adolescent inpatient units that admit young people with a variety of diagnoses (Green et al., 2007; Jaffa & Stott, 1999; Mattejat et al., 2001; Wells & Farragher, 1993; Wrate et al., 1994). Results generally show a picture of positive health gain and improvement in psychiatric symptoms which remain stable for at least two years.

Wrate et al. (1994), who conducted a prospective multi-centre research study found different goals were identified to be important for different disorders, however, overall effectiveness of treatment modality was supported. Green and colleagues (2001) used a broad range of outcomes in their study of general adolescent inpatient treatment. Their two-year study of treatment process and outcome was designed to apply a multiple perspectives methodology to the conceptualization and measurement of health gain and its predictors during inpatient treatment in two general

CAMHS inpatient units in the UK. Results indicated significant health gain during hospitalization across most measures, sustained to follow-up.

Building on this approach, the CHYPIE study (Green et al., 2007) found substantial treatment effects associated with inpatient admission over a range of diagnostic groups, maintained into one year follow-up.

Acute units and emergency admissions

A number of studies have investigated the feasibility and effectiveness of shorter-term and emergency admissions (Corrigall & Mitchell, 2002; Cotgrove, 1997; Goldston et al, 1999; Ivarsson, Larsson & Gilberg, 1998; Katz et al., 2004). It is not known whether young people admitted in an emergency might be managed as well by other means such as by specialist community services or in social service setting (Cotgrove, Zirinsky & Black, 1995; Cotgrove, 1997). Cotgrove (1997) contended that admitting both emergency and elective cases to the same ward may cause problems. These include disruption to the therapeutic programme, longer waiting lists for treatment beds, potential loss to the safe and containing environment, and the loss of planning prior to admission.

Inpatient treatment versus community alternatives

The few studies that have compared inpatient care with community and home-based treatment for adolescents with mental health problems (Harrington et al., 1998; Woolston, 1998; Mattejat et al, 2001) have reported few differences in outcomes in symptoms or adaptation at school. A recent RCT comparing inpatient, specialist out-patient and general CAMHS treatment for young people with an eating disorder indicated that although young people make considerable progress in all groups, neither inpatient or specialist out-patient therapy demonstrated advantages over general CAMHS treatment (Gowers et al., 2007).

1.6.3 Negative aspects of inpatient care

It has been argued that although some young people may experience relief at having respite from a difficult situation outside of hospital, for others admission can be a frightening and bewildering experience (Green, 2002; Green & Jones, 1998). There has been little research that has examined potential negative consequences and counter-therapeutic processes that may arise within inpatient treatment settings for adolescents (Bobier & Warwick, 2004; Gowers & Rowlands, 2005; Gowers, et al., 2000; Green, 2002; Green & Jacobs, 1998; Jaffa & Stott, 1999). What literature there is relies mainly on theoretical concerns and anecdotal accounts. Also, it is based more on clinical and professional opinion and perspectives, as opposed to the views of young people themselves (Green, 2002). The themes raised include risking disruption and loss of normal and family life, missing out on social, education and occupational opportunities, and the effects of stigma and labelling (Blanz & Schmidt, 2000; Green, 2002; Jaffa & Stott, 1999).

1.6.4 Patient satisfaction with inpatient CAMHS

Boylan (2004) compiled a database of reports, mostly from the UK, that examined young people's views of healthcare. For mental health, the most commonly reported findings related to:

1 Communications

- · young people don't always feel listened to
- there is a lack of continuity of staff
- if nurses are in a bad mood it can impact negatively on patients
- young people are sometimes spoken to at an inappropriate level

2 Environment

- there is sometimes a lack of activities for older children
- some units are in need of refurbishment
- sometimes there is too much noise at night-time
- there is a need for a quiet room or prayer room
- units should be gender specific
- young people need more privacy

3 Access

- young people may experience problems getting help
- GPs may not be helpful
- young people may be discharged if appointments are missed
- some young people report that family members are not helpful when you go to them for help
- the most helpful factor in a crisis is having someone to talk to

4 Involvement

- young people are not involved enough
- parents and young people should be involved in service provision decisions
- young people should be given respect and treated as individuals

Street and Svenberg (2003) used interviews and postal questionnaires to elicit the experience of young people of inpatient CAMHS. The resulting 'Where Next' reports highlight problems with communication, both within CAMHS and between CAMHS staff and other agencies and with a lack of information. The latter concerns information about: services; treatment options; individuals' problems; likely outcomes and the rules of inpatient units.

There have also been studies of the experience of young people who use community-based services. Day and colleagues (2006), using focus groups, identified four key themes: basic expectations of appointments; the process of therapy; the content of appointments and the outcome of appointments. Buston (2002) used semi-structured interviews to explore wider issue of

young people's experiences of their mental health care in Scotland. These data were reported under the following headings: doctor-patient relationship, treatment received, the health-care system, and the environs of the hospital/clinic. Similar themes are emergent in the American literature, with a particular emphasis on the quality of the patient-therapist relationship (Nabors et al, 1999; Garland et al, 1996).

1.7 Factors that influence the outcome of CAMHS inpatient care

1.7.1 Type and severity of the disorder

Despite the limitations of the outcome studies described above, the findings about factors that predict a favourable outcome for inpatient care are consistent (Pfeiffer & Strzelecki, 1990; Gossett, Lewis & Barnhart, 1983; Green et al. 2001 and Jacobs et al., 2004). Factors that are correlated with health gain and good long-term outcomes fall into three broad categories:

- Increased severity of patient psychopathology
- · having an emotional disorder
- the absence of psychosis

1.7.2 The family context

- absence of parental psychopathology
- good family functioning pre-admission

1.7.3 Length of stay

The trend in mental healthcare for all ages, and indeed in all forms of healthcare, is towards avoidance of admission when possible and towards minimising length of hospital stay when admission is unavoidable. This is also true for CAMHS where increasingly the emphasis is towards shorter admissions and treatment in the community (Blanz & Schmidt, 2000; Fennig et al., 2002; Henggeler et al., 1999). However, the evidence suggests that longer length of stay is associated with a better outcome (Green et al., 2007).

1.7.4 The organisation of care

Outcomes are better for young people who complete a well-organised treatment programme, who have a planned discharge and who continue therapy post discharge (Blanz & Schmidt, 2000).

1.7.5 Treatment climate and ward atmosphere

Most research regarding the relationship between treatment climate and the quality and outcome of mental health inpatient care has been undertaken on adult psychiatric wards. The data suggest that treatment climate influences clinical improvement (Mellei et al., 1996; Eklund & Hansson, 1997; Timko & Moos, 1998), drop out rates (Moos et al., 1973, Spiegel & Younger, 1972) and patient satisfaction (Friis, 1986; Gjerden & Moen, 2001; and Eklund & Hansson, 2001).

Haigh (2002), in a series of papers - 'Acute wards: problems and solutions' identified that "The most important single factor in the efficacy of the treatment appears to be an intangible element which can only be described as its atmosphere" (p.380). It has also been suggested that different characteristics of the ward atmosphere promote different kinds of outcomes (Collins et al., 1984; Ellsworth, 1983; Eklund & Hansson, 1997; Moos et al., 1973; Spiegel & Younger, 1972). Complementary research has focused on identifying the specific characteristics of treatment environments that may affect specific clinical outcomes (Erickson, 1975; Lehman et al., 1982).

There is less evidence about the relationship between treatment climate and outcomes in CAMHS wards. This is an important gap in knowledge because reviews of inpatient CAMHS report variation in service attributes that relate to treatment climate (Shingleton-Smith et al., 2006).

Factors that influence treatment climate include:

- 1. Staff 'attitude' and 'approach' to treatment (Squire, 1994) which relates in part to that of staff morale. Patients are more likely to improve in programs in which staff are more satisfied with their job and thus establish a more therapeutic environment (Moos, 1997).
- 2. The work environment. It has been suggested that some psychiatric hospitals have physical environments that may inhibit the behaviours that are the expressed goals of the treatment (Cotton & Geraty, 1984; Whitehead et al., 1976), or potentially foster or aggravate a patients' illness (Holahan, 1974; Winkel & Holahan, 1985). Gulak (1991) states that "many of the clinical and administrative problems hospitals are experiencing is due in part to unsatisfactory design and lack of architectural support" (p. 705). A review of the literature in this field proposes that even minor changes in the physical environment of psychiatric services are associated with positive changes in patients' behaviour, attitudes and perceptions (Tyson et al., 2002).
- 3. Staff-patient ratios. The staffing levels correlate with some aspects of ward atmosphere (Friis, 1986a). However, there has been some debate about the direction of causality. It is possible that settings with a poor treatment climate have a high staff turnover (Friis, 1986b). The Royal College of Psychiatrists' Council Guidance on staffing of child and adolescent inpatient psychiatric units' (CR76;

- 1999), emphasises that the appropriate 'quantity', 'quality' and 'organisation' of staffing is necessary to create a modern ward milieu.
- 4. Case-mix. Green and Jacobs (1998) contend that the complex needs of one young person can have an immediate and detrimental effect on the dependency needs of the rest of the inpatient group and the therapeutic environment. The Royal College of Psychiatrists (1999) recommends that both admissions and staffing levels should be informed by patient dependency measures.
- 5. Therapeutic alliance. This has received little detailed research (Diguiseppe et al., 1996; Green, 2006). The predictive power of positive alliance in studies either as an isolated variable (Green et al., 2001; Green et al., 2007) or as part of a composite variable (Pfeiffer and Strzelecki, 1990) is consistent with much of the adult literature (Hougaard, 1994). In addition, proxy alliance measures such as 'parental cooperation' often predict inpatient outcome in child and adolescent studies (Grizenko, 1997; Sourander et al., 1996).

1.8 Measurement approaches relevant to this study

1.8.1 General measures of clinical severity

Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA)

HoNOSCA (Gowers et al., 1999) is well established as a clinician-rated broad measure of outcome (Gerralda et al., 2000). HoNOSCA balances simplicity; it was designed for use by clinicians in routine practice, with reasonable reliability and validity (Brann et al., 2001). It is one of the outcome measures recommended for use by the Children's NSF and the CAMHS Outcome Research Consortium (CORC, 2007).

HoNOSCA is a set of 15 items each of which concerns a problem often experienced by young people with mental disorders. The 15 items are in two sections (those in section B are optional) and concern problems with:

Section A

- 1. Disruptive, antisocial or aggressive behaviour
- 2. Overactivity attention and concentration
- 3. Non accidental self injury
- 4. Alcohol, substance/solvent misuse
- 5. Scholastic or language skills
- 6. Physical illness or disability problems
- 7. Hallucinations and delusions

- 8. Non-organic somatic symptoms
- 9. Emotional and related symptoms
- 10. Peer relationships
- 11. Self care and independence
- 12. Family life and relationships
- 13. Poor school attendance

Section B

- 14. Lack of knowledge about the nature of the difficulties
- 15. Lack of information about services and care

Each item is scored on a scale of 0 (no problem) to 4 (severe problem). The item scores can be used separately or added to give a total score that reflects the overall severity of problems facing a young person (Gowers et al., 2002). Thus for section A, the total HoNOSCA score ranges from 0 to 52.

A number of studies have investigated the feasibility, acceptability, reliability and validity of the HoNOSCA (Gowers et al., 1999; Yates et al., 1999; Gerralda et al., 2000; Brann et al., 2001; Gowers et al., 2002). There is some evidence that HoNOSCA scores at admission predict length of treatment/stay and correlate moderately highly with the number of treatment sessions attended (Gerralda et al., 2000). It has been shown to correlate adequately with other measures of child psychopathology, functional handicap and clinical complexity (Yates et al., 1999).

The research team is familiar with HoNOSCA - Dr Lelliott was grant-holder for the NHS R&D grant that funded its development. The research team has used the instrument as an outcome measure in two previous major studies of inpatient CAMHS (NICAPS & CIRS). This also means that many of the CAMHS units are also familiar with HoNOSCA.

Children's Global Assessment Scale (CGAS)

CGAS (Schaffer et al., 1983) is a general measure of biopsychosocial functioning that is used widely in child and adolescent settings. It is also one of the outcome tools recommended by CORC (2007).

CGAS gives a global rating of impairment and, with repeated use, also provides a measure of change. It was adapted from the Global Assessment Scale for adults (Endicott et al., 1976). CGAS requires a rating to be made by selecting the appropriate descriptive level on a hypothetical continuum of health to illness that ranges from 1 to 100 (Jaffa & Stott, 1999). The lowest rating (1-10) indicates that the young person "needs constant supervision (24-hour care) due to severely aggressive or self-destructive behaviour or gross impairment in reality testing, communication, cognition, affect or personal hygiene". The highest rating (91-100) indicates that the young

person has "superior functioning in all areas (at home, at school and with peers); involved in a wide range of activities and has many interests (e.g., has hobbies or participates in extracurricular activities or belongs to an organised group such as Scouts, etc); likeable, confident; 'everyday' worries never get out of hand; doing well in school; no symptoms".

Although clinical judgement is required in making the rating (Bird et al., 1996), the use of CGAS requires no training. Although early research reported that the psychometric properties of the instrument were good (Bird et al., 1987; Steinhausen, 1987) more recent data suggest that CGAS has only moderate inter-rater reliability (Rey et al., 1995). Its reliability appears to depend on the experience of the rater (Dryborg et al., 2000). Research has also demonstrated gender differences with respect to impairment scores; CGAS may be more sensitive when used with females than males (Steinhausen & Metzke, 2001).

Jacobs and colleagues (2004) developed a series of exemplar case vignettes for all potential research raters participating in the CHYPIE study. Despite these, clinicians working in inpatient units gave significantly higher ratings of CGAS (indicating better levels of functioning) at admission than did referring clinicians. CGAS scores correlate highly with HoNOSCA total scores (Yates et al., 1999).

Paddington Complexity Scale (PCS)

The PCS (Yates et al., 1999; Gerralda et al., 2000) assesses the case complexity at presentation in a standardised way. Scores for 12 questions covering two domains (clinical and environmental), are summed to derive one total score. Each item (see below) is rated individually. The items in the PCS are:

- 1. Primary psychiatric condition
- 2. Duration of condition
- 3. Severity of condition
- 4. Secondary psychiatric condition
- 5. Chronic physical illness
- 6. Learning disability
- Schooling
- 8. Main carers
- Carers attitude and co-operation with assessment and treatment
- 10. Whether the patient's first contact with mental health services
- 11. Current involvement with other agencies
- 12. Current children act involvement

1.8.2 Measures commonly used for eating disorders

Tools used to assess young people with eating disorders can be broadly categorised as: i. interview schedules; ii. clinician-rated questionnaires; iii. questionnaires completed by the young person and iv. questionnaires completed by the parent.

Interview schedules: the Eating Disorder Examination (EDE)

The interview approach is useful with children and young people because the interviewer can explain the questions and tailor the interview to the needs of each individual (Fairburn & Beglin, 1994). The Eating Disorder Examination (EDE) (Fairburn & Cooper, 1993) is perhaps the most widely used interview schedule in both research and clinical practice. It is considered by some to be the 'gold standard' in eating disorder assessment (Wilson, 1993).

The EDE elicits the presence or absence of the key diagnostic features of anorexia nervosa and bulimia nervosa over the past three months based on DSM-IV criteria. It also assesses the severity of psychopathology associated with the eating disorder over the past four weeks and provides ratings of frequency and severity for behaviours and attitudes.

Although the EDE is regarded as reliable and valid (Bryant-Waugh et al., 1996), the disadvantage of the tool in large scale health services research is that the instrument takes a relatively long time to apply (approximately one hour) and also requires fairly extensive training.

Clinician-rated questionnaire: the Morgan-Russell Assessment Schedule (M-RAS)

There are few clinician-rated tools specifically designed for use with adolescents. The Morgan-Russell Outcome Assessment Schedule (M-RAS) (Morgan & Russell, 1975) is the most commonly used (Rosenvinge & Mouland, 1990; Ratnasuriya et al., 1991; Eckert et al., 1995; Herpertz Dahlmann et al., 1996). Those who developed M-RAS contend that its design and ease of use makes it particularly useful in routine clinical practice (Morgan & Hayward, 1988).

M-RAS is completed by the clinician independently, or in collaboration with the patient. The instrument is a structured interview comprising 14 items in five sub-scales. These cover: physical status; menstruation; mental state; sexual adjustment and socio-economic status. Each item is rated using a Likert scale which ranges from 0-12. The lower score represents more severe anorexia. Ratings are made on the basis of severity of the disorder within the previous six months (Lund et al., 1999). The ratings are averaged and reduced to a five-point profile which can be used in clinical assessment and to monitor change.

M-RAS has been reported to have satisfactory external validity (Gillberg, Råstam & Gillberg, 1994) and internal validity (Morgan and Hayward, 1988). It also has reasonable inter-rater reliability when used to assess patients with anorexia (Lund et al., 1999). It has been suggested that reliability may be improved by training the rater (Lund et al., 1999).

M-RAS has a been used in research to assess long-term outcome in eating disorder (e.g. Ratnasuriya et al., 1991; Walford & McCune, 1991; Hall et al., 1984), and the costs and benefits of both out-patient (Dare et al., 2001) and inpatient treatment (Gowers et al., 2000).

Self-report questionnaires

There are a number of self-report instruments available. Two of the most widely used are the Eating Attitudes Test (EAT) (Garner et al., 1982) and the Eating Disorders Inventory (EDI) (Garner, Olmsted & Polivy, 1983). However, critics have suggested that these instruments have a number of shortcomings including the lack of a specific time-frame and a failure to ask directly about the frequency of key eating disorder behaviours (Wilson, 1993). The self-report version of the EDE, the Eating Disorder Examination Questionnaire (EDE-Q) (Fairburn & Beglin, 1994), attempts to address some of these limitations (Carter, Stewart, & Fairburn, 2001).

The EDE-Q contains the same questions as the EDE, but in a shorter, self-report format. This has the advantage of being easier to apply and also may be more acceptable to some children and young people, as it does not involve the process of an interview with an adult. Scores from the EDE and the EDE-Q correlate highly in the key behavioural features and the three primary sub-scales (Luce & Crowther, 1999). However, less agreement was found for the binge-eating and shape concern sub-scales (Fairburn & Beglin, 1994).

Parent report: the Children's Eating Behaviour Inventory

The Children's Eating Behaviour Inventory (CEBI) (Archer et al. 1991) is perhaps the most commonly used parent report tool. It comprises 40 items which require a 'yes/no' response, as well as a rating on 5-point Likert scale, which are split into two (child and parent) domains. CEBI assesses a range of areas including: behaviour, skills, interactions and stressors. The CEBI is easy to read with clear instructions, and can be completed in around 15 minutes. In addition, the CEBI allows for identification of specific problems through investigation of individual items.

1.8.3 Measurement of treatment climate/ward atmosphere

The Ward Atmosphere Scale for adult psychiatric wards

Rudolph Moos and colleagues (1974) developed a common conceptual framework that enabled measurement of the complex factors that contribute to treatment climate and which might affect the outcome of treatment (see section 1.7.5). This resulted in the Ward Atmosphere Scale (WAS) (Moos, 1974 – Appendix 13). The WAS is the most widely used and researched instrument to evaluate the treatment climate of inpatients adult wards and its relationship to outcomes (Mellei et al., 1996; Timko and Moos, 1998 a & b; Røssberg & Friis, 2003).

The WAS is a sociometric instrument that measures the psychosocial climate of the psychiatric ward. The WAS comprises 100 statements,

covering 10 subscales which are individually rated, as true or false. The subscales are grouped conceptually into three higher order programme dimensions: i. relationship; ii. treatment programme and iii. administrative or system structure (see Table 1.4).

Table 1.4 WAS subscale and dimensions descriptions

Relationship Dimensions

- Involvement: how active and energetic patients are in the program
- Support: how much patients help and support each other; how supportive the staff are towards patients
- Spontaneity: how much the programme encourages the open expression of feelings by patients and staff

Personal Growth Dimension

- Autonomy: how self-sufficient and independent patients are in making their own decisions
- Practical orientations: the extent to which patients learn practical skills and are prepared for release from the programme
- Personal problem orientation: the extent to which patients seek to understand their feelings and personal problems
- Anger and aggression: how much patients argue with other patients and staff, become openly angry, and display other aggressive behaviour

System Maintenance Dimensions

- Order and organisation: how important order and organisation are in the programme
- Program clarity: the extent to which patients know what to expect in their day-to-day routine and the explicitness of program rules and procedures
- Staff control: the extent to which the staff use measure to keep patients under necessary controls

The WAS has been reported to have acceptable psychometric qualities (Moos, 1974; Friis, 1984; Friis, 1986b). Several studies have demonstrated that the ward atmosphere of a psychiatric setting, as measured by WAS, is

a stable phenomenon over time (Eklund & Hansson, 1996; Friis et al., 1982; Friis, 1986a; Moffett & Flagg, 1993; and Moos, 1974).

The measurement of ward atmosphere in CAMHS

There have been few reports of the evaluation of treatment climate in child and adolescent settings. Wolff and colleagues (1972) compared residents' and staff members' views of a residential centre for developmentally disabled adolescents, in addition the WAS has been used to examine the treatment environment in a residential centre for emotionally disturbed children and youths (McGee & Woods, 1978) and describe an inpatient children's unit (Steiner, 1982). In a follow-up to the latter study, Steiner et al. (1991) found high stability in both patient and staff perceptions of ward atmosphere even though there was a complete turn-over of young people, and the majority of the original staff team had changed.

WAS appears to be a trait measure in that it assesses enduring aspects of treatment climate. However, the experience of clinicians is that some aspects of ward atmosphere are states that are subject to fluctuation (Green, personal communication). The Ward Atmosphere Measure (WAM – Appendix 12) (Green & Imrie, Unpublished) was developed to capture this. The instrument was designed and piloted for the evaluation of milieu function in child and adolescent units (Jacobs & Green et al., 2004). In designing a measure suitable for investigating these phenomena in child and adolescent units, the authors were mindful of the adult research, but also of the adaptations necessary for the younger age settings. The emphasis was more on a staff rated measure in conjunction with simplified measures of therapeutic alliance from the patient's perspective. A 12 item questionnaire was designed using appropriate adaptations of the core dimensions from the WAS and piloted with weekly ratings from all ward staff over two periods of 3 months.

The measure is arranged into four domains. The first dimension relates to the organisational structure of the ward, children's involvement in therapeutic rather than counter therapeutic activities, and positive aspects of the peer group culture. The second dimension focuses on relationships between staff. Here the focus is on ratings of mutual support within the staff team, capacity to reflect together during care planning and a sense of coherence of work as part of a team. The third dimension relates to staff child relationships. This dimension addresses the quality of therapeutic relationships between the staff team and the group of patients. The focus is on the staff retaining an empathic therapeutic orientation rather than a sense of hopelessness or rejection. The fourth dimension relates to the personal feelings of the staff. Whether they feel secure and in control at work, enthusiastic about their activities and the levels of stress that they might carry over into their private lives. The initial analysis of the CHYPIE data suggests that WAM is sensitive to changes in ward atmosphere within units, and that the pattern of change is different across units.

1.8.4 Measurement of patient dependency

Patient dependency is an important determinant of the amount of care that a patient requires. The Audit Commission (1992) defines it as "an assessment of a patient's ability to care for him or herself, for instance, with regard to feeding, personal hygiene and mobility" (also see MacGuire, 1988). A measure of dependency of inpatients, and the summation of individual ratings to create a picture of the casemix on a ward, could have a range of uses including to set staff numbers and skills mix of a team and to inform decisions to admit a new patient.

A literature search (Abeles et al., 2007) revealed only one published study that had attempted to develop a measure of patient dependency relevant to CAMHS inpatient settings. Furlong and Ward (1997) described a scale developed at the Park Hospital, Oxford to assist in calculating the required staff numbers and skills mix. This required two nurses to rate patients on a range of items scaled with descriptions of increasing levels of dependency. Unfortunately, the scale was not published with the article and attempts to obtain it from both the authors and the hospital where the research was carried out have proven unsuccessful.

A research team comprising nurses and clinical psychologists from Manchester and Birmingham Children's Hospitals NHS Trusts has recently attempted to fill this gap. In consultation with staff working in inpatient CAMHS, the research team made a comprehensive list of the nursing activities and interventions made in response to patient dependency. This included the 'hidden work' (McWilliam & Wong, 1984) such as liaison with other agencies and the time taken to give informal support to families.

The resulting instrument, CAMHS-AID (Child and Adolescent Mental Health Services – Assessment of Inpatient Dependency) has 47 items (Hodgkinson et al., 2005). The items are organised into four different 'dependency modules': i. basic needs/achieving comfort; ii. intensity of supervision; iii. social communication (including effect on the group) and iv. working with family/carers and agencies away from the ward/hospital. Each item is rated on 0 (fully independent) to 4 (requires intensive input) scale which usually reflects the different amounts of nursing input required to manage the patient. Figure 1.1 is an example of the descriptors that accompany an item to assist rating.

Figure 1.1 CAMHS-AID rating descriptions

_		Specific	Example
0	Fully independent in personal care		
1	Requires minimal intervention	By one person	Young person is able to meet their personal care needs with a few verbal prompts and/or minimal assistance – buttons, laces

2	Requires moderate intervention	By one person	Young person able to meet personal care needs with frequent verbal prompts – can put on two garments, wash hands, recognises need to eliminate
3	Requires intensive intervention	By one person	Young person unable to meet one third of personal care needs without assistance, but able to recognise need to eliminate/attend to basic hygiene needs
4	Requires intensive intervention	By more than one person	Young person always unable to meet personal care needs and requires assistance

A dependency profile is created by summing the ratings of individual items within each of the CAMHS-AID modules. The developers have created a computerized scoring system to assist this, and a web-based version of the tool is also available (www.cmmmc.nhs.uk/camhsaid). Scores can be weighted by: estimating how long it would take in hours per day for each level of the task to be completed; determining whether it is a task which could be completed alongside others (for example, a staff member who supervises a patient who is at risk of self harm can also attend to any dietary needs), or whether it would need to be done on its own (for example, liaison work such as telephoning a family) and deciding which tasks instantly put a patient on 1:1 nursing care. These factors determine how the scale is scored. The CAMHS-AID has been completed by many CAMHS nurses of various levels of seniority. It usually takes a novice about 15 to 20 minutes to complete. An individual who is familiar with the instrument takes about 5 to 10 minutes.

The initial tests of CAMHS-AID are promising. Eighty-six nurses rated the CAMHS-AIDS items highly in a test of face and content validity (Abeles et al, 2008). A small-scale study found that ratings using CAMHS-AID correlated highly with ratings based on clinical opinion of dependency (Hodgkinson et al., 2005). A larger study to evaluate the reliability and validity of CAMHS-AID reliability and validity is nearing completion. The initial analysis of a sample of 50 young people in inpatient CAMHS units suggests that dependency groupings can be created on the basis of quartile scores on CAMHS-AID whereby a score below 12.5 denotes low dependency, between 12.5 and 25 is medium dependency, 25 to 35 is high dependency and above 35 is very high dependency.

1.8.5 Measurement of service user experience

Qualitative methods

Qualitative data collection methods have the advantage of providing service users with a mechanism which to describe their experiences in detail. Also, it has been suggested that service users are often more critical of services

when they are interviewed (Powell et al., 2004; Williams et al., 1998). The most common forms of qualitative research methods include: open-ended questions on questionnaires, depth interviews, semi-structured interviews, and focus groups (see section 1.6.4).

Some authors have highlighted difficulties in eliciting information from young people and suggested ways of overcoming these (Claveirole, 2004; Coyne, 1998). For example, Coyne (1998) found it helpful during the interview to engage in active listening and to be aware of non-verbal communication, and to use a tape-recorder in order to avoid long pauses and maintain eye-contact. Young people may be reluctant to criticise services if they are being interviewed by mental health staff, and may believe that access to services will be denied if they are too critical. Powell and colleagues (2004) suggest that the use of service users as interviewers may reduce this problem.

Quantitative methods

The Child and Adolescent Mental Health Services Satisfaction Scale (CAMHSSS) (Ayton et al., 2007) is the only scale that is designed specifically for the CAMHS inpatient population.

The CAMHSSS is a satisfaction scale with versions for rating by young people and by parents/carers. It was developed from the well validated Verona Service Satisfaction Scale (VSSS) (Ruggeri & Dall'Agnola, 1993). The VSSS provides a total score and sub-scores based on seven dimensions. These dimensions are retained in the CAMHSSS:

- 1. overall satisfaction
- 2. professionals' skills and behaviour
- 3. information
- 4. accessibility of services
- 5. effectiveness of treatment
- 6. relatives' involvement
- 7. types of intervention offered

Questions 1-31 ask the service user to rate their overall feelings about different aspects of the service on a five point likert scale. Questions 32-39 ask the respondent whether they have experience of a particular aspect of the service. If they answer 'yes' they are asked to rate it on a five point likert scale; if they answer 'no', they are asked whether they think having that aspect of service would have been helpful. Questions 40-42 are openended general questions.

There are three versions of the CAMHSSS. The shorter version (CAMHS-20) and the medium version (CAMHS-29) are intended to be used for an outpatient population. The longer version (CAMHS-Unit) is intended to be used for day-patients and inpatients.

Ayton et al. (2007) have examined the psychometric properties of the CAMHSSS. Face validity was tested through focus groups with CAMHS professionals and service users. Internal consistency for the questionnaire and for five of the seven dimensions is high. It is lower for the dimensions relating to accessibility of services and types of intervention offered. This is the same pattern that was found with the VSSS (Ruggeri et al., 2000). Test-retest reliability for questions 1-31 was found to be substantial to moderate. The coefficient was lower for questions 32, 33, 36 and 38. It was though that this was because these questions are not applicable to most participants. The tool was also found to be sensitive enough to differentiate between positive and negative experiences of treatment.

2 Methods

2.1 Overview

In the original protocol COSI-CAPS had four components:

- 1. A survey to describe the characteristics of the units including the ward environment, staffing, facilities and costs.
- 2. A six-month prospective cohort study of all admissions of young people to general adolescent and specialist eating disorder units in England.
- 3. A population-based study of admissions of young people (12 18 yrs inclusive) to inpatient adult psychiatric wards and paediatric wards.
- 4. Young peoples' and parents'/carers' experience of and satisfaction with inpatient care.

Before describing the methods for each component of the study, we first describe the problems encountered in gaining research ethics and governance approval for the study and the impact that this had.

2.2 Ethics and research governance approvals

2.2.1 Original assumptions

COSI-CAPS was designed in early 2003. The proposed methods for COSI-CAPS met the research and governance rules that operated at that time. The methods were modelled on those used in the National Inpatient Child and Adolescent Psychiatry Study which had been undertaken by the same research team. The protocol was based on two assumptions: i. that formal approval from NHS trusts would not be required for services to participate in the study, all we would need was for clinicians in the units to be willing to participate and ii. that individual patient consent would not be required. The latter was assumed because the data would be drawn from information collected as part of the routine clinical process; with the exception of the few young people who would have been interviewed and from whom informed written consent would have been obtained.

2.2.2 The changes to research ethics and governance

The Department of Health implemented new guidelines about research governance procedures in April 2004, the month that work on COSI-CAPS started. One of the changes was that, for all studies that involved patients,

the multi-centre research ethics committee (MREC) would require that each local research ethics committee (LREC) conduct a separate 'site-specific assessment' regarding the capacity of the service to engage in the research. The SSA requires the appointment of a local 'principal investigator' at each site who is held responsible for the service's participation in the research. For COSI-CAPS this problem was compounded because not only had the rules changed but, because we were undertaking the study at a time when trusts were adjusting to the new rules, there was no uniformity between NHS mental health trusts in the new systems that were being introduced.

2.2.3 MREC approval

The research team submitted the protocol to the South West MREC in February 2004 (SWMREC: 04/6/23). The committee deemed that the study would require a site-specific assessment from each participating NHS service and also that written consent would be required from young people participating in the cohort study. The research team appealed against the latter decision which would have made it difficult to undertake the research. It was agreed that, provided no patient identifiers were collected, that data collection could proceed without written consent provided that each young person and parent/carer was given a standard information sheet that described the study and emphasised their right not to participate.

Approval for the main elements of the study was granted in December 2004. Separate ethical approval was granted for the component of the study that involved focus groups (04/MRE06/45).

2.2.4 Impact of the ethics and research governance process

The impact of the MREC decision about patient identifiers

The decision by MREC that no patient identifiers could be collected made it difficult to link the post-discharge data collection with the admission (see 2.6.6 below).

The impact of site-specific assessments

The research team approached 66 research governance committees and made 126 separate applications for site-specific assessments. This was because more than one local investigator was required by services where more than one ward was participating in the study. A site-specific assessment involves identifying a local investigator who takes on local responsibility for the research. The local investigator had to complete paperwork and submit their CV to the local research ethics committee. This proved to be a time-consuming and difficult process for both the central research team and local services.

The average time taken by NHS trusts that managed CAMHS units to complete a site-specific assessment was four months. However, some took as long as 12 months. Some of the adult psychiatric and paediatric wards that would be involved in component 3 of the study only occasionally admit

a young person with mental health problems and it was likely that many would admit no patients who met study criteria during the recruitment period. For all of these wards, it is certain that the time required by clinical staff to undertake the site-specific assessment process would far exceed the time required for data collection. For this reason, the research team was unable to persuade clinicians in 70 of the 90 adult psychiatric and paediatric wards to participate and the research team was forced to abandon this component of the study.

Impact of local research governance and ethics process

Local services were introducing the required new procedures at the time that the project team was seeking approval. This was one of the reasons why it proved very difficult to obtain formal research governance approval from the 66 NHS trusts that manage CAMHS, adult psychiatric or paediatric wards that we wished to recruit into the study. Some trusts did not have a research and development department and the research team was directed to either the audit, clinical governance, or medical director's office. The research team had to make an average of six phone calls to each trust. Procedures for considering applications varied from trust to trust. Many had not adopted the COREC part D form, which had been designed to standardise the application process across trusts and had instead developed their own documents and process.

Although we would never have contact with patients participating in the cohort study, 31 trusts required the main research worker to apply for an honorary contract. As part of this, some trusts insisted on completion of an occupational health questionnaire and on undertaking their own criminal records bureau check (even though the research worker had already been cleared).

Despite MREC having approved the protocol, some trusts insisted on local academic review or required separate LREC approval.

The research team had to make an average of six phone calls to each trust and the research team submitted more than 7,000 pages of information to national and local committees to obtain national and local approval for the study. This delayed the study by 12 months and required the team to apply to NHS SDO for a one year extension.

We attach a paper that describes our experience with obtaining ethics and research governance approval for this and two other studies as appendix 3.

2.3 Study advisory group

The research team (Simon Tulloch, Debbie Banister, Anne O'Herlihy, Paul Lelliott and Jeni Beecham) was supported by a study advisory group that comprised psychiatrists (Jonathan Green, Patrick Byrne, Sube Banerjee and Agnes Ayton), a clinical psychologist (Paul Abeles), a social worker (Duncan Riley), an occupational therapist (Sharon Absolom) and two nurse consultants (Angela Sergeant & Tim McDougall). The advisory group met

six-monthly throughout the study. Advisory group members were reimbursed for travel and other expenses associated with attendance at the meetings.

Initial advisory group meetings focused almost exclusively on ethical and research governance issues. We therefore sought input from young people independently and for specific issues. In particular, we held focus groups with service users (SU), and parents/carers of SUs to support the development of the semi-structured interview schedule required for component 4 (see section 2.8.1).

2.4 Recruitment of units into the study

The CRTU maintains a directory of CAMHS inpatient units which is updated annually (www.rcpsych.ac.uk/crtu/centreforqualityimprovement/qnic.aspx). The directory includes both NHS and independent sector units. The research team wrote to all eligible units in 2004 to invite them to participate. When necessary, and if requested, a member of the research team visited units to describe the aims of the study and to discuss what participation would involve. Strenuous efforts were made to recruit all eligible specialist eating disorder units and adolescent units managed by the independent sector to ensure that numbers were sufficient for comparisons between the unit types. Patients with an eating disorder form the largest single diagnostic group of inpatients and were the focus of our second set of hypotheses. It was essential, therefore, to ensure that all seven eligible eating disorder units were included.

2.5 Component 1: description of the units

2.5.1 Design

A questionnaire postal survey of inpatient CAMHS units. Data items included basic descriptive and financial data, as well as detailed information regarding the staff compliment. This component would collect data required to test hypotheses 2.3 (that, for those admitted for the treatment of an eating disorder, there is no difference in the total cost of care for those admitted to a specialist vs a general unit) and 3.1 (that the qualities of the physical, social and therapeutic environment that young people value are no better provided by CAMH inpatient units than by adult psychiatric units or paediatric wards).

2.5.2 The data

The main questionnaire for this component of the study was based on that used in the NICAPS study (O'Herlihy et al., 2001) with changes

recommended by the advisory group. The questionnaire (which is given in full as appendix 6) enquired about:

- The ward environment and facilities
- The staffing of the unit
- Procedures relating to access, admission and discharge
- Educational facilities available to the young people
- Financial information

We also collected data about treatment climate and ward atmosphere using:

- The Ward Atmosphere Measure (WAM)
- The Ward Atmosphere Scale (WAS)
- The CAMHS Assessment of Inpatient Dependency (CAMHS-AID) (see 1.8.4)

2.5.3 Data collection

Ward managers/senior staff in participating services were asked to complete the questionnaire. In cases where inpatient staff did not have access to financial data, the research team liaised directly with the finance department of the organisation that provided the unit.

2.5.4 Data management and analysis

The data were analysed using SPSS version 14.

We used graphs, tabulations and simple descriptive statistics to describe the units and to compare and contrast the characteristics of units managed by the NHS and independent sector and of general adolescent units and specialist eating disorder units. When appropriate, Chi-square, t-test and the Mann Whitney U test were used to examine the statistical significance of differences. Ward atmosphere data were analysed using the same criteria.

2.5.5 Estimating costs per day in inpatient wards

The Unit Questionnaire included a 'nested' approach to estimating the costs of the inpatient units in which the data requested represented a balance drawn between the likelihood of the wards having information easily available and their willingness to provide it, and obtaining sufficient data to estimate accurate costs per day. The approach was similar to that used in the NICAP Study (Beecham et al, 2002).

The ideal set of information for each unit to provide was their staffing profile, the previous month's expenditure on all inpatient unit staff (nurses, doctors, psychologists, therapists and other personnel), the number of teachers working in the unit's school, the annual revenue overheads (clinical support, utilities, services etc), agency overheads (personnel, finance

department, etc), and capital charges. For units that did not meet this ideal, we used a range of methods to supplement the data. These are described more fully below (see section 3.4).

2.6 Component 2: study of admissions

2.6.1 Design

A prospective cohort study of young people admitted to CAMHS inpatient general adolescent units and specialist eating disorder units in England over a six-month period. Data were collected at three time points – admission, discharge and six months post-discharge. This component would collect data required to test hypotheses 1.1 (that, after allowing for differences in casemix, there are no differences in clinical and social outcomes or cost of care for patients treated in NHS vs independent sector units), 2.1 (that for those admitted for the treatment of an eating disorder, after allowing for any differences at admission, clinical and social outcomes are no better for those admitted to a specialist vs a general unit) and 2.3 (that, for those admitted for the treatment of an eating disorder, there is no difference in the total cost of care for those admitted to a specialist vs a general unit).

2.6.2 The cohort of young people

All young people, aged between 12 and 18 years, who were admitted to an eligible unit between 17th October 2005 and 16th April 2006 were included in the study.

2.6.3 Information and consent

The research team provided staff on participating units with a study information sheet (appendix 7) which they were asked to give to each young person, and parent/carer of a young person, admitted during the study recruitment period.

2.6.4 The data collection tools (DCT)

The data items were brought together into two data collection tools, one for the collection of information at both admission and discharge by ward staff and one for collection of information post-discharge by a CAMHS worker in a community service. Table 2.1 lists the information to be collected at each time-point. The assessment instruments included have been described in section 1.8.

Table 2.1 Information collected for each admission

Admission	Patient demographic information (no identifiers collected)
	Dates of referral, assessment, admission

Source of referral

Residency status

Involvement with other agencies

Consent to admission

Mental Health Act / Children Act Status

ICD 10 diagnosis (provisional)

HoNOSCA: a clinician-rated broad measure comprising 13 items, each rated on a five-point severity scale (0-4), that address problems commonly experienced by young people with a mental disorder. Two additional items assess parental understanding of the young person's difficulties and available services.

CGAS: a clinician-rated global measure of impairment. A rating is made by selecting the appropriate descriptive level on a hypothetical continuum of health to illness that ranges from 1 to 100. The lowest rating (1-10) indicates that the young person is severely ill, the highest rating (91-100) indicates superior functioning.

Paddington Complexity Scale: assesses the case complexity at presentation in a standardised way. Scores in four problem areas are summed to derive one total score and two main sub-scores: clinical and environmental.

CAMHS-AID: a clinician-rated measure of patient dependency. The items are organised into four different 'modules' and each item is rated on 0 (fully independent) to 4 (requires intensive input) scale which usually reflects the different amounts of nursing input required to manage the patient.

Morgan-Russell Assessment Scale (for those with eating disorder): a clinician-rated measure of severity based on the previous six-months. The instrument is a structured interview comprising 14 items in five sub-scales. These cover: physical status; menstruation; mental state; sexual adjustment and socioeconomic status. Each item is rated using a Likert scale which ranges from 0-12. The lower score represents more severe anorexia.

Body Mass Index (for those with an eating disorder)

Discharge

Date of discharge

Mental Health Act / Children Act Status

ICD 10 diagnosis (final)

Treatment received

Paddington Complexity Scale

	HoNOSCA				
	CGAS				
	CAMHS-AID				
	Morgan-Russell Assessment Scale (for those with eating disorder)				
	Body Mass Index (for those with an eating disorder)				
	Destination following discharge				
Six-months	Patient demographic information (no identifiers collected)				
post discharge	Contact with services (over previous 6-months)				
	Current accommodation				
	Involvement with other agencies				
	ICD 10 diagnosis				
	Paddington Complexity Scale, HoNOSCA, CGAS				

2.6.5 Procedure for collecting data at admission and discharge

At admission and discharge, the DCT was completed by the healthcare worker on the unit who knew the young person best. Members of the research team were in frequent contact with units to ascertain the total number of admissions during the recruitment period, to check on completeness of data returns. The research team visited those units that were having difficulty in completing the DCTs to support and assist. The members of the research team had no face to face contact with patients during these visits. Vignettes were made available for all services participating in the COSI-CAPS study to assist in the rating of the CGAS (see section 1.8.1).

2.6.6 Procedure for collecting data post-discharge

The research team asked inpatient units to provide contact details of the services providing care to the young person after he/she had been discharged. This service was often managed by a different agency to the inpatient unit and might be in a different and distant part of the country. The team contacted this service by fax and then by telephone with the intention of identifying the healthcare professional with lead responsibility for the young person's care six months following discharge. This person was sent an introductory letter, an information sheet and instructions on how to proceed with data collection.

It often proved difficult to set up this contact because the research team did not know the name of the young person nor did they have any personal identifying information. The research team attempted to set up a dialogue between the community service and the inpatient unit so that the latter

could communicate the identity of the patient to the former. Once the identity of the young person had been established, the community clinician completed the DCT either: i. in paper form and posted this back or ii. in electronic version and emailed it back or iii. by phone, with the research worker talking the clinician through the questions.

2.6.7 Data management and analysis

The data were analysed using SPSS version 14.

We used graphs, tabulations and simple descriptive statistics to describe the characteristics of the study sample and to compare and contrast the characteristics of young people admitted to NHS or independent sector units and of young people with an eating disorder admitted to a general adolescent unit or to a specialist eating disorder unit. When appropriate, Chi-squares and t-tests were used to examine the statistical significance of differences.

We summarised outcomes as determined by change scores in the various clinical measures and using descriptive statistics and compared outcomes and lengths of stay for the two main comparisons, NHS vs independent sector and general adolescent unit vs specialist eating disorders unit, using t-tests and the Mann Whitney U test.

We used multiple regression analysis to examine significant predictors of change in HoNOSCA scores between admission and discharge. The model included type of unit, severity of illness, diagnosis, number of beds in the ward to which the patient was admitted, Paddington Complexity Scale, the Ward Atmosphere Measure and the Ward Atmosphere Scale and waiting time as predictor variables and the difference between admission and discharge HoNOSCA as outcome variable. For the clinical severity measures, the score at baseline was included in the model as a covariate. A similar analysis was undertaken with the same predictor variables and with change in CGAS scores as the outcome variable. All the analyses were carried out by assuming the missing values as missing completely at random (MCAR).

We examined potential predictors of length of stay using a generalised linear model with negative binomial family and log link with length of stay as the outcome variable and type of unit, diagnosis, severity of illness, WAM, WAS, number of beds, total score on the Paddington Complexity Scale, HoNOSCA and CGAS on admission as predictor variables. We explored the degree of collinearity and none of the variables were collinear.

2.7 Component 3: population based study of admissions to non-CAMHS wards

This component was abandoned. This aspect of the study would have collected data required to test hypothesis 1.2 (that after allowing for differences in casemix, there are no differences in clinical and social outcomes or cost of care for young people admitted to adult psychiatric wards or paediatric wards vs adolescent units).

Three strategies were applied one after the other, in an attempt to overcome the reluctance of adult wards and paediatric wards to participate. Their main reluctance was due to the perceived burden of the research ethics requirement and in particular that of the need for a site-specific assessment. We had hoped that by reducing the burden of data collection to a minimum we might encourage wards to make the effort required to participate.

First, we adopted the approach used to collect data in CAMHS units. The research team wrote to all eligible units and, when necessary, visited to describe the aims of the study and to discuss what participation would involve. However, unlike with the inpatient CAMHS units, the research team had no prior relationship with the adult or paediatric wards. The research team offered to visit the wards concerned – a procedure that proved inefficient in that it required a lot of time but yielded a poor response.

Second, we modified the data collection tools to record basic data items only and in a summary or aggregated form that would allow for retrospective as well as prospective data collection. We asked the wards to provide the total number of admissions during the six-month period, basic demographic information and diagnosis and a simple severity measure. Each adult and paediatric ward were sent simple instructions regarding data collection. This yielded some data from approximately 10% of wards.

For our final attempt, we contacted the Trusts' 'Information Governance' teams and requested basic data items on all admissions. The research team contacted the Trusts by email, providing introductory letters and information sheets. These documents included details of ethical and research governance approval. The data requested concerned the total number of admissions of young people fulfilling the inclusion criteria during the study period. Two trusts provided data in response to this approach.

Feedback from Trusts in response to these approaches focussed on ethical or governance issues. In particular, adult services commented on the infrequency of admissions of young people fulfilling our inclusion criteria and therefore of the disproportionate burden of the site specific assessment.

2.8 Component 4: young peoples' and parents experiences of and satisfaction with inpatient CAMHS care

2.8.1 Design

Experiences of care data were collected from young people and parents using two approaches, interviews, guided by a semi-structured interview schedule (appendices 8 & 9), and the Child and Adolescent Mental Health Services Satisfaction Scale (CAMHSSS) (see section 1.8.5). This component would collect data required to test hypothesis 2.2 (that, for those admitted for the treatment of an eating disorder, young people and their families are

no more satisfied with the care provided by specialist units than with care provided by general units).

2.8.2 Development of the semi-structured interview schedule

The development of the schedule (appendices 8 & 9) was informed by two focus groups held at CAMHS inpatient units, one involving young people and the other parents. The areas of discussion by the focus group were informed by the literature review (see chapter 1.7.5) and by themes that had emerged from the interviews with young people undertaken by the team that manages the Quality Network for Inpatient CAMHS (QNIC). Both focus groups were facilitated by two non-clinical members of the research team and both were held at the same NHS eating disorder unit. All participants were provided with an information sheet and gave written consent to participate.

The focus group involving patients was initiated by the head of 'patient and carer involvement' at the unit. Nine young people participated. Seven participants were recruited to the parent focus group through a parents group at an inpatient unit which was attended by members of the research team.

The focus group for parents was recorded using a tape-recorder. Handwritten notes were made to record points of discussion at the patient focus group because this was considered less intimidating than a tape recorder. The transcripts were used to modify the material derived from the review of the literature and the interviews conducted as part of QNIC. The final semi-structured interview schedule contained a series of open questions covering participants' experiences of access, admission, care and treatment, and discharge from inpatient CAMHS.

2.8.3 Sampling and recruitment

Convenience sampling was used. We asked unit staff to identify young people or parents/carers who they thought might be willing to participate in this aspect of the study and who were nearing the end of an inpatient stay. This increased the chances of recruiting participants who could comment on all stages of an inpatient stay e.g. admission, treatment and discharge planning. The young people and parents/ carers recruited to this component of the study were not necessarily part of the COSI-CAPS study. To reduce the burden, participating inpatient units were asked to focus on either young people or parents/carers. This meant that we did not interview young people and parent/carer dyads and so did not obtain different perspectives of the same inpatient experiences. Individuals were recruited from the four different types of unit being studied: NHS units and independently funded units, and eating disorder patients from general adolescent units and eating disorder units.

The research team asked the staff member with whom the young person had had most contact to send the young person an introductory letter, an information sheets, a consent form and a service satisfaction scale. We recruited participants to the parent/carer interviews in the same way.

2.8.4 Data collection

Prior to attending the interviews, participants were asked to complete the CAMHS Service Satisfaction Scale (CAMHSSS; Ayton et al., 2007). Interviews with young people were conducted at the adolescent units. Interviews with parents were conducted either by telephone, at their home, at the inpatient unit, or at some other place of their choosing. All but one of the interviews were conducted by a female non-clinical researcher. Prior to the interview, participants were reminded of the purpose of study, their right to withdraw from the interview or to decline to answer specific questions. In addition, issues regarding confidentiality, and how and when they could access the final report were discussed. All interviews were conducted individually and lasted approximately 40 minutes.

Interviewees' responses were recorded on the schedule by hand.

2.8.5 Data management and analysis

Data from the CAMHSSS were entered directly into SPSS 14. The text derived from the interview transcripts was entered and managed on QSR NVIVO7 and subjected to a thematic analysis. The responses to each category of questions (access, admission, care and treatment and discharge) were analysed separately. Two researchers coded the data independently. They then met to discuss discrepancies.

3 RESULTS

3.1 The completeness of the data for units and patients

3.1.1 The cohort of units and overall rates of data return

Forty-two of the 55 eligible general adolescent units (GAU) and eating disorders units (EDU) in England (76%) agreed to participate in the study. Appendix 1 lists these units and for each gives the managing agency (NHS or independent sector) and the age range of young people admitted. Table 3.1 compares, by type and managing agency, the cohort of 42 units that participated with the national total. As can be seen, 82% of all NHS units (30 of 39) and 75% of all independent units (12 of 16) agreed to take part. In terms of main function this is 75% of all general adolescent units (30 of 48) and six of the seven specialist eating disorders units.

Table 3.1 also shows the proportion of participating units that made any returns for the various types of data collection (patient-level data, unit-level data, ward atmosphere data and cost data). In summary:

- i. a high proportion of all participating units returned some patient-level data (95%);
- ii. fewer participating units returned unit-level data and information about costs (74% and 55% respectively);
- iii. compared with NHS units, independent sector units were less likely to return both unit-level data (25 of 30 83% vs 6 of 12 50%) and information about costs (18 of 30 60% vs 5 of 12 42%). The difference in rate of return for unit-level data between NHS and independent units is significant (z=2.22, p=0.03).

Table 3.1 CAMHS units that participated in COSI-CAPS

	gible ur nd (n=5		The 42 units that agreed to participate and number (and %) that returned any data						
Sector No.		No.	No.	o. Patient-level Unit-level Ward Atmosphere Co					
GAU	NHS	37	28	27	23	25/18	17		
	Ind	11	8	7	2	3/2	2		

NHS EDU		2	2	2	2	2/2	1
	Ind	5	4	4	4	4/3	3
Total		55	42	40 (91%)	31 (74%)	34/25 (81%/60%)	23 (55%)

¹ More details regarding cost data are available in section 3.4

3.1.2 Completeness of patient data

During the six months of recruitment into the study, 542 young people were admitted to the 40 units that returned any patient-level data. Staff returned data collection tools at admission and discharge for 403 (74%) of these young people. We received follow-up data, six months post-discharge, for 105 young people (26% of the admitted cohort). Table 3.2 gives a more detailed breakdown of the overall completeness of returns for patient-level data.

Table 3.2 Overall completeness of data returns at the three time-points

Unit type		Total number of admissions	Any data at admission & discharge	Any data at 6 months post-discharge
GAU	NHS	361	257 (71%)	68 (26%)
	Ind	123	100 (81%)	19 (19%)
EDU	NHS	26	17 (65%)	9 (53%)
	Ind	32	29 (91%)	9 (31%)
Total		542	403 (74%)	105 (26%)

Table 3.3 shows the number of patients for whom staff made ratings on the three measures of clinical severity (HoNOSCA, CGAS and the severity item of the Paddington Complexity Scale). The low rate of return of CGAS scores for patients admitted to independent GAUs (33%) was largely accounted for by a single unit not wishing to use this measure. The unit has a large number of emergency admissions. The HoNOSCA data indicate that these young people are severely ill at admission.

Table 3.3 Completeness of clinical severity data collection at admission for the 403 young people for whom any patient-level data were returned

Unit type		Any patient Any clinical severity rating		HoNOSCA	CGAS	PCS severity item	
GAU	NHS	257	246	202	234	257	
	Ind	100	87	84	33	87	
EDU	NHS 17		16	14	16	17	
	Ind	29	29	29	23	29	
Total		403	378 (94%)	329 (87%)	306 (81%)	390 (97%)	

In addition to the clinical severity measures described above, units were asked to complete M-RAS and measure body mass index (BMI) for all young people with an eating disorder. Table 3.4 shows the completeness of returns for these data.

Table 3.4 Completeness of M-RAS and BMI data collection at admission for the young people for whom any patient-level data were returned

Unit type		Any patient data	M-RAS	вмі
GAU	NHS	55	45	49
	Ind	7	5	2
EDU	NHS	17	15	14
	Ind	29	21	26
Total		108	86 (80%)	91 (84%)

3.1.3 Implications for the data analysis

- We could not make detailed comparisons between staffing levels of different unit types because of low rates of return from independent sector units.
- Because of the high proportion of CGAS ratings missing for young people admitted to the independent sector, we did not include CGAS in comparisons between the NHS and the independent sector.
- 3. We undertook very limited analysis of post-discharge status because of the high proportion of data that are missing.
- 4. The adjustments to the analysis of the cost data are described in section 3.4.

3.2 Characteristics of the units

3.2.1 Availability of beds and unit admission practices

Access

Twenty-eight of the 31 units that returned unit-level data (90%) are open seven days a week. The three units that are open for five days a week are all NHS funded GAUs.

Fifteen of the 31 units (48%) report that they will admit young people in emergencies. This was true for 14 of the 26 GAUs and one of the six EDUs.

Age range

Appendix 1 lists the range of ages of young people eligible for admission to each of the units. The median is 12 years for the lower end of the range (38% of units) and 18 years for the upper (77% of units). At the extremes, two independent sector EDUs would admit young people between the ages of 8 and 18 and one independent sector EDU would admit young people between the ages of 13 and 25. Two other services, both NHS GAUs, will admit people older than 18 yrs (19 and 23).

Criteria for excluding young people from admission

Table 3.5 shows, in descending order of frequency, the number of units that applied certain criteria for excluding young people from admission. The only criterion that differentiated NHS and independent sector units was that a higher proportion of NHS units were unwilling to admit young people who lived outside of a defined catchment (10 of 23 NHS units apply this criterion compared with none of the six independent sector units).

Table 3.5 Exclusion criteria for admission

	Number of units that apply the crite				
Exclusion criterion	NHS	IND	Total		
	(n=25)	(n=6)	(n=31)		
Young person's age is outside unit's age range	23	6	29		
Unit unable to contain risk to others	22	4	26		
No available beds	22	3	25		
Unit unable to contain risk to self	18	3	21		
Young person or their relative(s) refused	17	3	20		
Young person has no evidence of mental disorder	17	3	20		
Young person's needs exceed staff capability	13	2	15		
Young person has severe problems with alcohol/substance misuse	11	3	14		
Young person is incompatible with current patient group	12	2	14		
Young person lives outside units catchment area	10	0	10		
Young person has a learning disability	4	2	6		

Day- and out-patient treatment

Twenty-three of the 31 units (74%) sometimes admit day-patients; 20 of these units are managed by the NHS (GAU n=18; EDU n=2). Sixteen of the units that admit day patients do so as a planned and funded activity. Seven units only admit day patients rarely, as an ad-hoc arrangement or they close a bed when a day patient is admitted because of staffing levels. A mean of four day patients (sd=3.5; range 0-16) attend these units at any one time.

An out-patient service is provided by 12 units, all of which also provide a day care service. All units that provide out-patient care are managed by the NHS and 11 are GAUs.

3.2.2 Physical environment, activities and contact with other services

Bed numbers

The 31 units which returned unit-level data provide a total of 391 beds. As Table 3.6 shows, the mean size of unit is 12.6 beds (median 12 beds, range 4-32 beds). Fifty-nine percent of beds (n=230) are located in single bedrooms and 41% of beds (n=161) in bedrooms that sleep two or more people. NHS units have a lower mean number of beds (m=10.9, sd=3.5) than do independent units (m=19.7, sd=7.3; t=-2.9, df=5.6, p<.05). One independent sector EDU with 32 beds has skewed the mean for bed numbers for independent sector units. Because the variances for the two groups were significantly unequal (F=6.7, p<.05), a t-test for unequal variances was used.

Table 3.6 Mean number of beds and their configuration

			Total numbe	Total number of beds (%) located in:				
Unit Type		Total beds	Single Bedrooms bedrooms with 2 beds		Bedrooms with >2 beds	number of beds (sd)		
GAU	NHS (n=23)	253	158 (62)	42 (17)	53 (21)	11 (3.7)		
	Ind (n=2)	35	35 (100)	0	0	17.5 (5.0)		
EDU	NHS (n=2)	20	12 (60)	2 (10)	6 (30)	10 (0.0)		
	Ind (n=4)	83	25 (30)	40 (48)	18 (22)	20.8 (8.7)		
Total (n=31)		391	230 (59%)	84 (21%)	77 (20%)	12.6 (5.6)		

Specialised rooms

Table 3.7 shows the number of units that have at least one of a range of specialised rooms for specific uses. Only three services, all NHS GAUs, provide rooms for family or friends to stay overnight. The units had a mean of 1.9 interview/therapy rooms (range 0 - 5 per unit), 1.7 recreational room (range 0 - 5) and 1.8 activity spaces (range 0 - 4). All but one unit has access to outdoor recreational space

Table 3.7 The number of units with at least one of a range of specialized rooms

Unit Type		Recrea- tional rooms	Quiet rooms	Over- night rooms	Inter- view/ therapy rooms	Video/ 1-way screen rooms	Activity spaces	Kitchen for young people
GAU	NHS (n=23)	22	16	3	20	17	22	14
	Ind (n=2)	2	2	0	2	1	2	1
EDU	NHS (n=2)	2	1	0	1	1	2	2
	Ind (n=4)	4	3	0	4	2	4	0
Total	(n=31)	30	22	3	27	21	30	17

Off-site activities

For all units (n=31) young people have access to local facilities and amenities (e.g. shopping trips, cinema) and 24 units (77%) have the use of a minibus. On average the in-patient units organised eight off-site activities over the preceding month. The number of off-unit activities varies greatly between units (range 0 - 32).

Contact with external services

Units rated the quality of their relationship with a range of external services on a scale of 0 (no contact or access) to 3 (excellent access and responsiveness). Table 3.8 shows in descending order the mean ratings by unit type.

Table 3.8 Ratings of quality of relationships with external services

	GAU	_	EDU		
External Service	NHS (n=23)	Ind (n=2)	NHS (n=2)	Ind (n=4)	Total (n=31)
CAMHS community services	2.2	2.0	2.5	2.0	2.2
Educational services	2.3	2.0	2.0	2.0	2.2
Laboratory services	2.0	2.5	2.5	2.0	2.1

Paediatrics	1.6	1.0	2.0	1.3	1.6
Social work/social services	1.5	2.0	1.0	1.7	1.5
General practitioners	1.2	1.5	1.5	1.7	1.3
Youth offending teams/courts	1.0	1.5	1.0	0.7	1.0
Learning disability services	1.1	0.5	0.0	0.7	1.0

Educational provision

Twenty-nine units provided information about their educational provision. All provide some form of facility for the appropriate educational level ('key-stage') of young people resident in the unit. Twenty-one units (72%) describe their provision as 'within the unit' and eight (28%) as 'outside the unit but on the hospital site'. Day patients share the educational facilities in fifteen units. Pupils are typically taught in 'mixed-ability' groups (n=25, 86%) but with consideration of pupils' emotional and behavioural needs (n=24, 83%). Eighteen (62%) units also provide one-to-one teaching. In twenty seven (93%) units, teachers contribute towards policy making. Table 3.9 shows the mean number of teaching staff, expressed as whole time equivalents (wte), providing input to units. The ratio of pupils per teacher in NHS units (mean 4.8, sd=2.6) is significantly lower (t=-2.6, df=24, p<.05) than that of independently managed units (mean 8.7, sd=4.7).

Table 3.9 Educational staff input based on unit type

Unit Type		Teachers (wte)	Teaching Assistants (wte)	Total (wte)
GAU	NHS (n=21)	2.2 (1.3)	0.8 (0.7)	2.9 (1.7)
	Ind (n=2)	1.3 (1.1)	0.5 (0.7)	1.8 (0.4)
EDU	NHS (n=2)	1.3 (0.4)	1.0 (-)	2.3 (0.4)
	Ind (n=4)	3.5 (0.7)	-	3.5 (0.7)
Total (n=29)		2.2 (1.3)	0.7 (0.7)	2.8 (1.6)

3.2.3 Staffing of units

Twenty-eight units returned detailed information about staffing. These were 21 NHS GAUs, 2 independent GAUs, 1 NHS EDUs and 4 independent EDUs. There were too few returns to make meaningful, detailed comparisons between the four types of unit.

Overall staffing numbers and the multi-disciplinary team

Between them, the 28 units employ 696 staff (a mean of 25 per unit; range 6 - 38). Table 3.10 shows the staffing establishment of all the units (expressed as wte posts) in descending order of number. Nurses are by far the most numerous group (67% of the total).

Table 3.10 Staffing numbers by staff type for 28 IP CAMHS units

Staff group	Total number wte employed by all units	Number of units with at least some input	Mean number wte per unit (sd; range) ²
Nurses	468.5	27 ¹	17.4 (6.6; 2.0-31.0)
Secretary/Administrator	44.6	23	1.9 (1.1; 0.8-5.6)
Consultant psychiatrists	33.9	28	1.2 (0.6; 0.5-3.1)
Clinical Psychologists	21.3	24	0.9 (0.4; 0.1-2.0)
Occupational Therapists	20.1	20	1.1 (0.9; 0.4-4.5)
Specialist Registrars	18.1	20	0.9 (0.3; 0.4-1.5)
Senior House Officers	15.3	15	1.0 (0.5; 0.3-2.6)
Social Workers	14.2	20	0.7 (0.3; 0.1-1.0)
Family Therapists	13.7	16	0.9 (0.4; 0.1-2.0)
Other	13.4	11	1.2 (0.9; 0.3-3.0)
Unit Managers	12.6	14	0.9 (0.3; 0.2-1.0)
Assistant Psychologists	9.5	7	1.4 (1.0; 0.5-3.0)
Music/Art Therapists	4.7	10	0.5 (0.4; 0.1-1.0)
Child Psychotherapists	3.1	6	0.5 (0.3; 0.2-1.0)
Dieticians	1.7	6	0.3 (0.1; 0.1-0.5)
Advocates	1.3	4	0.3 (0.5; 0.1-1.0)

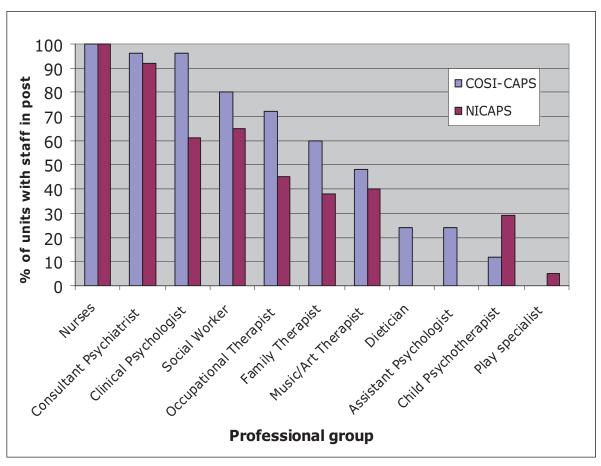
¹ One unit provided no information about nursing

² This column reports means (including sd and range) only for units that employ the category of staff concerned

The only unit that does not employ at least one consultant psychiatrist in a substantive capacity has a locum in post. Less than one-half of units employ a music or art therapist, a child psychotherapists or a dietician. In addition to the six units that directly employ a dietician, two other services have service level agreements with the trust that a dietician can be accessed if required. One EDU reported no direct or indirect input from a dietician.

Figure 3.1 compares the staffing of the 28 units that returned unit-level data in 2006 through their participation in COSI-CAPS with the 62 units that participated in the NICAP Study and returned data in 1999. Although NICAPS included data from child and adolescent in-patient services in England and Wales, there is considerable overlap in the units involved in both studies.

Figure 3.1 Comparison of staffing between COSI-CAPS units (n=28 – England only) and NICAPS child and adolescent units (n=62 – England and Wales)

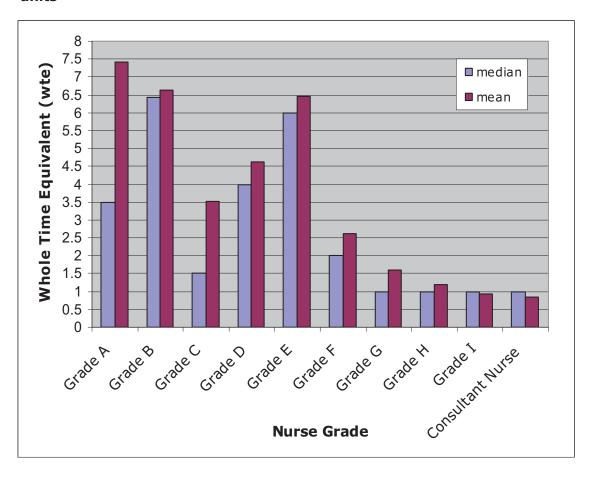


Note: This figure describes only staff in post working on the inpatient unit and not those on establishment.

Nursing

Figure 3.2 shows the distribution of nurses by grade (pre-Agenda for Change) for all 27 units that returned data about nursing levels. Although the total mean number of wte nursing staff employed is similar in NHS and independent sector units (16.4, sd=5.9 vs 20.5, sd=8.4), independent sector units employ a higher proportion of lower grade nursing staff compared to NHS units. In total, 20 units employ grade A nurses. Independent sector units (n=4) employ a mean of 10.9 Grade A nurses compared with NHS units (n=16) which employ a mean of 0.9 Grade A nurses. Although the difference does not reach statistical significance (t=2.6, df=3.1, two-tailed p=0.08) the data are indicative of a difference between the unit types.

Figure 3.2 Distribution of nursing grades (median and mean) across all units



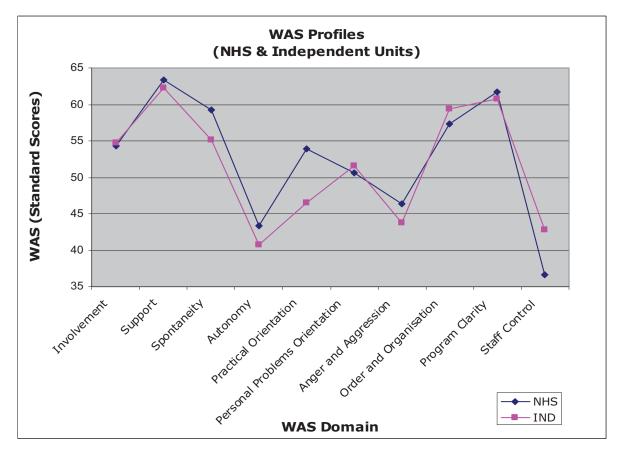
3.3 Ward Atmosphere

3.3.1 Ward Atmosphere Scale (WAS)

A total of 595 staff in 35 units (25 NHS GAUs, 4 independent GAUs, 2 NHS EDUs, 4 independent EDUs) completed the staff rated Ward Atmosphere Scale (WAS).

The only difference for the 10 WAS sub-scales that is significant (figure 3.3) is that the mean rating of the practical orientation sub-scale is higher for NHS than for independent units (m=55, sd=9.9 vs m=44; sd=11.1; t=2.7, df=33, p<0.05). There is also a trend for NHS units to score more highly on the spontaneity sub-scale (m=60, sd=6.9 vs m=54; sd=5.7; t=1.9, df=27, p<.1) and total WAS scores (m=53, sd=3.9; vs m=50, sd=4.7, p<.1).

Figure 3.3 Comparison of WAS profiles between NHS units (n=27) and independent units (n=8)



Compared with staff on GAUs, staff on EDUs rate their wards lower on the spontaneity sub-scale (m=60, sd=6.6 vs m=52, sd=4.7; t=2.7, df=32, p<.05) (figure 3.4 below).

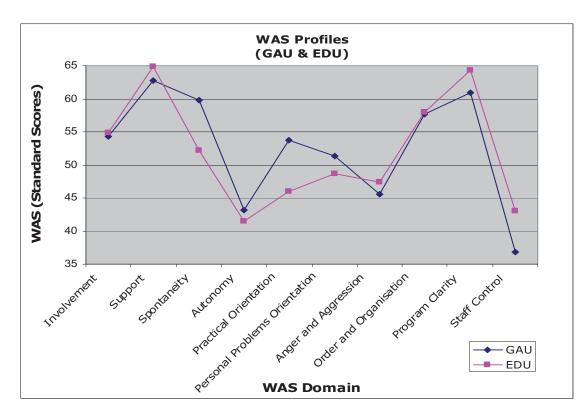


Figure 3.4 Comparison of WAS profiles between GAUs (n=29) and EDUs (n=6)

3.3.2 Ward Atmosphere Measure (WAM)

Twenty-five units (18 NHS GAUs, 2 independent GAUs, 2 NHS EDUs, 3 independent EDUs) completed weekly WAM ratings over an average of 25 weeks. There is no difference in mean WAM scores between GAUs and EDUs (m=46.2, sd=7.5 vs m=46.1, sd=8.7). The mean WAM ratings by staff working in NHS units are significantly higher than those by staff working in independent units (m=46.1, sd=3.9 vs m=41.4, sd=0.9; t=4.3, df=6.6, p<.01).

3.4 Inpatient cost data

3.4.1 Management of the missing costs data

Thirty-one units returned the Unit Questionnaire. Three NHS units could not provide information on their staffing profile. Staff commonly absorb a high proportion of the costs of running a service so without information on the number of full-time-equivalent staff by grade and profession costs per day could not be estimated. One independent sector unit provided staffing details but their associated costs were not estimated because the low return rate of cost-related data from independent sector providers meant there were insufficient data within the sample to use as a basis for estimates.

Twenty-four units provided data on their staffing profile and most of the associated monthly expenditure, with a further three just providing staffing information. Where expenditure data were missing, the within-sample mean for each grade and type of staff was used to estimate staffing expenditure. Annual staff costs were derived by multiplying these monthly staff expenditure figures by twelve. Fifteen units provided information on their annual revenue overheads, and ten on their agency and capital overheads. The proportion of these costs to ward staff costs was estimated and used to interpolate costs for wards not providing data on overhead costs; 15.8% for revenue overheads (such as for clinical support or utilities) and 29.8% for the combined agency and capital overheads (for finance department, buildings, etc). Teacher and teacher assistant salary costs were added using the proportions of teaching staff to pupils as an estimate where data on the numbers of teaching staff were missing. As schools were sited within the hospital, additional local education authority overheads were excluded. All costs are presented at 2005-2006 prices and rounded to the nearest £10 in the tables.

Of the 31 units that returned the Unit Questionnaire a cost per day could be estimated for 27, two of which did not return any patient-level data. Together, these units admitted 63% of the young people for whom patient level data were available. To include more inpatient units we looked at the availability of data in the CAMHS Mapping (www.camhsmapping.org.uk) which covers NHS child and adolescent mental health services. Eight more units that participated in the COSI-CAPS study reported sufficient data on staff, staff and non-staff costs for the unit, and items such as the number of beds. We also selected some units that had returned the COSI-CAPS Unit Questionnaire to ensure the Mapping data generated costs that were within a similar range to those calculated using the COSI-CAPS information. This source generated costs data for a further six units. Teaching and overhead costs were added to the staff and non-staff costs as described above. This meant that we could estimate a cost per day for 31 of the 40 units returning patient-level data, and brought the proportion of young people for whom the inpatient admission costs could potentially be estimated to 79% (n=317).

The total annual cost was estimated for each unit. Where day treatment was also provided, costs were then adjusted according to the balance of day and inpatient places (see section 3.2.1). A cost per day was estimated by dividing this 'total annual inpatient cost' by the number of beds within the unit and the number of days it is open per year.

One of the major causes of missing data on the costs of a young person's inpatient admission relate to the services provided by one independent sector organisation. This organisation admitted 15% of the young people with patient-level data to five different units but did not return any staffing or cost-related data. The four other inpatient units for whom costs per day could not be estimated brought this figure to 21%.

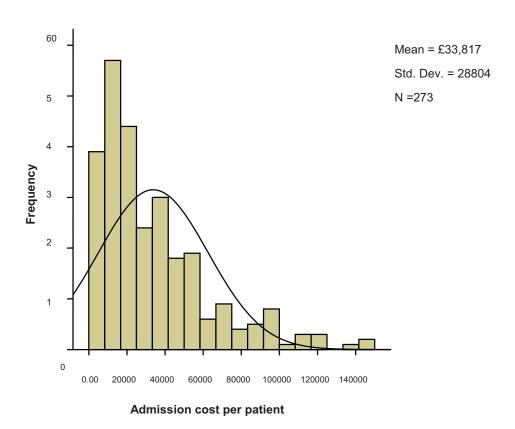
3.4.2 Costs per day and inpatient treatment costs

Costs per day, therefore could be estimated for 31 of the participating units, potentially covering 317 (79%) of the young people for whom some patient-level data were available as they entered an inpatient unit. Weighted for the number of young people in each unit, the mean cost per inpatient day was £356, although there was a six-fold difference between the lowest and highest cost unit; £114 per day for an independent sector provider and £680 per day for a London-based NHS tertiary unit. The median cost per inpatient day was only slightly lower than the mean at £343.

Data on their length of stay in the inpatient ward was available for 273 (86%) of these young people, with a wide variation (1-411 days) around a mean of 97 days (sd 76.4) and a median of 82 days. The cost of the inpatient admissions was calculated by multiplying each child's length of stay by the cost per day for the inpatient unit on which they were resident.

Again, a wide range was found. The minimum cost of admission (for one day's residence) was £341, up to a maximum of £148,567. The mean admission cost across these young people was £33,817 (sd 28,805) and the median was £24,482 suggesting that a few high cost treatment episodes were pulling the mean upwards (see Figure 3.5). Higher cost admissions are most likely to be due to longer admissions (length of stay) although the cost per day for each unit will exert some influence.

Figure 3.5 Admission costs for the full cost sample



Tables 3.11 and 3.12 show the costs of treatment by a range of demographic, social and clinical factors. Females tend to have more costly treatment episodes than males. This is accounted for by the fact that they are more likely to have a diagnosis of eating disorder (67 v. 5 males in the cost sample) which is associated with a longer length of stay in hospital (135 days v. 86). Otherwise none of the characteristics on their own appear to have any association with the costs of inpatient treatment. Eleven young people had been excluded or suspended from school prior to admission but the cost of their inpatient stay was not significantly different from the rest of the sample (n=212). Thirty-five young people had a learning disability or difficulty, but again their mean admission cost was not significantly higher than those without a learning disability (n=232).

Table 3.11 Costs and characteristics for the whole cost sample

Table 3.11 Costs and characteristics for the whole cost sample					
	(n)	Mean treatment cost (sd)	р		
Gender					
Male	92	£29040 (22950)	t=-2.180		
Female	181	£36290 (31180)	p=0.030		
Age					
12 - 15	139	£34310 (30100)			
16 - 18	131	£33430 (27450)	n.s.		
Ethnicity					
White British	214	£33090 (27230)			
Other	52	£36870 (35110)	n.s.		
Accommodation status					
Family home	225	£34520 (29750)			
Other	41	£30520 (24160)	n.s.		
Main carer					
Both natural parents	125	£34410 (30030)			
Other (Single parent, Nat. parent with partner, Relatives, Other)	122	£33740 (28250)	n.s.		
Source of referral					
CAMHS Psychiatrists	195	£36040 (28870)			
Other	43	£39020 (32250)	n.s.		

As table 3.12 shows, those who had received treatment before admission to the unit had higher treatment costs, and perhaps surprisingly, those who were subject to a section of the Mental Health Act were less costly to treat than those not subject to a Mental Health Act section. Neither the total

HoNOSCA nor the CGAS total score at baseline were associated with the costs of inpatient admission.

Table 3.12 Costs and clinical data for the full cost sample

Table 3.12 Costs and clinical data for the full cost sample					
Measures at Admission	(n)	Mean treatment cost (sd)	р		
Diagnosis					
Eating Disorder	72	£39380 (27600)			
Schizophrenia, del. or psychotic.	45	£39450 (34030)			
Mood disorder	50	£30110 (25270)			
Other diagnosis	106	£29400 (28110)			
All diagnoses	273	£33820 (28800)	n.s.		
Receiving treatment prior to admission					
No	78	£22170 (21470)	t=5.003		
Yes	194	£38450 (30140)	p<0.000		
Subject to Children Act					
No	258	£33930 (28840)			
Yes	13	£33390 (29530)	n.s.		
Subject to Mental Health act					
No	204	£38820 (30420)	t=-3.999		
Yes	34	£23520 (18540)	p<0.000		
Severity ¹					
Mild	7	£29590 (31500)			
Moderate	56	£33630 (30580)			
Severe	164	£32540 (26870)			
Extreme	42	£39170 (33820)			
total with data	269	£33730 (28880)	n.s.		
Risk to ¹					
Self	155	£35320 (27020)			
Others	12	£40800 (31510)			
Both	41	£34420 (30420)			
Neither	23	£45160 (36750)			
total with data	237	£36620 (29540)	n.s.		

 $^{^{\}mathrm{1}}$ As rated by the Paddington Complexity Scale

3.4.3 Comparing NHS and independent sector units

This sample includes 53 children and young people admitted to independent sector inpatient units and 220 (81%) admitted to NHS units. The mean admission costs for children and young people staying in NHS units was significantly higher than for those in independent units; £38,030 v. £16,310; t=8.094, p<0.000). Admission costs from the earlier CHYPIE study of eight NHS inpatient units show a slightly lower average admission cost of £36,270 (recalculated by author and up-rated to current prices; Curtis 2007).

Differences in the mean length of stay were in part responsible for the cost difference (101.6 days in NHS units and 78.8 days in independent sector units; t=1.961, p=0.051) but the cost per day, weighted for the number of study children resident in each unit, was also higher for NHS units than for the independent sector units; £385 v. £243 per day (t=8.857, p<0.000). Some care, however, should be taken in interpreting these inter-sectoral comparisons because of the small number of independent units (n=3) that we have been able to include.

3.4.4 The costs of treating eating disorders

In the cost sample there were 72 young people with a diagnosis of eating disorder. The mean admission cost was £39,370 within a range of £341-£122,100. The median admission cost was lower although within a similar range at £37,470. Thirty-eight young people were treated in GAUs and 34 in specialist EDUs. Mean admission costs were significantly higher for patients treated in GAUs than in EDUs (£47,430 v. £30,370; t=2.734, p=0.008). The weighted mean cost per day was also higher at £334 compared to £237 for specialist EDUs (t=4.189, p<0.000), however, nearly half of those in specialist EDUs, 15 young people, were treated in just one independent sector unit.

For this group of patients, admission costs were not significantly associated with the HoNOSCA or CGAS total score at admission, nor with the young people's BMI at admission.

The higher cost of treating young people with an eating disorder, which mainly affects females, accounts for the overall higher cost of inpatient care for females reported in table 3.11.

3.5 Characteristics of the patients at admission

3.5.1 Characteristics of the whole cohort and comparisons between those admitted to an NHS unit and those admitted to an independent unit

Table 3.13 shows the demographic characteristics and source of referral for the 403 young people for whom admission and discharge data were obtained and Table 3.13 shows the clinical features and severity ratings for the same group. The tables also compare those admitted to an NHS unit with those admitted to an independent sector unit. There are no significant differences between those admitted to an NHS unit and those admitted to an independent unit on any of the variables listed in Table 3.13.

Table 3.13 Demographic characteristics of the cohort (n=403) comparing those admitted to an NHS unit with those admitted to an IND sector unit¹

	NHS (%)	IND (%)	Total (%)
Gender			
Male	92 (34)	44 (34)	136 (34)
Female	181 (66)	84 (66)	265 (66)
total with data	273	128	401
Age			
12	9 (3)	3 (2)	12 (3)
13	18 (7)	7 (6)	25 (7)
14	35 (13)	15 (12)	50 (13)
15	78 (30)	29 (24)	107 (28)
16	60 (23)	37 (31)	97 (25)
17	59 (22)	27 (22)	86 (22)
18	4 (2)	3 (2)	7 (2)
total with data	263	121	384
Ethnicity			
White British	214 (79)	99 (86)	313 (81)
Mixed	20 (7)	6 (5)	26 (7)
Asian/Asian British	16 (6)	3 (3)	19 (5)
Black/Black British	17 (6)	5 (4)	22 (6)
Other	4 (1)	2 (2)	6 (2)
total with data	271	115	386
Accommodation status			
Family home	225 (83)	91 (83)	316 (83)

	1	1	
Local authority accomm	11 (4)	7 (6)	18 (5)
Hospital accommodation	24 (9)	9 (8)	33 (9)
Others	12 (4)	3 (3)	15 (4)
total with data	272	110	382
Main carer			
Both natural parents	125 (46)	54 (50)	179 (48)
Single parent	90 (33)	34 (32)	124 (33)
Nat. parent with partner	32 (12)	6 (6)	38 (10)
Relatives	5 (2)	4 (4)	9 (2)
Others	18 (7)	9 (8)	27 (7)
total with data	270	107	377
Source of referral			
CAMHS Psychiatrists	221 (82)	59 (81)	280 (81)
Other CAMHS professional	30 (11)	6 (8)	36 (11)
Others	20 (7)	8 (1)	28 (8)
total with data	271	73	344

¹ Missing cases for each item were excluded for calculating percentages

The majority of young people admitted are White British (81%), females (66%), and aged 15 to 17 years old (76%). Although these young people are typically living in the family home (83%), less than half (48%) are living with both natural parents. Referrals to inpatient units are predominantly from CAMHS psychiatrists (81%).

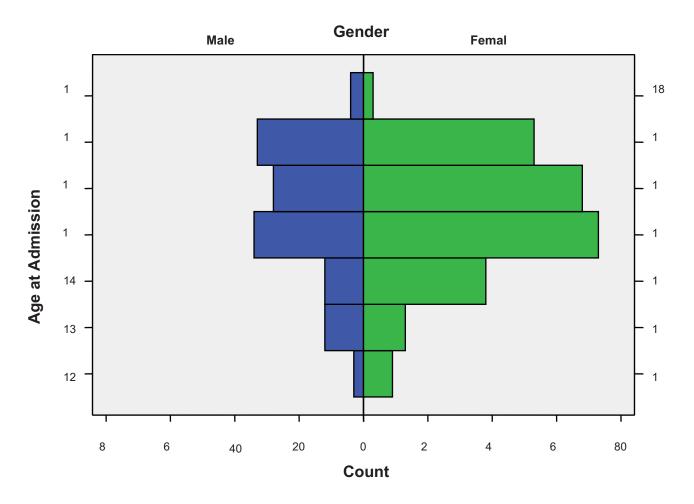
Table 3.14 Clinical features and severity ratings for whole cohort at admission (n=403) and comparison between those admitted to NHS and IND sector units¹

	NHS (%)	IND (%)	Total (%)
Diagnosis			
Eating Disorder	73 (28)	35 (33)	108 (29)
Schizophrenia, del. or psychotic.	49 (19)	20 (19)	69 (19)
Mood disorder	54 (20)	20 (19)	74 (20)
Mental & behavioural disorders due to psychoactive substance	8 (3)	3 (3)	11 (3)
Anxiety disorder	11 (4)	4 (4)	15 (4)
Obsessive compulsive disorder	6 (2)	0	6 (2)
Other neurotic disorder	23 (9)	4 (4)	27 (7)

			1
Disorders of adult personality	8 (3)	8 (8)	16 (4)
Hyperkinetic disorder	1 (<1)	0	1 (<1)
Conduct disorder	10 (4)	5 (5)	15 (4)
Behavioural syndrome ass. with physiological disturbance	0	1 (1)	1 (<1)
Disorders of psych. development	9 (3)	5 (5)	14 (4)
Other/Not know	12 (5)	1 (1)	13 (4)
total with data	264	106	370
Receiving treatment prior to admission			
No	48 (18)	64 (50)	112 (28)
Yes	225 (82)	64 (50)	289 (72)
total with data	273	128	401
Subject to Children Act			
No	258 (94)	112 (96)	370 (95)
Yes	16 (6)	5 (4)	21 (5)
total with data	274	117	391
Subject to Mental Health act ²			
No	230 (84)	66 (81)	296 (84)
Yes	43 (16)	15 (19)	58 (16)
total with data	273	81	354
Severity ²			
Mild	7 (3)	3 (3)	10 (3)
Moderate	59 (22)	29 (25)	88 (23)
Severe	169 (63)	65 (57)	234 (61)
Extreme	34 (13)	18 (16)	52 (13)
total with data	269	115	384
Risk to ²			
Self	166 (61)	59 (77)	225 (64)
Others	14 (5)	1 (1)	15 (4)
Both	53 (19)	13 (17)	66 (19)
Neither	39 (14)	4 (5)	43 (12)
total with data	272	77	349
Total HoNOSCA score	18.5	24.0	20.4
CGAS score ³	38.2	43.8	39.2

Figure 3.6 shows the distribution of ages by gender for the whole cohort. Females account for two-thirds of all admissions, however the age distribution is comparable. The majority (76%) of all young people admitted are age 15 to 17 yrs.

Figure 3.6 Distribution of ages for the whole cohort (n=384 – age was not given for 19 patients)



3.5.2 Characteristics of those with an eating disorder and comparison between those admitted to a GAU and those admitted to an EDU

Sixty-three of the 108 young people with an eating disorder (58%) were admitted to a GAU and 45 (42%) to a specialist EDU. Table 3.15 shows the

¹ Missing cases for each item were excluded for calculating percentages

² As rated by the Paddington Complexity Scale

demographic characteristics of the 108 young people with an eating disorder and compares those from this group who were admitted to the two types of unit.

None of the differences are significant.

Table 3.15 Demographic characteristics of young people with an eating disorder (n=108) comparing those admitted to an EDU with those admitted to a ${\sf GAU}^1$

	GAU (%)	EDU (%)	Total (%)
Gender			
Male	5 (8)	3 (7)	8 (7)
Female	58 (92)	42 (93)	100 (93)
Age			
12	3 (5)	6 (13)	9 (8)
13	5 (8)	2 (4)	7 (7)
14	5 (8)	11 (24)	16 (15)
15	23 (37)	12 (27)	35 (32)
16	16 (25)	10 (22)	26 (24)
17	10 (16)	4 (9)	14 (13)
18	1 (2)	0	1 (1)
Ethnicity			
White British	60 (97)	41 (91)	101 (94)
Others	2 (3)	4 (9)	6 (6)
Accommodation status			
Family home	54 (87)	38 (88)	92 (88)
Local Authority accommodation	0	1 (2)	1 (1)
Hospital accommodation	7 (11)	3 (7)	10 (10)
Others	1 (2)	1 (2)	2 (2)
Main carer			
Both natural parents	33 (54)	30 (71)	63 (61)
Single parent	19 (31)	8 (19)	27 (26)
Nat. parent with partner	9 (15)	2 (5)	11 (11)
Relatives	0	0	0
Others	0	2 (5)	2 (2)
Source of referral			
CAMHS Psychiatrists	47 (75)	36 (82)	83 (78)
Other CAMHS professional	9 (14)	5 (11)	14 (13)

Others	7 (11)	3 (7)	10 (9)

¹ Missing cases for each item were excluded for calculating percentages

Table 3.16 below shows the clinical features and clinical severity ratings at time of admission for young people with an eating disorder. Overall, 90% of patients (n=97) were rated as severe or extreme on the severity item of the Paddington Complexity Scale and 88% (n=91) were assessed as being a risk to self. The only difference between the young people with an eating disorder admitted to the two types of unit is that those admitted to an EDU had higher HoNOSCA scores, indicating greater severity of problems, than had those admitted to a GAU (t=-4.96, df =100, p<0.001). Neither the CGAS nor the M-RAS differentiated between the two groups of patients at admission.

Table 3.16 Clinical features and severity ratings for young people with an eating disorder (n=108) comparing those admitted to an EDU with those admitted to a GAU¹

admitted to a GAO		1	
	GAU (%)	EDU (%)	Total (%)
Receiving treatment prior to admission			
No	7 (11)	7 (16)	14 (13)
Yes	56 (89)	38 (84)	94 (87)
Subject to Children Act			
No	62 (98)	45(100)	107 (99)
Yes	1 (2)	0	1 (1)
Subject to Mental Health Act ²			
No	62 (98)	44 (98)	106 (98)
Yes	1 (2)	1 (2)	2 (2)
Severity ²			
Mild	0	0	0
Moderate	8 (13)	3 (7)	11 (10)
Severe	42 (67)	33 (73)	75 (69)
Extreme	13 (21)	9 (20)	22 (20)

Risk to ²			
Self	51 (81)	40(100)	91 (88)
Others	0	0	0
Both	5 (8)	0	5 (5)
Neither	7 (11)	0	7 (7)
Total HoNOSCA score (sd)	13.9 (6.9)	23.6 (7.2)	18.0 (8.5)
(95% confidence interval)	(11.3 to 16.6)	(20.2 to 27.0)	(15.5 to 20.4)
CGAS score (sd)	41.3 (14.8)	41.4 (7.1)	41.4 (12.1)
(95% CI)	(35.6 to 47.1)	(38.1 to 44.7)	(37.9 to 44.9)
M-RAS (sd)	4.4 (1.8)	5.3 (2.1)	4.8 (2.0)
(95% CI)	(3.7 to 5.1)	(4.3 to 6.3)	(4.2 to 5.4)
BMI (sd)	14.6 (1.7)	15.1 (2.0)	14.8 (1.8)
(95% CI)	(14.0 to 15.3)	(14.1 to 16.0)	(14.3 to 15.4)

¹ Missing cases for each item were excluded for calculating percentages

3.5.3 Characteristics of those with a diagnosis other than an eating disorder and comparisons between those admitted to an NHS unit and those admitted to an independent unit

Of the 261 young people who did not have an eating disorder (non-ED), 189 (72%) were admitted to a GAU managed by the NHS and 72 (28%) to a GAU managed by the independent sector. Table 3.17 compares these two groups of young people on their demographic characteristics. None of the differences are significant.

Table 3.17 Demographic characteristics of young people who did not have an eating disorder (n=261) comparing those admitted to an NHS-managed GAU with those admitted to a GAU managed by the independent sector¹

			
	NHS (%)	IND (%)	Total (%)
Gender			
Male	82 (44)	35 (49)	117 (45)
Female	106 (56)	37 (51)	143 (55)
Age			
12	1 (1)	1 (2)	2 (1)

² As rated by the Paddington Complexity Scale

			I
13	13 (7)	4 (6)	17 (7)
14	23 (13)	3 (5)	26 (11)
15	47 (26)	18 (28)	65 (27)
16	42 (24)	19 (30)	61 (25)
17	49 (28)	18 (28)	67 (28)
18	3 (2)	1 (2)	4 (2)
Ethnicity			
White British	137 (74)	59 (82)	196 (76)
Asian	14 (8)	3 (4)	17 (7)
Black	15 (8)	5 (7)	20 (8)
Mixed-Race	17 (9)	4 (6)	21 (8)
Other	3 (2)	1 (1)	4 (2)
Accommodation status			
Family home	152 (81)	54 (78)	206 (80)
Local Authority accommodation	10 (5)	5 (7)	15 (6)
Hospital accommodation	15 (8)	7 (10)	22 (9)
Others	10 (5)	3 (4)	13 (5)
Main carer			
Both natural parents	80 (43)	29 (43)	109 (43)
Single parent	62 (34)	25 (37)	87 (34)
Nat. parent with partner	23 (12)	2 (3)	25 (10)
Relatives	2 (1)	3 (4)	5 (2)
Others	18 (10)	9 (13)	27 (11)
Source of Referral			
CAMHS Psychiatrists	156 (84)	27 (82)	183 (84)
Other CAMHS professional	18 (10)	2 (6)	20 (9)
Others	12 (6)	4 (12)	16 (7)

Table 3.18 shows the clinical features and severity ratings at time of admission for young people with a diagnosis other than of an eating disorder. Compared with those young people admitted to an NHS unit, those admitted to an independent unit:

- i. were less likely to have been receiving treatment prior to admission (z=6.34, p<0.001);
- ii. have higher HoNOSCA scores (t=4.35, p<0.001).

Table 3.18 Clinical features and severity ratings for non-eating disorder patients (n=261) comparing those admitted to an NHS-managed GAU with those admitted to a GAU managed by the independent sector¹

	NHS (%)	IND (%)	Total (%)
Diagnosis			
Schizophrenia, del. or psychotic	49 (26)	20 (28)	69 (26)
Mood disorder	54 (28)	20 (28)	74 (28)
Mental & behavioural disorders due to psychoactive substance	8 (4)	3 (4)	11 (4)
Anxiety disorder	11 (6)	4 (6)	15 (6)
Obsessive compulsive disorder	6 (3)	0	6 (2)
Other neurotic disorder	23 (12)	4 (6)	27 (10)
Disorders of adult personality	8 (4)	8 (11)	16 (6)
Hyperkinetic disorder	1 (1)	0	1 (<1)
Conduct disorder	10 (5)	5 (7)	15 (6)
Behavioural syndrome ass. with physiological disturbance	0	1 (1)	1 (<1)
Disorders of psych. development	9 (5)	5 (7)	14 (5)
Other/Not know	12 (6)	1 (1)	13 (5)
Receiving Treatment Prior to Admission			
No	39 (21)	40 (56)	79 (31)
Yes	149 (79)	31 (44)	180 (69)
Children Act			
No	177 (94)	66 (93)	243 (93)
Yes	12 (6)	5 (7)	17 (7)
Mental Health act			
No	149 (79)	26 (68)	175 (77)
Yes	39 (21)	12 (32)	51 (23)
Severity ²			
Mild	5 (3)	3 (4)	8 (3)

Moderate	49 (26)	22 (31)	71 (28)
Severe	113 (61)	37 (51)	150 (58)
Extreme	19 (10)	10 (14)	29 (11)
Risk to ²			
Self	97 (52)	22 (58)	119 (53)
Others	14 (7)	1 (3)	15 (7)
Both	52 (28)	11 (29)	63 (28)
Neither	24 (13)	4 (11)	28 (12)
Total HoNOSCA score (sd)	20.1 (7.1)	25.2 (8.1)	21.8 (7.8)
CGAS score (sd)	37.0 (13.7)	45.6 (15.1)	38.2 (14.1)

¹ Missing cases for each item were excluded for calculating percentages

3.6 Patient levels of dependency

3.6.1 CAMHS-AID by unit type

The mean total CAMHS-AID scores of the sample at admission are tabulated in Table 3.19 and compares the dependency levels of NHS and Independent sector patients. No difference was found between the average dependency scores in the two sectors. The mean CAMHS-AID dependency score for the sample at discharge had dropped to 10.56 (standard deviation 13.50). A paired t test confirmed the statistically significant reduction in dependency levels (p< 0.001).

Table 3.19 Mean CAMHS-AID scores by admissions to unit types

Unit type	Mean CAMHS-AID score at admission (sd)		
NHS (n=197)	21.49 (16.49)		
IND (n=37)	19.07 (16.57)		
Both sectors (n=234)	21.11 (16.57)		

3.6.2 CAMHS-AID by diagnosis

The average CAMHS-AID scores at admission across all units for the most prevalent diagnoses (with n at least 30) are displayed below in Table 3.20. Independent t tests found a significant difference between the lower eating

² As rated by the Paddington Complexity Scale

disorder dependency score relative to both the other two groups (p<0.001), but there was no difference in dependency between the high dependency levels in the mood disorder and the schizophrenia/psychotic disorders group (p>0.05).

Table 3.20 Mean CAMHS-AID scores by diagnosis

Principle diagnosis	Mean CAMHS-AID score (sd)
Eating disorder (n=77)	12.92 (17.46)
Schizophrenia, delusional or psychotic disorder (n=41)	26.65 (18.60)
Mood (affect) disorder (n=44)	23.08 (13.17)

3.7 Length of stay and clinical outcomes

3.7.1 Length of stay

The median length of stay for the whole cohort is 79 days. For young people with an eating disorder, there was no difference in length of stay between those admitted to a GAU (mean=138.2 days, sd=88.1, median=120 days) and those admitted to an EDU (mean=139.5 days, sd=68.6, median=125 days) (Mann Whitney U test: Z=-0.61, p=0.54). For young people with a diagnosis other than an eating disorder, the length of stay for those admitted to an NHS unit (mean=101.2 days, sd=78.6, median=86 days) is significantly longer than for those admitted to an independent sector unit (mean=87.2 days, sd=74.7, median=67 days) (Mann Whitney U test: z=-2.9, p<0.01).

3.7.2 Clinical outcomes

The clinical outcome is assessed by the change from admission to discharge in HoNOSCA and CGAS scores and also, for patients with an eating disorder, in M-RAS scores and in body mass index (BMI). The amount of missing data varies between measures (see tables 3.3 and 3.4).

Overall clinical outcomes

Table 3.21 shows the scores on clinical outcome measures at admission and discharge for the whole cohort and for the two sub-groups of patients (those with an eating disorder and those with a diagnosis other than an eating disorder).

Table 3.21 Mean scores on outcome measures (and sd) at admission and discharge for all patients and for the two main sub-groups

	All patients (n=403)		Eating disorders (n=108)		Other diagnoses (n=261)	
	admission	discharge	admission	discharge	admission	discharge
HoNOSCA	20.4 (8.4)	11.9 (7.8)	17.5 (8.8)	9.7 (7.2)	21.8 (7.8)	13.0 (7.7)
(95% CI)	(19.5 to 21.3)	(11.1 to 12.7)	(15.8 to 19.2)	(8.3 to 11.1)	(20.7 to 22.8)	(11.9 to 14.0)
CGAS	39.2 (13.5)	57.7 (14.9)	40.8 (11.7)	60.4 (15.3)	38.2 (14.1)	56.3 (14.8)
(95% CI)	(37.7 to 40.7)	(56.0 to 59.4)	(38.4 to 43.2)	(57.1 to 63.6)	(36.2 to 40.1)	(54.1 to 58.5)
M-RAS	N/A	N/A	4.9 (2.0)	7.8 (2.3)	N/A	N/A
(95% CI)			(4.4 to 5.4) 15.22 (3.3)	(7.2 to 8.4) 18.3 (2.3)		
BMI (95% CI)	N/A	N/A	(14.5 to 15.9)	(17.8 to 18.8)	N/A	N/A

For all groups on all measures, the change in score in direction of improvement is highly significant (p<.001).

Comparison of outcomes for those with an eating disorder admitted to a GAU vs an EDU

Table 3.22 compares the scores at admission and discharge on the clinical severity measures for young people with an eating disorder admitted to a GAU or to an EDU. Those admitted to an EDU show a significantly greater reductions in mean HoNOSCA scores (t=-3.5, p<0.001) indicating greater improvement. Neither the change in CGAS scores (t=0.6, p=0.54) nor in M-RAS scores (t=-0.7, p=0.51) is significantly different between patients admitted to the two types of unit.

Table 3.22 Mean scores on clinical severity measures (and sd) at admission and discharge for patients admitted with an eating disorder to the two types of service

the two types of service						
	Admitted to a GA	U	Admitted to an EDU			
	admission discharge		admission	discharge		
HoNOSCA	14.9 (5.7)	8.9 (6.7)	23.7 (8.3)	10.0 (5.0)		
(95% CI)	(11.0 to 18.2)	(4.7 to 13.2)	(19.1 to 28.3)	(7.2 to 12.8)		
CGAS	37.3 (11.8)	59.8 (24.4)	40.8 (6.8)	62.9 (10.8)		
(95% CI)	(29.8 to 44.9)	(44.3 to 75.4)	(37.0 to 44.6)	(57.0 to 68.9)		
M-RAS	4.4 (2.1)	6.2 (2.7)	5.6 (2.2)	8.0 (2.6)		
(95% CI)	(3.0 to 5.7)	(4.4 to 7.9)	(4.4 to 6.8)	(6.6 to 9.5)		
ВМІ	15.2 (1.9)	16.9 (2.4)	15.3 (2.2)	19.6 (1.8)		
(95% CI)	(14.1 to 16.4)	(15.3 to 18.4)	(14.1 to 16.5)	(18.6 to 20.6)		

Comparison of outcomes for non-ED patients admitted to a NHS vs an independent sector GAU

For young people with a diagnosis other than eating disorder, there is no significant difference in change in mean HoNOSCA score from admission to discharge (z=-0.42, p=0.68) between NHS and Independent units (table 3.23). We do not compare change in CGAS scores because of missing data.

Table 3.23 Mean scores on outcome measures (and sd) at admission and discharge for non-eating disorder patients admitted to the two types of service

	Admitted to	an NHS GAU	Admitted to a	n independent AU
	admission	discharge	admission	discharge
HoNOSCA	20.2 (7.2)	11.4 (7.2)	24.8 (7.9)	15.9 (7.7)
(95% CI)	(19.0 to 21.4)	(10.2 to 12.6)	(22.9 to 26.8)	(14.0 to 17.8)

3.8 Predictors of outcome

3.8.1 Predictors of outcome for the whole cohort

Table 3.24 shows the effect of predictor variables, their significance and 95% confidence intervals for the two clinical severity measures (HoNOSCA and CGAS) using the model predicted scores.

For the patients with an eating disorder, the HoNOSCA and CGAS scores at admission significantly predict the amount of change in HoNOSCA and CGAS scores (HoNOSCA: t=-7.95, p<0.001; CGAS: t=-3.05, p<0.01). There is no significant difference between eating disorder cases admitted to EDUs and GAUs with respect to the change in HoNOSCA or in CGAS. None of the other variables significantly predict the change in HoNOSCA or in CGAS scores.

For the group of patients with a diagnosis other than eating disorder, the HoNOSCA and CGAS scores at admission significantly predict the amount of change in HoNOSCA and CGAS scores from admission to discharge; those with higher scores show greater change (HoNOSCA: t=-7.52, p<0.001; CGAS: t=-7.96, p<0.001). The amount of change in HoNOSCA and in CGAS does not differ significantly between NHS and Independent units (P>0.05 for both CGAS and HoNOSCA). However, the total score on the Paddington Complexity Scale, the Ward Atmosphere Scale and diagnosis significantly predict the amount of change in HoNOSCA (p<0.05 for all variables); greater levels of severity and better ward atmospheres predict more improvement. The amount of change in CGAS scores among those with a diagnosis of schizophrenia is significantly different from those with a mood disorder and all other diagnoses; people with schizophrenia improving more. In addition to baseline scores, number of beds in the unit admitted, ward atmosphere and type of illness significantly predict (p<0.001 for all variables) the amount of change in CGAS scores; a lower number of beds, better ward atmospheres and a diagnosis of schizophrenia are associated with greater change.

The HoNOSCA at admission is the only significant predictor of length of stay (t=2.05, p<.05). Those with greater severity of problems, as measured by HoNOSCA, have longer hospital stays.

Table 3.24 Significant predictors of various outcome measures

Predictor	Effect	t	p value	95% Confidence Interval
	Eati	ing disorder	cases	
Outcome measure: Ho	NOSCA			
Admission score	0.73	-7.95	<0.001	0.54 to 0.91
EDU v GAU	-0.67	-0.43	0.665	-3.75 to 2.41
Outcome measure: CG	AS			
Admission score	-0.66	-3.05	0.003	-1.09 to -0.23
EDU v GAU	-5.15	-1.26	0.211	-13.29 to 2.99

Non-Eating disorder cases					
Outcome measure: Ho	NOSCA				
Admission score	0.67	7.52	<0.001	0.49 to 0.84	
NHS v Independent	3.42	1.16	0.247	-2.41 to 9.25	
PCS (sum)	-0.38	-2.17	0.032	-0.74 to -0.03	
WAS	0.44	2.27	0.025	0.06 to 0.82	
Schizophrenia with					
Mood disorder	-4.39	-2.83	0.006	-7.46 to -1.32	
Others	-4.19	-2.85	0.005	-7.10 to -1.27	
Outcome measure: CG	AS				
Admission score	-0.70	-7.96	<0.001	-0.88 to -0.53	
NHS v Independent	6.13	0.92	0.359	-7.05 to 19.32	
Beds (n)	-1.48	-4.44	<0.001	-2.13 to -0.82	
WAS	1.38	3.84	<0.001	0.67 to 2.09	
Schizophrenia with					
Mood disorder	-7.39	-2.34	0.021	-13.62 to -1.15	
Others	-6.36	-2.17	0.032	-12.17 to -0.55	
Outcome measure: Length of stay					
Admission HoNOSCA	0.02	2.05	0.041	0.00 to 0.05	
WAS	-0.01	-0.47	0.641	-0.06 to 0.04	
Beds (n)	0.00	0.06	0.954	-0.04 to 0.04	
PCS (sum)	-0.01	-0.29	0.77	-0.06 to 0.04	

3.9 Costs and outcomes

Table 3.25 repeats the information in Table 3.21 but limits the sample to those for whom we have information on the costs of their admission. The mean total CGAS score at admission and the mean total HoNOSCA score at discharge were lower for those for whom treatment costs could be estimated compared to those for whom treatment costs could not be estimated (t=-2.245, p=0.025; t=-2.221, p=0.027 respectively). The change in mean CGAS score between admission and discharge was also larger for those for whom admission costs could be estimated (t=2.267, p=0.026). The differences were small however; just 4 points on the CGAS

at admission, 2 points on the HoNOSCA at discharge, and 6 points on the CGAS change score.

Table 3.25 Outcomes for the costs sample

	All patients		Eating disorders		Other diagnoses	
	Mean score (sd)		Mean score (sd)		Mean score (sd)	
	admission	discharge	admission	discharge	admission	discharge
HoNOSCA	20.0 (8.3)	11.3 (7.3)	17.2 (8.5)	8.6 (6.2)	21.2 (7.9)	12.5 (7.4)
HONOSCA	N=224	N=225	N=68	N=70	N=156	N=155
CCAS	38.2 (13.1)	57.9 (14.0)	40.5 (11.3)	61.6 (14.3	37.2 (13.7)	56.3 (7.4)
CGAS	N=226	N=216	N=70	N=67	N=156	N=149

The change scores for the CGAS and the HoNOSCA between admission and discharge reflect the outcomes of inpatient treatment. We looked at the associations between these scores and the inpatient admission costs. The small number of independent units that we could include within the 'costs sample' has meant that cost-outcomes associations could not be estimated for independent sector and NHS units separately.

There were no cost-outcome associations for these variables within the sample of children diagnosed with eating disorder. The Morgan-Russell change score (between admission and discharge) was available for 40 young people and positively associated with costs (p=0.017).

For the full costs sample, longer admissions and the change in HoNOSCA (n=220) and CGAS (n=219) scores between admission and discharge were associated (ANOVA; p=0.011 and 0.043 respectively). However, the associations between these outcome measures and the costs of admission for each child showed much poorer significance values (p=0.102 and p=0.091), although the direction of influence remained positive. Using a simple linear regression, neither the cost per day in each ward of residence nor the admission cost per child were statistically significant, once length of stay had been taken into account.

The change score for CGAS between admission and follow-up was available for 80 young people for whom the inpatient admission costs could be estimated and just three for whom admission costs could not be calculated. There was no significant association between this longer-term outcome

measure and admission costs for these patients, nor when we looked at the data for those with eating disorders (n=28) and other diagnoses separately.

3.10 Service satisfaction

3.10.1 Participants

Nineteen young people and 12 parents completed the CAMHSSS and were interviewed using a semi-structured schedule that enquired about young people's and parents' satisfaction with care. Table 3.26 shows how the 31 young people and parents were distributed across the unit types.

Table 3.26 Young people and parents that provided data about satisfaction

	General adolescent unit		Eating disorder unit	
	Young people Parents (of YP with an ED)		Young people	Parents
Independent	7 (4)	3 (1)	1	0
NHS	6 (0)	8 (4)	5	1
Total	13 (4)	11 (5)	6	1

3.10.2 Overall satisfaction as measured by CAMHSSS

As Table 3.27 shows, both parents and young people were generally satisfied with all aspects of their inpatient care. Parental ratings of satisfaction are consistently lower than those of the young people across all domains. The differences were not significant.

Table 3.27 Mean Scores for CAMHSSS Domains¹

Domain	Young people (N=21) Mean (sd)	Parents (N=12) Mean (sd)
Overall satisfaction	4.0 (0.7)	3.7 (1.1)
Access	3.5 (0.9)	3.3 (0.9)
Effect of services	3.8 (0.8)	3.5 (0.9)
Information	3.8 (1.0)	3.6 (0.9)
Professionals' skills and behaviour	4.0 (0.5)	3.5 (1.0)
Relatives	3.9 (0.8)	3.4 (1.1)
Type of intervention	3.6 (0.6)	3.5 (0.9)

¹CAMHSSS items are scored as: 1 = very unhappy, 2 = unhappy, 3 = mixed, 4 = happy and 5 = very happy.

3.10.3 Differences between NHS and independent sector units

Because of the low numbers of participants, ratings by young people were combined with those by parents for the comparison of CAMHSS scores between those with experience of NHS care and those who experienced care in an independent unit. The results presented in Table 3.28 should be interpreted with extreme caution because of: i. the low numbers; ii. the fact that they combine ratings by both young people and by parents; and iii. because the sample was not randomly selected.

Table 3.28 Mean Scores for CAMHSSS Domains NHS vs. Independent sector (young people and parents combined)

sector (young people und parents combined)			
CAMHSSS Domain	NHS (N=20) Mean (sd)	IND (N=11) Mean (sd)	Significance
Overall satisfaction	4.1 (0.8)	3.5 (1.1)	t=1.89, df=29, p<0.1
Access	3.7 (0. 7)	3.1 (1.1)	t=1.51, df=29, NS
Effect of services	3.7 (0.8)	3.5 (1.0)	t=0.49, df=29, NS
Information	4.0 (0.7)	3.2 (1.2)	t=2.60, df=29, p<0.05
Professionals' skills and behaviour	4.0 (0.5)	3.4 (1.0)	t=2.30, df=29, p<0.05
Relatives	3.9 (0.8)	3.3 (1.2)	t=1.49, df=29, NS
Type of intervention	3.7 (0.7)	3.4 (0.8)	t=1.00, df=29, NS
Total (mean of domains)	3.9 (0.5)	3.3 (1.0)	t=1.99, df=29, p<0.1

Ratings of satisfaction were consistently lower for the independent units. The domains of 'Information' and 'Professionals' skills and behaviour' show significant differences between types of unit.

Young people and parents also participated in semi-structured interviews. The aim of the interviews was to help expand on the areas covered in the CAMHSSSS. These data are presented below.

3.10.4 Themes emerging from qualitative interviews with young people and parents

Staff attitudes, interpersonal skills and communication

"Mark was made to feel welcome. Normal people would be frustrated with him but the patience that he was shown was wonderful." (Parent, NHS)

"There's a few [members of staff] that I'm quite attached to. If they're on shift I'm really glad because I can talk and respond to them. I feel easy around them. With others, I hope they don't want to talk to me, because I don't want to talk about how I feel with them." (Young person, NHS)

"At [name of service] I was seen every week – it helped hugely. We discussed parenting issues and just communicated." (Parent, NHS)

Both young people and parents think it important that staff are friendly, understanding, caring and communicate well. For young people it is important that staff listen to them and can engage in light-hearted chat as well as talk about more serious issues. They enjoy talking to staff who they think understand them, but if they think that staff do not understand them they avoid talking. Negative staff characteristics that were mentioned include inflexibility, an authoritarian attitude and rudeness.

Both young people and parents appreciate staff members who are good communicators, which includes finding time to talk to them. Some participants find it difficult to speak with staff for whom English is not their first language. As a consequence, they find it difficult to develop a relationship. Some parents report wanting more regular discussions with staff about how their son or daughter is progressing.

Information

The young people and parents raised issues relating to three types of information giving.

1. Information about the nature of the problem

"The most helpful thing is the support and knowing how to deal with your illness – and knowing everything to do with your illness. I didn't realise how my mood was connected to it." (Young person, Independent)

2. Information about treatment and care

"I got information about CBT and MRI scans. They explained everything to my son and us. He was treated like an adult respected." (Parent, NHS)

However, other parents reported that they knew little about the care provided for their son or daughter.

"We weren't given any information about life-skills, but I'm very interested in it. I want to know what happens during the day as it's a bit of a mystery." (Parent, NHS)

For both young people and parents, receiving information about treatment enables them to be more involved in the management of the young person's problems. Parents are often motivated to access information about treatments, and actively seek it out when it is not provided, for example on the internet.

3. Information about the unit

"I had an information pack and visited as well. It was definitely useful because I had built it up in my head, but the visit reassured me because the unit was nice." (Young person, NHS)

Most interviewees report having been given some information about the unit where they or their child will be staying, and their comments suggest they find it useful. The internet serves as a further source of information, and some participants visit the web-sites of units to which they or their child will be admitted. Both parents and young people find visiting the unit particularly helpful and reassuring because it enables them to get a better idea of what the unit will be like. However, some participants report problems with accessing information before their admission, for example, if they are admitted from a paediatric ward or admitted in an emergency. However they tend to appreciate being offered the information on admission or during outreach visits.

"I didn't visit the unit (was in a paediatric unit), but someone visited me. It was helpful." (Young person, Independent)

Confidentiality, rights and consent

The interviewees highlighted a number of incidents where young people believe that confidentiality has been breached or that the rights of a young person has not been respected. Several of the young people report that other patients have found out information that is personal to them.

"They (other patients) know too much about other people's problems – they've overheard or staff tell them things. They know if I've lost or gained weight and if I've been exercising. They tell each other – I don't like it." (Young Person, Independent)

The young people interviewed reported that they had differing amounts of input into treatment decisions. Whilst some young people were clear that they only received treatment that they wanted, others felt that they had no say in what treatment they received. Young people with eating disorders often seemed to understand why their wishes were not fully incorporated into their care plan.

"It was difficult to give me what I wanted, because with anorexia what you want is to be thin. They listened to me, but didn't take my pleading on board." (Young person, NHS)

Two young people from the same unit raised concerns about the use of physical restraint.

"I saw them drag people across the floor – one girl got carpet burns across her face." (Young person, Independent)

Staffing systems and the use of agency nurses

The use of agency staff is a sensitive issue and some young people report that it adversely affects their experience of care. Young people find it harder to build up relationships with agency staff because they are there for such short periods of time. This was a particular problem when an agency nurse is assigned to provide 1:1 supervision.

"I don't bother with the agency staff because they don't say anything helpful. They don't understand or take an interest in trying to understand." (Young person, NHS)

Responses regarding the use of key-workers/named nurse and key-teams are inconsistent. Although some people find it helpful to have a named nurse, others mention problems when they were not available.

"All of the hospitals had a key worker system and this caused issues. Sometimes there was no one there who knew about my daughter – especially at weekends. I think everyone should know everything about all the patients." (Parent, NHS and Independent)

The quality of food

A number of young people express dissatisfaction with the quality of the food. Some select items from the menu that then are not available and there are complaints that food is of a poor standard. These issues may be particularly problematic for young people with eating disorders. Positive comments are made about the use of fresh ingredients, and an on-site kitchen and chef.

Access and contact with family

Both parents and young people mention delays in accessing help before admission due to long waiting lists and staff shortages in community CAMHS. These delays reportedly cause extra stress for the parents as they struggle to keep their child safe and distress for the young person because they are not receiving help that is appropriate to their needs.

Participants report delays in accessing in-patient mental healthcare. These are sometimes due to problems with the young person's physical health, such as low weight. One young person was admitted to a paediatric ward whilst she waited for funding at a specialist eating disorder unit to be secured.

"During the wait for funding I got worse and I went to a paediatric unit. I was there for two months. While I was there the staff didn't understand my condition, but they did try to. I got worse and had to start being tube-fed. That was a very negative experience." (Young person, NHS)

Young people placed in inpatient units which are some distance from their family home, find it difficult to have regular contact with families.

"They visit on visiting days, but it's hard – they live one and a half hours away. We talk on the phone." (Young person, independent)

Some parents reported that travel costs caused financial problems. Despite these concerns, participants consider the quality of care at the unit is more important than the distance that the unit is from their family home.

Choice between GAU and EDU

Interviewees gave varied responses to the question about whether young people with an eating disorder should be admitted to a general adolescent unit or to a specialist eating disorders unit. Some believe that young people with an eating disorder should be treated in an EDU, as the behaviour of patients with other problems can cause further distress.

"Young people with eating disorders should be treated in eating disorder units. They have to look at other YP with depression, psychosis etc. In an eating disorder unit they can support each other. She could have been pushed over the edge by the other stuff in the unit." (Parent, GAU)

Others think it helpful to be with other young people who had different problems.

"It's a mixed problem unit – in some ways it's good to have someone you can ask who doesn't feel the same way. They don't have your problems and you don't have theirs." (Young person, GAU)

A number of the interviewees explored the benefits and disadvantages of being with other young people with eating disorders. Although it may be helpful to have peers who can more easily relate to your problems, some young people learn ways of controlling their weight from other patients, and some feel competitive towards other patients.

"Sometimes we share tips – how to avoid putting weight on – I don't want to hear, but it gets in your head. It's mostly very positive though." (Young person, GAU)

No interviewee questioned the knowledge and skills of the permanent staff from GAUs or EDUs with regard to the care of people with an eating disorder. However some considered that agency staff and staff on paediatric wards sometimes lacked the necessary competence.

3.11 Illustrative case studies

We present here some brief case vignettes to illustrate the types of young people admitted to the units, the types of problems they experienced and the course of care provided to them.

3.11.1 Young person admitted to a specialist eating disorder service

Jane was a fifteen year old white female living at home with both parents. She was attending an LEA special needs school due to problems with her psychological development and her eating disorder, for which she was receiving treatment from a community CAMHS team. She was referred by her consultant psychiatrist to a specialist inpatient eating disorder unit (EDU) when her condition, primarily her very low weight, became unmanageable at home. The independently managed EDU to which she was referred accepts referrals from across the country and can accommodate 30 patients.

Due to the severity of her condition, Jane was assessed and admitted within a week of referral. Her care package was developed by the inpatient multi-disciplinary team (MDT) in co-ordination with the young person's parents and the community CAMHS team. The inpatient team assessed the young person using a range of clinical measures and concluded that the severity of her condition was 'extreme'. For example, she had a BMI of 14.8, substantially below what is regarded as appropriate for her age and height.

During an inpatient stay, which lasted 106 days, Jane's treatment package included cognitive behaviour therapy, family therapy, occupational therapy and dietetic work. The inpatient MDT met twice a week to review her progress. At discharge, the severity of her condition was rated again and was judged to have improved. For example, HoNOSCA scores had changed from 25 at admission to 9 at discharge. Similarly, CGAS scores had improved from 41 to 61 and MRAS from 4.9 to 5.3. Her BMI had increased to 20.7. Jane was discharged back to the care of her community CAMHS team and continued to receive follow-up care from the inpatient unit.

3.11.2 Young person with schizophrenia admitted to independently managed unit

Alemayehu was a sixteen year old male of African descent who lived at home with his mother. He had been in contact with community CAMHS services for a number of years due a combination a learning disability and episodes of psychosis. When his psychotic illness worsened, Alemayehu was admitted as an emergency to the nearest available bed in an independently funded general adolescent unit. Alemayehu was admitted under section 3 of the Mental Health Act on the same day that he had been assessed as requiring admission.

Alemayehu was assessed by ward staff as experiencing hallucinations and delusions and of posing a risk both to himself and to other people. He was therefore put onto one-to-one observation.

Alemayehu was resident at the unit for 134 days and received a range of treatments including antipsychotic medication. At discharge back to the community CAMHS team he had shown significant health improvement. Follow-up contact from the service continued for six months.

3.11.3 Young person with a mood disorder admitted to an NHS managed service

Zoe, a 14 year old girl, had been in contact with a range of services including social services, police and the child sexual abuse team for a considerable length of time. She was cutting her arms, misusing substances, had problems with her peer relationships and was complaining of a range of bodily symptoms that were thought to be somatoform. The community CAMHS team working with Zoe were increasingly concerned about her self-harm behaviour and felt unable to contain this safely in the community. The consultant psychiatrist referred her to a six bedded general adolescent unit managed by a neighbouring NHS trust. Her admission process was planned, which allowed Zoe to visit the service prior to admission.

On the unit, a care plan was developed which specified input from the various agencies involved in Zoe's care. Although the original admission diagnosis indicated a mood disorder, the discharge diagnosis was described as 'other neurotic, stress-related somatoform disorder'. Her levels of severity as measured by HoNOSCA were reduced from 12 to 2 and a CGAS score at discharge of 81 indicated a high level of functioning.

Zoe was fully involved in the development of her discharge plan and was discharged back to her mother and step-father after an inpatient stay of 85 days. Zoe maintained contact with the inpatient psychiatrists and her key worker as well as re-establishing her contact with the community CAMHS team.

4 Discussion

4.1 Limitations of the study

4.1.1 Study design

COSI-CAPS is the largest inpatient CAMHS outcomes study to have been undertaken in the UK. However, it cannot provide definitive evidence of the effectiveness of inpatient CAMHS because there is no control group of young people treated in an alternative manner, for example by intensive community care. Neither, because there was no random allocation, can it conclusively address the question of which type of inpatient unit achieves better outcomes or is preferred by the young people. Also, it proved possible to examine only short-term outcomes; that is outcomes at discharge.

There are significant challenges in undertaking controlled trials of inpatient CAMHS (Green & Jacobs, 1998; Green et al., 2007). Given the likely small effect size, as indicated by the COSI-CAPS study, such a trial would need to be large to be adequately powered. However, the prevailing system for research ethics and governance (see below) might make it impossible to undertake a large controlled trial that compares the effectiveness of NHS and independent sector units or of general adolescent and specialist eating disorder units.

4.1.2 Completeness of data

The response rate for the various components of the study was mixed and generally disappointing. One-quarter of the 55 eligible units chose not to participate. Three-quarters of those that did returned unit-level data and 55% returned cost data. Although 90% of participating units returned some patient data, there were sufficient data for analysis for three-quarters of patients at admission and discharge and for just one-quarter of patients at six months follow-up. In addition, we had to abandon attempts to collect data about young people admitted to adult psychiatric wards and to paediatric wards and we interviewed just 31 young people – too few to make meaningful comparisons between the experiences of those admitted to different types of unit.

The COSI-CAPS research team conducted the National Inpatient Child and Adolescent Psychiatry Study (NICAPS) which collected data in 1999. This achieved returns of patient data from 89% of all CAMHS units (71 of 80) (O'Herlihy et al., 2004) and data about staffing and costs from 88% of units that agreed to participate in that element of the study (58 of 66) (O'Herlihy et al., 2003). Our experience with NICAPS informed the design of COSI-CAPS. With hindsight, we were perhaps over-ambitious.

Two factors contributed most directly to the low rates of data return in this study. The first was the impact of changes in research governance and ethics processes that were introduced between the time that COSI-CAPS was designed and data collection started. This created obstacles to undertaking the research that added greatly to the workload of the team (Meenaghan et al., 2007) and of the clinicians in participating services. It caused us to abandon the attempt to collect data from adult psychiatric wards and from paediatric wards, and also contributed greatly to the low rate of return of patient data at follow-up.

The second factor is what appears to be reluctance by independent sector units to provide unit-level data including data about costs. This was likely to be due to the conflict of interest for private providers, who regard the cost and income information as sensitive. In the competitive healthcare market, it is likely that most providers will be increasingly reluctant to share this information with researchers. However, the charges made by providers are known to commissioners of services and in future studies this obstacle could be overcome if commissioners were included in the research.

Other, more local factors might have played a part in the low rates of return. Individual units were expected to collect detailed research information with no additional funding. The size of the central research team did not allow direct data collection by the researchers. Many CAMHS units lack the extra capacity in the team to perform this task easily - clinical priorities inevitably come first. Two approaches might be taken to address this problem to assist future research.

First, research assistants might be employed to collect the data at individual sites. Whilst this would be expensive, it would increase objectivity and reduce the risk of bias as the researchers would be independent of the clinical team who provide the service, and who have an interest to demonstrate good outcomes. However, apart from the cost, it would also complicate ethical issues even further: patients would have to consent to the researchers accessing their health care information. This may reduce the number of participants, and it may be necessary to introduce patient incentives to ensure participation.

The second approach is to introduce outcome measures into the routine clinical process in these units as part of their clinical governance. This is being done by the team managing the Quality Network for Inpatient CAMHS who have worked alongside the COSI-CAPS team during the later stages of the study as part of the QNIC-Routine Outcomes Measurement initiative.

4.2 The extent to which the findings address the research hypotheses

Hypothesis 1: That, after allowing for differences in casemix, there are no differences in clinical and social outcomes or cost of care:

1.1 for patients treated in NHS vs independent sector units.

The findings support the hypothesis with respect to outcomes. There were insufficient returns to compare costs.

1.2 for young people admitted to adult psychiatric wards or paediatric wards vs adolescent units.

This component of the study was abandoned (see section 2.7). However, in England and Wales, young people only exceptionally receive their full inpatient care in these settings. Usually, the admission to adult and paediatric wards is a temporary solution until a CAMHS bed is available, and it is mainly due to the lack of emergency beds in CAMHS units. 'Pushed into the shadows' research by YoungMinds has used a qualitative approach to explore young people's experiences of adult settings (The Children's Commissioner for England, 2007).

Hypothesis 2: That those admitted for the treatment of an eating disorder:

2.1 after allowing for any differences at admission, clinical and social outcomes are no better for those admitted to a specialist vs a general unit.

More than half of young people with eating disorders were treated in NHS general adolescent units. As indicated by HoNOSCA scores, young people admitted to a specialist EDU were more severely ill and showed a greater degree of clinical improvement than did young people with an eating disorder who were admitted to a general unit. These differences were not apparent on the other measures of clinical severity (e.g. CGAS, MRAS). Also, there is no difference in the severity of clinical problems at discharge on any measures. This suggests that inpatient treatment in either type of setting can achieve a positive outcome for young people with an eating disorder.

2.2 young people and their families are no more satisfied with the care provided by specialist units than with care provided by general units.

There were too few interviews conducted to test this reliably.

The semi-structured interviews reflected mixed views.

2.3 there is no difference in the total cost of care for those admitted to a specialist vs a general unit.

Mean treatment costs were significantly higher for young people admitted to a general unit compared with those admitted to a specialist unit. However, this result must be treated cautiously because nearly half of those in a specialist EDU were treated in just one independent sector unit.

Hypothesis 3: That the qualities of the physical, social and therapeutic environment that young people value:

3.1 are no better provided by CAMHS inpatient units than by adult psychiatric units or paediatric wards.

This component of the study was abandoned.

4.3 Other findings

4.3.1. Clinical severity and treatment outcome

The mean total CGAS and HoNOSCA scores at admission (39.3 and 19.6 respectively) are similar to those of other recent studies of inpatient samples (Green et al., 2007; Gowers et al., 2007). Also, consistent with these other studies, scores on clinical severity measures improved substantially from admission to discharge for most types of condition. The mean HoNOSCA score at discharge (11.2) is the same as that of the largest cohort of patients receiving care from community CAMHS for whom HoNOSCA has been reported (Gowers et al., 1999). Detailed outcome data for the various diagnostic groups are given in appendix 2.

4.3.2 Factors associated with better outcome

Those young people with higher HoNOSCA scores at admission had longer length of stays. Also, consistent with previous research (Green et al., 2007), longer length of stay and greater clinical severity at admission were associated with greater improvement in clinical severity. The study also found that, as has been reported for adult psychiatric wards (Mellei et al., 1996; Eklund & Hansson, 1997; Moos, 1997; Timko & Moos, 1998), the better the treatment climate, and specifically the better the ward atmosphere, the better the clinical outcome.

4.3.3 Differences between NHS and independent units

Units managed by the independent sector tend to have more beds, to have a higher proportion of the staff group who are employed on the lowest

nursing grade, higher levels of agency staff, higher pupil to teacher ratios and to be less likely to offer day care or out-patient care.

A higher proportion of young people admitted to the independent sector have not received treatment prior to admission, were admitted as an emergency and would therefore not have had the opportunity to visit the unit prior to admission. Interestingly, there was no difference between the legal status of young people between the two sectors. This finding suggests that some of these emergency admissions could be planned in a better way.

Those admitted to the independent sector have more severe problems at admission, as measured by HoNOSCA. These findings might be due to the inability of the NHS to admit young people in an emergency (Cotgrove et al., 2007). The CAMHS Inpatient Referral Study found that the great majority of young people who are denied admission to an NHS unit and are then referred on, are subsequently admitted to an independent sector unit (O'Herlihy et al., 2007). These factors may account for the differences found in mean lengths of stay. For example, a young person who was referred to an independently managed service as an emergency may be transferred to an NHS service closer to home once a space became available.

In terms of the treatment climate, a number of differences were identified. NHS units had higher levels of practical orientation, spontaneity and better total scores on the Ward Atmosphere Scale compared to independently funded units. These findings were supported by the Ward Atmosphere Measure data which indicated significantly better ward atmospheres in NHS managed services. There was less information returned about cost, and treatment from independent units. However, the outcomes were comparable with the NHS.

4.3.4 Differences between eating disorder and general units

Staff in specialist eating disorder units perceive their services to have lower levels of spontaneity than do staff in general adolescent units. There is also a trend towards lower levels of practical orientation and higher levels of staff control. This presumably reflects the treatment regime that prevails in wards designed to meet the needs of a group of patients with a common diagnosis. More than half of the young people with eating disorder were managed by GAUs in the NHS. The outcome at discharge was comparable between EDUs and GAUs suggesting that young people can benefit from treatment provided in both settings. Although HoNOSCA scores suggest greater severity and improvement for patients admitted to EDUs, Morgan Russell, CGAS scores, and BMI measures were comparable on admission and discharge.

4.3.5 The costs of CAMHS inpatient care

The provision of finance-related data from the participating units meant that we could estimate costs per day for 27 units, two of which did not return

any patient-level data. Using data on the costs of overheads from these units, costs for a further six units could be estimated from publicly available information. Inpatient admission costs could be estimated for 273 patients, just over two-thirds of the young people with patient-level data.

Inpatient admission costs are high; on average £33,820 although the median was much lower at £24,480. Females tend to have higher cost treatment episodes because they are more likely to have a diagnosis of an eating disorder which is associated with a longer stay. Young people who have had treatment prior to admission and who are not subject to a Mental Health Act section also have higher admission costs. In the earlier CHYPIE study of eight NHS inpatient units, cost associations were found with younger age, exclusion from school, higher levels of aggression and externalising behaviour and greater impairment on the CGAS at admission (Green et al, 2007; Jacobs et al, 2004). This might be explained by the different age range in the CHYPIE study. Patients admitted to children's units present with a very different type of pathology, and there is also a higher proportion of males, which is the opposite in the adolescent population.

There is a difference between the cost of running the service and the cost to the commissioners, taxpayers, and NHS as a funding body. The COSI-CAPS study only collected information concerning the actual costs, rather than the charges. Future studies will need to take into consideration the charges paid by commissioners for services.

There were no associations between inpatient treatment costs and HoNOSCA or CGAS scores at admission or the change scores between admission and discharge.

5 Implications and conclusions

5.1 Implications for policy

5.1.1 Research governance and ethics

Research governance and ethics approval procedures make large-scale health services research that involves patient data difficult to undertake. As well as greatly increasing the cost, perhaps to the point of rendering such studies uneconomic, it can be difficult to convince local clinical staff to participate in such research if they believe that the "burden" of obtaining approval is greater than that of data collection. Scandinavian countries have been able to carry out large scale, long-term outcome research, because of national healthcare registers (Thomsen, 1996; Sourander et al, 1998a & b; Sourander and Turunen, 1999). Current research governance guidelines mitigate against similar studies in the UK. Service research (as compared to interventional research) presents low risks. Therefore excessive concerns regarding confidentiality are difficult to understand. For example, we were not able to collect systematic service satisfaction information due to concerns about patient confidentiality. Research governance guidelines must be drawn up to reflect an appropriate balance between concern about patient confidentiality and data protection, and the potential health benefits of better knowledge about the structures and processes that underpin high quality care.

5.1.2 A continuing role for CAMHS inpatient units in England?

Young people admitted to inpatient units have more severe problems than those treated by existing community services, improve substantially during their inpatient stay and are generally satisfied with their care.

However, these findings must be considered in the context of very limited research about the effectiveness, safety and cost of alternatives to inpatient care for young people in England. It is possible that some of the young people admitted to these units could have been cared for as well by intensive community services. For other young people such community services could shorten the duration of the hospital stay.

5.1.3 The role of the independent sector

With the present configuration of services, the independent sector appears to be an indispensable element of tier 4 CAMHS. It provides the commonest place for emergency admissions and produces outcomes that appear to be as good as those achieved by the NHS.

5.1.4 The role of specialist eating disorder units

Young people admitted to specialist eating disorder units have more severe problems at admission than do young people with an eating disorder admitted to general adolescent units, as measured by HoNOSCA. At discharge, the severity of problems is the similar for both groups.

5.2 Implications for practice

5.2.1 The impact of treatment climate on outcomes

The study found that, as in adult psychiatric wards, clinical outcome is affected by treatment climate and specifically by ward atmosphere. This should cause services to pay close attention to factors that might impact on treatment climate such as staff levels and morale, access to therapies and activities and procedures to identify and prevent disturbance. Also:

- 1 Patients and parents place great value on the attitudes and interpersonal and communication skills of staff. These attributes might be actively considered at job interviews, discussed during supervision and might be assessed by eliciting feedback from young people and parents perhaps as part of a 360-degree assessment that might form one component of staff appraisal.
- The use of agency nurses to cover shifts adversely affects young people's experience of care. This is also likely to result in increased disturbance, and an increased need for one to one observation, which is expensive. The last review cycle of the Quality Network for Inpatient CAMHS highlighted the problems faced by units with recruitment (Shingleton-Smith et al., 2006) and recommended that unavoidable long-term absences should be covered by bank as opposed to agency staff.
- The level of satisfaction experienced by patients and parents is influenced by the quality of information that units provide about the young person's problem and treatment, and about the unit itself. The CAHMSSS (Ayton et al., 2007) data indicated a lower level of satisfaction with the private providers as compared to the NHS. This may have been due to the less frequent pre-admission visits, the lack of information available about the units prior to admission, and the higher rate of non-qualified staff who are less likely to be able to provide the necessary information for young people and families.
- 4 Young people with an eating disorder have mixed feelings about whether it was better to be admitted to a specialist unit or to a general

unit. With regard to the former, staff in specialist units should be aware that there can be counter-therapeutic interactions between young people with an eating disorder who live together.

5.2.2 The potential value of routine outcomes measurement

Despite the problems encountered with research ethics and governance, the majority of CAMHS inpatient units in England were able to collect information about clinical status and outcomes for the majority of consecutive admissions. The team that led the study have worked with colleagues managing the Quality Network for Inpatient CAMHS to build on this by offering units the opportunity to continue with data collection as part of a system for allowing inpatient staff to monitor outcomes and compare casemix and outcomes with other units.

5.3 Implications for future research

5.3.1 The need for better understanding of what influences treatment climate in inpatient CAMHS

This is potentially an important area for future research. We know little about factors that might impact on treatment climate such as skill mix (the balance between senior trained and untrained staff), the make-up of multidisciplinary teams and the role of different psychological therapies.

5.3.2 The sustainability of outcomes post-discharge

Future studies must be designed to overcome the obstacles raised to long-term follow-up of young people discharged from inpatient care. What research there is (Green et al., 2007) suggests that gains are maintained.

5.3.3 The effectiveness of alternatives to inpatient care in preventing admission and/or reducing length of stay

Further research is needed about interventions that can shorten hospital stays without compromising outcomes. This might include different transition and aftercare models, when the young person still has a high level of needs but when the risks have subsided to the extent that the patient may be managed in the community. For example, is it more effective if the young person is managed as a day-patient, by an outreach team from the unit or by an intensive community service in their locality (Gowers et al., 2007)? Crucial in this process is the need to include the collection of long-term follow-up data.

5.3.4 The pros and cons of specialist eating disorder units

There were insufficient data to compare cost effectiveness between specialist and general units in the treatment of eating disorders, or to reach conclusions about the long-term benefits of each model. There needs to be further comparative research on these topics. Until now, most eating disorder research emerged from specialist services. The present study highlights that a large number of cases are managed with similar success on general units, and future studies need to compare the strengths and weaknesses of both models to optimise treatment outcome for this difficult to treat patient population. This is particularly important, as the evidence base of inpatient treatment of severe eating disorders is poor despite the high cost of this illness both for sufferers, and for the NHS.

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Appendix 1 List of inpatient units participating in the COSI-CAPS study (incl. age range)

CAMHS IP Unit		Managing Agency	Туре	Age range
1	Alpha Hospital	Independent	General Adolescent Unit	11 - 18
2	Aquarius Adolescent Unit	NHS	General Adolescent Unit	12 - 18
3	Berkshire Adolescent Unit	NHS	General Adolescent Unit	12 - 18
4	Bethlem Adolescent Unit	NHS	General Adolescent Unit	12 - 18
5	Brookside Adolescent Unit	NHS	General Adolescent Unit	13 - 18
6	The Cassel Hospital - Adolescent Unit	NHS	General Adolescent Unit	16 - 23
7	Coborn Adolescent Unit	NHS	General Adolescent Unit	12 - 18
8	Colwood Adolescent Unit	NHS	General Adolescent Unit	12 - 18
9	Darwin Centre	NHS	General Adolescent Unit	12 - 18
10	Darwin Unit (formerly: Wall Lane House)	NHS	General Adolescent Unit	12 - 18
11	Ellern Mede Centre for Eating Disorders	Independent	Eating Disorder Unit	8 - 17
12	Fant Oast Adolescent Unit	NHS	General Adolescent Unit	12 - 17
13	Highfield Family & Adolescent Unit	NHS	General Adolescent Unit	13 - 18
14	Huntercombe Maidenhead - Kennet	Independent	Eating Disorder Unit	12 - 25
15	Huntercombe Maidenhead - Tamar	Independent	General Adolescent Unit	13 - 19

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16	Huntercombe Stafford - Eating Disorder Unit	Independent	Eating Disorder Unit	13 - 25
17	Leigh House Adolescent Unit	NHS	General Adolescent Unit	12 - 18
18	Lime Trees Child, Adolescent & Family Unit	NHS	General Adolescent Unit	11 - 18
19	McGuinness Unit - Adolescent Service	NHS	General Adolescent Unit	12 - 18
20	Mount Gould Adolescent Unit	NHS	General Adolescent Unit	13 - 18
21	Marlborough House Adolescent Unit	NHS	General Adolescent Unit	12 - 18
22	New Beginnings Young People's Unit	NHS	General Adolescent Unit	13 - 18
23	Newberry Centre for Young People	NHS	General Adolescent Unit	12 - 18
24	Northgate Clinic	NHS	General Adolescent Unit	13 - 18
25	Oakham House Adolescent Unit	NHS	General Adolescent Unit	12 – 17 (18 if in full time education)
26	Orchard Lodge Adolescent Unit	NHS	General Adolescent Unit	13 - 18
27	Orchard Young People's Unit	Independent	General Adolescent Unit	13 - 17
28	Pine Cottage Adolescent Unit	NHS	General Adolescent Unit	12 - 18
29	The Priory Hospital - Altrincham	Independent	General Adolescent Unit	13 - 18
30	The Priory Hospital Bristol - Heath House	Independent	General Adolescent Unit	12 - 18
31	The Priory Hospital Chelmsford	Independent	General Adolescent Unit	12 - 17
32	The Priory Hospital North London - The Bourne	Independent	General Adolescent Unit	12 - 18
33	The Priory Hospital - Woodbourne	Independent	General Adolescent Unit	12 - 17
34	Pine Lodge Young People's Centre	Independent	General Adolescent Unit	12 - 18

		T		
35	Phoenix Centre	NHS	Eating Disorder Unit	11 - 17 (18 if in full time education)
36	Riverside Adolescent Unit	NHS	General Adolescent Unit	13 - 18
37	Rhodes Farm - Eating Disorder Unit	Independent	Eating Disorder Unit	8 - 18
38	Snowsfield Adolescent Unit	NHS	General Adolescent Unit	12 - 18
39	St Georges Eating Disorder Unit	NHS	Eating Disorder Unit	12 - 18
40	Simmons House Adolescent Unit	NHS	General Adolescent Unit	13 - 18
41	The Sir Martin Roth Young People's Unit	NHS	General Adolescent Unit	14 - 19
42	West End Adolescent Unit	NHS	General Adolescent Unit	12 - 18

Appendix 2 Detailed clinical data for each diagnostic group by unit type

2.1 The clinical outcomes of patients admitted to either a general adolescent or specialist service

Table 1. Eating Disorder population (GAU)

Table 1. Eating Disorder population (GAU)						
General Adolescent U	Jnit					
Variable	n	Mean (median)	Sd	Min	Max	
HoNOSCA						
Admission	60	14.2	8.2	4	38	
Discharge	59	9.5	8.5	0	48	
Post-Discharge	5	6.8	5.0	0	13	
CGAS						
Admission	56	41.6	13.4	11	91	
Discharge	51	60.2	17.6	15	90	
Post-Discharge	14	61.03	15.6	26	85	
Difference						
HoNOSCA	57	5.2	7.8	-16	21	
CGAS	51	19.7	16.8	-20	59	
LoS	45	138.2 (121)	88.2	1	371	

Table 2. Eating Disorder population (EDU)

Eating Disorder Unit						
Variable	n	Mean (median)	Sd	Min	Max	
HoNOSCA						
Admission	42	22.1	7.6	10	38	
Discharge	44	10.0	5.1	1	22	

Post-Discharge	7	6.9	7.6	0	20
CGAS					
Admission	38	39.7	8.8	6	56
Discharge	37	60.6	11.7	29	91
Post-Discharge	18	56.4	17.1	31	85
Difference					
HoNOSCA	42	12.0	7.0	-5	32
CGAS	37	20.9	13.8	-3	66
LoS	42	139.5 (124.5)	68.6	14	380

2.2 Non-Eating Disorder Population (Clinical Outcomes – Diagnosis and unit wise)

Table 3. Schizophrenia, delusional or psychotic disorder

NHS					
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	45	21.6	7.5	4	39
Discharge	44	10.2	7.1	0	30
Post-Discharge	3	15.7	2.5	13	18
CGAS					
Admission	49	30.5	11.9	5	62
Discharge	45	58.0	14.9	25	85
Post-Discharge	20	58.9	22.9	25	95
Difference					
HoNOSCA	43	11.7	9.6	-6	33
CGAS	44	27.0	16.8	0	65

LoS	38	110.5 (83)	84.8	13	411

Table 4. Mood (Affect) disorder

NHS					
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	44	20.7	5.8	10	33
Discharge	43	12.6	6.6	1	32
Post-Discharge	7	19.6	9.3	6	35
CGAS					
Admission	47	37.3	11.6	5	55
Discharge	46	53.7	11.8	31	81
Post-Discharge	14	48	13.2	30	75
Difference					
HoNOSCA	43	8.0	8.3	-8	30
CGAS	46	16.4	16.7	-5	66
LoS	46	79.7 (64.5)	62	11	284

Table 5. Mental and Behavioural disorders due to psychoactive substances

NHS					
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	4	20.8	9.4	12	33
Discharge	4	13	7.6	6	21
Post-Discharge	0	-	-	-	-
CGAS					

Admission	8	36.9	13.4	15	60
Discharge	7	48.7	16.8	30	70
Post-Discharge	2	45	14.1	35	55
Difference					
HoNOSCA	4	7.75	3.4	5	12
CGAS	7	13	9.7	0	23
LoS	9	52.1 (37)	49.4	14.0	174

Table 6. Anxiety disorder

Table 6. Allxiety dis	oraci				
NHS		,			
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	7	18.1	10.5	4	31
Discharge	7	12.3	9.4	2	28
Post-Discharge	0	-	-	-	-
CGAS					
Admission	11	42.4	18.2	9	71
Discharge	11	59.1	14.0	34	80
Post-Discharge	0	-	-	-	-
Difference					
HoNOSCA	7	5.9	6.0	-1	17
CGAS	11	16.7	15.6	0	46
LoS	12	137 (115)	92.1	25.0	366

Table 7. Obsessive compulsive disorder

NHS		

Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	5	21	2.2	18	24
Discharge	5	12.8	6.3	6	22
Post-Discharge	0	-	-	-	-
CGAS					
Admission	6	31.2	6.8	22	39
Discharge	6	55.7	8.5	45	65
Post-Discharge	1	75	-	75	75
Difference					
HoNOSCA	5	8.2	7.4	-1	16
CGAS	6	24.5	14.2	7	40
LoS	9	100 (88)	49.0	43	175

 Table 8. Other neurotic, stress-related or somatoform disorders

NHS					
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	17	17.2	6.8	8	29
Discharge	17	7.2	4.4	2	14
Post-Discharge	2	3	4.2	0	6
CGAS					
Admission	22	42.1	15.4	5	74
Discharge	22	60.9	12.3	35	81
Post-Discharge	6	51.5	17.7	25	75
Difference					
HoNOSCA	17	9.9	6.3	2	23

CGAS	22	18.7	14.3	0	50
LoS	16	87.6 (34)	87.6	17	292

Table 9. Disorders of adult personality and behaviour

NHS		personancy and b			
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	6	22.3	9.2	12	39
Discharge	6	12.8	9.8	4	28
Post-Discharge	0	-		-	-
CGAS					
Admission	7	37.4	9.5	21	50
Discharge	6	64.2	21.5	30	80
Post-Discharge	0	-	-	-	-
Difference					
HoNOSCA	6	9.5	5.1	0	14
CGAS	6	28	13.4	9	40
LoS	6	116.7 (103)	130.2	11	366

Table 10. Conduct disorder (including mixed CED)

NHS			-		
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	8	16.3	4.6	9	22
Discharge	8	13.5	8.2	5	27
Post-Discharge	1	19	-	19	19
CGAS					

Admission	10	47.8	13.3	35	70
Discharge	10	53	14.6	20	70
Post-Discharge	4	52	10.1	43	65
Difference					
HoNOSCA	8	2.8	7.1	-11	11
CGAS	10	5.2	11.7	-15	21
LoS	3	16.3 (15)	4.2	13	21

Table 11. Disorders of psychological development

NHS					
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	6	17	10.1	10	37
Discharge	6	11.7	8.1	4	23
Post-Discharge	2	18	4.2	15	21
CGAS					
Admission	8	44.9	12.1	20	59
Discharge	6	54.8	11	45	75
Post-Discharge	3	38	3	35	41
Difference					
HoNOSCA	6	5.3	8.5	-9	17
CGAS	6	11.2	9.9	0	25
LoS	4	51.3 (39)	34.5	25	102

Table 12. Other diagnoses

NHS		
		_

Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	2	23	8.5	17	29
Discharge	2	26	4.2	23	29
Post-Discharge	0	-	-	-	-
CGAS					
Admission	3	35.3	24.5	11	60
Discharge	3	27	33.0	5	65
Post-Discharge	1	25	-	25	25
Difference					
HoNOSCA	2	-3	4.2	-6	0
CGAS	3	-8.3	18.9	-30	5
LoS	2	132.5 (132.5)	143.5	31	234

2.2.1 Independent Units

Table 13. Schizophrenia, delusional or psychotic disorder

Independent					
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	20	24.3	9.3	11	42
Discharge	20	14	8.2	1	31
Post-Discharge	0	-	-	-	-
CGAS					
Admission	8	44.8	15.7	25	75
Discharge	7	60	19	39	85
Post-Discharge	3	70.7	19.1	55	92

Difference					
HoNOSCA	20	10.2	8.2	-2	30
CGAS	7	14.9	24.9	-6	60
LoS	21	58.7 (43)	46.9	4	197

Table 14. Mood (Affect) disorder

Table 14. Mood (Affect) disorder							
Independent			1				
Variable	n	Mean (median)	Sd	Min	Max		
HoNOSCA							
Admission	19	24.8	7.5	7	38		
Discharge	20	17.6	8.7	3	31		
Post-Discharge	1	10	-	10	10		
CGAS							
Admission	11	47.4	18.2	5	75		
Discharge	9	56.4	17.4	15	72		
Post-Discharge	5	48.6	7.1	41	60		
Difference							
HoNOSCA	19	7.9	6.6	-6	24		
CGAS	9	5.1	14.6	-25	26		
LoS	20	71.4 (48.5)	69	12	244		

Table 15. Mental and Behavioural disorders due to psychoactive substances

Independent							
Variable	n	Mean (median)	Sd	Min	Max		
HoNOSCA							
Admission	3	34	8.7	28	44		

Discharge	2	13.5	2.1	12	15
Post-Discharge	0	-	1	1	-
CGAS					
Admission	2	35	7.1	30	40
Discharge	1	61	-	61	61
Post-Discharge	0	-	-	-	-
Difference					
HoNOSCA	0	-	-	-	-
CGAS	0	-	1	1	-
LoS	3	40.7 (49)	36.2	1	72

Table 16. Anxiety disorder

Independent						
Variable	n	Mean (median)	Sd	Min	Max	
HoNOSCA						
Admission	4	23.5	7.4	14	32	
Discharge	4	15	7.9	4	22	
Post-Discharge	0	-	-	-	-	
CGAS						
Admission	0	-	-	-	-	
Discharge	0	-	-	-	-	
Post-Discharge	0	-	-	-	-	
Difference						
HoNOSCA	4	8.5	2.4	5	10	
CGAS	0	-	-	-	-	
LoS	5	107.8 (98)	53.6	29	168	

Table 17. Other neurotic, stress-related or somatoform disorders

Independent					
Variable	n	Mean (median)	Sd	Min	Max
HoNOSCA					
Admission	4	18.5	4.9	13	24
Discharge	4	11.3	2.6	9	15
Post-Discharge	0	-	-	-	-
CGAS					
Admission	0	-	-	-	-
Discharge	0	-	-	-	-
Post-Discharge	0	-	-	-	-
Difference					
HoNOSCA	4	7.3	5.6	4	14
CGAS	0	-	-	-	-
LoS	3	12.3 (14)	8.6	3	20

Table 18. Disorders of adult personality and behaviour

Independent						
Variable	n	Mean (median)	Sd	Min	Max	
HoNOSCA						
Admission	8	25.6	6.6	15	35	
Discharge	8	17.3	8.5	5	27	
Post-Discharge	0	-	-	-	-	
CGAS						
Admission	2	55	0	55	55	
Discharge	2	74.5	4.9	71	78	
Post-Discharge	3	57	7.2	51	65	

Difference					
HoNOSCA	8	8.4	4.2	3	14
CGAS	2	19.5	4.9	16	23
LoS	6	43.5 (27)	45.8	13	136

Table 20. Conduct disorder (including mixed CED)

Table 20. Conduct disorder (including mixed CED)						
Independent						
Variable	n	Mean (median)	Sd	Min	Max	
HoNOSCA						
Admission	5	29.5	9.4	15	41	
Discharge	5	21.2	6.1	13	30	
Post-Discharge	0	-	_	-	-	
CGAS						
Admission	0	-	-	-	-	
Discharge	0	-	-	-	-	
Post-Discharge	2	47	7.1	42	52	
Difference						
HoNOSCA	5	8.6	4.5	2	14	
CGAS	0	-	-	-	-	
LoS	4	43.8 (44.5)	22.9	17	69	

Table 21. Disorders of psychological development

	The second of populations of property and the property of the second of					
Independent						
Variable	n	Mean (median)	Sd	Min	Max	
HoNOSCA						
Admission	5	25.8	8.1	17	36	
Discharge	5	19	5.3	12	26	

Post-Discharge	2	19	0	19	19
CGAS					
Admission	0	-	-	-	-
Discharge	0	-	-	-	-
Post-Discharge	2	52.5	10.8	42	65
Difference					
HoNOSCA	5	6.8	10.8	42	65
CGAS	0	-	-	-	-
LoS	5	59.2 (63)	44.9	13	125

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A 55 kg Paper Mountain: The impact of new research governance and ethics processes on mental health services research in England

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Abstract

Background: The guidelines about research ethics and research governance, implemented by the Department of Health, present new challenges to undertaking mental health service research within the National Health Service (NHS).

Aims: This paper describes how these new ethical and research governance procedures have adversely affected three multi-centre mental health service research studies, funded by the Department of Health.

Methods: The workload, time, and cost of meeting these requirements for each study is described. Conclusion: The implementation of Government guidance has resulted in a level of bureaucracy that threatens the future of the type of research that underpins policy development and service planning. For the researcher, the work involved in meeting these new requirements can be greater than the work of data collection, and for the trust, greater than the cost of participation in the research itself. The Department of Health has made recommendations to streamline the research ethics process. However this will not address the tension between research ethics systems and localized research governance procedures.

Declaration of interest: None.

Keywords: Research governance, ethical approval, mental health service research

Introduction

Despite the common adoption of the Declaration of Helsinki, there is substantial variation between European countries in the requirements for approval by a research ethics committee. There is also evidence that the research ethics process in England is relatively arduous (Hearnshaw, 2004). Recent changes to this process in England, in response to the European Clinical Trials Directive, have made it yet more demanding (Alberti, 2000; Glasziou, 2004; Jamrozik, 2004; Wald, 2004). The problem has been compounded by the introduction of new procedures for obtaining agreement to conduct research that are separate from the research ethics system. The English Department of Health required this because of public concern about a highly publicized episode. For the purposes of research and teaching a medical hospital had retained children's organs without parental consent.

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One of the conclusions from the subsequent inquiry was that there had been a failure of research governance (House of Commons, 2001).

This paper shows the impact of the English research ethics and governance processes, in place between 2003 and 2005, on three mental health research studies, conducted by a single research unit. It argues that they pose a significant threat to the future of this type of research. In the discussion we will examine how the recent recommendations could influence the processes described here.

The procedures

Research ethics approval

The whole ethics approval system in England is overseen by the Central Office for Research Ethics Committees whose current Standard Operating Procedures for Research Ethics Committees run to 208 pages (National Patient Safety Agency, 2005). Since 1998, research studies that involve more than five English health care providers must submit an application for approval by one of 12 Multi-centre Research Ethics Committees (MRECs). These were established to obviate the need to apply separately to the Local Research Ethics Committees (LRECs) of each provider organization. Once approval is granted by an MREC, the researchers must notify the LREC of each National Health Service (NHS) health care provider involved in the study. The system was recently modified to take account of the EU Clinical Trials Directive that outlines the statutory framework for the conduct of clinical trials of medicinal products in Europe. Although such trials only account for 15% of research ethics applications, the English Department of Health decided that the new guidance would apply to all types of research conducted in England, and not just to clinical trials (Department of Health, 2005a). The Department of Health stated that this was to avoid confusion that could arise from the use of different systems. Consequently, the same 19-page MREC application form applies to all studies submitted for research ethics approval. For studies that involve patient contact, or the collection of any data other than that derived from routine care, the MREC will deem that each LREC will also need to conduct a separate "site-specific assessment" (SSA) regarding the capacity of the service to engage in the research. This assessment requires the appointment of a local "principal investigator" at each site who is held responsible for the service's participation in the research.

The local research governance process

The Department of Health's research governance framework, first issued in 2001, specifies the responsibilities of health care providers in relation to local research (Department of Health, 2001). Its main aim is to encourage services to "manage any significant risk to patients, users and carers, staff and other individuals covered by a health care organisations' duty of care" (Department of Health, 2001). The framework is subject to local interpretation. Most mental health care providers have responded by setting up a committee structure, separate from the LREC system, and overseen by one or more administrators.

The three studies

All three studies were funded by the English NHS Research and Development (R&D) Programme and were subject to independent academic review as part of the commissioning process.

Study 1 examined provision of specialist care for substance misuse problems available to patients in all 25 medium-secure psychiatric units in England. The one-year study involved telephone interviews, postal surveys and focus groups with staff in the units, and in-depth interviews and focus groups with a small number of staff from some of the units. No data were collected from or about individual patients.

Study 2 which involves 102 English health care providers (a mix of acute, primary care and mental health) examines the pathways through care of young people who are referred to, but not admitted by, Child and Adolescent Mental Health in-patient units. The study was commissioned because of concern that many of these young people are diverted to inappropriate services, including the criminal justice system and adult psychiatric wards. It was estimated that the study would collect information about 300 young people. Questionnaire data would be drawn from existing information sources about the young people and provided by the practitioners responsible for the patients' care. In addition, a researcher would interview a sub-sample of patients and their families. Consent for these interviews would be obtained from the young people and their parents or carers.

Study 3 which began in April 2004 compares costs, outcomes and satisfaction with care for young people admitted to general adolescent and specialist eating disorder mental health in-patient units (both NHS and independent sector services). It also examines the same factors for young people admitted to adult psychiatric and paediatric wards. Sixty-six health care providers are participating. The data collection process, a combination of questionnaires completed by staff and interviews with a sub-sample of young people, is similar to Study 2.

The process of obtaining research ethics approval

All three studies were approved by different MRECs. The MREC considering Study 1 decided that LRECs would not have to be notified because the research involves no patient contact. Study 2 was approved with the requirement that all LRECs be informed. This involved submission to the LRECs of a letter and an information sheet outlining the study. The MREC considering Study 3 decided that a SSA was required for each participating service. This involves identifying a local investigator who takes on local responsibility for the research. This proved to be a time-consuming and difficult process for both the central research team and local services. For 70 out of the 90 adult psychiatric and paediatric wards that would occasionally admit a young person relevant to the study, the time and effort required to undertake the SSA was so great that they decided to withdraw. Some, however, did agree that they would reconsider involvement if the study only involved collecting data on a young person if and when a case relevant to the study was admitted during the recruitment phase.

The process of obtaining local research governance approval

Although securing research ethics approval was a considerable task, getting agreement from research governance committees proved more difficult. For some services, several telephone calls were required just to obtain the contact details for the committee or manager responsible for research governance. During this period many services were unable to specify precisely what the local procedure was, and others changed the procedure during the application process. There was little standardization between services. For example, despite the provision by the Central Office for Research Ethics Committees (COREC) of a standard application form for research governance approval, the central research team was required to

complete 19 different forms for Study 1 and 58 different forms for Study 2. The committees requested a range of attachments to accompany the application. Although the requirement varied from committee to committee, most included a core set of the MREC application form and approval letter, copies of correspondence with the LREC, specimen information sheets and letters to potential participants and a sponsor letter from the funding body. Some research governance committees required the LREC letter of approval before the R&D application process could be completed or, in a few instances, prior to initiating this process.

For all three studies, some services required members of the central research team to apply for honorary contracts of employment. This was despite the fact that the central researchers would have little or no involvement in on-site data collection, and would not even visit some of the services involved. Obtaining an honorary contract was a lengthy process that involved: the submission of a CV; the provision of two references; the completion of an occupational health form; and presentation of proof of clearance from the Criminal Records Bureau (CRB). Five trusts would not accept the current CRB check previously obtained by the researchers who were subsequently asked to visit the human resources department with the required documentation.

Similar to examples reported in other journals (Elwyn et al., 2005; Galbraith et al., 2006), some services made further idiosyncratic demands. These included: refusal to provide an application form until a subject had been identified for the study. This created a "Catch 22" because we could not identify study subjects without research governance approval; subjecting a study proposal to academic review despite the fact that it had been extensively peer-reviewed during the grant application stage; in one case even requesting that the researchers visit the trust in order to have Hepatitis B injections.

The cost

Table I summarizes the work involved in obtaining approval to conduct these three studies and the quantity of paper that had to be submitted to the many committees involved. Although Study 3 involved only 66 research governance committees, 126 applications for site-specific assessments had to be made. This was because more than one local investigator was required by services where more than one ward was participating in the study. A single copy of all of the paperwork submitted for these three studies would weigh 55 kg.

The work of obtaining these approvals occupied a full-time research worker for 4 months for Study 1 and 12 months for Study 2 and 3. This has delayed these projects (studies 2 and 3) by 12 months. For those trusts that required the central researchers to have honorary

Table I. The administrative burden of applying for research governance a	approval for the three studies.
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	Study 1	Study 2	Study 3
Number of services participating in the study	25	102	74
Number of LRECs to which an application was submitted ¹	0	0	As below
Number of research governance committees to which an application was submitted ¹	25	62	66
Number of pages submitted to LRECs	N/A	512	1260
Number of pages submitted to research governance committees	2450	5929	6039
Total number of pages submitted to obtain approval to conduct the study ²	2539	6530	7388
Number of trusts requiring an honorary contract	5	25	31
Average number of phone calls and letters per trust	15	9	6

¹Some LRECs and research governance committees serve more than one service. ²Includes MREC applications.

contracts, the process of obtaining CRB checks and occupational health clearance added up to two months to these times.

For Study 3, the average time to complete the SSA process, i.e., engaging with a service, identifying a local principal investigator, explaining the process and responsibilities involved, and completing the necessary documents. The average time to complete the SSA process took four months; the research team did however experience processes that required up to 12 months for completion.

For all three studies, the time and effort required to obtain ethics and research governance approval will be greater than that of data collection and data analysis. The delays to Studies 2 and 3 have meant that the English Department of Health has had to provide additional funding for both projects (£67,699 for Study 2 and £97,469 for Study 3). Although we are not able to estimate the time it has taken NHS staff to process our applications, it is likely that this too will far exceed the time that these staff will spend in data collection during the course of their participation in these three studies.

Discussion

Research conducted in England over the past 50 years has made a significant contribution to understanding the relationship between mental health service structures and processes, and quality of care and patient outcome. One of the factors that have enabled this is the presence of a National Health Service with its single, top-level management structure and common policy direction. This has encouraged collaboration between services in large-scale health services research. Our experience with these three studies suggests that the future of such research is being put at risk by the cumbersome research ethics and governance processes introduced in response to the European Union Clinical Trials Directive and high profile scandals. These guidelines have been applied indiscriminately to types of research, such as the studies described here that pose little risk of causing harm to patients (Doll, 2001).

English Department of Health guidance about research governance states that "the NHS is expected to manage risk, minimise bureaucracy, and facilitate research" (Department of Health, 2004). Our experience suggests that, in relation to large national health services research, the NHS has achieved the opposite of the last two aims, and only looks likely to achieve the first by making it virtually impossible to conduct such studies at all. A recent review suggests applications to local research ethics committees are down by around 40% (Bently & Enderby, 2005). In our opinion, the cost of implementing the Department of Health guidance requirements far outweighs any potential benefit. The cost is both quantitative in terms of finance, resources, and time, and qualitative in terms of the future of this type of health services research upon which policy development and service planning depend. We question the ethics both of this use of NHS funds and of a system that creates almost insurmountable obstacles to research conducted about the disadvantaged groups of people who are the subject of our three studies.

It is evident that our experiences are far from unique. This phenomenon transcends research fields within the UK (Boshier et al., 2005; Elwyn et al., 2005; Galbraith et al., 2006), and exists in Canada (Burgess & Brunger, 2000; McDonald, 2001), Australia (Roberts et al., 2004; Walsh et al., 2005) and America (Brody et al., 2005).

As researchers, we have no argument with the principles of research governance; nor do we blame staff in the R&D departments of English mental health services or members of the LRECs. In fact we are grateful for their help, support and forbearance in our quest for approval. Our impression is that many of these staff share our frustration at the extensive

bureaucracy that has been imposed and are unsettled by the lack of clarity about what is expected.

We thought that we might have been unfortunate in our timing when making the applications for Studies 1 and 2, in that we sought approval for our studies during a period when research governance committees were establishing themselves. However, the fact that the task of obtaining approval for the most recent study, Study 3, was the most arduous suggests little evidence of a reduction in the bureaucratic process.

In response to the clamour from the research community, the Government established an Ad-Hoc Advisory Group to examine the research ethics process in England. This recommended that a distinction be made between different types of research and data collection, and that the ethics approval process be modified to take account of these differences (Department of Health 2005a; National Patient Safety Agency, 2006). The sentiment behind these recommendations is welcome, as is the Advisory Group's calls for the adoption of "common national systems" and improved links between ethics reviews and local research governance procedures that could make "multiple use of information supplied once" (Department of Health 2005a). The bureaucratic processes experienced by national health service research studies, as described in this paper, would only be addressed if the information supplied once for ethical review and research governance approval could be transferable across all the RECs and NHS trusts nationwide, as supported by other members of the research community (Boshier et al., 2005). This would also constitute part of a drive towards a more knowledge-based approach and with it an emphasis on joined-up thinking and policy (Newman, 2001).

Only time will tell whether action arising from these recommendations will result in a reduction in the paper mountain facing researchers. There are two reasons for caution. First, and contrary to the intention, previous moves to centralize the ethics review process have led to greater bureaucratization. It remains to be seen whether the further centralization, recommended by the Advisory Group through the reduction in the number of ethics committees, can solve the problem. Second, neither COREC nor the National Patient Safety Agency, which now manages COREC, have any jurisdiction to oversee local research governance procedures. These were the major obstacles to our studies. The tension between centralized ethics review process and local research governance procedures remains.

The stakes are high. If action is not taken to streamline and simplify both the research ethics and governance processes, the UK will not achieve the government's stated aim of becoming "the best place in the world for health research and innovation" (Department of Health, 2005b), and will not be viewed as an attractive partner for international research collaborations. This will apply particularly to the type of large-scale health service research referred to here.

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The Costs, Outcomes and Satisfaction for In-patient Child & Adolescent Psychiatric Services (COSI-CAPS) Study

COSI-CAPS RESEARCH PACK

FOR EACH YOUNG PERSON ADMITTED TO THE SERVICE BETWEEN:

17.10.2005 - 16.04.2006

1. Provide each parent/legal guardian and young person – **aged 12 to 18 years inclusive** – with an information sheet (Version 6; 20 February 2006).

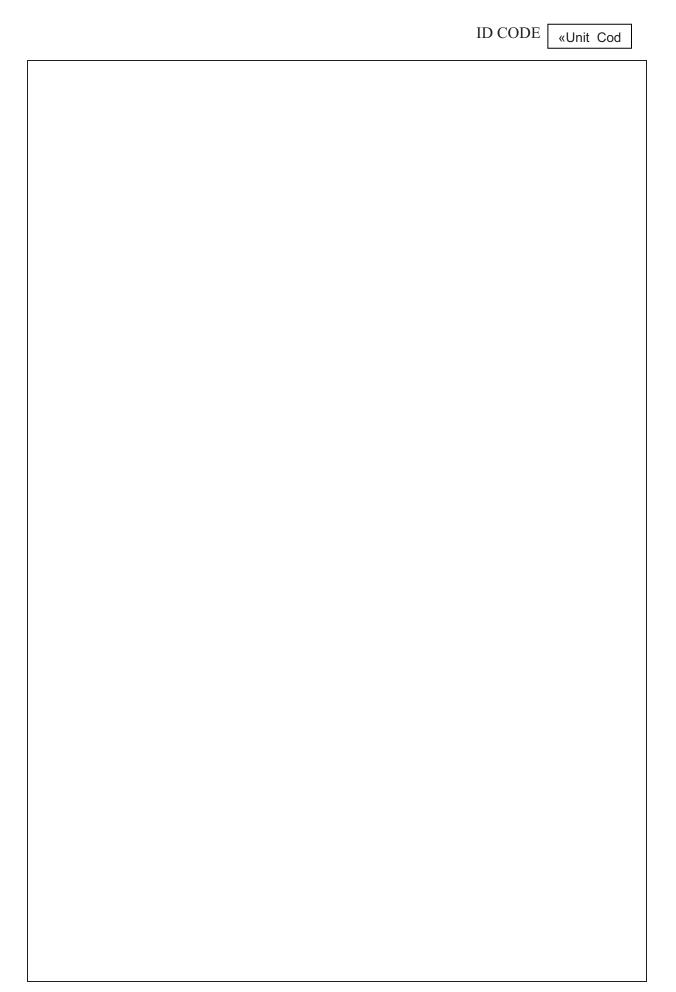
Please note: Information sheets are provided in the pockets at the front of this research pack file. For each potential participant, you will need to address the enclosed white A5 stamped envelope to the parent/legal guardian (as appropriate). Please distribute an Information sheet to the young people in person, and post the information sheet to parents/legal guardians (as appropriate) using the stamped envelope.

- 2. If parents/legal guardians or young people wish to withdraw from the study they must inform the unit staff or the research team. **No formal consent to participate is required**.
- 3. Please complete the Admission Data Collection Tool (Section 1) for each admission over the study period.
- 4. When the discharge date is known:
 - a) Contact the research team at the CRU so that we can arrange to invite the young person to participate in an interview (we will only aim to invite two or three young people from each unit).
 - b) Complete the Discharge Data Collection Tool (Section 2).
- 5. Only return the DCT's once you have completed all items and provided contact details of the professional in contact with the young person post discharge.

N.B. If the young person is admitted but is an in-patient for fewer than 2 weeks, only complete Sections in the table of contents that are marked with an asterisk (*).

This pack file contains:

- YOUNG PERSON'S INFORMATION SHEET (GREEN)
- PARENT'S or LEGAL GUARDIANS INFORMATION SHEET (BLUE)
- x1 STAMPED A5 ENVELOPE: to be addressed by you and mailed to the parent/legal guardian (as appropriate) containing their information sheet
- SECTION 1 Admission Data Collection Tool (WHITE)
- SECTION 2 Discharge Data Collection Tool (YELLOW)



All information received will be treated in the strictest confidence and the young people, Trusts, referrers or in-patient units will not be identified in the final report. If you have any queries, please contact Simon Tulloch (Research Worker) or Debbie Bannister (Research Assistant) by phone on 020 7977 6662/3 or email: stulloch@cru.rcpsych.ac.uk or dbannister@cru.rcpsych.ac.uk.

Section 1

ADMISSION TOOLS

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Costs, Outcomes and Satisfaction for In-patient Child and Adolescent Psychiatric Services (COSI-CAPS)

'ADMISSION' Data Collection Tools for all young people admitted to an In-patient Psychiatric Unit, aged 12 to 18 yrs inclusive.

- THIS QUESTIONNAIRE IS DOUBLE-SIDED.
 (You can make notes anywhere on this tool or use the notes pages provided)
- The member of staff who knows the young person best, i.e. 'key worker'/consultant, should complete the Paddington complexity scale, HoNOSCA/CGAS, Morgan-Russell Assessment Scale, and CAMHS-AID.

Section	Description	Page number/s
	Admission Data Collection Tool	
1 – A*	Patient Information & Referral details	2 – 5
1 – B*	Diagnosis & Paddington Complexity Scale	6 – 8
1 – C*	Clinical severity rating (HoNOSCA) & (CGAS)	10 – 12
1 – D	Eating disorder tool (Morgan-Russell Assessment Schedule)	14 – 16
1 – E	CAMHS-AID	18 – 27
1 – F	Notes	28

N.B. If the young person is admitted but is an in-patient for fewer than 2 weeks, only complete Sections marked with an asterisk (*).

Form completed by (please use CAPITALS - thank you):	
Name(s):	
Position(s):	
Service:	

All information received will be treated in the strictest confidence and the young people, Trusts, referrers or in-patient units will not be identified in the final report. If you have any queries, please contact Simon Tulloch (Research Worker) or Debbie Bannister (Research Assistant) by phone on 020 7977 6662/3 or email: stulloch@cru.rcpsych.ac.uk or dbannister@cru.rcpsych.ac.uk.

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SECTION 1A:

PATIENT INFORMATION & REFERRAL DETAILS

(Including Children & Mental Health Act Status)

*Note: It is essential that you complete the first two items so that we can track the progress of each individual young person. This information will be kept securely, held only on paper and will be known solely by the researchers.

1	*YOUNG PERSON'S INITIALS			
2	*YOUNG PERSON'S POSTCODE (Only first four components e.g. WS7 8 or WS11 8)	 		

PLEASE GIVE YOUR RESPONSES BY PLACING THE APPROPRIATE NUMBER IN THE BOXES IN THE RIGHT HAND COLUMN, OR BY *TICKING* THE APPROPRIATE BOXES WHERE INSTRUCTED. FREE TEXT SHOULD BE PLACED IN THE BOXES PROVIDED OR IN THE NOTES PAGE AT THE BACK (P28).

					CODE ↓
DAT	TE OF BIRTH (dd/mm/yyyy)				
DAT	TE OF REFERRAL (dd/mm/yyyy)				
DAT	TE OF ASSESSMENT (dd/mm/yyyy)		//		
	TE OF ADMISSION (dd/mm/yyyy)		///		
DA	TE OF ADMISSION (dd/mm/yyyy)				
GEN	NDER (enter ONE number in the box)	1 = M	ale 2	= Female	(1 or 2)
	INICITY: As recorded in the young personartment of Health categories:	on's medical fi	le (enter ONE number i	n the box)	(1 to 16)
WH	ITE	ASIA	N OR ASIAN BRITISH		
1=	British	8 =	Indian		
2 =	Irish	9 =	Pakistani		
3 =	Any other white background [†]	10 =	Bangladeshi		
MIX	ED	11 =	Any other Asian back	ground [†]	
4 =	White & Black Caribbean	BLAC	K / BLACK BRITISH		
5 =	White & Black African	12 =	Caribbean		
6 =	White & Asian	13 =	African		
7 =	Any other mixed background [†]	14 =	Any other Black back	ground [†]	
		OTHE	R ETHNIC GROUPS		
		15 =	Chinese		
16 =	Any other ethnic group (†Please spec	cify for 3, 7, 1	1, 14 & 16)		
Is th	ne young person's first language Eng	lish? (enter O	NE number in the box)		(0 or 1 / 77)
		0 = No	1 = Yes 77 =	Don't know	
If no	o, please specify the young person's	first languag	a :		
	-, promise opening and journey belowing				
L					

SECTION 1A: PATIENT INFORMATION & REFERRAL DETAILS (continued) (please use 77 or DK for 'Don't Know') CODE Residency status: (please code for the criterion that applies to this young person) 10 5 = 1 = **UK** national Refugee status granted 2 = Foreign national visiting 6 = Temporary leave to remain 3 = Foreign national with residency 7 = Exceptional leave to remain 4 = Asylum Seeker Other (please specify): (1 to 13) 11 Source of referral to the in-patient CAMHS unit: (enter ONE number in the box) 1 = CAMHS psychiatrist 7 = **Educational services** 2 = Other CAMHS professional (Please specify 8 = Social worker / Social Services under Other, e.g. clinical psychologist) 9 = General practitioner 3 = Paediatrician (acute) 10 = Accident & emergency 4 = Paediatrician (community) 11 = Youth offending team / courts 5 = Adult mental health team 12 = Police Force medical examiner 6 = Self / parents or guardian 13 = Other (if 2, please specify): (0 or 1 / 77) 12 Was the young person receiving treatment prior to admission? (enter ONE number in the box) 0 = No1 = Yes12a If yes, what types of treatment were received? (please tick) 12a A A = Drug therapy 12a B B = Cognitive behavioural therapy 12a C C = Group therapy 12a D D = Family therapy and family work 12a E E = Brief or solution-focused problem-solving therapy F = 12a F Occupational therapy 12a G G = Parent training / counselling / guidance H = Social skills training 12a I |= Creative therapies (art / music / play / drama) 12a J J = Dietetic advice 12a K K = Physiotherapy L= 12a L Other (please specify) (0 or 1) 13 At the decision to admit, did the young person exhibit hostile or aggressive behaviours? (enter ONE number in the box) 0 = No1 = Yes

SECTION 1A: PATIENT INFORMATION & REFERRAL DETAILS (continued)

	VI	00 11 01 511101	Don't Know')		C
Wha	t was the young person's accom	modation status	at the time the referral was r	made?	(1 to 15 /
(ente	er ONE number in the box)				
1 =	Family home	8 =	Homeless		
2 =	Foster care home	9 =	Other CAP in-patient unit		
3 =	Living independently	10 =	Children's home		
4 =	Living with friends	11 =	In police custody		
5 =	Living with relatives	12 =	Educational residential unit		
6 =	Adult psychiatric ward	13 =	Local authority secure home		
7 =	Paediatric ward	14 =	Young offenders institution		
15 =	Other (please specify):	77 =	Don't know		_
Has	funding been secured to support	the young person	on's placement in an in-patie	nt service?	(0 or 1 /
(ente	r ONE number in the box)		0 = No	1 = Yes	
Sour	ce of funding (enter ONE number	in the hox)			(1 to 3)
	Co or ramaning (orner orne marrison	iii alo box,			
		2 =	NHS		
1 = 3 = C	Private Other (Please specify): IS, please specify the name of the	2 = e funding author	NHS]]
1 = 3 = C	Private Other (Please specify): IS, please specify the name of the	e funding author	ity:		
1 = 3 = C	Private Other (Please specify): IS, please specify the name of the	e funding author	ity:		16 A
1 = 3 = C If NH Who A =	Private Other (Please specify): IS, please specify the name of the gave consent for the young person	e funding author	ity:		16 A 16 B
1 = 3 = C	Private Other (Please specify): IS, please specify the name of the gave consent for the young person Parent / Legal Guardian	e funding author	ity:		
1 = 3 = C	Private Other (Please specify): IS, please specify the name of the gave consent for the young person Parent / Legal Guardian Carer	e funding author	ity:		16 B
1 = 3 = C If NH Who A = B = C =	Private Other (Please specify): IS, please specify the name of the gave consent for the young person Parent / Legal Guardian	e funding author	ity:		16 B
1 = 3 = C If NH Who A = B = C = D =	Private Other (Please specify): IS, please specify the name of the gave consent for the young person Parent / Legal Guardian Carer	e funding author	d? (please tick all that apply)		16 B
1 = 3 = C If NH Who A = B = C = D = Do y	Private Other (Please specify): IS, please specify the name of the gave consent for the young person Parent / Legal Guardian Carer Local authority	e funding author	d? (please tick all that apply)	1 = Yes	16 B 16 C 16 D
1 = 3 = C If NH Who A = B = C = D = Do y (enter	Private Other (Please specify): IS, please specify the name of the gave consent for the young pers The young person Parent / Legal Guardian Carer Local authority ou consider this placement to be	e funding author	d? (please tick all that apply) this young person? 0 = No	1 = Yes	16 B 16 C 16 D
1 = 3 = C If NH Who A = B = C = D = Do y (enter	Private Other (Please specify): IS, please specify the name of the gave consent for the young pers The young person Parent / Legal Guardian Carer Local authority ou consider this placement to be er ONE number in the box)	e funding author	d? (please tick all that apply) this young person? 0 = No	1 = Yes	16 B 16 C
1 = 3 = C If NH Who A = B = C = D = Do y (ente	Private Other (Please specify): IS, please specify the name of the gave consent for the young person Parent / Legal Guardian Carer Local authority ou consider this placement to be er ONE number in the box) O, what is the reason for non-trans	e funding author con to be admitted appropriate for sferral? (please t	d? (please tick all that apply) this young person? 0 = No	1 = Yes	16 B 16 C 16 D
1 = 3 = C If NH Who A = B = C = D = Do y (ente If NC A =	Private Other (Please specify): IS, please specify the name of the gave consent for the young person Parent / Legal Guardian Carer Local authority ou consider this placement to be er ONE number in the box) O, what is the reason for non-trans Appropriate facility unavailable	e funding author con to be admitted appropriate for sferral? (please to	d? (please tick all that apply) this young person? 0 = No	1 = Yes	16 B 16 C 16 D (0 or 1)
1 = 3 = C If NH Who A = B = C = D = Do y (ente If NC A = B = B = B = D C C C C C C C C C	Private Other (Please specify): IS, please specify the name of the gave consent for the young person Parent / Legal Guardian Carer Local authority ou consider this placement to be er ONE number in the box) O, what is the reason for non-trans Appropriate facility unavailable Appropriate facility full / will not admit	e funding author con to be admitted appropriate for sferral? (please to	d? (please tick all that apply) this young person? 0 = No	1 = Yes	16 B 16 C 16 D (0 or 1)
1 = 3 = C If NH Who A = B = C = Do y (ente If NC A = B = C = C = C = C = C = C = C = C = C	Private Other (Please specify): IS, please specify the name of the gave consent for the young person Parent / Legal Guardian Carer Local authority Ou consider this placement to be er ONE number in the box) O, what is the reason for non-trans Appropriate facility unavailable Appropriate facility full / will not admit Lack of funds to pay for appropriate	e funding author con to be admitted appropriate for sferral? (please to	d? (please tick all that apply) this young person? 0 = No	1 = Yes	16 B 16 C 16 D (0 or 1)

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	(please use 77 or DK for 'Don't Know')	CODE
18	Which services were involved in the development of the care package? (tick all that apply)	V
	A = CAMHS psychiatrist B = Other CAMHS professional (Please specify under Other, e.g. clinical psychologist) C = Parents or legal guardian D = Social worker / Social Services E = Educational Services F = General Practitioner G = Youth offending team / courts H = Other (if B, please specify):	18 A 18 B 18 C 18 D 18 E 18 F 18 G
18a	Was information / a brochure regarding the service provided to the young person, family or carer prior to admission? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1)
18b	Did the young person, family or carer visit the unit prior to admission? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1)
18c	If the answer to 18a or 18b is no, please use the space below to explain why:	
19	At the time of admission, was the young person subject to a section of the Children Act 1989? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1 / 77)
19a	If yes, please tick all that apply:	
	A = Section 17 – Children in need	19a A
	B = Section 20 – Accommodated: looked after by Social Services	19a B
	C = Section 31 – Care and supervision order	19a C
	D = Section 25 – Secure accommodation order	19a D
	E = Other (please specify):	19a E
1		
20	At the time of admission, was the young person subject to a section of the Mental Health Act 1983? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1 / 77)
20a	If yes, please tick all that apply:	
	A = Section 2 – Admission for assessment	20a A
	B = Section 3 – Admission for treatment	20a B
	C = Section 4 – Emergency admission	20a C
	D = Section 37 – Hospital order for convicted persons E = Section 38 – Interim hospital order	20a D 20a E
	F = Section 38 – Interim nospital order F = Section 41 – Restriction order	20a F
	G = Sections 47, 48 & 49 – Convicted prisoners removed to hospital	20a G
	H = Section 136 – For mentally disordered persons in public places	20a H
	I = Other (please specify):	20a l

End of Section 1A

Patient information & referral details

SECTION 1B:

(Based on the Paddington Complexity Scale, Yates et al, 1999)								
21	RATER'S PROFESSION:							
21a	RATER'S NAME:							
	<u>I</u>	(please use 77 or	DK for 'D	on't Know')	CODE			
22	DIAGNOSIS (ICD-10): What (Enter ONE number in the bo		orobable	diagnosis for this young person?	(1 to 14 / 77)			
	1 = Eating disorder (F50)		8 =	Disorders of adult personality and behaviour (F	F60-F69)			
	2 = Schizophrenia, delusio	nal or psychotic	9 =	Hyperkinetic disorders (F90)	F02)			
	disorders (F20-F29) 3 = Mood (affective) disord	lers (F30-F39)	10 = 11 =	Conduct disorders (including mixed CED) (F91 Organic, including symptomatic, mental	-F92)			
	4 = Mental and behavioura	, ,		disorders (F00-F09)				
	psychoactive substance		12 =	Behavioural syndromes associated with				
	5 = Anxiety disorders (F40	-F41)		physiological disturbances (F50-F59)				
	6 = Obsessive-compulsive	disorder	13 =	Disorders of psychological development (F80-	- 89)			
	7 = Other neurotic, stress-	related and	77 =	Diagnosis not known				
	somatoform disorders	•						
	14 = Other diagnosis (plea	ise specify):			7			
22a	Age: Height: Weight: N.B. Please complete the Mc	Height:						
22b	If primary diagnosis is 1 = 1			,				
	1: Anorexia (typical & atypical &							
23	If a primary diagnosis is no (Enter ONE number from the		code fo	r possible or likely diagnosis if known.	(1 to 14 / 77)			
24	Please specify the young p (Enter ONE number from the		diagnosi	s if known.	(1 to 14 / 77)			
25	Please specify any other di	agnosable co-morb	idity: (ple	ease use notes pages if required)				
26	What has been the duration (enter ONE number in the bo				(0 or 1)			
27	Has an analysis of risk bee (enter ONE number in the bo			0 = No 1 = Yes	(0 to 1 / 77)			

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SECTION 1B: DIAGNOSIS & PSYCHOSOCIAL COMPLEXITY (continued) (please use 77 or DK for 'Don't Know') CODE $\mathbf{\Psi}$ 28 Is this the patient's first contact with mental health services? 0 = No (enter ONE number in the box) 1 = Yes (0 to 3) 29 What is the severity of the condition? (enter ONE number in the box) 0 =Mild 2 = Severe 1 = Moderate 3 = Extreme (1 to 4) 30 **Is this young person viewed to be at risk to:** (enter ONE number in the box) 1 = 3 = Both 1 & 2 2 = Others 4 = Not at risk to self or others 31 Does this young person have a history of any of the following: (tick all criteria that apply) 31 A Physical abuse 31 B B = Sexual abuse Emotional abuse 31 C C = 31 D D = Neglect E = Child Protection Registration 31 F F = None of the above 31 G G = Don't know 32 (1 to 5) What level of observation does this young person require? 4 = 1:1 4:1 1 = 2:1 2 = 5 = None of the above 3:1 3 = 33 Does this young person have a learning disability or specific learning difficulty? (0 to 6) (enter ONE number in the box) Generalised – moderate (e.g. F71: IQ 35 to 49) None Generalised - severe (e.g. F72: IQ 20 to 34) 1 = Specific learning difficulty 4 = 2 = Generalised – mild (e.g. F70: IQ 50 to 69) 5 = Generalised but IQ not been tested 6 = Other, please specify: (0 or 1 / 77) 34 Does this young person have a statement of special educational needs? (enter ONE number in the box) 0 = No1 = Yes (0 to 11) 35 What school or education service did this young person attend or receive? (enter ONE number in the box) 0 = No school (exclusion & no other provision) 5 = Further or higher educational college 1 = Mainstream secondary school 6 = LEA special needs day school 2 = 7 = Special unit in mainstream school LEA special needs boarding school 3 = Pupil referral unit 8 = Independent special needs day school 4 = Home tuition provided by LEA 9 = Independent special needs boarding school 11 = Other (please specify): 10 = Not applicable (left school-post 16)

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SECTIO)N 1B:	N 1B: DIAGNOSIS & PSYCHOSOCIAL COMPLEXITY (continued)						
		(please use 77 or DK for 'Don't Know')						
36	In the last term of school prior to this referral, was the young person excluded or suspended from school? (enter ONE number in the box): 0 = No 1 = Yes							
36a	If yes	s, number of days permanently e	xcluded:			Number		
36b	If yes	s, number of days temporarily ex	cluded / suspe	ended:		Number		
37		is this young person's main car	`	,		(0 to 9)		
	0 =	Both natural parents	4 =	Relative(s) (other the	nan grandparents)			
	1 =	Single parent	5 =	Formal foster parer	nts			
	2 =	Natural mother with mother's partne	r 6 =	Adoptive parents				
	3 =	Natural father with father's partner	7 =	Local authority (chi	ldren's home)			
	9 =	Other carers, please specify:	8 =	Grandparents				
						_		
38		se indicate the carer's attitude to er ONE number in the box)	and co-operat 0 = Facilitative	tion with assessme 1 = Indifferent	ent or treatment. 2 = Counter-productive	(0 to 2)		
39	Door	s the parent / carer have a diagno	sabla mantal k	scalth problem?		(0 or 1 / 77)		
39		r ONE number in the box)	Sabie illelitai i	lealth problem?	0 = No 1 = Yes			
	(Citto	one number in the boxy			0 - 140 1 - 163			
40		e any other agencies been involves indicate 1 or 2 for each question		g person's care? 1 = Currently	2 = Previously			
	A =	Other CAMHS in-patient unit				40 A		
	B =	Community teams				40 B		
	C =	Paediatrics				40 C		
	D =	Adult mental health				40 D		
	E=	Social Services				40 E		
	F=	Youth offending team / courts / proba	ation			40 F		
	G =	Other (please specify):				40 G		
		Carron (produce apoenty).						
						J		

End of Section 1B

DIAGNOSIS & PSYCHOSOCIAL COMPLEXITY

ID CODE	«Unit Cod

SECTION 1C:

CLINICAL SEVERITY RATING

(Please complete HoNOSCA, and CGAS on p 16)

Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) – Score Sheet

Gowers, S.G., Harrington, R.C., Whitton, A., Beevor, A.S., Lelliott, P., Jezzard, R., Wing, J.K (1998). (See glossary on pages 62-64)

Before you complete the HoNOSCA score sheet, please take time to read and refer to the definitions and instructions outlined in the Glossary on pages 62 - 64. The HoNOSCA training materials are available free of charge to all CAMHS in the UK and may be ordered from the HoNOSCA website: http://www.liv.ac.uk/honosca and http://www.liv.ac.uk/cru/honosca/training.htm.

Even if you have not received formal training in the use of HoNOSCA, we still ask that you provide a rating for this young person on the following behavioural domains. This data will allow us to compare the clinical severity of those not admitted with those admitted, and we can run comparisons with the HoNOSCA scores for previously studied populations (NICAPS in-patient population and the Audit Commission's 'Children in Mind' population data).

Please rate, to the best of your knowledge, the severity of difficulties the patient has experienced <u>two weeks prior to</u> admission in the following areas:

41	HoNOSCA rater's profession:					
SECTION A 42	No.	Scale	Score scale 0-4 Rate 9 if not known			
	1.	Disruptive, antisocial or aggressive behaviour				
	2.	Overactive, attention or concentration				
	3.	Non-accidental self-injury				
	4.	Alcohol, substance or solvent misuse				
	5.	Scholastic or language skills				
	6.	Physical illness or disability problems				
	7.	Hallucinations and delusions				
	8.	Non-organic somatic symptoms				
	9.	Emotional and related symptoms				
	10.	Peer relationships				
	11.	Self-care and independence				
	12.	Family life and relationships				
	13.	Poor school attendance				
43		SECTION A total score				
SECTION B	1.	Lack of knowledge – nature of difficulties				
	2.	Lack of information – services / management				
44		SECTION B total score				
45		SECTION A & B TOTAL SCORE				
46		Have you been trained to use the HoNOSCA scales? 0 = No 1 = Yes	CODE:			

	Children's Global Assessment Scale (CGAS) M.D., Madelyn S. Gould, Ph.D. Hector Bird, M.D., Prudence Fisher, B.A. Adaptation of the Adult Global cale (Robert L. Spitzer, M.D., Nathan Gibbon, M.S.W., Jean Endicott, Ph.D.) DOING VERY WELL Superior functioning in all areas (at home, at school and with peers), involved in a range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organised group
Assessment Sc 100 – 91	cale (Robert L. Spitzer, M.D., Nathan Gibbon, M.S.W., Jean Endicott, Ph.D.) DOING VERY WELL Superior functioning in all areas (at home, at school and with peers), involved in a range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organised group
100 – 91	DOING VERY WELL Superior functioning in all areas (at home, at school and with peers), involved in a range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organised group
	Superior functioning in all areas (at home, at school and with peers), involved in a range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organised group
90 – 81	such as Scouts, etc.). Likeable, confident, everyday worries never get out of hand. Doing well in school. No symptoms.
	DOING WELL
	Good functioning in all areas. Secure in family, school, and with peers. There may be transient difficulties and "everyday" worries that occasionally get out of hand (e.g. mild anxiety associated with an important exam occasional "blow-ups" with siblings, parents or peers).
80 – 71	DOING ALL RIGHT – minor impairment
	No more than slight impairment in functioning at home, at school, or with peers. Some disturbance of behaviour or emotional distress may be present in response to life stresses (e.g. parental separations, deaths birth of a sibling) but these are brief and interference with functioning is transient. Such children are only minimally disturbing to others and are not considered deviant by those who know them.
70 – 61	SOME PROBLEMS – in one area only
	Some difficulty in a single area, but generally functioning pretty well (e.g. sporadic or isolated antisocial acts such as occasionally playing hooky, petty theft, consistent minor difficulties with school work, mood changes o brief duration, fears and anxieties which do not lead to gross avoidance behaviour; self-doubts). Has some meaningful interpersonal relationships. Most people who do not know the child well would not consider him/he deviant but those who do know him/her well might express concern.
60 – 51	SOME NOTICEABLE PROBLEMS – in more than one area
	Variable functioning with sporadic difficulties or symptoms in several but not all social areas. Disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not to those who see the child in other settings.
50 – 41	OBVIOUS PROBLEMS – moderate impairment in most areas or severe in one area Moderate degree of interference in functioning in most social areas or severe impairment functioning in one area, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and othe forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, frequent episodes of aggressive or other antisocial behaviour with some preservation of meaningful social relationships.
40 – 31	SERIOUS PROBLEMS – major impairment in several areas and unable to function in one area
	Major impairment in functioning in several areas and unable to function in one of these areas, i.e. disturbed a home, at school, with peers, or in society at large (e.g. persistent aggression without clear instigation, markedly withdrawn and isolated behaviour due to either mood or thought disturbance, suicidal attempts with clear lethal intent). Such children are likely to require special schooling and/or hospitalisation or withdrawal from school (but this is not a sufficient criterion for inclusion in this category).
30 – 21	SEVERE PROBLEMS – unable to function in almost all situations
	Unable to function in almost all areas, (e.g. stays at home, in ward or in bed all day without taking part in social activities OR severe impairment in reality testing OR serious impairment in communication—e.g. sometimes incoherent or inappropriate).
20 – 11	VERY SEVERELY IMPAIRED – considerable supervision is required for safety Needs considerable supervision to prevent hurting others or self, (e.g. frequently violent, repeated suicide attempts OR to maintain personal hygiene OR gross impairment in all forms of communication—e.g. severe abnormalities in verbal and gestural communication, marked social aloofness, stupor, etc.).
10 – 1	EXTREMELY IMPAIRED – constant supervision is required for safety Needs constant supervision (24-hour care) due to severely aggressive or self-destructive behaviour or gross impairment in reality testing, communication, cognition, affect, or personal hygiene.
	Specified time period: 1 month

End of Section 1C

CLINICAL SEVERITY RATING

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SECTION 1D:

MORGAN-RUSSELL ASSESSMENT SCHEDULE (ADOLESCENT VERSION 2.0)

SCALE A: FOOD INTAKE

Sub Scale A1 - Dietary restriction

Is the subject restricting her diet, or has she done so at any time in the last month?

Restricts at all meal	More than half meal	About half the time	Less than half the time	Nil
times	times			
•	_	_	_	
0	3	6	9	12

Coding instructions: Ignore minor carbohydrate restriction to the extent of being careful about the amount of sugar or bread, because such attitude is common even in normal individuals. Only true reduction in food intake below average levels is taken as significant for the purpose of rating on this scale.

Sub Scale A2 - Worry about body weight or appearance

Has she been worried about her weight or her appearance in any other way at any time in the last month?

Severe concern at all times	Moderate preoccupation most of the time	Frequent concerns	Only occasional mild concern	Nil
0	3	6	9	12

Sub Scale A3 - Body weight as a %

< 65%	65 – 70%	70 – 75%	75 – 80%	80 – 85%	85 – 90%	> 90%
0	2	4	6	8	10	12

SCALE B: MENSTRUAL PATTERN (in previous 3 months)

No menstruation at any time	Transient occasional menstrual loss, which is never cyclical	Irregular menstrual loss with some cyclical pattern	Regular and cyclical throughout
0	4	8	12

SCALE C: MENTAL STATE (as observed at interview and reported abnormalities in the last month)

Grossly abnormal and psychotic with delusions and hallucinations	Marked disturbance but not psychotic	Mild disturbance	Normal
0	4	8	12

Coding instructions: This scale is based on a mental state assessment during interview, and information about the psychiatric status during the previous six months. The distinction between "marked" and "mild" disturbance of one type was made on the basis of interference with general activities. Thus, symptoms which prevented the patient working at any time in the six month period would be rated as "marked". If symptoms are judged as present and significant (excluding marked ideas about food), yet they have not interfered with normal activities, these are rated as "mild".

SECTION 1D: MORGAN-RUSSELL ASSESSMENT SCHEDULE (ADOLESCENT VERSION 2.0) (continued)

SCALE D: PSYCHOSEXUAL STATE

Sub Scale D1 - Attitude towards psychosexual development

Attitude towards sexual matters - taking into account the developmental norms of the subject's age

Active dislike	Disinterested or mild discomfort	Little interest or incomplete adjustment	Appropriate interest and adjustment in psychosexual development
0	4	8	12

Sub Scale D2 - Overt sexual behaviour: assessed against norms for subject's age

No sexual behaviour	Intermittent non sexual relationships	Regular age appropriate sexual relationships
0	6	12

Sub Scale D3 - Attitude to menstruation

Active dislike	Mild aversion	Disinterest	Positive attitude
0	4	8	12

SCALE E: SOCIO-ECONOMIC STATE

Sub Scale E1 - Relationship with nuclear family

Relationship with parents (and siblings)?

Very unsatisfactory	Unsatisfactory	Indifferent	Satisfactory
0	4	8	12

Coding instructions: In view of the fact that relationship may vary with different members of the family, the lowest individual rating is taken, whether it is with parent or sibling. When another informant is seen beside the patient, the final rating is taken as the average of these two scores.

Sub Scale E2 - Emancipation from family (degree of age appropriate autonomy without transferred dependency)

Many difficulties, sees no prospect of becoming independent to a satisfactory degree	As for 0, but at times feels that difficulties can be surmounted	Some difficulties but they are surmountable	No difficulties
0	4	8	12

Sub Scale E3 - Personal contacts (apart from family)

None	Superficial	Many, but superficial	Many close and superficial friends
0	4	8	12

SECTION 1D: MORGAN-RUSSELL ASSESSMENT SCHEDULE (ADOLESCENT VERSION 2.0) (continued)

Sub Scale E4 - Social activities (appropriate to status)

Nil outside family	Solitary outcome family	Variable, mainly solitary but some group activities outside family	Adequate group activities: mixes well outside family
0	4	8	12

Sub Scale E5 - Employment or education record over the last month

No paid employment or schooling	Up to 50% of the period in paid employment or occasional unpaid employment or up to 50% of the period in education	More than 50% of the period in paid employment or education, but less than 100%	Regular full time paid employment without absences; or full time education without absences
0	4	8	12

Please use the space below to provide any other relevant information:	

End of Section 1D

MORGAN-RUSSELL ASSESSMENT SCHEDULE

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	SECTION 1F: NOTES		
Thank you.	PLEASE USE THIS PAGE TO WRITE ANY EXTRA NOTES YOU FEEL ARE RELEVENT TO THE QUESTIONS ASKED. Thank you. (Please place the number of the question you are referring to in the left hand column.)		
Question Number	Notes		
Tumbo.			

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Section 2

DISCHARGE TOOLS

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Costs, Outcomes and Satisfaction for In-patient Child and Adolescent Psychiatric Services (COSI-CAPS)

'DISCHARGE' Data Collection Tools for all young people discharged from an In-patient Psychiatric Unit, aged 12 to 18 yrs inclusive.

- THIS QUESTIONNAIRE IS DOUBLE-SIDED.
 (You can make notes anywhere on this tool or use the notes pages provided)
- The member of staff who knows the young person best, i.e. 'key worker'/consultant, should complete the Paddington complexity scale, HoNOSCA/CGAS, Morgan-Russell Assessment Scale, and CAMHS-AID.

Section	Description	Page number/s
	Discharge Data Collection Tool	
2 – A	Patient Information & Treatment Received	34 – 36
2 – B	Discharge Information	38 – 39
2 – C	Children Act and Mental Health Act Status	40
2 – D	Discharge Diagnosis	42
2 – E	Clinical Severity Rating (HoNOSCA) & (CGAS)	44 – 46
2 – F	Eating disorder tool (Morgan-Russell Assessment Schedule)	48 – 50
2 – G	CAMHS-AID	52 – 61
2 – H	Glossary (HoNOSCA)	62 – 64
2 – I	Notes	65

Discharge date:	
-----------------	--

Form completed by (please use CAPITALS - thank you):				
Name(s):				
Position(s):				
Service:				

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SECTION 2A:

PATIENT INFORMATION & TREATMENT RECEIVED

Has	any patient information prov	vided in Section 1A	(p 2 - 5) chang	ed since adm	nission?	
e.g.	Residency status (please sp	ecify – include ques	stion number)			
Г						
Has	a Care Programme Approac	h (CPA) meeting he	en held?			(0
	er ONE number in the box)	ii (oi A) iiiccaiig bc	on noid.	0 = No	1 = Yes	
The	CPA was delivered on whicl	n lovel 2				(0
	er ONE number in the box)	i lever?	0 = Standard	1 :	= Enhanced	
`	,	4ha dayadan oo 6 1	[4]n) /mla=== (' '	١ ١ ٠٠٠٠ ١ ١ ١ ١ ١ ١	
	ch services were involved in	the development of	the care plan	(please tick	ali that apply)	3 /
A =	CAMHS psychiatrist	'r 1 0'l				37
B =	Other CAMHS professional (Pl	•	er, e.g. clinical ps	ycnologist)		3 (
C =	Social worker / Social Services	3				3
D =	Educational services					3
E = F =	General practitioner					31
Г – G =	Youth offending team / courts Other (if B, please specify):					3
о- Г	Other (II b, please specify).					
L						
	involved were the young pe	-	•		•	(0
(ente	er ONE number in the box)	0 = Not at all	1 = Partly	2 = Mostly	3 = Fully	L
How	involved was the YP in dev	eloping the care pla	n?			(0
(ente	er ONE number in the box)	0 = Not at all	1 = Partly	2 = Mostly	3 = Fully	
·	. 41 1 41 4	lak the ODA				(1
	the in-patient stay, how reg r ONE number in the box)	Jularly was the CPA	reviewed?			(.
1 =	Weekly	4 =	Monthly			
2 =	Fortnightly	5 =	Bi-monthly			
_	Every three weeks	6 =	If / when requ	iired		
3 =						

SECTION 2A: PATIENT INFORMATION & TREATMENT RECEIVED (continued)

(please use 77 or DK for	or 'Don't Know'
--------------------------	-----------------

ypes of treatment received: (Please complete the ta Treatment Received	100000		ber of se	ssions	
	0	1 - 5	6 - 10	11 - 15	16 +
Cognitive and / or behavioural therapy					
Group therapy					
Family therapy and family work					
Brief or solution-focused problem-solving therapy					
Occupational therapy					
Parent training / counselling / guidance					
Social skills training					
Creative therapies (art / music / play / drama) (please specify)					
Dietetic advice					
Other (please specify)					
rug Therapy: please list all drugs prescribed duri lease use notes pages if required)	ng in-pa				
	ng in-pa	tient stay		ation.	;)
lease use notes pages if required)	ng in-pa				3)
lease use notes pages if required)	ng in-pa				e)
lease use notes pages if required)	ng in-pa				÷)
lease use notes pages if required)	ng in-pa				e)
lease use notes pages if required)	ng in-pa				3)
lease use notes pages if required)	ng in-pa				3)
lease use notes pages if required)	ng in-pa				÷)
lease use notes pages if required)	ng in-pa				3)
lease use notes pages if required)	ng in-pa				e)

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SECTIO	N 2A: PATIENT INFORMATION & TREATMENT RECEIVED (continued)	
	(please use 77 or DK for 'Don't Know')	CODE ↓
9	Would additional treatment have been suitable if available? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1 / 77)
9a	If yes, please use the space below / notes page to explain.	
10	Was a restriction of the young person's liberty required at any time during the in-patient stay? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1 / 77)
10a	If yes, detail the form and duration the table below:	
	e.g. Restraint, Physical Liberty Number of occasions Duration (hrs/mins)	
10b	Was rapid tranquillisation used at any time during the in-patient stay? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1 / 77)
11	Do you consider the in-patient stay to have had a negative effect on the young person? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1)
	If yes, please use the space below / notes page to explain:	

End of Section 2A

PATIENT INFORMATION & TREATMENT RECEIVED

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SECTION 2B: DISCHARGE INFORMATION

	(please use 77 or DK for 'Don't Know')	CODE
12	Has a written discharge plan been completed? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1)
12b	If yes, who completed the discharge plan?	
13	Has the young person been involved in developing the discharge plan? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1)
14	Have the young person's parents / carers been involved in developing the discharge plan?	(0 or 1)
	(enter ONE number in the box) 0 = No 1 = Yes	
15	Does the discharge plan appear in the CPA documentation?	(0 or 1)
	(enter ONE number in the box) 0 = No 1 = Yes	
16	Which services were involved in the development of the discharge plan? (please tick all that apply)	
	A = CAMHS psychiatrist	16 A
	B = Other CAMHS professional (Please specify under other e.g. clinical psychologist) C = Parents or guardian	16 B
	D = Social worker / Social Services	16 D
	E = Educational services	16 E
	F = General practitioner	16 F
	G = Youth offending team / courts H = Other (if B, please specify):	16 H
17	Was the young person's discharge delayed for any reason? (enter ONE number in the box) 0 = No 1 = Yes	(0 or 1)
17a	If yes, why? (please tick all that apply)	
	A = Diagnosis	17a A
	B = Family refuse	17a B
	C = Difficulty arranging local follow-up / community support D = Provision of educational support	17a D
	E = Delays in agreement / funding of residential placement	17a E
	F = No permanent accommodation available	17a F
	G = Other (please specify):	17a G
17b	How long was the young person's discharge delayed?	-
	Months: Weeks: Days:	

SECTION 2B: DISCHARGE INFORMATION (continued)	
(please use 77 or DK for 'Don't Know')	CODE ↓
What follow-up arrangements have been made? A = Referred back to referrer B = Follow-up provided by unit C = Referral to other agency (please specify below) D = Other (please specify):	18 A 18 B 18 C
What is the young person's destination following discharge? 1 = Home	
Which type of service is the young person being referred to after they are discharged from the unit? (please tick all that apply) A = Out-patient community CAMHS B = Forensic adolescent community treatment teams C = Adolescent outreach teams D = Early intervention for psychosis teams E = Adult psychiatric ward F = Community general psychiatry G = Youth offending team H = Social Services I = Educational services J = Home-based treatment K = Child and family centres L = Other (if A, please specify):	20 A 20 B 20 C 20 D 20 E 20 F 20 G 20 H 20 I 20 J 20 K 20 L
Why was this service chosen? (please outline)	
Contact details for the principal professional the young person will be in contact with: Professional's name: Position: Service name: Service address:	- - -
Telephone No. & extension	

End of Section 2B

DISCHARGE INFORMATION

SECTION 2C:

CHILDREN ACT AND MENTAL HEALTH ACT STATUS

\Box			now')	CO
		y time during the admission was the young person subjectives (enter ONE number in the box)	ect to a section of the Children 0 = No 1 = Yes	(0 or 1/77)
	If yes	, please tick all that apply:		
	A =	Section 17 – Children in need		23a A
	B =	Section 20 – Accommodated: looked after by Social Services		23a B
	C =	Section 31 – Care and supervision order		23a C
	D =	Section 25 – Secure accommodation order		23a D
	E =	Other (please specify):		23a E
	Healt	y time during the admission, was the young person subj h Act 1983? (enter ONE number in the box)	ect to a section of the Mental 0 = No 1 = Yes	(0 or 1 / 77
	Healt			(0 or 1 / 77)
	Healt If yes	h Act 1983? (enter ONE number in the box) , please tick all that apply:		
	Healt If yes A =	h Act 1983? (enter ONE number in the box) , please tick all that apply: Section 2 – Admission for assessment		24a A
	Healt If yes A = B =	h Act 1983? (enter ONE number in the box) , please tick all that apply: Section 2 – Admission for assessment Section 3 – Admission for treatment		24a A 24a B 24a C 24a D
	Healt If yes A = B = C =	h Act 1983? (enter ONE number in the box) p, please tick all that apply: Section 2 – Admission for assessment Section 3 – Admission for treatment Section 4 – Emergency admission		24a A 24a B 24a C 24a C 24a D
	Healt If yes A = B = C = D = E = F =	h Act 1983? (enter ONE number in the box) please tick all that apply: Section 2 – Admission for assessment Section 3 – Admission for treatment Section 4 – Emergency admission Section 37 – Hospital order for convicted persons Section 38 – Interim hospital order Section 41 – Restriction order	0 = No 1 = Yes	24a A 24a B 24a C 24a D 24a E 24a F
	Healt If yes A = B = C = D = E = F = G =	h Act 1983? (enter ONE number in the box) please tick all that apply: Section 2 — Admission for assessment Section 3 — Admission for treatment Section 4 — Emergency admission Section 37 — Hospital order for convicted persons Section 38 — Interim hospital order Section 41 — Restriction order Sections 47, 48 & 49 — Convicted prisoners removed to ho	0 = No 1 = Yes	24a A 24a B 24a C 24a D 24a E 24a F 24a G
	Healt If yes A = B = C = D = E = F =	h Act 1983? (enter ONE number in the box) please tick all that apply: Section 2 – Admission for assessment Section 3 – Admission for treatment Section 4 – Emergency admission Section 37 – Hospital order for convicted persons Section 38 – Interim hospital order Section 41 – Restriction order	0 = No 1 = Yes	24a A 24a B 24a C 24a D 24a E 24a F

End of Section 2C

CHILDREN ACT AND MENTAL HEALTH ACT STATUS

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SECTION 2D:

DISCHARGE DIAGNOSIS

(please use 77 or DK for 'Don't Know')

CODE
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25		AGNOSIS (ICD- nter ONE number		orincipal or pro	bable d	iagnosis for this young person?	(0 to 14 / 77)
	1 =	Eating dis	sorder (F50)		8 =	Disorders of adult personality and behaviour (F	60-F69)
	2 =	Schizoph	renia, delusional or p	sychotic	9 =	Hyperkinetic disorders (F90)	
		disorders	(F20-F29)		10 =	Conduct disorders (including mixed CED) (F91	-F92)
	3 =	Mood (aff	fective) disorders (F3	80-F39)	11 =	Organic, including symptomatic, mental	
	4 =	Mental ar	nd behavioural disord	lers due to		disorders (F00-F09)	
		psychoac	ctive substance use (F10-F19)	12 =	Behavioural syndromes associated with	
	5 =	Anxiety d	isorders (F40-F41)			physiological disturbances (F50-F59)	
	6 =	Obsessiv	e-compulsive disorde	er	13 =	Disorders of psychological development (F80-F	- 89)
	7 =	Other neu	urotic, stress-related	and			
		somatofo	rm disorders (F43-F4	18)			
	14	= Other dia	agnosis (please spe	ecify):			1
05-	16		ala la 4 – Fatino d		-1		
25a	пр	orimary diagnos	sis is 1 = Eating o	lisoraer (F50),	piease	give measurements for:	
		Age:					
		Height:					
		Weight:					
	N F) Diagon commi	lata tha Mayran D	aadl Aaaaa		ala (n. 40 . 50)	
	IN.E	s. Please compl	ete the Morgan-R i	usseli Assessi	ment Sc	ale (p 46 - 50).	
25b	If p			lisorder (F50),	please	specify type below:	1
			ypical & atypical)				
		() (oical & atypical)				
		3: Other					
26			e young person's er from the list above		agnosis	if known.	(0 to 14 / 77)
	`			•			
27	Ple	ase briefly des	scribe any comorl	bidity (please ι	ise notes	s pages if required):	1

End of Section 2D

DISCHARGE DIAGNOSIS

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SECTION 2E:

CLINICAL SEVERITY RATING

(Please complete HoNOSCA, and CGAS on p 46)

Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) – Score Sheet

Gowers, S.G., Harrington, R.C., Whitton, A., Beevor, A.S., Lelliott, P., Jezzard, R., Wing, J.K (1998). (See glossary on pages 62 - 64)

Before you complete the HoNOSCA score sheet, please take time to read and refer to the definitions and instructions outlined in the Glossary on pages 62 - 64. The HoNOSCA training materials are available free of charge to all CAMHS in the UK and may be ordered from the HoNOSCA website: http://www.liv.ac.uk/honosca and http://www.liv.ac.uk/honosca and http://www.rcpsych.ac.uk/cru/honoscales/honosca/training.htm.

Even if you have not received formal training in the use of HoNOSCA, we still ask that you provide a rating for this young person on the following behavioural domains. This data will allow us to compare the clinical severity of those not admitted with those admitted, and we can run comparisons with the HoNOSCA scores for previously studied populations (NICAPS inpatient population and the Audit Commission's 'Children in Mind' population data).

Please rate, to the best of your knowledge, the severity of difficulties the patient has experienced <u>two weeks prior</u> to admission in the following areas:

29	HoNOSCA rater's profession:				
SECTION A 30	No.	Scale	Score scale 0-4 Rate 9 if not known		
	1.	Disruptive, antisocial or aggressive behaviour			
	2.	Overactive, attention or concentration			
	3.	Non-accidental self-injury			
	4.	Alcohol, substance or solvent misuse			
	5.	Scholastic or language skills			
	6.	Physical illness or disability problems			
	7.	Hallucinations and delusions			
	8.	Non-organic somatic symptoms			
	9.	Emotional and related symptoms			
	10.	Peer relationships			
	11.	Self-care and independence			
	12.	Family life and relationships			
	13.	Poor school attendance			
31		SECTION A total score			
SECTION B	1.	Lack of knowledge – nature of difficulties			
	2.	Lack of information – services / management			
32		SECTION B total score			
33		SECTION A & B TOTAL SCORE			
34		Have you been trained to use the HoNOSCA scales? 0 = No 1 = Yes	CODE:		

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SECTION 2E: CLINICAL SEVERITY RATING (continued)					
Children's Global Assessment Scale (CGAS)					
David Shaffer, M.D., Madelyn S. Gould, Ph.D. Hector Bird, M.D., Prudence Fisher, B.A. Adaptation of the Adult Global Assessment Scale (Robert L. Spitzer, M.D., Nathan Gibbon, M.S.W., Jean Endicott, Ph.D.)					
100 – 91	DOING VERY WELL				
	Superior functioning in all areas (at home, at school and with peers), involved in a range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organised group such as Scouts, etc.). Likeable, confident, everyday worries never get out of hand. Doing well in school. No symptoms.				
90 – 81	DOING WELL				
30 01	Good functioning in all areas. Secure in family, school, and with peers. There may be transient difficulties and "everyday" worries that occasionally get out of hand (e.g. mild anxiety associated with an important exam, occasional "blow-ups" with siblings, parents or peers).				
80 – 71	DOING ALL RIGHT – minor impairment				
	No more than slight impairment in functioning at home, at school, or with peers. Some disturbance of behaviour or emotional distress may be present in response to life stresses (e.g. parental separations, deaths, birth of a sibling) but these are brief and interference with functioning is transient. Such children are only minimally disturbing to others and are not considered deviant by those who know them.				
70 – 61	SOME PROBLEMS - in one area only				
	Some difficulty in a single area, but generally functioning pretty well (e.g. sporadic or isolated antisocial acts, such as occasionally playing hooky, petty theft, consistent minor difficulties with school work, mood changes of brief duration, fears and anxieties which do not lead to gross avoidance behaviour; self-doubts). Has some meaningful interpersonal relationships. Most people who do not know the child well would not consider him/her deviant but those who do know him/her well might express concern.				
60 – 51	SOME NOTICEABLE PROBLEMS – in more than one area				
	Variable functioning with sporadic difficulties or symptoms in several but not all social areas. Disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not to those who see the child in other settings.				
50 – 41	OBVIOUS PROBLEMS – moderate impairment in most areas or severe in one area Moderate degree of interference in functioning in most social areas or severe impairment functioning in one area, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and other forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, frequent episodes of aggressive or other antisocial behaviour with some preservation of meaningful social relationships.				
40 – 31	SERIOUS PROBLEMS – major impairment in several areas and unable to function in one area Major impairment in functioning in several areas and unable to function in one of these areas, i.e. disturbed at home, at school, with peers, or in society at large (e.g. persistent aggression without clear instigation, markedly withdrawn and isolated behaviour due to either mood or thought disturbance, suicidal attempts				
	with clear lethal intent). Such children are likely to require special schooling and/or hospitalisation or withdrawal from school (but this is not a sufficient criterion for inclusion in this category).				
30 – 21	SEVERE PROBLEMS – unable to function in almost all situations				
	Unable to function in almost all areas (e.g. stays at home, in ward or in bed all day without taking part in social activities OR severe impairment in reality testing OR serious impairment in communication—e.g. sometimes incoherent or inappropriate).				
20 – 11	VERY SEVERELY IMPAIRED – considerable supervision is required for safety				
	Needs considerable supervision to prevent hurting others or self (e.g. frequently violent, repeated suicide attempts OR to maintain personal hygiene OR gross impairment in all forms of communication—e.g. severe abnormalities in verbal and gestural communication, marked social aloofness, stupor, etc.).				
10 – 1	EXTREMELY IMPAIRED – constant supervision is required for safety Needs constant supervision (24-hour care) due to severely aggressive or self-destructive behaviour or gross impairment in reality testing, communication, cognition, affect, or personal hygiene.				
	Specified time period: 1 month				
CGAS Score =					

End of Section 2E

CLINICAL SEVERITY RATING

SECTION 2F:

MORGAN-RUSSELL ASSESSMENT SCHEDULE (ADOLESCENT VERSION 2.0)

Note: This tool has not been altered for usage with males; please adapt where appropriate.

SCALE A: FOOD INTAKE

Sub Scale A1 - Dietary restriction

Is the subject restricting her diet, or has she done so at any time in the last month?

Restricts at all meal times	More than half meal times	About half the time	Less than half the time	Nil
0	3	6	9	12

Coding instructions: Ignore minor carbohydrate restriction to the extent of being careful about the amount of sugar or bread, because such attitude is common even in normal individuals. Only true reduction in food intake below average levels is taken as significant for the purpose of rating on this scale.

Sub Scale A2 - Worry about body weight or appearance

Has she been worried about her weight or her appearance in any other way at any time in the last month?

Severe concern at all times	Moderate preoccupation most of the time	Frequent concerns	Only occasional mild concern	Nil
0	3	6	9	12

Sub Scale A3 - Body weight as a %

< 65%	65 – 70%	70 – 75%	75 – 80%	80 – 85%	85 – 90%	> 90%
0	2	4	6	8	10	12

SCALE B: MENSTRUAL PATTERN (in previous 3 months)

No menstruation at any time	Transient occasional menstrual loss, which is never cyclical	Irregular menstrual loss with some cyclical pattern	Regular and cyclical throughout
0	4	8	12

SCALE C: MENTAL STATE (as observed at interview and reported abnormalities in the last month)

Grossly abnormal and psychotic with delusions and hallucinations	Marked disturbance but not psychotic	Mild disturbance	Normal
0	4	8	12

Coding instructions: This scale is based on a mental state assessment during interview, and information about the psychiatric status during the previous six months. The distinction between "marked" and "mild" disturbance of one type was made on the basis of interference with general activities. Thus, symptoms which prevented the patient working at any time in the six month period would be rated as "marked". If symptoms are judged as present and significant (excluding marked ideas about food), yet they have not interfered with normal activities, these are rated as "mild".

SECTION 2F: MORGAN-RUSSELL ASSESSMENT SCHEDULE (ADOLESCENT VERSION 2.0) (continued)

SCALE D: PSYCHOSEXUAL STATE

Sub Scale D1 - Attitude towards psychosexual development

Attitude towards sexual matters – taking into account the developmental norms of the subject's age

Active dislike	Disinterested or mild discomfort	Little interest or incomplete adjustment	Appropriate interest and adjustment in psychosexual development
0	4	8	12

Sub Scale D2 - Overt sexual behaviour: (assessed against norms for subject's age)

No sexual behaviour	Intermittent non sexual relationships	Regular age appropriate sexual relationships
0	6	12

Sub Scale D3 - Attitude to menstruation

Active dislike	Mild aversion	Disinterest	Positive attitude
0	4	8	12

SCALE E: SOCIO-ECONOMIC STATE

Sub Scale E1 - Relationship with nuclear family

Relationship with parents (and siblings)?

Very unsatisfactory	Unsatisfactory	Indifferent	Satisfactory
0	4	8	12

Coding instructions: In view of the fact that relationship may vary with different members of the family, the lowest individual rating is taken, whether it is with parent or sibling. When another informant is seen beside the patient, the final rating is taken as the average of these two scores.

Sub Scale E2 - Emancipation from family (degree of age appropriate autonomy without transferred dependency)

Many difficulties, sees no prospect of becoming independent to a satisfactory degree	As for 0, but at times feels that difficulties can be surmounted	Some difficulties but they are surmountable	No difficulties
0	4	8	12

SECTION 2F: MORGAN-RUSSELL ASSESSMENT SCHEDULE (ADOLESCENT VERSION 2.0) (continued)

Sub Scale E3 - Personal contacts (apart from family)

None	Superficial	Many, but superficial	Many close and superficial friends
0	4	8	12

Sub Scale E4 - Social activities (appropriate to status)

Nil outside family	Solitary outcome family	Variable, mainly solitary but some group activities outside family	Adequate group activities: mixes well outside family
0	4	8	12

Sub Scale E5 - Employment or education record over the last month

No paid employment or schooling	Up to 50% of the period in paid employment or occasional unpaid employment or up to 50% of the period in education	More than 50% of the period in paid employment or education, but less than 100%	Regular full time paid employment without absences; or full time education without absences
0	4	8	12

Please use the space below to provide any other relevant information:

End of Section 2F

MORGAN-RUSSELL ASSESSMENT SCHEDULE

(ADOLESCENT VERSION 2.0)

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SECTION 2H:

GLOSSARY (HoNOSCA)

Health of the Nation Outcome Scales Child and Adolescent Mental Health (HoNOSCA)

Glossary for HoNOSCA Score Sheet*

S.G. GOWERS, R.C. HARRINGTON, A. WHITTON, A.S. BEEVOR, P. LELLIOTT, J.K. WING and R. JEZZARD

Summary of Rating Instructions:

- (a) Rate each scale in order from 1 to 13 followed by the additional Scales 14 15 if required.
- (b) Do not include information rated in an earlier item.
- (c) Rate the MOST SEVERE problem that occurred during the period rated.
- (d) All scales follow the format:0=no problem
- 1=minor problem requiring no action
- 2=mild problem but definitely present
- 3=moderately severe problem
- 4=severe to very severe problem Rate 9 if not known

SECTION A

1. Problems with disruptive, antisocial or aggressive behaviour

Include behaviour associated with any disorder, such as hyperkinetic disorder, depression, autism, drugs or alcohol. Include physical or verbal aggression (e.g. pushing, hitting, vandalism, teasing), or physical or sexual abuse of other children.

Include antisocial behaviour (e.g. thieving, lying, cheating) or oppositional behaviour (e.g. defiance, opposition to authority or tantrums).

Do not include overactivity rated at

Do not include overactivity rated at scale 2. Truancy, rated at scale 13, self-harm rated at scale 3.

- 0=No problems of this kind during the period rated.
- 1=Minor quarrelling, demanding behaviour, undue irritability, lying etc.
- 2=Mild but definite disruptive or antisocial behaviour, lesser damage to property, aggression, or defiant behaviour.

- 3=Moderately severe aggressive or antisocial behaviour such as fighting or persistently threatening or very oppositional or more serious destruction to property or moderate delinquent acts.
- 4=Disruptive in almost all activities, or at least one serious physical attack on others or animals, or serious destruction to property.

2. Problems with overactivity, attention or concentration

Include overactive behaviour associated with any cause such as hyperkinetic disorder, mania or arising from drugs.

Include problems with restlessness, fidgeting, inattention, or concentration due to any cause, including depression.

- 0=No problems of this kind during the period rated.
- 1=Slight overactivity or minor restlessness etc.
- 2=Mild but definite overactivity and/or attentional problems but these can usually be controlled.
- 3=Moderately severe overactivity and/or attentional problems that are sometimes uncontrollable.
- 4=Severe overactivity and/or attentional problems that are present in most activities and almost never controllable.

3. Non-accidental self injury

Include self harm such as hitting self and self cutting. Suicide attempts, overdoses, hanging, drowning etc.

Do not include scratching, picking as a direct result of a physical illness rated at scale 6.

Do not include accidental self injury due e.g. to severe learning or physical disability, rated at scale 6. Illness or injury as a direct consequence of drug/alcohol use, rated at scale 6.

- 0=No problem of this kind during the period rated.
- 1=Occasional thoughts about death, or of self harm not leading to injury. No self harm or suicidal thoughts
- 2=Non hazardous self-harm, such as wrist scratching, whether or not associated with suicidal thoughts.
- 3=Moderately severe suicidal intent (including preparatory acts e.g. collecting tablets) or moderate non hazardous self harm (e.g. small overdose)
- 4=Serious suicidal attempt (e.g. serious overdose), or serious deliberate self injury.

4. Problems with alcohol, substance/solvent misuse

Include problems with alcohol substance/solvent misuse taking into account current age and societal norms.

Do not include aggressive/disruptive behaviour due to alcohol or drug use, rated at scale 1. Physical illness or disability due to alcohol or drug use, rated at scale 6.

- 0=No problems of this kind during the period rated.
- 1=Minor alcohol or drug use, within age norms
- 2=Mildly excessive alcohol or drug use.
- 3=Moderately severe drug or alcohol problems significantly out of keeping with age norms.
- 4=Severe drug or alcohol problems leading to dependency or incapacity.

5. Problems with scholastic or language skills

Include problems in reading, spelling, arithmetic, speech or language associated with any disorder or problem, such as a specific developmental learning problem, or physical disability such as hearing problem.

Children with generalised learning disability should not be included unless their functioning is below the expected level

Include reduced scholastic

performance associated with emotional or behavioural problems.

Do not include temporary problems resulting purely from inadequate education.

^{*} HoNOSCA glossary and score sheet protected by Crown copyright and may be copied freely.

- 0=No problems of this kind during the period rated
- 1=Minor impairment within the normal range of variation
- 2=Mild but definite impairment of clinical significance
- 3=Moderately severe problems, below the level expected on the basis of mental age, past performance or physical disability
- 4=Severe impairment much below the level expected on the basis of mental age, past performance or physical disability.

6. Physical illness or disability problems

Include physical illness or disability problems that limit or prevent movement, impair sight or hearing, or otherwise interfere with personal functioning.

Include movement disorder, side effects from medication, physical effects from drug/alcohol use, or physical complications of psychological disorders such as severe weight loss.

Include self injury due to severe learning or physical disability or as a consequence of self-injury such as head banging.

Do not include somatic complaints with no organic basis, rated at scale 8.

0=No incapacity as a result of physical health problem during the period rated 1=Slight incapacity as a result of a health problem during the period (e.g. cold, non serious fall etc.)

- 2=Physical health problem imposes mild but definite functional restriction
- 3=Moderate degree of restriction on activity due to physical health problem 4=Complete or severe incapacity due to physical health problems

7. Problems associated with hallucinations, delusions or abnormal perceptions

Include hallucinations, delusions or abnormal perceptions irrespective of diagnosis.

Include odd and bizarre behaviour associated with hallucinations and delusions.

Include problems with other abnormal perceptions such as illusions or pseudo-hallucinations, or over valued ideas such as distorted body image, suspicious or paranoid thoughts.

Do not include disruptive or aggressive behaviour associated with hallucinations or delusions, rated at scale 1. Overactive behaviour associated with hallucinations or delusions, rated at scale 2.

0=No evidence of abnormal thoughts or perceptions during the period rated.

1=Somewhat odd or eccentric beliefs not in keeping with cultural norms.

2=Abnormal thoughts or perceptions are present (e.g. paranoid ideas, illusions or body image disturbance) but there is little distress or manifestation in bizarre behaviour, i.e. clinically present but mild. 3=Moderate preoccupation with, abnormal thoughts or perceptions or delusions, hallucinations, causing much distress and/or manifested in obviously bizarre behaviour.

4=Mental state and behaviour is seriously and adversely affected by delusions or hallucinations or abnormal perceptions, with severe impact on child/adolescent or others.

8. Problems with non organic somatic symptoms

Include problems with gastrointestinal symptoms such as non organic vomiting or cardiovascular symptoms or neurological symptoms or non organic enuresis or encopresis or sleep problems or chronic fatigue.

Do not include movement disorders such as tics, rated at scale 6; physical illnesses that complicate non organic somatic symptoms, rated at scale 6.

0=No problems of this kind during the period rated.

1=Slight problems only; such as occasional enuresis, minor sleep problems, headaches or stomach-aches without organic basis.

2=Mild but definite problem with non organic somatic symptoms.

3=Moderately severe, symptoms produce a moderate degree of restriction in some activities.

4=Very severe or symptoms persist into most activities. The child is seriously or adversely affected.

9. Problems with emotional and related symptoms

Rate only the most severe clinical problem not considered previously.

Include depression, anxiety, worries, fears, phobias, obsessions or compulsions, arising from any clinical condition including eating disorders.

Do not include aggressive, destructive or overactive behaviours attributed to fears, phobias, rated at scale 1.

Do not include physical complications of psychological disorders, such as severe weight loss, rated at scale 6.

0=No evidence of depression, anxieties, fears or phobias during the period rated.

1=Mildly anxious; gloomy; or transient mood changes.

2=A mild but definite emotional symptom is clinically present but is not preoccupying.

3=Moderately severe emotional symptoms, which are preoccupying, intrude into some activities and are uncontrollable at least sometimes.

4=Severe emotional symptoms which intrude into all activities and are nearly always uncontrollable.

10. Problems with peer relationships

Include problems with school mates and social network. Problems associated with active or passive withdrawal from social relationships **or** problems with over intrusiveness **or** problems with the ability to form satisfying peer relationships.

Include social rejection as a result of aggressive behaviour or bullying.

Do not include aggressive behaviour, bullying rated at scale 1; problems with family or siblings rated at scale 12.

0=No significant problems during the period rated.

1=Either transient or slight problems, occasional social withdrawal.

2=Mild but definite problems in making or sustaining peer relationships. Problems causing distress due to social withdrawal, overintrusiveness, rejection or being bullied.

3=Moderate problems due to active or passive withdrawal from social relationships, over intrusiveness and/or to relationships that provide little or no comfort or support: e.g. as a result of being severely bullied.

4=Severe social isolation with no friends due to inability to communicate socially and/or withdrawal from social relationships.

11. Problems with self care and independence

Rate the overall level of functioning: e.g. problems with basic activities of self-care such as feeding, washing, dressing, toileting, also complex skills such as managing money, travelling independently, shopping etc., taking into account the norm for the child's chronological age.

Include poor levels of functioning arising from lack of motivation, mood or any other disorder.

Do not include lack of opportunities for exercising intact abilities and skills, as might occur in an over-restrictive family, rated at scale 12; enuresis and encopresis rated at scale 8

0=No problems during the period rated; good ability to function in all areas

1=Minor problems only; e.g. untidy, disorganised.

2=Self-care adequate, but definite inability to perform one or more complex skills (see above).

3=Major problems in one or more areas of self care (eating, washing, dressing) or inability to perform several complex skills.

4=Severe disability in all or nearly all areas of self care and/or complex skills.

12. Problems with family life and relationships

Include parent-child and sibling relationship problems.

Include relationships with foster parents, social workers/teachers in residential placements. Relationships in the home and with separated parents/siblings should both be included. Parental personality problems, mental illness, marital difficulties should only be rated here if they have an effect on the child.

Include problems with emotional abuse such as poor communication, arguments, verbal or physical hostility, criticism and denigration, parental neglect/rejection, over restriction, sexual and/or physical abuse.

Include sibling jealousy, physical or coercive sexual abusive by sibling.

Include problems with enmeshment and overprotection

Include problems associated with family bereavement leading to reorganisation.

Do not include aggressive behaviour by child, rated at scale 1.

0=No problems during the period rated.

1=Slight or transient problems.

2=Mild but definite problem e.g. some episodes of neglect or hostility or enmeshment or overprotection.

3=Moderate problems e.g. neglect, abuse, hostility. Problems associated with family/carer breakdown or reorganisation.

4=Serious problems with child feeling or being victimised, abused or seriously neglected by family or carer.

13. Poor school attendance

Include truancy, school refusal, school withdrawal or suspension for any cause.

Include attendance at type of school at the time of rating e.g. hospital school, home tuition etc.,.

If school holiday, rate the last two weeks of the previous term.

0=No problems of this kind during the period rated.

1=Slight problems, e.g. late for two or more lessons.

2=Definite but mild problems, e.g. missed several lessons because of truancy or refusal to go to school.
3=Marked problems, absent several days during the period rated.

4=Severe problems, absent most or all days. Any school suspension, exclusion or expulsion for any cause during the period rated.

SECTION B

Scales 14 and 15 are concerned with problems for the child, parent or carer relating to lack of information or access to services. These are not direct measures of the child's mental health but changes here may result in long term benefits for the child.

14. Problems with knowledge or understanding about the nature of the child's/adolescent's difficulties (in the previous two weeks)

Include lack of useful information or understanding available to the child/adolescent, parents or carers.

Include lack of explanation about the diagnosis or the cause of the problem or the prognosis.

0=No problems during the period rated. Parents/carers have been adequately informed about the child's problems

1=Slight problems only

2=Mild but definite problem

3=Moderately severe problems. Parents/carers have very little or incorrect knowledge about the problem which is causing difficulties such as confusion or self blame

4=Very severe problem. Parents have no understanding about the nature of their child's problems.

15. Problems with lack of information about services or management of the child's/adolescents difficulties

Include lack of useful information available to the child/adolescent, parents or carers or referrers.

Include lack of information about the most appropriate way of providing services to the child such as care arrangements or educational placements or respite care or statementing.

0=No problems during the period rated. The need for all necessary services has been recognised.

1=Slight problems only.

2=Mild but definite problem.

3=Moderately severe problems. Parents/carers have been given little information about appropriate services or professionals are not sure where a child should be managed.

4=Very severe problem. Parents have no information about appropriate services or professionals do not know where a child should be managed.

SECTION 2I: NOTES				
Thank you.	HIS PAGE TO WRITE ANY EXTRA NOTES YOU FEEL ARE RELEVENT TO THE QUESTIONS ASKED.			
(Please place the number of the question you are referring to in the left hand column)				
Question Number	Notes			

ID CODE	



Name(s): _

Costs, Outcomes and Satisfaction for In-patient Child and Adolescent Psychiatric Services (COSI-CAPS)



'6 Months Post-Discharge' Data Collection Tool for all young people discharged from an in-patient unit, aged 12 to 18 yrs inclusive.

THIS QUESTIONNAIRE IS DOUBLE-SIDED.
 (You can make notes anywhere on this tool or use the notes section provided)

Form completed by (please use CAPITALS - thank you):

- Questions 1 to 6 have been completed based on data from the Admission & Discharge DCT to assist in the identification of the YP.
- Contact details of the in-patient unit are provided if you require further information to identify the YP. (Please liaise with the in-patient unit first, as the CRU does not have details of the YP's name or D.o.B.)

Position	on(s):				
Servic	ce:				
Teleph	hone:				
E-mail	l:				
Sec	tion 3A: Identifying Patient Info	rmation			
1	Age & Year of Birth:	&			
2	Gender:	Male	Female		
3	Date of discharge from in-patient service	Date of discharge from in-patient service: / /			
4	Discharge Diagnosis (ICD-10):				
_					
5	Ethnicity:				
6	Contact details of the in-patient service:				
	Name:				
	Service:				
	Telephone / Fax:				

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Section 3B: Contact and Treatment Details (Including Children & Mental Health Act Status)

Please give your responses by placing the appropriate number in the boxes in the right hand column, or by *ticking* the appropriate boxes where instructed. Free text should be placed in the boxes provided or in the notes page.

	(please use 77 c	or DK for 'Don't K	now)			
ate	of first contact with this YP:		_/	_/		
/hic	h service(s) below:					
=	Community CAMHS psychiatrist	7 = Adol	escent Outr	each Team	S	
2 =	Other CAMHS professional (Please specify	8 = Educ	ational ser	vices		
	under Other, e.g. clinical psychologist)	9 = Socia	al worker / S	Social Servi	ces	
3 =	Early Intervention	10 = Gene	eral practition	oner		
4 =	Paediatrician (community)	11 = Out-	oatient facil	ity		
5 =	Adult mental health team	12 = Yout	n offending	team / cour	ts	
3 =	Child and Family Centres	13 = Othe	r (if 2, plea	se specify)	:	
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ID CODE	

Section 3C: Diagnosis & Psychosocial Complexity

		u ····	0 400 77 01 211	for 'Don't Know')		C
Wha	t is the curre	ent diagnosis (ICD-10) f	for this youn	g person?		
If pri	inciple diagr	nosis = Eating disorder	(F50), please	e give measuremen	ats for:	
Н	ge: eight: /eight:				e the Morgan-Russell hedule (p 6 – 8).	
If pri	inciple diagr	nosis = Eating disorder	(F50), please	e specify type belov	w:	
2		/pical & atypical) ical & atypical)				
Plea	se specify a	ny other diagnosable c	o-morbidity:	: (please use notes p	age if required)	_]
W ha	t is the seve	erity of the condition? (6		umber in the box) Severe	3 = Extreme	(0 to 3
ماء ماء	!=		ok to v /omton (ONIT was made on the de-	a.d	(1 to 4
1 s tn 1 =	Self	rson viewed to be at ris 2 = Others	3 = Both 1		ox) It risk to self or others	(1104
		education service does per in the box)	this young p	person attend or re	ceive?	(0 to 1
	er ONE numb			person attend or re		(0 to 1
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Section 3D: Clinical severity (Please complete HoNOSCA and CGAS on p 5)

Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) – Score Sheet

Gowers, S.G., Harrington, R.C., Whitton, A., Beevor, A.S., Lelliott, P., Jezzard, R., Wing, J.K (1998). (See glossary sent separately)

Before you complete the HoNOSCA score sheet, please take time to read and refer to the definitions and instructions outlined in the Glossary. The HoNOSCA training materials are available free of charge to all CAMHS in the UK and may be ordered from the HoNOSCA website: http://www.liv.ac.uk/honosca and http://www.rcpsych.ac.uk/cru/honoscales/honosca/training.htm.

Even if you have not received formal training in the use of HoNOSCA, we still ask that you provide a rating for this young person on the following behavioural domains. This data will allow us to compare the clinical severity of those not admitted with those admitted, and we can run comparisons with the HoNOSCA scores from the 'Admission & Discharge' DCT and from previously studied populations (NICAPS in-patient population and the Audit Commission's 'Children in Mind' population data).

Please rate, to the best of your knowledge, the severity of difficulties the patient has experienced <u>over the past two</u> <u>weeks</u> in the following areas:

20	HoNOSCA rater's profession:				
SECTION A 21	No. Scale		Score scale 0-4 Rate 9 if not known		
	1.	Disruptive, antisocial or aggressive behaviour			
	2.	Overactive, attention or concentration			
	3.	Non-accidental self-injury			
	4.	Alcohol, substance or solvent misuse			
	5.	Scholastic or language skills			
	6.	Physical illness or disability problems			
	7.	Hallucinations and delusions			
	8.	Non-organic somatic symptoms			
	9.	Emotional and related symptoms			
	10.	Peer relationships			
	11.	Self-care and independence			
	12.	Family life and relationships			
	13.	Poor school attendance			
22		SECTION A total score			
SECTION B	1.	Lack of knowledge – nature of difficulties			
	2.	Lack of information – services / management			
23		SECTION B total score			
24		SECTION A & B TOTAL SCORE			
25		Have you been trained to use the HoNOSCA scales? 0 = No 1 = Yes	CODE:		

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Section 3D: Clinical Severity (Continued) Children's Global Assessment Scale (CGAS) David Shaffer, M.D., Madelyn S. Gould, Ph.D. Hector Bird, M.D., Prudence Fisher, B.A. Adaptation of the Adult Global Assessment Scale (Robert L. Spitzer, M.D., Nathan Gibbon, M.S.W., Jean Endicott, Ph.D.) N.B. Please rate the young person's functioning based on the descriptions below. 100 - 91DOING VERY WELL Superior functioning in all areas (at home, at school and with peers), involved in a range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organised group such as Scouts, etc.). Likeable, confident, everyday worries never get out of hand. Doing well in school. No symptoms. 90 – 81 **DOING WELL** Good functioning in all areas. Secure in family, school, and with peers. There may be transient difficulties and "everyday" worries that occasionally get out of hand (e.g. mild anxiety associated with an important exam, occasional "blow-ups" with siblings, parents or peers). 80 - 71DOING ALL RIGHT – minor impairment No more than slight impairment in functioning at home, at school, or with peers. Some disturbance of behaviour or emotional distress may be present in response to life stresses (e.g. parental separations, deaths, birth of a sibling) but these are brief and interference with functioning is transient. Such children are only minimally disturbing to others and are not considered deviant by those who know them. 70 – 61 SOME PROBLEMS - in one area only Some difficulty in a single area, but generally functioning pretty well (e.g. sporadic or isolated antisocial acts, such as occasionally playing hooky, petty theft, consistent minor difficulties with school work, mood changes of brief duration, fears and anxieties which do not lead to gross avoidance behaviour; self-doubts). Has some meaningful interpersonal relationships. Most people who do not know the child well would not consider him/her deviant but those who do know him/her well might express concern. 60 – 51 SOME NOTICEABLE PROBLEMS - in more than one area Variable functioning with sporadic difficulties or symptoms in several but not all social areas. Disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not to those who see the child in other settings. 50 – 41 OBVIOUS PROBLEMS - moderate impairment in most areas or severe in one area Moderate degree of interference in functioning in most social areas or severe impairment functioning in one area, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and other forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, frequent episodes of aggressive or other antisocial behaviour with some preservation of meaningful social relationships. 40 – 31 SERIOUS PROBLEMS - major impairment in several areas and unable to function in one area Major impairment in functioning in several areas and unable to function in one of these areas, i.e. disturbed at home, at school, with peers, or in society at large (e.g. persistent aggression without clear instigation, markedly withdrawn and isolated behaviour due to either mood or thought disturbance, suicidal attempts with clear lethal intent). Such children are likely to require special schooling and/or hospitalisation or withdrawal from school (but this is not a sufficient criterion for inclusion in this category). 30 - 21SEVERE PROBLEMS – unable to function in almost all situations Unable to function in almost all areas, (e.g. stays at home, in ward or in bed all day without taking part in social activities OR severe impairment in reality testing OR serious impairment in communication-e.g. sometimes incoherent or inappropriate). 20 – 11 VERY SEVERELY IMPAIRED – considerable supervision is required for safety Needs considerable supervision to prevent hurting others or self, (e.g. frequently violent, repeated suicide attempts OR to maintain personal hygiene OR gross impairment in all forms of communication—e.g. severe abnormalities in verbal and gestural communication, marked social aloofness, stupor, etc.). 10 – 1 EXTREMELY IMPAIRED – constant supervision is required for safety Needs constant supervision (24-hour care) due to severely aggressive or self-destructive behaviour or gross impairment in reality testing, communication, cognition, affect, or personal hygiene. Specified time period: previous 1 month CGAS score = e.g. = 56

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Section 3D: Morgan-Russell Assessment Schedule (adolescent version 2.0)

Note: Only complete for those young people diagnosed with an eating disorder.

SCALE A: FOOD INTAKE

Sub Scale A1 - Dietary restriction

Is the subject restricting her diet, or has she done so at any time in the last month?

Restricts at all meal times	More than half meal times	About half the time	Less than half the time	Nil
0	3	6	9	12

Coding instructions: Ignore minor carbohydrate restriction to the extent of being careful about the amount of sugar or bread, because such attitude is common even in normal individuals. Only true reduction in food intake below average levels is taken as significant for the purpose of rating on this scale.

Sub Scale A2 - Bingeing

Is the subject bingeing on food, or has she done so at any time during the last six months?

Twice or more per week	Once to twice per week	Less than one per week	Once per month	Never
0	3	6	9	12

Sub Scale A3 – Vomiting

Does the subject vomit food deliberately in an attempt to control her weight, or has she done so at any time during the last six months

Twice or more per week	Once to twice per week	Less than one per week	Once per month	Never
0	3	6	9	12

Sub Scale A4 - Worry about body weight or appearance

Has she been worried about her weight or her appearance in any other way at any time in the last month?

Severe concern at all times	Moderate preoccupation most of the time	Frequent concerns	Only occasional mild concern	Nil
0	3	6	9	12

Sub Scale A5 - Body weight as a %

< 65%	65 – 70%	70 – 75%	75 – 80%	80 – 85%	85 – 90%	> 90%
0	2	4	6	8	10	12

SCALE B: MENSTRUAL PATTERN (in previous 3 months)

No menstruation at any time	Transient occasional menstrual loss, which is never cyclical	Irregular menstrual loss with some cyclical pattern	Regular and cyclical throughout
0	4	8	12

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Section 3E: Morgan-Russell Assessment Schedule (Continued)

SCALE C: MENTAL STATE (as observed at interview and reported abnormalities in the last month)

Grossly abnormal and psychotic with delusions and hallucinations	Marked disturbance but not psychotic	Mild disturbance	Normal
0	4	8	12

Coding instructions: This scale is based on a mental state assessment during interview, and information about the psychiatric status during the previous six months. The distinction between "marked" and "mild" disturbance of one type was made on the basis of interference with general activities. Thus, symptoms which prevented the patient working at any time in the six month period would be rated as "marked". If symptoms are judged as present and significant (excluding marked ideas about food), yet they have not interfered with normal activities, these are rated as "mild".

SCALE D: PSYCHOSEXUAL STATE

Sub Scale D1 - Attitude towards psychosexual development

Attitude towards sexual matters - taking into account the developmental norms of the subject's age

Active dislike	Disinterested or mild discomfort	Little interest or incomplete adjustment	Appropriate interest and adjustment in psychosexual development
0	4	8	12

Sub Scale D2 - Overt sexual behaviour: assessed against norms for subject's age

No sexual behaviour	Intermittent non sexual relationships	Regular age appropriate sexual relationships
0	6	12

Sub Scale D3 - Attitude to menstruation

Active dislike	Mild aversion	Disinterest	Positive attitude
0	4	8	12

Sub Scale D4 – Attitude to menstruation (if it has not returned or has never occurred)

Pleased not returned	Variable: dislike or disinterest	Disinterest	Pleased that is has returned
0	4	8	12

SCALE E: SOCIO-ECONOMIC STATE

Sub Scale E1 - Relationship with nuclear family

Relationship with parents (and siblings)?

Very unsatisfactory	Unsatisfactory	Indifferent	Satisfactory
0	4	8	12

Coding instructions: In view of the fact that relationship may vary with different members of the family, the lowest individual rating is taken, whether it is with parent or sibling. When another informant is seen beside the patient, the final rating is taken as the average of these two scores.

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SECTION 3D: MORGAN-RUSSELL ASSESSMENT SCHEDULE (Continued)

Sub Scale E2 - Emancipation from family (degree of age appropriate autonomy without transferred dependency)

Many difficulties, sees no prospect of becoming independent to a satisfactory degree	As for 0, but at times feels that difficulties can be surmounted	Some difficulties but they are surmountable	No difficulties
0	4	8	12

Sub Scale E3 - Personal contacts (apart from family)

None	Superficial	Many, but superficial	Many close and superficial friends
0	4	8	12

Sub Scale E4 - Social activities (appropriate to status)

Nil outside family	Solitary outcome family	Variable, mainly solitary but some group activities outside family	Adequate group activities: mixes well outside family
0	4	8	12

Sub Scale E5 - Employment or education record over the last month

No paid employment or	Up to 50% of the period in paid	More than 50% of the period in	Regular full time paid
schooling	employment or occasional	paid employment or education,	employment without absences;
	unpaid employment or up to	but less than 100%	or full time education without
	50% of the period in education		absences
0	4	8	12

Section 3E: Notes (Please place the number of the question you are referring to in the left hand column).		

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Costs, Outcomes and Satisfaction for In-patient Child and Adolescent Psychiatric Services (COSI-CAPS)

COSI-CAPS Unit Questionnaire

- Please complete and return this Questionnaire by 1st March 2006.
- Please complete each item on the questionnaire please do not leave any blanks.
- All information will be treated in the strictest confidence.
- Trusts and in-patient units will not be identified in the final report.
- Please return the <u>ORIGINAL</u> document to: COSI-CAPS, Royal College of Psychiatrists CRU
 4th Floor Standon House, 21 Mansell St. London E1 8AA

Section	Description	Page number(s)
Α	Environment and Facilities	3
В	Staff	5 - 9
С	Access, Admission and Discharge	11
D	Educational Facilities	12 - 13
E	Financial Information	15
F	Organisational Changes	16

- PLEASE NOTE THAT THIS QUESTIONNAIRE IS DOUBLE-SIDED.
- Guidance notes are incorporated in this questionnaire.
- Please make any explanatory notes next to each question. There are also 'notes' pages.

Form completed by (please use CAPITALS - thank you):		
Name:		
Position:		
Unit name & address:		
Telephone no. (& Ext):		
Email (optional):		

All information received will be treated in the strictest confidence and the young people, Trusts, referrers or inpatient units will not be identified in the final report. If you have any queries please contact Simon Tulloch (Research Worker), Debbie Bannister (Research Assistant) or Anne O'Herlihy by phone on 020 7977 6662/3/0 or email: stulloch@cru.rcpsych.ac.uk / documents-decru.rcpsych.ac.uk / documents-documents-decru.rcpsych.ac.uk / documents-document

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PLEASE USE THIS PAGE TO WRITE ANY EXTRA NOTES YOU FEEL ARE RELEVENT TO THE QUESTIONS ASKED.			
Thank you.			
(Please place th	(Please place the number of the question you are referring to in the left hand column)		
Question	Notes		
Number			

Guidance Notes

Question 6.1

- A = Usually day (non-residential) patients are NOT treated on this ward. However, some of our patients stay in their own homes at night for a small part of their treatment programme ('on leave') or as part of the discharge plan. Usually, that patient's bed is not filled by another patient during that period.
- B = Sometimes this ward admits day (non-residential) patients but it is a rare occurrence.
- C = On this ward we have a policy of admitting day (non-residential) patients if the child's circumstances allow. Our staffing/budget/funding arrangements are such that if a young person is treated as a day patient then we would usually 'close' that bed to ensure we can give appropriate support to all the patients.
- D= Our in-patient ward is organised and funded to admit both in-patients and day (non-residential) patients. The balance between in- and day- patients remains very similar throughout the year.
- E = Our in-patient ward is organised and funded to admit both in-patients and day (non-residential) patients. The balance between in- and day- patients varies greatly throughout the year.

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SECTION A: ENVIRONMENT & FACILITIES

		CODE√
1	How many beds does this unit have?	(number)
2	How many bedrooms does the unit have of the following types?	(number)
_	A = Single bedrooms	2A
	B = Shared bedrooms (2 people)	2B
	C = Shared bedrooms (2 - 4 people)	2C
	D = Other (please specify):	
	Other (please specify).	
2	Do Voung Boardo house seems to any of the following?	(0 or 1)
3	Do Young People have access to any of the following? 0 = NO 1 = YES	3A
	A = Outdoor recreational space	
	B = Local facilities and amenities (e.g. shopping trips, cinema)	3B
	C = Minibus	3C
	D = Other (please specify):	
4	How many of the following rooms are available on site?	(number)
	A = Recreational rooms open to Young People	4A
	B = Quiet rooms open to Young People	4B
	C = Rooms where family/friends can stay overnight	4C
	D = Interview/therapy rooms separate from offices used as these	4D
	E = Rooms with video equipment/a one-way screen	4E
	F = Activities space for performances, group work, etc.	4F
	G = Own kitchen for Young People	4G
5	How many off-unit activities has the unit organised in the last month?	(number)
	(If you have a weekly/monthly activity plan, please attach to the questionnaire)	
6	Does your in-patient unit also admit day (non-residential) patients? 0 = NO 1 = YES	(0 or 1)
	(,)	
6.1	If YES, which ONE of the descriptions opposite best describes how day patient treatment is organised? (please insert letter)	(letter)
	(please filsert letter)	
7	Typically, how many patients who are admitted for day treatment do you have at any one	(number)
	time?	
8	How many total occupied bed days were devoted to in-patients during the last financial	(number)
	year?	
9	How many total day attendances occurred in the same period?	(number)
-		
		(04)
10	Is an outreach service provided from within the unit? 0 = NO 1 = YES	(0 or 1)
	(If yes, please use the notes pages to describe the arrangements in place)	

Page 198

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11	Nursing Staff Please refer t	staff fer to the no	tes on page 4 before you co	mplete these tables - To complete	Nursing Staff Please refer to the notes on page 4 before you complete these tables - To complete this section you may wish to contact your personnel or finance department.	or finance dep	artment.	
	Grade of	Grade of Nursing/	l Whole fime equivalent	II Expenditure for previous one	≡		≥	
	Health C	Health Care Staff	(WTE) Staff working on	month of WTE staff working	Comments	Please ind	cate WTE si	Please indicate WTE staff numbers
	(pre & p	(pre & post AfC)	the in-patient unit	on the in-patient unit		Filled	Vacant	Agency/bank
	Example Grade D	(4)	4.5	£7345	Due to expansion of service, two WTE grade D nurses to start as of 01.03.06.	2.5	1.0	1.0
	Grade A							
	Grade B							
	Grade C							
	Grade D							
	Grade E							
	Grade F							
	Grade G							
	Grade H							
	Grade I							
		Total						

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Thank you.	THIS PAGE TO WRITE ANY EXTRA NOTES YOU FEEL ARE RELEVENT TO THE QUESTIONS ASKED. the number of the question you are referring to in the left hand column)
Question Number	Notes
Example	
Q. 12 - C	Re: Music/art therapist – Our service pays for external practitioners to visit if/when required. In last financial year
	there were a total of 14 visits = £1900.

SECTION B: STAFF (Continued) - N.B. Teaching Staff details are required in section E

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12	Other Unit Staff							
		V	В	၁			۵	
		Whole time	Expenditure for			Pos	Post filled	
	Job Title	equivalent (WTE)	previous one month	Comments	_	(please ind	icate amoun	t)
		staff working on	of WTE staff working		Filled	Vacant	Agency	Locum
		me in-patient unit	on the III-patient unit				or bank	
	Consultant child & adolescent psychiatrist							
	Senior registrar/specialist registrar							
	Senior house officer/house officer							
	Clinical psychologist - Grade B							
	Clinical psychologist – Grade A							
	Child psychotherapist							
	Family therapist							
	Social Worker							
	Occupational therapist							
	Play specialist							
	Music/art therapist							
	Family liaison worker							
	Secretary/ administrative staff							
	Unit manager							
	Dietician							
	Asst Psychologist/Research Asst							
	Advocate							
	Other staff:							
	Total							

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Thank you.	THIS PAGE TO WRITE ANY EXTRA NOTES YOU FEEL ARE RELEVENT TO THE QUESTIONS ASKED. The number of the question you are referring to in the left hand column)
Question Number	Notes
Example	
Q. 13	Staff (numbers 7 & 9) are currently undertaking their ENB 603. They will be have completed their qualification
	by June 2006.

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SECTION B: STAFF (continued)

13 Qualifications (nursing staff/health care assistants)

Please record the qualifications of the nursing/HCA staff who work with in-patients on the unit. NB: Please indicate in 'Time in post' if <u>substantive</u> (*SUB*) or <u>temporary</u> (*TEMP*) staff.

Nurses	QUALIFICATIONS					Time in post	
or HCA's	RSCN	RMN	ENB 603	SEN	Other (Please specify)	Years months	
Example		✓	✓		(Please specify) Solution focused therapy for individuals and groups.	(SUB) 2 - 7	
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							
11							
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25							
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28							
29							

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Thank you.	e the number of the question you are referring to in the left hand column)
Question Number	Notes
Example	
Q. 16	Although age range is 12 to 18 yrs, we currently have a patient aged 19 as it was agreed that it would not be
	appropriate for this individual to be on an adult ward.

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SECTION C: ACCESS, ADMISSION AND DISCHARGE

 $\mathsf{CODE} \boldsymbol{\downarrow}$

A = NHS Trust B = Independent non-profit organisation C = Independent sector profit organisation For how many days each week does the unit typically provide in-patient care? (insert number) Please state the age range accepted for admission: Do you admit emergency referrals 'out of hours'? Do you admit emergency referrals 'out of hours'? Why would a young person NOT be admitted? (Tick in box all criteria that apply) A = Young person's (YP) age is outside the unit's age-range for admission B = YP lives outside admission boundaries of the unit C = YP has no evidence of mental disorder D = YP has a learning disability E = YP has high alcohol or substance misuse needs F = Incompatibility with current patient group G = Unit unable to contain current risk to self H = Unit unable to contain current risk to others I = No available beds J = Needs of patient exceed current staff capability (please specify using notes page opposite) K = YP or their relative(s) refused L = Other reason (please specify): Are the referral/admission criteria are in written form? 0 = NO	A B C (0 to 7) to (0 or 1) 18A 18B 18C 18D 18E
For how many days each week does the unit typically provide in-patient care? (insert number) Please state the age range accepted for admission: Do you admit emergency referrals 'out of hours'? 0 = NO 1 = YES Why would a young person NOT be admitted? (Tick in box all criteria that apply) A = Young person's (YP) age is outside the unit's age-range for admission B = YP lives outside admission boundaries of the unit C = YP has no evidence of mental disorder D = YP has a learning disability E = YP has high alcohol or substance misuse needs F = Incompatibility with current patient group G = Unit unable to contain current risk to self H = Unit unable to contain current risk to others I = No available beds J = Needs of patient exceed current staff capability (please specify using notes page opposite) K = YP or their relative(s) refused L = Other reason (please specify): Are the referral/admission criteria in written form? 0 = NO 1 = YES NB: If your referral/admission criteria are in written form please attach a copy to this form and return to the CRU. How would you describe the relationship the unit has with the following services? (Please tick appropriate intensity criteria) D = No 1 = YES A = CAMHS community team B = Paediatricians C = Educational services D = Social worker/social services E = General practitioners F = Youth offending team/courts G = Learning disability services I = Other (please specify):	(0 to 7) to (0 or 1) 18A 18B 18C
For how many days each week does the unit typically provide in-patient care? (insert number) Please state the age range accepted for admission: From	(0 to 7) to (0 or 1) 18A 18B 18C 18D
Please state the age range accepted for admission: Do you admit emergency referrals 'out of hours'?	(0 or 1) 18A 18B 18C
Please state the age range accepted for admission: Do you admit emergency referrals 'out of hours'?	(0 or 1) 18A 18B 18C
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SECTION D: EDUCATIONAL FACILITIES (To be completed by the Teacher in charge)

				CODE
Nam	e of the teacher in charge and contact details:			
	is education provided for YPs on this unit?	0 = NO	1 = YES	
A =	Within the unit?			A
B =	Outside the unit but on the hospital site?			В
C =	Outside the unit and off the hospital site?			С
D =	Other:			_
What	t is the total number of pupils on the school roll?			insert number
l	N-1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1			insert number
How	many YP from the unit are on the school roll?			insert number
How	many day patients from the unit are on the school roll?			insert number
	Please enter N/A if not applicable.			
How	many YP currently on the unit require one-to-one teachi	ng?		insert number
If the	pupils are taught in groups:	0 = NO	1 = YES	
A =	Are the pupils grouped with children of similar age?			A
B =	Do the pupil groups include children from a wide age range?			В
C =	Are the groups of mixed ability?			С
D =	Are pupils grouped according to their educational needs?			D
	Are the pupils' emotional and behavioural needs considered who	en grouping?		E
E =)	

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SECTION D: EDUCATIONAL FACILITIES (continued)

			CODE√
	Please state the number of whole time equivalent (WTE) teachers and ass	istants as follows:	
28	Number of WTE teachers normally active in the educational facility.		insert number
28.1	Number of WTE teaching assistants normally active in the educational fac	cility.	insert number
29	For a typical pupil, do teachers in the unit visit the pupil's home school? $0 = N$	NO 1 = YES	(0 or 1)
30	Who usually sets the pupil's coursework?	se tick)	
	A = Home school		A
	B = Unit teachers		В
	C = There is an agreed plan between home and unit school		С
	D = Other (please use below):		D
	Salet (piedos dos pelow).		
31	Are specialist subject teachers, who are trained to teach at secondary lev		(0 or 1)
	teach in the unit? 0 = N	1 = YES	
32	Do you have the educational resources available to support teaching and	learning in:	(A or B)
	A = All the curriculum areas? B = Only some of the curriculum areas?		(A OI B)
33	If B, please list the curriculum areas that are prioritised and taught below:	:	
34	Do you have the educational resources available to support teaching and following key stages?	learning in the	
	A = Key stage 3 0 = N	1 = YES	(0 or 1)
	B = Key stage 4 0 = N	1 = YES	(0 or 1)
35	Do teachers in the unit contribute towards policy making on the unit?	NO 1 = YES	(0 or 1)
36	During the YP's admission, are teachers involved in their care and treatm $0 = N$		(0 or 1)

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Guidance Notes
N.B.: Please indicate whether the data includes expenditure for day patients that are treated on your unit and include in the figures provided for Questions 7 and 9.
Question 38
Please indicate the charge or fee per day applicable to a placing agency outside your area / trust / authority (equivalent to your ECR rate).
Question 39A
These are the direct and indirect revenue costs over and above total care staffing costs. These costs are associated with running the unit and include heating, lighting, catering/cleaning personnel and consumables, clinical support services etc.
Direct costs are those which can be directly attributed to the CAP cost centre (e.g. pharmacy costs)
 Indirect costs are those costs which cannot be directly allocated to a particular cost centre but can be shared over a number of them (e.g. laundry services). Apportionment of support services should follow the principles and procedures outlined in the NHS Costing Manual (available in Portable Document Format at www.doh.gov.uk/nhsexec/costing.htm).
Question 39B
Agency overheads are the costs associated with service management and administration, such as finance and personnel functions. These costs need to be apportioned on a consistent and logical basis. Apportionment of overheads should follow the principles and procedures outlined in the <i>NHS Costing Manual</i> . In certain cases, it may only be possible to establish a percentage add-on to known revenue costs.
Question 39C
Capital charges are the recharge costs applicable to NHS capital assets. It may be necessary to apportion a percentage of the total capital charges of the hospital to the CAP unit.
Contact Details of Finance Department:
Name:
Address:
Post code:

Tel:	Fax:			
E-mail:				
SECTION E: FINANCIAL INFORMATION				

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37	Do these figures include costs for day patients?		□ NO □ YES	
38	What is the fee or charge per resident day to a placing agency?		£	
39	Revenue and overhead costs of the	in-patient unit		
	(If this section can not be completed, please return the Unit Questionnaire, but provide contact details of the Finance dept. for the research team to follow-up).			
	Financial year (please give most up t	o date year):	20:	
	A. Revenue costs (excluding care staff costs)	Notes	Total annual costs	
	i. Clinical support costs		i. £	
	(lab tests, pharmacy etc.)	Please provide actual (apportioned) expenditure or state below the percentage:		
		Based on:% of total hospital cos		
	ii. Water, electricity, gas		ii. £	
	iii. Cleaning, catering, laundry iv. Transport		iii. £	
	v. Maintenance		iv. £	
	vi. Other operating costs		v. £ vi. £	
	The Outer operating cools		VI. L	
	Total (i – vi)		£	
	B. Agency overheads	Notes	Total annual costs	
	i. Personnel & administration	Please provide actual (apportioned) expenditure <u>or</u> state below the percentage:	i. £	
		Based on:% of total hospital cos	t	
	ii. Finance, accounts		ii. £	
	iii. Other functions		iii. £	
	Total (i – iii)		£	
	C. Capital charges	Notes	Total annual costs	
	i. Land	Please provide actual (apportioned) expenditure or state below the percentage: Based on:% of total hospital cos	i. £	
	ii. Buildings	Dased on/0 of total hospital cos	ii. £	
	iii. Equipment		iii. £	
	Total (i – iii)		£	
SECTIO	N F: ORGANISATIONAL CHANGES			

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40	If you think we would benefit from knowing more about the unit in terms of its organisation or management, please inform us using the space below or on the notes pages provided.
41	We would also like to know of any plans to expand or change the way the unit delivers its Service. This may include for example, plans to expand day patient facilities or provide a new specialised facility.
42	Have there been any changes in the last 12 months that have had an impact (positive or negative) on the running of the unit?

Please return this Questionnaire by 1st March 2006, using the envelope provided, to:

COSI-CAPS, Royal College of Psychiatrists' Research & Training Unit, Standon House, 21 Mansell St. London E1 8AA

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COLLEGE RESEARCH UNIT

The Royal College of Psychiatrists 4th Floor Standon House, 21 Mansell Street, London E1 8AA Telephone: 020 7977 6655 Fax: 020 7481 4831



(Charity Registration Number: 228636)

The In-patient Child & Adolescent Mental Health Services Study (COSI-CAPS) Information Sheet (General)

This service is taking part in a study looking at admissions to different in-patient units/wards over a period of 6 months. The study is being carried out at the Royal College of Psychiatrists' Research Unit and is being funded by the NHS Service Delivery & Organisation National Research & Development Programme (SDO).

1. What is the purpose of this study?

We know from a previous study that young people are admitted to different types of units/wards. We would now like to find out whether or not young people (12-18 year olds) do better in one type of unit compared to another type. To find out more about this we will be collecting routine data from about 1000 young people who are admitted to a number of different types of units/wards.

This study will run for 2 years and will try to find out:

- what different in-patient services are accessed by young people
- if there are any differences in the progress young people make in these different types of units/wards
- which of these services are preferred by young people, parents and carers
- how much it costs for each young person to stay in an in-patient unit or on an adult psychiatric ward.

The information from this study is essential to make sure that all young people in the country get access to high quality mental health care when they need it.

If this study applies to you (or your child), please read the questions and answers below.

- What happens if I am not happy about information being collected?
 - If you do not want any information collected regarding you (or your child) and the services you (or your child) are receiving, then simply tell your key worker or doctor at this service, and they will not pass on any information. If you prefer, you can also call us directly on 020 7977 6660, or write to us at the address below. Any objection will not affect the care you receive. You can object to data being collected at any time, and if you do, any data already collected about you (or your child) will not be used in the study.
- What happens to the information the study collects, and will it be kept confidential?

Any information we gather would be kept confidential and would be anonymised (e.g. your name will be replaced with a number, and will not be recorded or used in a report). The information will be combined with information gathered about other young people who have stayed at in-patient units/wards, and will be used to write a report for the SDO. No one apart from the researchers will know anything about your stay or your progress after discharge.

2. What will the study involve?

First part of the study

We will ask professionals within each ward/unit to give us information about the care the young people on the ward are receiving, and the progress that they are making. This information will be collected at three times during the study:

- i) shortly after they are admitted
- ii) just before or shortly after they are discharged
- six-months after discharge (at this time we will contact either their key worker or the professional with whom they last had contact).

For the second part of the study, we will want to contact some young people directly.

We will invite 40 randomly chosen young people and 40 randomly chosen parents or carers to be interviewed shortly before or after discharge by one of the researchers. We want to get your views on what you thought about your stay (or your child's stay) at the in-patient unit/ward. If you are invited to an interview, your key worker will be asked to give you a letter inviting you to agree to an interview, an information sheet about the interview, and a consent form. You would only be contacted by your key-worker, and only he or she would know who you are. You will be given plenty of time to say whether you wish to be interviewed. It will be your decision and it will not affect your care.

3. Who will the researchers collect information about?

Information will be collected anonymously on young people, aged 12-18, who are admitted to an inpatient mental health service between 17/10/05 and 16/4/06.

4. What are the possible benefits the study?

The study does not involve any new or changed treatments, so you are unlikely to get any health benefit from taking part. However, we will be combining all the information that we collect and using it to write a report which will be passed on to the Department of Health SDO. This report will help to improve services for other young people in the future.

5. Who are the researchers?

Our names are Anne O'Herlihy, Simon Tulloch and Debbie Bannister. We are based at the Royal College of Psychiatrists' Research Unit and all have experience of working with young people.

6. What will happen to the results of the research study?

We expect to have the final report on the College Website (http://www.rcpsych.ac.uk/cru) by the autumn of 2007. All of the information that we include in the report will remain anonymous and it will not be possible to link any information to any particular person.

7. Who can I contact if I have any concerns or need further information about the study?

If you have any concerns or other questions about this study or the way it has been carried out, you should contact the principal investigator Anne O'Herlihy, or if you wish to make a complaint you may contact the Director of the College Research Unit, Paul Lelliott, at the address bellow. The Royal College of Psychiatrists has a professional indemnity insurance cover for all its activities, including those of the Research Unit.

If you have any questions please feel free to contact us (Anne or Simon) at any time at:

The Royal College of Psychiatrists' Research Unit 4th Floor, Standon House 21 Mansell Street London E1 8AA

Tel: 020 7977 6660/62

E-mail: aoherlihy@cru.rcpsych.ac.uk or stulloch@cru.rcpsych.ac.uk

COLLEGE CENTRE FOR APPLIED RESEARCH

COSI-CAPS

<u>Semi-Structured Interviews with</u> Parents/Carers.



Researcher Instructions:

- State the aims of the research, how it will be reported, emphasise confidentiality and the opportunity to ask the RT questions.
- Provide overview of the areas (e.g. Access, Admission, etc.) that will be covered by interview
- Allow questions to be asked (e.g. re: research, RT, etc.).

1. Access:
1.1 What are your experiences of your child/YP accessing this service?
1.2. How do you feel about the contact you had with the service prior to your child/YP being referred to the service?
a. Which Professionals (psychologists, psychiatrists, nurses, etc.), were you in contact with before your child/YP was admitted to this service?
b. Who spoke to you about being the service? c. Did they explain what kind of service it was? (If so how?)
d. Did you feel listened to? e. Did you feel that the professional took your needs seriously/cared?
f. Did you feel the professional really understood your child's/YP's problems?
g. Were follow-up meetings planned? h. Did you see the same professionals on each occasion?
i. Was your child/YP admitted to any other units before they came here?
1.3. Is there anything you would change?
L
b. Was the time between assessment and admission appropriate?
1.4. What else, if anything, do you feel could have been done to improve this process?

a. Would you change anything?

2. Admission:
2.1. How did you find the admission process?
a. What contact did you have with the service prior to your child/YP being admitted?
b. Did you receive enough information/visit the service? c. Was the info/visit useful? (If so, why?)
d. Was the info that you received appropriate? (e.g. specific to illness).
e. what was your understanding of why your child/YP was being admitted?
2.2. At the time of admission, what was your understanding of why your child/YP was being admitted?
a. Did you feel listened to?
b. Where you aware of what the process of admission was?
c. Were all your questions/concerns answered?
2.3. If you were to give advice to other parents/carers about the admission process, what would you recommend?
2.4. During the process of admission, what were you most satisfied with and least satisfied with?
a. Did you receive enough information/visit the service?
b. Was the info/visit useful? (If so, why?) c. Was the info that you received appropriate? (e.g. specific to illness).
c. was the title that you received appropriates (e.g. specific to littless).
3. <u>Care & Treatment:</u>
3.1. What is your experience of the care and treatment your child/YP has received during their stay at the service?

a. Was the level of contact you had with your child/YP satisfactory

3.2. What have you found most helpful about their stay at this service?	
a. Has the 'break' from normal routine been useful?	
3.3. What kind of information did you receive about the kind of treatment your child/YP would receive?	
a. What did you find helpful?	
3.4. What involvement did you have in terms of the kind of care/treatment your child/YP had while in this service?	
a. Did you feel you listened to/respected?	
b. Do you feel the staff have collaborated with you in the development of the care treat- ment plan?	
3.5. What were your experiences in terms of contact with the staff?	
a. Did you feel the staff understood your needs? b. Could you talk to them when you wanted to?	
c. Did you feel supported?	
3.6. What was your experiences of the atmosphere (or feel) of the unit?	
3.6. What was your experiences of the annosphere (of feet) of the office	
a. Did it feel warm and comfortable?	
3.7. What were your experiences of the other parents & carers?	
3.7. What were your experiences of the other parents & carers:	
a. What was helpful/unhelpful about being with the other parents/carers?	
b. Did you feel supported?	

3.8. Do you feel your child's/YP's educational needs were met during their stay?
a. Did you like the way the school was run?b. What kind of input did you have into their education?c. How was it for your child/YP to be with the other young people in their lessons?
3.9. What was a typical day like?
 a. Were there periods which your child/YP found difficult? (e.g. evenings, weekends, etc.). b. Have you been satisfied with the number of activities provided for your child during their stay?
4 Disabarras
4. <u>Discharge:</u>
4.1. How do you feel about the discharge process?
4.1. How do you leet about the discharge process:
a. How have you been supported through this process?
4.2. How involved have you been in the discharge process?
a. Are you satisfied with this level of involvement?
4.3. Do you feel your child/YP is ready for discharge?
4.4. What arrangements are in place for when your child/YP is discharged?
a. Are you satisfied with these arrangements?

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э. <u>А</u>	ddition	al Quest	ions:									
5 .1.	Have y	ou found	d their st	ay usefu	ار? (If so,	why/wł	nat?)					
5.2.	What w	ere the	<u>THREE</u> m	ost impo	ortant thi	ings abo	out their s	stay?				
1.												
2.												
3.												
	Would's	vou oba		dhin a 2 (If an auch	- 42\						
5.3.	would	you cha	inge any	thing? (ii so, wn	iair)						
5.4 .	If some	one's cl	hild, who	o vou kn			. horo	hat wou	ld vou re	comme	nd?	
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THANK YOU FOR YOU TIME

COSI-CAPS



Semi-Structured Interviews with Young People.



Researcher Instructions:

- State the aims of the research, how it will be reported, emphasise confidentiality and the opportunity to ask the RT questions.
- Provide overview of the areas (e.g. Access, Admission, etc.) that will be covered by interview.
- Allow questions to be asked (e.g. re: research, RT, etc.).
- Early on in interview ask how they feel in terms of recovery from illness.

1. Access (C	Coming in	to the	unit):
--------------	-----------	--------	--------

1.1 What are your experiences of coming to UNIT NAME?	
a. Which Professionals (psychologists, psychiatrists, nurses, etc.), were you in contact with before you were admitted to this service?	
b. Who spoke to you about being admitted to the service?	
c. Did they explain what kind of service it was? (If so how?)	
d. Did you feel listened to?	
e. Did you feel that the professional took your needs seriously/cared?	
f. Did you feel the professional really understood your problems?	
g. Were follow-up meetings planned?	
h. Did you see the same professionals on each occasion? i. Were you admitted to any other units before you came here?	
i. Were you durnined to driy other offits before you carrie here?	
1.2. Is there anything about this process you would change?	
1.3. Did you feel you required admitting to UNIT NAME?	
a. Did contact with other services influence how you feel about this service?	
,	
2. Admission:	
2.1. How did you find the admission process?	
a. What contact did you have with the service prior to being admitted?	
TO MURAT CORTACT AIR VALLERAVA WITH THA CARUAA BRIAR TO BAIRA AAMITTAAZ	

- a. What contact did you have with the service prior to being admitted?
- b. Did you receive enough information/visit the service?
- c. Was the info/visit useful? (If so, why?)
- d. Was the info that you received appropriate? (e.g. specific to illness).
- e. Was this a long process?
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2.2. At the time of admission, what was your understanding of why you were being admitted?
a. Did you feel listened to/treated with respect?b. Were you aware of what the process of admission was?
c. Were all your questions/concerns answered?
2.3. What would you say to another young person to help them through the admission process?
2.0. What would you say to another young person to help ment intrograme damission process.
3. <u>Care:</u>
3.1. What information did you receive about the kind of help (treatment) you would get at UNIT
NAME?
a. What did you find helpful?
3.2. Did you have a say in the decisions about the help you received?
a. Did you feel you listened to/respected?
3.3. What type of contact did you have with the staff?
a. Did you feel the staff understood your needs?
b. Could you talk to them when you wanted to?
3.4. What were your experiences of the other young people in UNIT NAME?
a. What was helpful/unhelpful about being with the other young people?
3.5. Do you feel your educational needs were met during your stay?

a. Did you like the way the school was run?

b. How was it to be with other young people for your lessons?
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3.6. What does a typical day feel like?
a. Are there periods which are difficult? (e.g. evenings, weekends, etc.)? b. Are you satisfied with the number of activities provided for you during your stay?
3.7. What was the atmosphere (or feel) of UNIT NAME like?
a. Did it feel warm and comfortable? b. Was the atmosphere influenced by other YP or staff?
3.8. Could you keep contact with your family/friends?
a. Was their involvement useful?
4. <u>Discharge:</u>
4.1. How do you feel about the discharge process?
a. How have you been supported through this process?
4.2. How involved have you been in the discharge process?
4.3. Do you feel ready for discharge?
4.4. Will you see anyone (professionals) when you are discharged?
4.4. Will you see difyone (professionals) when you are discharged:
a. Are you satisfied with these arrangements?

5. <u>Add</u>	<u>itional</u>	Questic	ns:								
5.1. Ha	ve you	J found	your sta	y useful?	? (If so, w	vhy/who	t?)				
5.2. Wh	nat we	re the <u>TI</u>	HREE mo	st helpfu	l things (about yo	our stay?	?			
1.											
2.											
3.											
3.											
5.3. Wo	ould yo	ou chan	ge anyth	hing? (If	so, what	l?)					
5 4 If v	ou we	ere to ra	te how s	atisfied y	vou wer	e with vo	ur stav	out of te	n – 0 be	ina 'tota	lly un-
				y satisfie							
	0	1	2	3	4	5	6	7	8	9	10
5.5. A.:		. 1' 0									
5.5. An	y Que	stions?									
5.6. An	ything	you wo	ould like	to add tl	hat we h	naven't c	overed:	but you	feel is ir	mportan	ł?

THANK YOU FOR YOU TIME

Cont.

A Ayton et al

38 Did your parents/carers have the opportunity to meet regularly with other parents of children with similar problems (parents' group), to help them to understand and help you?

No O → Do you think that this may have been helpful.... Yes O No O Don't Know O

Did you receive sufficient help from the service with your education (keeping up with schoolwork, taking exams)? 39

➡ What is your overall feeling about this...... YesO

Yes O No O Don't KnowO → Do you think that this may have been helpful.... O N

For questions 40-42 please write in your own words what you <u>liked</u> and <u>disliked</u> most about your experience on the unit, and what you would like to change

The things I liked most about my experiences on the unit: 40

The things disliked most about my experiences on the unit: 4

The things I would like to change: 4

Thank you for your time © Queen's Printer and Controller HMSO 2007

Young person's questionnaire

CAMHSSS-Uni

We would like to know of your opinion about the services you received from the unit. All information that you give will be treated in the strictest confidence. Feed-back from parents and young people is an important part of the regular reiew and development of the services.

Questions 1 to 31 all begin with the phrase 'WHAT IS YOUR OVERALL FEELING ABOUT'... For each question please express whether your overall feelings were very happy, happy, mixed, unhappy or very unhappy, by shading in a circle using the key below:

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Please ensure that you shade the circle in fully (for example:)	WHAT IS YOUR OVERALL FEELING ABOUT'	1. the effect of services in helping you deal with your problems 💝 😊 🐑 🐑

how the professionals (doctors, psychologists, nurses, therapists) listened to and understood your problems...... 3

the appearance and comfort level of the rooms..

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the professionals keeping time of appointments......

> 4. ς. 6.

how much it cost your family to use the service, for example, in

the effect of services in helping you to prevent the return of your 🕲 🖭 🖭 🔊

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the confidentiality and respect for your rights...... problems....

the explanation given about the treatment...... 6

the effect of services in helping you to feel better..... 10.

the response of services to crises and urgent needs during working 11.

the arrangements after working hours..... 12.

being referred to other services if needed, for example, to a paediatrician, educational psychologist, or social services..... 13.

how well different services worked together to help you (for ex-

ample, arranging help after discharge).....

the information about the unit.....

15. 16.

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Page 223

WHAT IS YOUR OVERALL FEELING ABOUT...

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20. how effective the service was in helping the relationship be-	tween you and your family or carers
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23. the ability of professionals to listen to and understand the worries your family or carers may have about you		

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. how effective the service was in helping you establish good re-	lationships with people outside your family (friends, neighbours, 👿 🖳 📛 🖄 🖄	people at school)
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25. how information was given to your family or carers about your	problem and what to expect
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27. how effective the service was in helping your family or carers	better w
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28. how effective the service was in helping you do better at school	or college

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	30. the length of time before a first appointment was arranged	

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Questions 32 to 39 require a 'Yes' or 'No' answer first. Please respond by colouring in the correct circle.

If you answered 'Yes' then please respond to the additional question' What is your overall feeling about this' by colouring in a circle using the key (as before).

If you answered 'No' then please respond to the additional question: 'Do you think that this may have been helpful', by colouring in the 'Yes', 'No' or 'Don't know' circle.

Was medication prescribed or recommended for you by a Child and Adolescent Psychiatrist?

→ Do you think that this may have been helpful....... Yes O No ODon't Know O

O % 33 Did you receive help from the service to cope with social and school life (e.g. going to school, getting on with people, or changing courses)?

: :		es ONo ODon't KnowO
1 1 1 2 3 3 3 4 3 4 3 4 3 4 3 4 3 4 4 3 4 4 4 4 5 4 4 5 4 4 5 4 4 5	➤ What is your overall feeling about this	No O 4 Do you think that this may have been helpfulYes

34 Did you have the opportunity to meet alone, on a regular basis with a therapist?

No O Do you think that this may have been helpful......Yes ONoODon't Know O

36 Did your family have regular meetings with a family therapist (i.e. to improve the relationship between family members)?

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Yes O 4 What is your overall feeling about this	
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No O Do you think that this may have been helpful......YesO No O Don't Know O

No O **4** Do you think that this may have been helpful.......Yes O NoO Don't Know O

A Ayton et al

Cont.

Solution betwee the opportunity to meet regularly with other parents of children with similar problems (parents' group), to help you to understand and help your child?

39 Did your child receive sufficient help from the service with your education (keeping up with schoolwork, taking exams)?

For questions 40-42 please write in your own words what you <u>liked and disliked</u> most about your experience on the unit, and what you would like to change

40 The things I liked most about our experiences on the unit:

The things <u>disliked</u> most about our experiences on the unit:

42. The things I would like to change:

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16.

the information about the unit.....

how well different services worked together to help your child (for 5

4.

example, arranging help after discharge).....

being referred to other services if needed, (for example, to a pae-

diatrician, educational psychologist, or social services).....

hours....the arrangements after working hours.....

12.

Parents' questionnaire CAMHSSS-Unit

We would like to know of your opinion about the services you received from the unit. All information that you give will be treated in the strictest confidence. Feed-back from parents and young people is an important part of the regular review and development of the services.

Questions 1 to 31 all begin with the phrase 'WHAT IS YOUR OVERALL FEELING ABOUT'… For each question please express whether your overall feelings were very happy, happy, mixed, unhappy or very unhappy, by shading in a circle using the key below:

Very Happy = 5 Happy = 4 Mixed = 3 Unhappy = $\frac{3}{3}$ Very Unhappy = 1 Please ensure that you shade the circle in fully (for example:)

WHAT IS YOUR OVERALL FEELING ABOUT'

WHAT IS YOUR OVERALL FEELING ABOUT...

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\bigcirc	m	m	m	m	m	m	m	m	m	m	m	m	w w
\bigcirc	4	4	4	4	4	4	4	4	4	4	4	4	4 4
7. the service you have received, in a general sense	3. the advice given to you about how you could help your 5 child	19. how effective the service was in helping your child improve his/ 5 her knowledge and understanding of the problems). how effective the service was in helping the relationship become tween your child and you	how effective the service was in helping you to understand your 5 child's problems	. how information was given to the child about the nature of the $\stackrel{5}{\bigcirc}$ problems and what to expect in the future	3. the ability of professionals to listen to and understand the worries you may have about your child	I. how effective the service was in helping your child establish good relationships with people outside your family (friends, Oneighbours, people at school)	5. how information was given to you about your child's problem and what to expect in the future	5. the advice your child was given about what to do when on be leave	7. how effective the service was in helping you deal better with 5 your child's problem	3. how effective the service was in helping your child do better at school or college	same people)). the length of time before a first appointment was arranged the length of time between discharge and follow-up appoint- ments
$\overline{}$	18.	1.	20.	21.	22.	23.	24.	25.	26.	27.	28.	29.	30.

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Questions 32 to 39 require a 'Yes' or 'No' answer first. Please respond by colouring in the correct circle.

If you answered 'Yes' then please respond to the additional question' What is your overall feeling about this' by colouring in a circle using the key (as before).

If you answered 'No' then please respond to the additional question: 'Do you think that this may have been helpful', by colouring in the 'Yes', 'No' or 'Don't know' circle.

32	Was medication prescribed or recommended for your child by a Child and Adolescent Psy-
	chiatrist ?

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O \rightarrow What is your overall feeling about this	No O Up Do you think that this may have been helpful Yes O
Yes	ž

(e.g. going to	
ne/she receive help from the service to cope with social and school life	I, getting on with people, or changing courses)?
33 Did l	school

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Yes O 🕁 What is your overall feeling about this	No O D Do you think that this may have been helpfulYes

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Was your child detained under the Mental Health Act?

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y have regular meetings with a family therapist (i.e. to improve the	tween family members)?
36 Did your family have regular	relationship between family

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Did your child receive group therapy (e.g. meetings of a group of c	Yes O \rightarrow What is your overall feeling about this
37	

Ward Atmosphere Measure

Date of period covered: week - month - year

This is a questionnaire about how the ward has felt to work in over the last week.

Under each heading are three sets of extreme statements. Read the statements and decide where your viewpoint comes in between, or at them, and mark one of the numbered boxes between the two statements. Mark 1 to agree entirely with the answer the left, 5 to agree entirely with the answer on the right, or one of the numbers from 2-4, which best fits where your view lies between the two statements.

This measure should be completed by at <u>least two</u> members of staff. <u>Mark one box only for each item.</u>

This component should only take about 3-5 minutes to complete.

Young people's behaviour (observable)

The YP are generally participating in and involved in both individual and group sessions and activities.	1	2	3	4	5	The YP show very low levels of participation and involvement in individual and group sessions and activities.
All attempts to stick to or introduce structure or routine into the ward running seem to be failing badly.	1	2	3	4	5	The structure and routine of the ward is running exactly as desired.
Disruptive and antisocial behaviour can be contained and does not spread to other young people. Generally, behaviour on the ward is positive and protherapeutic and acts as a role model for disruptive young people.	1	2	3	4	5	Disruptive and antisocial behaviour by one young person tends to spread to other young people and is only contained with great difficulty. The general level of behaviour seems to be getting more counter therapeutic.

Staff to staff relationships, attitudes and behaviour.

It does not feel as though other staff members are available to help with difficult situations. All staff members seem to be having difficulty and I am reluctant to ask for help for problems I am dealing with.	1	2	3	4	5	If a situation is becoming difficult to manage or a young person is causing me great problems I feel that other staff members are on hand to help me out. I feel fine about asking for help if it seems appropriate.
A good proportion of the time care is planned and relates to the overall treatment plan. There is time to reflect and plan care. The ward is able to provide care with generally good therapeutic value.	1	2	3	4	5	Nearly the whole time seems to be spent reacting to problems and there is little room for planned, reflective carer. The ward often seems to be providing no more therapeutic value than containment.
Staff seem to feel like isolated individuals, there is little sense of being a real team. There is very little laughter, fun or good humour between staff members.	1	2	3	4	5	There is a real sense of comradeship between staff members; staff feel part of a team. There is a good deal of laughter, fun and good humour between staff members.

Staff to young person relationships, attitudes and behaviour.

However the young people behave, staff feel in control on the ward. No particular young person is a threat to this.	1	2	3	4	5	It often feels as though one (or more) particular young person has more control over the ward than the staff. There may be a general feeling of relief if a problematic young person does not come to the ward one day.
One (or more) particular young person's behaviour is so problematic that staff members may feel inclined just to write the young person off and not try to understand them, empathise with them or try to help them.	1	2	3	4	5	There is a definite attempt with even the most problematic young people to understand and empathise with their behaviour and a real desire to help them overcome their problems.
With most of the young people, staff are positive about the future and expect change. There is a belief in the therapeutic ability of the ward.	1	2	3	4	5	There is a general sense of hopelessness on the ward. There is little belief that the ward can be much real help to its patients.

Staff personal feelings.

Staff feel besieged and out of control on the ward. The pressures of work seem overwhelming.	1	2	3	4	5	Staff feel secure and in control at work. Staff are able to have a reflective, planned and unstressed approach to work.
Coming to work in the mornings is a pleasant prospect. Enthusiasm and job satisfaction are high among the staff.	1	2	3	4	5	Staff would give anything not to have to come in to work. There is no enthusiasm and low job satisfaction.
Staff are able to enjoy an active life outside the ward, the pressures of work do not intrude on their home and social lives.	1	2	3	4	5	Pressure and stress from work is taken home at the end of the day. Staff are often too drained and tired to have fulfilling and active social and home lives.

Please use the	lease use the space below to add any addition information, expand on any areas or clarify an issue.							

Thank you for your time in completing this form. Please return the questionnaire to Simon Tulloch Royal College of Psychiatrists' Research Unit, Standon House, 21 Mansell St. London E1 8AA Tel: 020 7977 6662 - stulloch@cru.rcpsych.ac.uk

WAS

Instructions Form R

There are 100 statements here. They are statements about treatment programs. Please decide which statements are true of your program and which are false. Please be sure to answer every statement and to fill in your name and the other information requested.

Please provide the following information:										
Today's date:	Today's date:									
Your name or ID: _	our name or ID: Age:									
Name of program: _										
Gender (<i>Please circ</i>	cle):	Male	Fem	ale						
How long have you	lived o	or work	ed in t	his prog	ıram?	Years	s 🔲 М	onths	Day	/s
If you are a staff me	ember,	check	here							
and indicate your st	aff pos	sition/ti	tle:					***************************************		
Please decide which	h state	ements	are tr ı	ue of yo	ur pro	gram ar	nd whic	n are no	ot.	
True - Circle the T i	f you t	hink the	e state	ment is	true o	or most	ly true	of your	prograr	n.
False - Circle the F	if you	think th	ne stat	ement is	s fals e	or mo	stly fals	se of yo	ur prog	ram.
Please be sure to answer every statement.										
Do not write below this	s line									
,	ı	S	SP	A	РО	PPO	AA	00	PC	sc
R/S										
S/S										
Copyright © 197	Copyright © 1974, 1996; Rudolf Moos. All rights reserved. WASCD Duplication Set									

FOI	m K	True	False
1.	Patients put a lot of energy into what they do around here.	. Т	F
2.	Doctors have very little time to encourage patients.	T	F
3.	Patients tend to hide their feelings from one another.	. Т	F
4.	The staff act on patients' suggestions.	. т	F
5.	New treatment approaches are often tried in this program	Т	F
6.	Patients hardly ever discuss their sex life	. Т	F
7.	Patients often gripe.	. Т	F
8.	Patients' activities are carefully planned.	. Т	F
9.	The patients know when doctors will be on the unit.	. Т	F
10.	The staff very rarely punish patients by restricting them.	. Т	F
11.	This is a lively program.	. Т	F
12.	The staff know what the patients want	. Т	F
13.	Patients say anything they want to the doctors.	. Т	F
14.	Very few patients have any responsibility here	. Т	F
15.	There is very little emphasis on teaching patients solutions to practical problems.	. Т	F
16.	Patients tell each other about their personal problems.	. Т	F
17.	Patients often criticize or joke about the staff.	. T	F
18.	This is a very well-organized program.	. Т	F
19.	Doctors do not explain what treatment is about to patients.	. T	F
20.	Patients may interrupt when a doctor is talking.	. Т	F
21.	The patients are proud of this program.	. T	F
22.	Staff are interested in following up patients once they leave the program.	. T	F
23.	It is hard to tell how patients are feeling here.	. T	F
24.	Patients are expected to take leadership here.	. T	F
25.	Patients are strongly encouraged to plan for the future	. Т	F
26.	Personal problems are openly talked about.	. Т	F
27.	Patients in this program rarely argue	. Т	F
28.	The staff make sure that the unit is always neat	. Т	F
29.	If a patient's medicine is changed, a nurse or doctor always explains why	. Т	F
30.	Patients who break the rules are punished for it	. Т	F
31.	There is very little group spirit in this program.	. T	F
32.	Nurses have very little time to encourage patients.	. T	F
33.	Patients are careful about what they say when staff are around.	. Т	F

Go on to next page.

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ror	rm R (Continued)	True	False
34.	Patients here are encouraged to be independent	Т	F
35.	There is very little emphasis on what patients will be doing after they leave	T	F
36.	Patients are expected to share their personal problems with each other	Т	F
37.	Staff sometimes argue openly with each other	T	F
38.	The unit sometimes gets very messy.	T	F
39.	The patients clearly understand the program rules.	. T	F
40.	Patients who argue with other patients will get into trouble with the staff	Т	F
41.	Very few patients ever volunteer around here.	T	F
42.	Doctors spend more time with some patients than with others.	T	F
43.	Patients freely set up their own activities here	Т	F
44.	Patients can leave the unit whenever they want to	T	F
45.	There is very little emphasis on making plans for getting out of this program.	T	F
46.	Patients talk very little about their past.	Т	F
47.	Patients sometimes play practical jokes on each other	Т	F
48.	Most patients follow a regular schedule each day.	. Т	F
49.	Patients never know when staff will ask to see them	T	F
50.	Staff do not order the patients around.	T	F
51.	Patients are quite busy all of the time.	Т	F
52.	The healthier patients here help take care of the less healthy ones	. Т	F
53.	When patients disagree with each other, they keep it to themselves.	. Т	F
54.	Patients can wear whatever they want	. Т	F
55.	This program emphasizes training for new kinds of jobs	. T	F
56.	The staff rarely ask patients personal questions.	. T	F
57.	It's hard to get people to argue around here	. Т	F
58.	Many patients look messy.	. T	F
59.	In this program, everyone knows who is in charge	. T	F
60.	Once a schedule is arranged for a patient, the patient must follow it.	. Т	F
61.	The program has very few social activities.	. т	F
62.	Patients rarely help each other.	. т	F
63.	It's okay to act crazy around here	. т	F
64.	There is no patient government in this program.	т.	F
65.	Most patients are more concerned with the past than with the future.	т.	F
66.	Staff are mainly interested in learning about patients' feelings	. Т	F

Go on to next page.

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Foi	rm R (Continued)	True	False
67.	Staff here never start arguments.	т.	F
68.	Things are sometimes very disorganized around here	. т	F
69.	Patients who break the rules know what will happen to them.	. т	F
70.	Patients can call nursing staff by their first name.	. т	F
71.	Very few things around here ever get people excited	. Т	F
72.	The staff help new patients get acquainted here.	. т	F
73.	Patients tend to hide their feelings from the staff	. т	F
74.	Patients can leave the unit without saying where they are going.	. т	F
75.	Patients are encouraged to learn new ways of doing things.	. т	F
76.	The patients rarely talk with each other about their personal problems.	. Т	F
77.	In this program, staff think it is a healthy thing to argue.	. т	F
78.	The staff set an example for neatness and orderliness.	. т	F
79.	People are always changing their minds here.	. т	F
80.	Patients will be transferred from this unit if they do not obey the rules	. т	F
81.	Discussions here are very interesting	т.	F
82.	Staff sometimes do not show up for their appointments with patients	. T	F
83.	Patients are strongly encouraged to show their feelings.	. т	F
84.	Staff rarely give in to patients' pressure	т.	F
85.	Staff care more about how patients feel than about their practical problems.	. Т	F
86.	Staff strongly encourage patients to talk about their past	. т	F
87.	Patients here rarely become angry	. Т	F
88.	Patients are rarely kept waiting when they have appointments with staff	т.	F
89.	Patients never know when they will be transferred from this program.	т.	F
90.	It is not safe for patients to discuss their personal problems around here.	т.	F
91.	Patients often do things together on weekends.	т.	F
92.	Staff go out of their way to help patients	Τ.	F
93.	The program always stays just about the same.	Τ.	F
94.	The staff discourage criticism.	т.	F
95.	Patients must make specific plans before leaving the program	Τ.	F
96.	It is hard to get a group together for card games or other activities.	. T	F
97.	A lot of patients just seem to be passing time here.	т	F
98.	The day room is often messy	Τ.	F
99.	Staff tell patients when they are getting better	т.	F
100.	It is a good idea to let the doctors know that they are in charge	Т	F

Stop here.

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Addendum

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