Patient Choice and the Organisation and Delivery of Health Services: Scoping review

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Appendices

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

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prepared by

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Appendix 1 Details of the second search strategy for choice theories

1.1 Keywords

1 Choice: words beginning "choice" or "choos" or "judg" or "decision"

2 Theory: words beginning "theor"

3 Particular theories or concepts: phrases beginning "social choice theor" or "collective choice theor" or "public choice theories" or "communitarianism" or "Marxism" or "socialist theories" or "social choice" or ("rights" and "responsibility") or "citizenship" or "consumerism" or "exclusion" or "consumer behaviour" or "game theory" or "bounded rationality" or "multi-attribute" or "prescriptive theor" or "descriptive theor" or "normative theor" or "fuzzy trace theor" or "process tracing" or "protocol analysis" or "lens model" or "fast and frugal" or "exit voice theor" or "behavioural choice" or "filter theor" or "rational choice theory" or "utility theories" or "informed choice" or "clinical psychology" or "clinical decision making" or "collaborative decision making" or "risk preferences" or "uncertainty" or "reasoned action theory" or "Bayesian analysis" or "prospect theory" or "heuristics" or "choice models" or "heuristic models" or "framing" or "carer-patient communication" or "doctor-patient communication" or "health professional-patient communication" or "risk communication" or "decision analysis" or "social judgements" or "problem solving" or "neural network approach" or "cognitive processing" or "decision theory" or "libertarianism" or "discourse analysis"

4 Type of article: words beginning "review" or "meta-analys" or "critique"

5 Time period: generally all years covered by the database, as core theories may be quite old

6 Language: English language only

7 Databases: ASSIA (1987–current), Political Science: A SAGE Full-Text Collection (1982–current), Social Services Abstracts (1980–current), Sociological Abstracts (1963–current), Sociology: A SAGE Full-Text Collection (1982–current), BIDS/IBSS (1980–2004), Medline, International Political Science Abstracts, PAIS International, Philosophers Index, SIGLE, Social Sciences Index, CINAHL, Embase (1980–2004), HMIC, PsycInfo (1985–2004), Social Work Abstracts (1977–2004), Econlit

1.2 Strategy search for evidence of impact

1.2.1 a Keywords

1 Choice: "decision making" or "decision control" or "decision makers" or "information processing" or "decision support systems" or "decisions" or

"contracts" or "judgements" or "consumerism" or "consumers" or "consumer attitudes" or "consumer behaviour" or "consumer participation" or "market liberalization" or "markets" or "social care market" or "free markets" or "informed choice" or "social choice" or "choice models" or "discrete choice" or "public choice theories" or "rational choice theory"

2 Who makes the choice?: "patients" or "clients" or "users" or "parents" or "children" or "young people"

3 Service/professional area: "care" or "health services" or "health maintenance organizations" or "general practice" or "medical professionals" or "doctors" or "treatment" or "schools" or "teachers" or "social workers" or "helping professionals"

4 Time period: 1985 onwards unless stated otherwise

5 Language: English language only

6 Databases: ASSIA, Sociological Abstracts, Medline (1993–current)

1.2.2 b Keywords

1 Choice: words beginning "choice" or "choos" or "judg" or "decision" or "market" or "consumer"

2 Who makes the choice?: words beginning "patient" or "user" or "client" or "parent" or "child" or "young people"

3 Service/professional area: words beginning "care" or ("health" and "service") or "NHS" or "hospital" or ("health" and "maintenance" and "organization"/"organisation") or ("general" and "practice") or ("health" and "profession") or "doctor" or "treatment" or "school" or "teacher" or ("social" and "work")

4 Time period: 1985 onwards unless stated otherwise

5 Language: English language only

6 Databases: IBSS (restricted to words in the title), PAIS International, SIGLE, Philosophers Index, Social Science Index

1.2.3 c Keywords

1 Choice: words beginning "choice" or "choos" or "judg" or "decision" or "market" or "consumer"

2 Who makes the choice?: words beginning "patient" or "user" or "client" or "parent" or "child" or "young people"

3 Service/professional area: words beginning "care" or ("health" and "service") or "NHS" or "hospital" or ("health" and "maintenance" and "organization"/"organisation") or ("general" and "practice") or ("health" and "profession") or "doctor" or "treatment" or "school" or "teacher" or ("social" and "work")

4 Time period: 1985 onwards unless stated otherwise

5 Language: English language only

6 Databases: CINAHL, HMIC

CINAHL keywords

"decision making" or "decision making, patient" or "judgment" or "access to information" or "information needs" or "information seeking behaviour" or "contracts" or "consumers" or "consumer attitudes" or "consumer participation" or "market liberalization";

"health services" or "health maintenance organizations" or "general practice" or "health personnel" or "school admissions" or "schools" or "schools, elementary" or "schools, middle" or "schools, nursery" or "schools, secondary" or "teachers";

"patients" or "parents" or "child" or "child, disabled" or "child, hospitalised" or "adolescence"

HMIC keywords

"consumers" or "consumer behaviour" or "consumer choice" or "consumer complaints" or "consumer education" or "consumer information" or "consumer needs" or "consumer representation" or "consumer research" or "consumer rights" or "consumerism" or "user friendly services" or "patient choice" or "decision making" or "decision support systems" or "judgement" or "information exchange" or "information needs" or "contracts" or "internal nhs contracts" or "quasi contracts" or "service level agreements" or "markets" or "internal markets" or "market economy" or "market structure" or "choice" or "consumer choice" or "options" or "selection";

"patients" or "patient attitudes" or "patient autonomy" or "patient consent to treatment" or "clients" or "social welfare users" or "client information" or "client participation" or "client rights" or "parents" or "children" or "young people";

"care" or "care management" or "social services" or "social work" or "care in the community" or "health services" or "health care" or "health organisations" or "health service staff" or "public services" or "social services" or "nhs" or "health systems" or "nhs hospitals" or "nhs structure" or "health maintenance organisations" or "primary care" or "general practice" or "general practice fundholding" or "general practitioner fundholders" or "medical profession" or "health professions" or "medical staff" or "nursing profession" or "medical staff" or "schools" or "teachers" or "social workers"

1.3 Additional search strategies for the evidence of impact

1.3.1 Search strategy for direct payments

1 Search of Caredata, the electronic library for social care (keywords: direct payments): http://195.195.162.66/elsc/caredata/caredatasearch.htm (returned 255 records); http://www.elsc.org.uk/

2 Search of relevant websites: www.jrf.org.uk, www.nimhe.org.uk, www.dh.gov.uk, www.psi.org.uk

3 Search of CSA Social Sciences (direct payment* or service broker* anywhere): 220 non-duplicate references found

4 Search of Social Work abstracts (direct payments anywhere): 6 references (3 duplicating references already found): none relevant

5 Search of HMIC (direct payments anywhere): 220 references (36 duplicating references already found)

6 Search of Department of Health research register (keywords direct payments): 5 projects found (2 have already been reported in the articles already found). Contact made with the other 3 projects by e-mail, requesting information/results

7 Search of DARE (direct payments): no relevant articles found

8 Search of John Rylands University Library holdings/COPAC (351 results)

9 Personal communication with 1 author

10 ASLIB Index to theses ("direct payments") found 2 theses, 1 relevant, but the author has published an article covering similar ground

11 Search on British Library www.bl.uk found 2 relevant articles

12 Digital dissertations found no relevant articles

13 Search on COPAC: 274 references found (including duplicates), 1 new

14 Search on SIGLE: 54 references, none new

15 Search on Zetoc

16 Search on BIDS/IBSS for direct payments found 41 references

17 Search for articles citing key articles or with related reference lists: Web of Science – Social Sciences database

Approximately 25 references that seemed relevant (to direct payments in relation to patient choice) were found. Some of these were summaries of longer reports, but it didn't seem a good use of time to obtain the original reports, given the lack of similarity between direct payments and patient choice.

Appendix 2 Summary of workshops and meetings

2.1 Workshop 1 15th March 2005

2.1.1 Attendees

Susan Barber, Council of Ethnic Minority Voluntary Sector Organisations (CEMVO)

Frances Blunden, Principle Policy Advisor, Which?

Sally Brearley, Health Link

Dr Aileen Clarke, Reader in Health Services Research, Institute of Community Health Sciences, London Queen Mary's School of Medicine & Dentistry

Diane Dawson, Senior Research Fellow, Centre for Health Economics, University of York

Professor Ewan Ferlie, Head of School of Management, Centre for Public Services Organisation, Royal Holloway University of London

Peter Hirsch, GMSHA, Medical Director

Professor Julian Le Grand, London School of Economics, Chief Health Policy Advisor to Prime Minister, 10 Downing Street Policy Unit

Hannah Lowry, GMSHA Project Research Manager, c/o Modernistation (Choice)

Naomi Le Maistre, Public Health and Policy Research Unit, Centre for General Practice and Primary Care, Institute of Community Health Sciences, Queen Mary, University of London

Rose Moran, Choice Programme Manager, Liverpool & South Sefton LHC

Alan Boyd, Research Associate in Healthcare and Public Sector Management, Centre for Public Policy and Management

Dr Adrian Edwards, Reader in Primary Care, University of Wales Swansea Clinical School

Dr Marianna Fotaki, Lecturer in Healthcare and Public Sector Management, Centre for Public Policy and Management

Professor Glyn Elwyn, Professor, Primary Medical Care, University of Wales Swansea Clinical School

Dr Ruth McDonald, National Primary Care Research and Development Centre

Dr Liz Smith, Research Associate in Healthcare and Public Sector Management, Centre for Public Policy and Management

2.1.2 Agenda: speakers / discussions

1 Greetings and introduction

Overview of the project and methodology, Marianna Fotaki and Alan Boyd

2 Impact of the London Choice Project on waiting times

Diane Dawson, followed by 20 minutes' discussion

3 Patient and user experience: London Patient Choice project

Naomi Le Maistre, followed by 20 minutes' discussion

4 The impact of London Patient Choice on organisations

Ewan Ferlie, followed by 20 minutes' discussion

Rose Moran

5 Users' views on choice – what are the issues?

Sally Brearley, Frances Blunden, Susan Barber

10-minute presentations followed by 25 minutes' discussion

6 Why is choice important and how will it work?

Julian Le Grand, followed by 20 minutes' discussion

7 What do we know and what we do not know about choice?

Marianna Fotaki, Ruth McDonald, Liz Smith, Adrian Edwards, Glyn Elwyn

10-minute presentations followed by 25 minutes' discussion

2.2 Workshop 2 15th March 2005

2.2.1 Attendees

Rose Moran, Choice Programme Manager, Liverpool & South Sefton LHC

Frances Blunden, Principle Policy Advisor, Which?

Susan Barber, CEMVO

Amanda Cumberland, Senior Policy Officer, Public Services, National Consumer Council

Sally Brearley, Healthlink

Joe Rafferty, Cumbria and Lancashire SHA

Michael Yates, SDO

Damien O'Boyle, SDO

Dr Aileen Clarke, Reader in Health Services Research, Public Health & Policy Research Unit, Barts and Queen Mary, University London,

Naomi Le Maistre, Public Health and Policy Research Unit, Queen Mary, University of London

Jatinder Singh, Communications and Engagement Manager Patient Choice, Birmingham and the Black Country SHA

Professor Martin Roland, Director, National Primary Care Research and Development Centre

Dr Marianna Fotaki, Lecturer in Healthcare and Public Sector Management, Centre for Public Policy and Management

Alan Boyd, Research Associate in Healthcare and Public Sector Management, Centre for Public Policy and Management

Dr Liz Smith, Research Associate in Healthcare and Public Sector Management, Centre for Public Policy and Management

Dr Ruth McDonald, National Primary Care Research and Development Centre

Dr Rod Sheaff, Senior Research Fellow, National Primary Care Research and Development Centre

Professor Kieran Walshe, Director and Professor of Health Policy and Management, Centre for Public Policy and Management

2.2.2 Agenda: speakers / discussions

1 Introduction and overview of the project

Marianna Fotaki, followed by discussion

2 Choice, Competition and Efficiency in Healthcare, the role of information

Ruth McDonald, followed by discussion

3 How people make choices

Liz Smith

4 Choice in Social Care and Education

Alan Boyd and Marianna Fotaki, followed by discussion

5 Summing up key points and discussion

6 Scenario planning (group work)

7 Identify gaps in research

8 Summing up

Appendix 3 Theories relevant to patient choice

3.1 Mixed theories of choice: neo-classic macroeconomics

Most neo-classical microeconomics represent the economic theory of choice as a hypothetico-deductive, not a realist, theory. That is, economic theories of choice are usually represented as being an 'as if' theory. They do not claim to describe literally the deliberations by which most patients (except perhaps for ill microeconomists) actually consciously use in choosing what services to use. Rather, neo-classical microeconomic theory postulates the deliberations which, if a patient had ever actually made them, would have led them to make the choices that economic theory predicts. Then, in so far as patients are observed to choose in the predicted ways, it is argued that it is 'as if' the neo-classical microeconomic theory of choice is true. In the late twentieth century, attempts were made to operationalise and test the neo-classical microeconomic theory of choice empirically, particularly in experimental settings (Gefen and Ridings, 2002; Collins *et al*., 1998; Evan and Simmons, 1969), but this attempt at evidence-basing is historically rather an afterthought. Giving them the benefit of considerable doubt (cf. Allais, 1953), the present review treats economic accounts of choice as mixed rather than purely normative models or purely scientific theory.

3.1.1 Consumer choice theory

Consumer choice theory defines rational consumer choices as those that lead the consumer to maximise her utility (satisfaction, happiness). It assumes that utility is derived, by getting more of the goods that express the buyer’s preferences. Although the marginal benefit of each additional unit of goods or services successively declines, consumer choice theory assumes it is always positive and never reaches zero. Thus, consumers are not only unsatiated but actually insatiable. For them, more is always better. Rational consumer choice thus consists of adjusting the pattern of one's spending in order to maximise one's utility. This is achieved by adjusting the quantity of one's purchases and responding to changes in their prices so as to equalise the marginal rate of substitution between all goods. In order to describe and explain in a mathematically coherent way how consumer choices aggregate in order to form market demand, consumer choice theory has to make many ancillary assumptions.

These include the assumption that consumers (or at least, rational ones; consumer choice theory does not consider irrational consumers or their choice except to dismiss them as 'irrational' or an 'imperfection') have well-defined, transitive, complete and 'convex' preferences (Samuelson, 1983). Consumers are assumed to be uninterested in their income relative to others (an assumption which Duesenberry (1960) challenges; see main text, Section 2.3.2) Milton Friedman, in his permanent income theory, argued for example that past experience was of no importance in decision-making because individuals had a very short memory and that context has absolutely no effect on judgements in relation to spending (Friedman, 1957). The theory also tends to conflate the demands of individuals, consumers or households, using the terms quite interchangeably (Sudgen, 1992).

Whereas some theorists content themselves with arguing that it is simply necessary to assume that individuals act as if they were completely rational (Coleman, 1990), others have seen rationality as a result of unconscious psychological conditioning (e.g. Freud, 1936). Because it is difficult to give the concept of utility a plausible evidential basis, variants of consumer choice theory have been developed which, so far as possible, either refine the assumption of utility-maximisation or replace it. The variant closest to classical consumer choice theory is expected utility theory (von Neumann and Morgenstern, 1944). It suggests that people make decisions in order to maximise the gain to themselves, when the actual outcome for that individual is uncertain and the decision is made on the basis of probabilities. The expected utility hypothesis is the hypothesis that the utility of an agent facing uncertainty is calculated by considering utility in each possible state and constructing a weighted average, where the weights are the agent's estimate of the probability of each state. That presupposes that evidence about all the relevant outcomes and their probabilities is available.

Arrow (1963) attributes to Daniel Bernoulli (1738/1954) the earliest known written statement of this hypothesis. Expected utility theory is operationalised in both economic decision-making and also in initiatives for individual health care encounters, such as decision analysis, and informally perhaps in some understandings of shared decision-making where patients are invited to weigh up not only the pros and cons, but also the risks, of options pertaining to a decision. Decision theory (Edwards and Newmann, 1982; Fishbein and Ajzen, 1975) also uses utility- or risk-based models and looks at decisions in terms of utility distribution among the set of options to be decided upon. A widely used version is the multi-attribute utility model (MAUT; Edwards and Newmann, 1982). It was developed for models of riskless decision-making. Here multi-attribute utility of an option is the sum of the utility of the weighted attributes. MAUT can take into account the uncertainty of the decision when expected attribute utilities are used instead of attribute utilities. This is important in studying patient choice as there is much uncertainty embodied in medical consultations.

One way to avoid the problematic concept of utility is to replace it with a more concrete concept of revealed preference, which since the mid-twentieth century has partly supplanted it. Consumers' actual choices are held to reveal what their underlying preferences are. It then becomes possible to argue that in making their consumer choices, consumers are seeking to maximise the satisfaction of their preferences (which are observable in consumer's choices), not an unobservable entity, utility. Another substitute for the idea of utility is to propose that in choosing, consumers attempt to maximise benefits net of costs. Then, benefits and costs can be understood either in terms simply of consumers' preferences (see above) or in a monetarised way.

This approach can be nuanced by discounting the benefits and costs using methods analogous to (indeed, based upon) the calculation of compound interest. On this view, a rational patient would choose immediate rather than long-term health gains, for the further in the future a health gain (or cost) is, the more a rational patient would discount it. Quality-adjusted life-years (QALYs) are an attempt to translate the notion of utility into more concrete terms that are relevant and intelligible to health workers and patients. Then, for the patient, rational choice consists of maximising the number of QALYs that can be obtained. For managers and policy-makers, however, the problem of choice is different; it is to maximise the production of QALYs over the health system as a whole (see below).

3.1.2 Public choice theory

Public choice theory is a branch of economics that developed from the study of taxation and public spending. It emerged in the 1950s and received widespread public attention in 1986, when James Buchanan, one of its two leading architects (the other was his colleague Gordon Tullock), was awarded the Nobel Prize for Economics. Public choice theory developed after studying spending and the way large bureaucracies function, applying to collective decision-making the same analytic principles that economists use to analyse people's actions in the marketplace. Public choice theory assumes that people are motivated mainly by self-interest. Although most people base some of their actions on their concern for others, the dominant motive in people's actions in the marketplace whether they are employers, employees, or consumers is a concern for themselves. Public choice economists make the same assumption that although people acting in the political marketplace have some concern for others, their main motive, whether they are voters, politicians, lobbyists, or bureaucrats, is self-interest. In Buchanan's words the theory "replaces romantic and illusory... notions about the workings of governments [with]... notions that embody more scepticism" (Buchanan and Tullock, 1962).

The behaviour and choices made by public sector bureaucracies is, however, a topic tangential to the present review. Nevertheless, public choice theory does have one implication for the present review. It argues that state and bureaucratic means of allocating goods and services are intrinsically allocatively inefficient (Niskanen, 1971). Consumer power, and hence patient choice, is called upon to redress these problems.

3.1.3 Criterion-related (ranked) choice

The foregoing all assumes that consumer choice either consists of, or occurs 'as if' it were, a set of quantitative estimates (of marginal rates of substitution, discount rates or QALY values of particular health outcomes). A more radical departure is to consider choice in more qualitative but equally formalised ways. The simplest of these is criterion-related (ranked) choice. This assumes that a consumer ranks various demands for goods or services, then satisfies them in rank order. So, for instance, having purchased the food needed, our hypothetical consumer next purchases housing, continuing to ever lower-ranked goods until the budget runs out. Such a theory is compatible with some cognitive-psychological accounts of motivation. Like

Maslow's account of needs (Maslow, 1954), criterion-related choice assumes that consumers can and do rank their needs and satisfy them in order of importance (Sheaff 1996). Note that one can accept this general theory of consumer choice without having to accept Maslow's altogether more questionable account of what people's substantive needs are and their relative rankings.

A recent variant of this approach applies Bayes' theorem as a normative model of statistical decision-making (Allais, 1953; Bayes 1958), as generalised by Laplace (1951). It is a mathematical law that determines the degree of confidence that can be applied to the possible outcomes in a given situation based on the evidence available. It enables us to modify the probability attached to a hypothesis as new evidence becomes available but incorporates the decision-maker's perceived prior likelihood of a given outcome. The Bayesian approach to decision-making has received increased interest in medical decision-making in the era of evidence-based medicine as some data or evidence are available and which can inform prior views to influence choices made by patients (alone or with their health care professionals).

Bayes' theorem provides a basis for some of the developments in evidence-based health care, and in particular 'evidence-based patient choice' (Edwards, 2001) – that is, an attempt to find a middle or common ground between the (as perceived by some) prescriptive evidence-based medicine and the patient choice, autonomy, empowerment trends. Patients' decisions in situations of choice may be influenced in part at least by the information they have to hand. When this is enhanced, as is increasingly the case now with Internet availability of information, then the prospects of evidence-based or evidence-informed patient choice are real (Entwistle *et al*., 1998). Increasingly also much investment is devoted to utilising the opportunities from information and communication technology in health care (e.g. Connecting for Health in the UK).

3.1.4 Game theory and rational choice theory

Game theory is a branch of mathematics that uses models to study interactions with formalized incentive structures ('games'). It has applications in a variety of fields, including economics, evolutionary biology, political science and military strategy. Game theorists study the predicted and actual behaviour of individuals in games, as well as optimal strategies. Game theory is also underpinned by two main assumptions: 'common knowledge' and 'rationality'. The game is specified by the strategy sets and payoff functions, which are assumed to be common knowledge in the game, together with everything that can be deduced from this common knowledge. Rationality assumes that players choose strategies that maximise their individual expected utilities, relative to their knowledge and beliefs at the time of acting. Seemingly different types of interaction can exhibit similar incentive structures, thus all exemplifying one particular game. John von Neumann and Oskar Morgenstern first formalized the subject in 1944 in their book *Theory of Games and Economic Behavior* (von Neumann and Morgenstern, 1944). Game theory is applicable to any social interaction involving two or more decision-makers (players), each with two or more ways of acting (strategies), so that the outcome depends on the strategy choices of all the players, each player having well-defined preferences among the possible outcomes. These preferences enable corresponding utilities (payoffs) to be assigned. Game theory can embrace a wide range of social interactions.

Game theory has not been much applied to human interactions around health choices or to choice at the level of micro interactions (screening, investigation and treatment-choice frameworks). The quantification of risks, cost and benefits that underpins game theory is sometimes used in health care today but it may lack credibility with patients, who are expected to assign number or betting odds to an outcome they haven't yet experienced. Choice in the NHS is being constructed along provider options, in that patients and/or their agents are being told to make a choice between provider organisations as to where to receive services that are requested or required. To apply game theory we would have to see providers (and/or policy-makers) as one group and patients and their agents (referrers; e.g. GPs or others) as another group of players trying to maximise their payoffs. Models could be built to demonstrate the effect of different levels of information on payoffs. Most game theory models depend on repeated cycles of decisions. This would work at the 'agent' level, for example when a health care professional is making recommendations to many patients, but would have no real relevance at the patient level, who mostly make one-off decisions regarding provider.

Rational choice theory extends elements of game theory and of the neo-classical theory of consumer choice into a more general account of prudential – or, in Roemer's hands (Roemer, 1982), moral – choice. This last development however takes us beyond the remit of the present review.

3.2 Descriptive theories of choice: psychological accounts

3.2.1 Simple heuristics

A number of specific heuristics have been described.

- *The availability heuristic*, which estimates the likelihood of an event occurring based on how readily related instances come to mind (Tversky and Kahneman, 1973). For example, how easy a person thinks it will be to get a GP's appointment is likely to be based on how easy or hard it was on the most recent occasions they tried.
- *The representative heuristic* describes a tendency to make a decision that fits our preconceptions or stereotypes of a given situation (Kahneman and Tversky, 1973). For example, someone may expect a more sympathetic hearing from a female GP because she's a woman even though they have never met a female GP.
- *The anchor-and-adjust heuristic*, in which when making a judgement based on ambiguous information we attempt to reduce the ambiguity by relating to a starting point or anchor and then adjusting it (for example, making judgements about other people based on ourselves and our

actions; Tversky and Kahneman, 1973). For example, the mother who thinks a medicine works for her child's father: "so if I just give him half the dose…".

3.2.2 Framing

Framing is the expression of logically equivalent information in different ways (Wilson *et al*., 1998). All of the variations in the ways statistical information may be presented fall broadly under this heading. However, studies of framing, and the effects it has on interpretations and decisions made, initially focused on positive 'versus' negative framing, and gain 'versus' loss framing (Kahneman and Tversky, 1979). Positive and negative frames refer to whether an outcome is described, for example as a 97% chance of survival (positive) or a 3% chance of dying (negative). There is evidence from health care settings that positive framing is more effective than negative framing in persuading people to take risky options, such as treatments (Edwards *et al*., 2001a; Kuhberger, 1998; Gurm and Litaker, 2002).

However, a slightly broader variation concerns gain- and loss-framing. This is more relevant to clinical risk communication as it addresses the implications of choosing tests or not choosing tests for the individual concerned. Loss-framing considers the potential losses from not having a test. For example, in mammography the losses might include loss of good health, longevity and family relationships. Loss-framing appears to influence screening-test uptake more than gain-framing (maintenance of good health, relationships, etc.; Edwards *et al*., 2001b; Kuhberger, 1998). Other numerical variations include altering the base rate or denominator (for example, to compare 25 out of 100 with 40 out of 1000; Yamagishi, 1997). All of these are essentially variations in the external representations of information and serve to foster our innumeracy and confusion unnecessarily. Other verbal variations include altering the level of detail, or the language intensity used to describe treatment options and outcomes (Buller and Burgoon, 2000). These play on our selective interpretation and response to specific cues, such as fear arousal.

Pictorial representations of risk information can also be subject to manipulation to produce different decisions or interpretation by patients. This may be through using different formats such as bar charts and population crowd figures (Schapira *et al*., 2001) or the representation could appear to support short-term benefits from one treatment rather than long-term benefits from another (Mazur and Hickam, 1994). Alternatively within one format, changes in base rate may produce greatly differing perspectives on risks in question. People may respond differently but if the information is accurate and balanced, some prefer such visual formats to numerical ones (Fuller *et al*., 2002). Visual representations may improve comprehension substantially (Lipkus and Hollands, 1999). They may enhance the time efficiency of consultations. A further advantage is that they obviate the need to discuss relative or absolute risk concepts at all, so avoiding some the potential for confusion noted above.

Below more detailed information on decision-making theories is provided.

3.2.3 The decision theory approach

The decision theory approach uses utility- or risk-based models and looks at decisions in terms of profitability among the set of options to be decided upon. The majority of the theories look at the structure of a decision rather than the process. The main focus is on the decision and the decision-maker’s perception of the decision. A widely used model is the multi-attribute utility model (MAUT; Edwards and Newmann, 1982). It was developed for models of riskless decision-making. Here the multi-attribute utility of an option is the sum of the utility of the weighted attributes. MAUT can take into account the uncertainty of the decision when expected attribute utilities are used instead of attribute utilities. This is important in studying patient choice as there is much uncertainty embodied in medical consultations.

The theory of reasoned action is another such model (Fishbein and Ajzen, 1975), and has been used to describe and predict people’s treatment preferences (e.g. Figon *et al*., 1992). This theory assumes that the behaviour is under volitional control and that in a specific situation a person forms a particular behavioural intention that determines subsequent behaviour to a great extent. In other words, a person’s behaviour is largely determined by his/her intention to perform that behaviour. This intention is, in turn, determined by his/her attitude towards the behaviour and his/her subjective norm (Ajzen and Fishbein, 1980).

Ajzen and Fishbein (1980) proposed that a person's attitude towards behaviour is determined by the set of salient beliefs held about performing the behaviour. Salient beliefs, according to Ajzen and Fishbein, are a small number of beliefs – perhaps numbering between five and nine – that a person can attend to at any given moment. The subjective norm is a person's perception that most people who are important to them think they should or should not perform the behaviour in question. Ajzen and Fishbein explain that to form a subjective norm an individual considers the normative expectations of others who are important to him/her. The person’s motivation to comply is also taken into account; that is, how much they want to do what other people who are important to them think they should do.

3.2.4 The problem-solving approach

The problem-solving approach (Newell and Simon, 1972) was developed from the fields of cognitive science, psychology and artificial intelligence. It looks at decisions as problems and uses process-tracing techniques to reconstruct the underlying cognitive processes involved in the making of a decision or judgement. The problem-solving approach in contrast to the decision theory approach tries to describe the usually tacit process of the decision-making rather than the structure, perception and evaluation of the decision. Process-tracing techniques were developed in the investigation of problem solving (Newell and Simon, 1972). The data can be collected during the decision-making processing or afterwards. The process is mapped through time in terms of pieces of information attended to. The two main methods used in process-tracing techniques are protocol analysis and information search. They focus on the acquisition of the information phase of the decision- or judgement-making and how information is then combined by the decision-maker (Einhorn *et al*., 1979). 'Talk-through' is probably the best known use of process-tracing techniques in medical situations.

3.2.5 Social judgement theory

Social judgement theory has its roots exclusively in the domain of psychology (Hammond *et al*., 1975), examining the information used to make the decisions or judgement and using judgement analysis to do this. Social judgement theory can be traced back to Egon Brunswik's (1952, 1956) probabilistic functionalism theory of psychology and the technique of multiple linear regression analysis. Researchers (e.g. Gigerenzer and Hoffrage, 1995; Cosmides and Tooby, 1996) have argued that humans are adapted by evolution to reason about naturally sampled frequencies rather than single events.

Theories of decision-making whose roots lie in economic, game or probability theory tend to measure human judgement or decision performance against a normative standard and assume that decision-makers are fully rational (in the sense of conforming to the theorist's preferred normative standard) and fully informed. In contrast, social judgement theory addresses the uncertainties embedded in the environment that decision-makers face, and does not assume they are fully informed. Social judgement theory provides insight into human decision processes, and particularly into the weighting of information used to make the decision. Taking social judgement theory (or any regression-based model of decision-making) literally, it suggests that people take in information from some or all of the cues embedded in their environment and weight each of these cues. Subsequently they integrate the weighted cues to form a decision. Much mental processing is required to carry out these tasks and yet the human mind is characterized by limited cognitive processing capacity (e.g. Kahneman, 1973; Miller, 1956). The social judgement theory approach describes the judgements or decisions made in terms of the information available.

Typically in judgement analysis, participants are asked to make decisions on a set of cases, which can be real or hypothetical, and which consist of a combination of cues (pieces of information). Each participant's judgement policy is then inferred from his or her actual behaviour. Despite social judgement theory being a productive tool for investigating decision-making in applied domains, a number of researchers (e.g. Gigerenzer and Goldstein, 1996; Gigerenzer and Todd, 1999) began to question the plausibility of regression models of decision-making because of the amount of mental effort required if people were making decisions in this way. In addition, there are many published examples of people violating rational decision principles, which have generally been attributed to the nature of the human mind. Regression models are structural models that provide a static description of judgement behaviour where the same information is used in the same way when deciding on each case. However, in health care for example, options are not always mutually exclusive as doctors and/or patients could choose a combination of drugs and referral, for instance.

Research has found that judgement strategies are chosen relative to the structure and demands of the judgement task (e.g. Einhorn, 1971; Einhorn and Hogarth, 1975). For example, making judgements under time pressure seems to influence individuals to become more inconsistent (Davis and Davis, 1996), switch to simpler judgement strategies (Ford *et al*., 1989), not use all the relative information (Rothstein, 1986) and become more selective in information use and increase their use of non-compensatory strategies (Edland 1979). Consequently the psychological plausibility of regression models of decision-making can be questioned.

However, people do not always apply the statistical knowledge that they have. Kahneman and Lovello (1993) illustrate this point by using a project. They say that when forecasting how long it will take to complete a project, people may fail to consider previous projects they have written. Instead they think only about the current project and about their plans leading to a successful completion. Using simple heuristics may, depending on the nature of the task, improve the way in which choice is performed. In probability judgements, for example, Tversky and Khaneman (1983) found that conjunction errors were greatly reduced when frequencies were used in the wording of the judgement task instructions instead of probabilities.

Social judgement theory methods have been used to investigate a variety of issues within medical settings (Wigton, 1988, 1996; Engel *et al*., 1990; Smith *et al*., 2003). Examples include the comparison of judgements of haemodynamic status in critically ill patients with X-ray outcomes (Speroff *et al*., 1989), disagreement and sources of disagreement in drug-therapy decisions of psychiatric staff (Gillis *et al*., 1981), comparison of tacit policies used by physicians in prescribing lipid-lowering agents with their stated policies (Evans *et al*., 1995), and even examination of diagnostic and prescribing decision policies of GPs in depression. Although this method has been used widely in medical contexts, it has not been used to compare treatment decisions of physicians with evidence-based practice guideline recommendations. Probability is established by near-identical repetitions of events whereas most decisions in medical consultations are unique situations (with each patient being different) and there are very limited judgement probabilities available for GPs and patients made on actual data. In addition the theories discussed here all require a good understanding of the decision situation in order to identify all the options and potential outcomes. This may also be difficult in the medical consultation as situations vary so widely and all possible outcomes cannot be known.

3.2.6 Fast and frugal heuristics

Gigerenzer argues that often people use very little in the way of information to make good decisions, which raises the question of what information do they really use? Gigerenzer and colleagues have applied this type of model particularly to situations where people have to choose between two options. For example, in their well known paper in *Psychological Review* (Gigerenzer and Goldstein, 1996) participants were given the name of two German cities and had to decide which was the larger of the two. They found that the single cue of ‘whether or not the name was recognised’ could essentially predict which city would be judged the larger. However the recognition heuristic used in the city-size judgement task may not apply in the kind of task being dealt with in health care decisions. The model, known as the matching heuristic (Dhami and Ayton, 1998, 2001), was derived from Dhami's judicial decision-making research and is more applicable to the kind of tasks being dealt with in health care decisions (Smith and Gilhooly, 2006). The approach of this model is that judges (in the arena of patient choice these would be patients or physicians) search through a certain number of cues until the first critical cue is found and then they stop and decide to bail out (or in the present domain, this could be to take medication or to go for an operation, for example).

Appendix 4 Literature review on choice of residential care home

4.1 Background

Older people whose care is being arranged by local authorities have had the statutory right to be placed in a care home of their choice in the UK since April 1993, subject to certain conditions (Department of Health, 1992). People can choose to move to a home that is more expensive than usually paid for, if there is a third party able and willing to pay the difference. Recent guidance to councils about ensuring that people can exercise genuine choice states that in certain circumstances residents may make top-up payments themselves (Department of Health, 2004b).

Assessments should lead to older people in need of long-term care, and their representatives, being provided with information that helps them to select a care home that meets their health and social care needs (Department of Health, 2002). From January 2002 care home owners have been obliged to provide various pieces of information to people that should help them choose an appropriate home. These include: a statement of purpose, which includes the facilities and services provided; a service user's guide to the home, which includes the terms and conditions (including the amount and method of payment of fees); and the most recent inspection report (Care Home Regulations, 2001).

4.2 Evidence base

The Office of Fair Trading (2005) has recently published the results of a study looking at how well the care homes market serves people over 65 in the UK, following a so-called super complaint made by Which? in 2003. The study included a review of the literature on consumer behaviour and care homes (Williams, 2005), and in particular the context in which older people and their representatives make choices about a care home and how this affects competition in the market. This review is, in our view, of a high quality and very relevant to this scoping review topic, so we have used it as the basis for much of this section.

A search of various bibliographic databases had already been conducted before finding the literature review done as part of the Office of Fair Trading study. References from this search have been included where they address issues not covered by Williams (2005). Many of these additional references relate to residential care in the USA, an area not covered in any depth by Williams (2005). The following sources were searched, generally using the following keywords: (choice or choosing or market* or placement* or deci*) and (residential care or care home* or nursing home* or social care) and (user* or people or famil* or person or carer* or customer* or consumer*) (* is a wild-card character which can be replaced by any number of characters to form a word). For most databases, the search was restricted to publication dates from 1980 onwards.

- CSA Social Sciences (175 references found, 66 judged relevant based on title/abstract).
- Ovid Social Work abstracts and HMIC (718 references found HMIC, a further 102 non-duplicate references found on Social Work abstracts).
- SIGLE (13 references found).
- ASLIB Index to theses (17 theses found, two judged relevant based on title/abstract).
- Digital dissertations (52 dissertations found, five judged relevant based on title/abstract).
- Caredata (155 references found).
- Cochrane Library (all databases; five reviews found, none judged relevant, based on title/abstract).
- Ovid Medline, CINAHL and EMBASE (2073 references found initially; reduced to 1191 by various exclusions (e.g. mental health, foster care, end-of-life care, child protection, elder abuse); 280 judged relevant based on title/abstract).
- http://www.refer.nhs.uk/ (two relevant report summaries found).
- Department of Health research register (a small number of relevant projects were found and contacts attempted).
- BIDS/IBSS (38 references found, most found already by other searches).
- Zetoc (some additional references found).
- Individual: www.jrf.org.uk, www.dh.gov.uk, www.adss.org.uk, www.csci.org.uk.
- Google Scholar and Google (some additional references found).
- British Library (www.bl.uk; some additional references found).
- Personal communication with two authors.

Some 127 references were judged to be relevant, and a further 175 possibly relevant, based on their title, abstract or full text, as available. Bearing in mind time and resource constraints, these abstracts were reviewed again, and over 80 references were obtained in full.

4.3 Overview

Williams (2005) identified the following factors as influencing the nature and degree of consumer behaviour in the care home market.

4.3.1 Supply factors

- Availability of homes in preferred location.
- Availability of homes that can meet the older person's needs.
- Suitability of rooms within homes.
- Availability of vacancies in suitable, or any, homes.

4.3.2 Structural factors (organisational, professional)

- Eligibility criteria for services/needs assessment (council, NHS, providers).
- Demands and priorities of practitioners (care managers).
- Gatekeeping procedures of care home providers.

4.3.3 Economic factors

- Care home fee levels.
- For publicly funded residents – councils' fee threshold and the willingness and ability of a third party to pay a top up.
- For private payers – their ability and willingness to pay.

4.3.4 The nature of the process of moving

- Circumstances of the move (acute ill-health may mean person temporarily unable to make a decision; hospital is not the best place to make major decisions).
- Degree of involvement of older people and relatives in process by practitioners.
- Who is involved in decisions?
- Time available to search for, compare and select homes (and possibly to wait for a vacancy).
- Access to information and support/advice (to discuss feelings, advise on selection).
- Ability to visit prospective homes (influenced by availability of transport, possibly specialist).

4.3.5 Personal factors/characteristics of consumers

- Presence of relatives or close friends.
- Functional ability, dementia may mean person unable to participate in initial choice or to judge/indicate dissatisfaction with home.
- Presence or absence of relatives, informal carers or close friends to help.
- Degree of anticipation and planning.
- Attitudes and expectations:

– about care homes (may contribute to a lack of planning; beliefs may hinder willingness and ability to anticipate and engage in process/rationalise and plan);

– perceived role as consumer (may find active and personal interaction with others different to past experience as consumer);

– willingness to be consumer (may prefer to hand over responsibility);

– about moving and ability to cope (life histories, prior experience of relocation/number and pattern);

– initial move perceived as unchangeable.

- Knowledge about what they want/criteria to select a home.

- Emotions:

− distress of older person;

− reactions of carers (turmoil, ambivalence, sadness, failure, loss, guilt).

There appears to be consensus about a number of features of the context in which older people and their relatives make choices about care homes (Williams, 2005:56).

- Some people lack information on which to base selection decisions and would value guidance on how to choose an individual home.
- People have low expectations of the care that will be provided by care homes.
- Decisions about moving to residential care are often made during a crisis.
- The decision to move to a care home is often 'expert-driven'.
- Moves are often perceived as pressured and hurried.
- A significant proportion of older people report having little or no choice about the home they move to, although this may be due to them having delegated the choice to a relative.

These conditions largely conform to the conditions highlighted by Barnes and Prior (1995) as likely to mean that choice is experienced as difficult and stressful.

Various processes have been identified as promoting a positive experience of moving to a care home among older people: anticipation, participation, information and exploration (Nolan *et al*., 1996a; Davies and Nolan, 2003). Control is thought to be key to participation and also important for acceptance of the move and adaptation to the care home environment. Conditions identified as promoting resident choice in subsequent moves between care homes include awareness among residents of their rights and choices, an ability to communicate and debate their choices with others and the ability to access and evaluate information (Reed *et al*., 2003). Factors thought to improve the experience for relatives also include the opportunity to explore their feelings and emotional reactions.

4.4 Benefits of choice

We found little if any literature on the benefits of choice of residential care home, either in terms of improvements in the well-being of older people, or in terms of increases in quality or efficiency of the sector as a whole. One of the themes in the literature is the lack of choice for many people, due to supply shortages, Local authority policies, pressure to make quick decisions, and 'cream skimming' by care homes (Knapp *et al.*, 1994, cited by Williams, 2005; Perri 6, 2003; Williams, 2005). Nevertheless, Jenkins and Gibson (2005) found that satisfaction levels among care home residents were high, and practically everyone (95%) would recommend their current care home to a friend, either definitely (79%) or possibly (16%). In the USA, Prawitz *et al.* (1991) suggest that satisfaction with a nursing home among families of residents was greater if they had more time to make the decision, and had used this to investigate all the homes in an area before selecting one. Castle

(2003) found that residents and family members were more likely to be very satisfied with the nursing home they had chosen if they:

- had spent a greater than average time looking for a home;
- had visited the home;
- were not hospitalised when making the choice;
- had previously considered long-term care;
- were less highly educated (i.e. up to 12th grade).

Thus, where people are in a position to make a considered choice, it would seem that they are more likely to be satisfied with their residential care home.

Due to a variety of factors, quasi-markets in social care do not appear to have increased quality or efficiency in the UK or in Sweden (Fotaki and Boyd, 2005), but to have produced the following results:

- increasing provision by the private sector;
- less diversity of supply;
- local authorities constraining individual choices, due to financial pressures;
- increasing central regulation;
- no reduction in bureaucracy;
- no demonstrated increase in quality;
- some increased responsiveness for relatively ’strong’ clients;
- politicians have struggled to ‘let go’;
- public expenditure has risen;
- public trust has declined.

Harrington (2001) notes that poor quality of care in nursing homes in the USA has continued to be a problem for 30 years, because regulation is weak, and the government, concerned about costs, is reluctant to impose higher standards.

4.5 Factors people take into account when choosing a care home

Maintaining continuity with the past is considered important for older people's well-being and this is often associated with maintaining links with a place, location or community (Corden and Wright, 1993, cited by Williams, 2005:26). Data suggests that about 15% of care home placements may be in a different council area to the one in which the older person lived previously (Williams, 2005:27). But this figure is subject to a variety of uncertainties, and only a proportion of them will result from choice. Jenkins and Gibson (2005) found that location was the single most important reason for choice of home – particularly being near family (44%), but also being in the area where they used to live (20%) or near to friends (8%). Other important considerations found in this survey were:

- availability – only one available/there was a room free when needed (31%);

- reputation/recommendation of home (27%);
- knowing someone there (14%).

Castle (2003) found that location was the most important factor in choosing a nursing home, followed by quality – particularly cleanliness – and price.

Research does suggest that relatives and residents lack criteria on which to compare homes. Interviews have indicated that some base their choices on criteria that are not necessarily related to quality of care, such as appearance or décor, because they lack advice about what they should be looking for (Nolan and Dellasega, 2000). Décor, furnishings and the 'feel' of a home have also been identified in another study (Davies and Nolan, 2003). Rodgers (1997) found that for most people the general impression of the facility gained on a personal visit, especially with regard to ’cleanliness’ was the deciding factor. How a residential care facility looks, smells and feels may be a factor in whether it is chosen as a place to live (Sales *et al.*, 2005).

Tudor and Carley (1995) found that the most important attributes were competence and attitude of staff, cleanliness, and quality of physical care, but also notes that ‘gut-level’ responses to a facility or its staff members could well be the basis of many decisions, especially when the decision-maker feels they lack the time or expertise needed for a cognitive judgement. Smith (1984) found that observable variables such as cleanliness were the most important aspects in the selection decision. Bell (1996) found cleanliness (absence of odours) and proximity of the home to the family to be among the greatest concerns of rural families making nursing home placement decisions.

Family looked for staff to appreciate the elder as a person; and what staff considered to be minor details were very visible signs of an impersonal institutional setting for the families. Auken (1992) found proximity to the family to be most often regarded as important in selecting a nursing home, followed by quality of nursing care and cleanliness. Shemwell and Yavas (1997) found staff attitudes to be the most important consideration, followed by location, and then quality of nursing care. Prawitz *et al.* (1994) found that families ranked quality of care as the most important characteristic of nursing homes, but the researchers questioned this, and suggested that location might be a key limit to choice. The rankings showed that families are concerned about the surroundings of the patients, perhaps because they recognise that a nursing home is not a hospital but a new home environment.

People have indicated that they would value expert advice on the quality of particular homes: 'No one would tell me which was a good home or which was a bad one' (Nolan and Dellasega, 2000). Some have described relatives as desperate for 'insider knowledge' (Davies and Nolan, 2003). The value placed on personal recommendation has been identified (Davies and Nolan, 2003; Davies *et al.*, 2000, cited by Williams, 2005; Williams *et al.*, 2003).

Relatives and residents have been found to select a home based on its familiarity (Reed *et al.*, 1998a; Davies *et al.*, 2000, cited by Williams, 2005). The basis for 'knowing' a particular home, or its location, may at first appear tenuous, such as having driven past a home on the way to work or having known the village when a child, but indicate links to personal histories and may help establish an important sense of continuity (Reed *et al.*, 1998a). Practical criteria that relatives and residents have reported trying to consider include the distance to the home (Davies *et al.*, 2000, cited by Williams, 2005; Davies and Nolan, 2003), the cost (Davies and Nolan, 2003), an absence of odour (Davies and Nolan, 2003) and closeness to amenities, town centre or public transport to enable residents to visit others or allow them to be visited or 'dropped in' on by friends and neighbours (Reed *et al.*, 1998b, cited by Williams, 2005).

Relatives have also reported looking at other residents living in homes, presumably to gauge if they are similar to the prospective resident (Davies and Nolan, 2003). Self-funded residents are often aware of the existence of a home because it is located in an area that they know (Netten *et al.*, 2001, cited by Williams, 2005). Twenty-seven percent said that they knew of the chosen home because it was close to where the resident had lived. A further 16% said that they knew of its existence because it was close to where a member of the resident's family lived. The survey also found that 31% had considered the distance from the resident's former home and 57% the distance from family and friends when selecting a home. The general atmosphere was identified most frequently as a factor that influenced the selection of a home (cited by 77% of respondents) and as typically having been the most important reason (identified by 31% of respondents). The availability of a place was the next most frequently cited factor (identified by 65% of respondents) and the next most popular important reason (identified as such by 14% of respondents).

When marketing a nursing home, the key attributes of the home to focus on are those which consumers perceive both to be important and to differ between homes (Hill, 2001). Such attributes are (in order) cleanliness, location, reputation, competent/caring staff, bed availability and comfort of rooms. Taking account of perceived differences between homes increases the salience of location and decreases the salience of competent/caring staff.

Most care homes responding to a survey said that the quality of brochures and information is important in attracting new residents (Office of Fair Trading, 2005:72). There are conflicting research findings from the USA about the value of advertising. Castle (2003) found that family members’ most important source of information was advertising, but Smith (1984) and Auken (1992) found that advertising aimed at potential residents and their families had minimal effect.

4.6 Issues

Concerns expressed since the Community Care reforms include (Williams, 2005:21):

- a lack of involvement of older people and their carers in the assessment process, or decision to move to residential care (Allen *et al.*, 1992);
- a lack of timely and helpful information about what services are available;

- insufficient information about homes to support choice, often not provided within a useful timescale (Office of Fair Trading, 2005:61; 1998);
- local shortages of care homes and shortages of homes providing dementia services.

Many of the older people who move to a care home do so after having been in hospital (Williams, 2005:33), and admission from hospital can be associated with relatives feeling pressured and/or that they have to select a home quickly (Nolan and Dellasega, 2000; Davies *et al.*, 2000, cited by Williams, 2005; Wright, 2000, cited by Williams, 2005).

Another consequence of being in hospital is that prospective residents may be physically unable to visit homes themselves and this, combined with their lack of prior consideration and/or knowledge of care homes, can mean the move is very much a 'step in the dark' (Reed and Morgan, 1999). It may also mean they are unable or unwilling to take part in decision-making. Moving to a care home from hospital is thought to be associated with the least positive type of admission process.

Evidence about older people's willingness and ability to change homes is limited (Williams, 2005:32). When moving a second time, a resident and their relatives will have experience of the general process involved in selection and the information sources available. They are also likely to have developed opinions about what they value in a home and what to look for when looking around. There do however appear to be a number of constraints (Barnes, 1997, cited by Williams 2005; Challis and Bartlett, 1988, cited by Williams, 2005:32), including:

- lack of alternatives;
- not being able to judge quality of the current service;
- lack of information on which to base a choice;
- no help to find an alternative home.

4.7 Involvement of older people in making choices

The literature about the decision whether or not to enter residential care is quite numerous, but studies are usually small in size. The literature suggests that (Williams, 2005:39):

- older people and their relatives are rarely involved in the decision, although they are more likely to be involved in the UK than in the USA;
- the choice is often ’expert-driven’;
- older people may prefer others to make choices on their behalf.

Most people moving into a care home have not considered alternatives, such as care at home (Jenkins and Gibson, 2005).

Evidence about whether older people have a choice of individual care home is similar to that about their involvement in the decision to move into residential care (Williams, 2005). The consensus of the evidence appears to be that a significant proportion of older people who move to care homes have no choice about the home they move to, although the size of the proportion identified varies.

Often the choice is made by a relative or carer (Williams, 2005:43), and this is a relief to the older person. An Office of Fair Trading study found that among residents who reported having had no choice of home, 54% said a relative, and 20% said a social worker, or the hospital or consultant had made the selection (Office of Fair Trading, 1998). Jenkins and Gibson (2005) found that in the majority of cases, family were involved in the decision-making process to choose a particular home – either solely (37%) or jointly with the resident (37%). Some 18% of residents claimed they had made the decision alone and 29% of respondents in a US survey said that doctors most influenced their choice of home (Smith, 1984). Castle (2003) found that a family member was most influential in the search for and selection of a nursing home, followed by the residents themselves, and then by hospital staff (somewhat or extremely influential in about 35% of cases). Auken (1992) also found that the experience of others is the most frequently checked information source when developing a shortlist of homes, followed by a physician’s referral.

4.8 Timely and helpful information on services

The amount of time available may restrict choice (Nolan *et al.*, 1996b, cited by Williams, 2005:44). A minority of care home residents surveyed said they felt under pressure to choose quickly, or would have liked a little more time (Jenkins and Gibson, 2005). Pressure might come from the care home, the family or from the hospital, if the person is discharged to the care home from hospital. Family members have reported wanting information early in the process, rather than when they visit a care home (Rodgers, 1997).

The time-consuming nature of the task of contacting care homes and making visits has been described in interviews with relatives. People reported spending as much as an hour a day for 26 days telephoning homes and visiting up to 25 homes in an Australian study (Cheek and Ballantyne, 2001). This was said to have a negative effect on family relations. Typically, however, the selection process is short, taking about a week for 35% of respondents in a US survey (Smith, 1984).

In a UK survey, 26% of care home residents made no visit, either to the home they subsequently moved into or to any other, 41% visited just their current home, and a third visited more than one (Jenkins and Gibson, 2005). In the USA, Castle (2003) found that residents visited 1.4 nursing homes on average, and family members 2.4 homes on average. Only 31% of residents visited the home of choice, and only 63% of family members. Auken (1992) found that 31% of residents/families evaluated only a single nursing home. But for those families who did evaluate more than one care home, a visit to the home was the most frequently mentioned source of information to help discriminate between homes, followed by information from friends and physician referrals. Another US study found that the average number of facilities visited, called or inquired about by post was 3.4 (Smith, 1984).

Because of the difficulty in visiting homes, people narrowed the list of possibilities based on anecdotal reports and personal experience (Rodgers, 1997). In choosing a nursing home, residents' most important source of information was a friend (Castle, 2003).

Choice of home can also be hampered by a lack of information. A study of older people moving to care homes from hospital concluded that older people did not consider themselves to be informed consumers (Reed and Morgan, 1999). One study found that 65% of carers had not been given all the information they wanted and that 50% had not received all the help they would have liked (Nolan and Dellasega, 2000). On the other hand, staff may be able to help people searching for a nursing home by sheltering them from information overload (Travis and McAuley, 1998).

Family and social services are the main sources of information and advice about care homes in an area (Jenkins and Gibson, 2005). The majority of those who did not receive guidance were happy not to be helped, with 23% saying they would have liked help. In terms of informing service users more generally, a survey of eight councils in 2001–2 concluded that the levels of information provided to social services staff in information-giving roles were 'alarmingly low' (Rhodes, 2003). In a survey of residents in care homes for older people, 34% of residents found out about their care home through their local authority or the NHS (Office of Fair Trading, 2005:65). More (40%) relied on family, and a substantial proportion (20%) knew about their care home anyway or had friends already in the home (7%).

In 1999 just over half of self-funded residents and their relatives surveyed reported having had no advice or guidance about the process of finding an appropriate home and arranging a place (Netten *et al.*, 2001, cited by Williams, 2005). Just over half had been given advice from a social worker or care manager. Seventeen percent had received some advice from a health care professional and 3% from a home care worker. Information from independent organisations such as Age Concern had been sought by less than 2% of the sample. In relation to residents in receipt of NHS funding the Health Service Ombudsman has reported that patients and relatives often complain about a lack of information about how decisions are made (Health Service Ombudsman for England, 2003).

Little is known about the degree and nature of communication between prospective residents and their representatives and prospective homes. An Office of Fair Trading survey (1998) found that only 35% of relatives/friends and 23% of residents had received written information from a leaflet or brochure prior to staying at the home. Recent evidence from the national regulator shows that although care homes are now required to make certain information available to prospective residents, only 25% of homes met or exceeded the information standards in 2002–3 (Unsworth *et al.*, 2004). Of the 75% who failed to meet it, 51% were said to have almost met it, but 24% to have definitely failed it. The report concluded that the 'information currently provided by the care sector in England is often deficient' (Unsworth *et al.*, 2004).

A mystery shopping survey (Office of Fair Trading, 2005:69) found that it can be difficult to get clear, timely information about fees and services from care homes. The survey showed that under half were rated by the researchers as 'informative'. Homes that are part of a chain are more likely to give residents brochures, information and contracts than homes run by smaller providers, and large homes (more often part of a chain) are more likely than small ones to provide such a range of information (Jenkins and Gibson, 2005). Green *et al.* (2005) found that care homes took a kindly but limited interest in the individual older person. No suggestion was made to any older person that other types of accommodation might be more suitable for them. Most brochures relied on generalities, printing few specifics about the service that could be checked, such as staff/resident ratios, or staff training and qualifications. In the USA, Lawrence *et al.* (1998) concluded that families selecting a nursing home found visits and personal investigation more helpful than printed materials.

Macknick (1998) suggests relatively simple ways in which care homes can influence people to choose their home. In the absence of measures of quality of care, there is clearly scope for poor-quality homes to manipulate people into choosing them.

In the context of home closures, relatives and residents said that up-to-date and accurate vacancy information would be more useful than lists of all of the care homes in the area provided by social services (Williams *et al.*, 2003). This indicates the importance of appropriate information. Researchers that have investigated older people's views on information more generally have highlighted that, for them, information is a means to an end (Quinn *et al.*, 2003, cited by Williams, 2005). When service users identify a lack of information it may not indicate a lack of provision, but rather a lack of useful information or awareness of the existence of information. There are many sources of information and advice about what people might ask when visiting homes from various organisations, which suggests that to some extent the problem is one of access, rather than availability.

Office of Fair Trading (2005:61) found that older people and their representatives have low levels of awareness of the sources of information about care home availability. And research has identified a lack of awareness of inspection reports; in 1999 none of the 30 relatives who were interviewed in one council were aware that they could look at inspection reports (Davies *et al.*, 2000, cited by Williams, 2005). Only 20% of the residents surveyed by Office of Fair Trading (2005:72) recalled that they or their family saw an inspection report, and these reports are not always 'user friendly'. In a mystery shopping exercise (Jenkins, 2005), few mystery shop transactors were told about the care home's inspection report. Of those that were, half were informed it is available upon request.

Williams *et al.* (2003) found that relatives had not necessarily become 'experts' in the process merely because they might have helped find the first home. Some seemed unaware of the information sources available. One relative had used the *Yellow Pages* to find homes in the area and another relative of a self-funded resident only found out about the council's list of homes by chance from a friend.

The Office of Fair Trading (2005:74) recommends the setting up of a central information source for people to get information about care for older people. A large amount of information relevant to choosing a nursing home in the USA is obtainable on the Internet (Katz *et al.*, 2001), but there does not appear to be any published evaluation of the usefulness of these information sources.

The Office of Fair Trading also recommends (Office of Fair Trading, 2005:135) that care home regulators should make public the outcome of non-trivial substantiated complaints about care homes.

Care managers have reported being unable to advise people properly, and sometimes having to accept, or propose, individual homes that were not, in their view, the most appropriate (Williams *et al.*, 2004, cited by Williams, 2005). In some cases residents or their relatives chose homes that the care managers would not have chosen, sometimes because of their knowledge of the standards of care provided. A few care managers spoke of 'steering relatives in the right direction' or suggesting that they continue to look at alternatives or inspection reports, while knowing that they were not supposed to advise relatives against particular homes, as this could be considered a constraint on trade. Others spoke of being powerless in such circumstances: ‘If they pick a home that is not going to be completely suitable – there is not a lot we can do.’

4.9 Range of care homes considered

Sometimes there are relatively few suitable care homes to choose from locally. In a consumer survey (Office of Fair Trading, 2005), only 17% of residents felt they had had a wide choice, and although for some it was not an important issue, 27% said their choice was limited and a further 16% said it was very limited. Fifty-nine percent of residents considered only one home, while 12% considered four or more homes (Jenkins and Gibson, 2005). When residents chose the home on their own, 77% considered only one home when making their decision to move.

4.10 Implications for health care

Choosing a residential care home (either a residential home or a nursing home) is perhaps the closest analogy in social care to the NHS choose and book policy of patients being able to choose a hospital for a specialist consultation, with a view to an elective surgical operation. Potential choices open to consumers in the care home market include the following (Williams, 2005).

1. To move to a care home or not (other service options might include home care, for example).
2. To select a particular home, including its
   - location and
   - sector of provision (public, private or voluntary).
3. On admission, to stay or move.

Corresponding choices in the NHS related to choose and book might be viewed as the following.

1. To be referred for an operation or not (other options might include 'watchful waiting', for example).
2. To select a particular hospital, including its
- location and
- sector of provision (public, private or voluntary).
3. After an initial outpatient appointment, to have an operation at the same hospital, or to seek an outpatient appointment/operation at a second hospital (e.g. to get a second opinion).
4. In the event of requiring a longer-than-expected stay in hospital, to transfer to a second hospital for ongoing treatment.

In this scoping review we have focused mainly on choice 2 above, which corresponds most closely with the NHS choose and book policy. We have not covered choice 1, because care managers and GPs both perform a similar 'gatekeeping' role with regard to this choice, there are no proposals that we know of to purposely alter the nature of this choice. For choices 3 and 4 it is unclear to us how the choose and book policy will be applied, although these scenarios would appear likely to occur in a relatively small proportion of cases. We have therefore looked at some of the literature related to choice 3 in social care, but in less detail.

In drawing any conclusions about what the experience of choice in residential care might imply for choose and book, the many differences between the social and health care sectors need to be borne in mind. In addition to the differences listed in the section of this report on direct payments, are the following.

- The financial circumstances of individuals and of local authorities limit the homes that can be chosen, whereas the national tariff for operations means that this should not be a consideration for NHS patients.
- People whose care home placements are funded by a local authority (the majority) are further restricted by the contracts, which the local authority has, whereas it is planned that NHS patients will be able to choose from all organisations offering the procedure that they are thought to require.
- Choosing a care home is about choosing a permanent place to live in, whereas choosing a hospital is likely to result in a patient being away from their usual home for only 1 or 2 days (Reed *et al.*, 1998b, cited by Williams, 2005), so the decision is a 'bigger' one, with greater impacts on other family members, some of whom may well be carers. It is often perceived as an experience of loss.
- Care home consumers are more likely to be unable to express their preferences or lack capacity to make decisions than candidates for elective surgery.
- Care home consumers are more likely to be female, and to be older, than elective-surgery patients, but less likely to be from ethnic minority groups.

- The negative image of residential care among the public (Williams, 2005:37), which may lead to a lack of planning by potential residents, contrasts with widespread support for the NHS and belief in the professionalism of its staff.
- People have been more willing to be actively involved in decision-making with regard to social services than with regard to health services, where they feel staff have more specialist expertise (Roberts, 2001).

With regard to choose and book, the analogy with choice of residential care home suggests that the following factors are likely to influence patients' behaviour in the hospital market.

4.10.1 Supply factors

- Availability of relevant services locally, although what will constitute local is unclear.
- Hospital waiting lists.

4.10.2 Structural factors (organisational, professional)

- Demands and priorities of practitioners (GPs and hospital consultants).
- Gatekeeping procedures of hospitals.

4.10.3 The nature of the process of choice

- Degree of involvement of patients and relatives in the process by practitioners.
- Who is involved in decisions?
- Time available to search for, compare and select hospitals (and possibly to wait for an operation).
- Access to information and support/advice (to discuss feelings, advise on selection).
- Ability to visit prospective service providers (influenced by availability of transport).

4.10.4 Personal factors/characteristics of patients

- Degree of anticipation and planning.
- Attitudes and expectations:

− perceived role as consumer (may find active and personal interaction with others different to past experience as consumer);

− willingness to be consumer (may prefer to hand over responsibility).

- Knowledge about what they want/criteria to select a hospital.

Patients are likely to be influenced by experiences of particular hospitals – their own experiences and the experiences of relatives, friends and acquaintances. These experiences are likely to reflect easily observable attributes of hospitals, such as cleanliness, appearance of the building, staff attitudes. Patients' experiences may however also include attributes more closely linked to clinical care, such as post-operative pain. Given the high levels of satisfaction expressed by most patients, such word-of-mouth information would appear likely to reinforce historical patterns of hospital use.

Various factors suggest that patients will be more likely to choose local hospitals, although what constitutes local is not known, and may well be a wider area than for residential care homes:

- patients may prefer hospitals that they have visited or at least seen before;
- transport links/costs will be a consideration.

A proportion of patients are likely to prefer their GP to make the choice of hospital on their behalf, and, should they wish to do so, GPs are likely to be able to exercise some influence over the choices of many patients.

Patients who want to make a choice should generally be encouraged to take some time to make their decision and to investigate options, although most people are unlikely to want to make a large investment of time in the decision. A single point of access to comprehensive, relevant, accessible information and advice would be helpful for these people.

4.11 Implications for research

Possible topics for future research include the following.

- Patient and staff awareness, use and views about particular sources of information, such as inspection reports, and the extent to which these influence choices (Williams, 2005; Castle, 2003).
- The impact of support for disadvantaged groups on their abilities to make and take-up choices.
- The influence of service reputation and marketing on choices.
- The actual distances to which patients travel to hospitals under the choose and book scheme, and the factors which affect this.
- Which patients make ’active’ choices under the choose and book, and the factors which affect this (Williams, 2005).
- How stakeholders such as GPs, consultants and hospitals react to choose and book, and, in particular, how they seek to influence/manage the market.
- The impact of patient choice on the health care market (Williams, 2005).
- The impact of patient choice on health and other outcomes, at system and individual levels (Williams, 2005).

Appendix 5 Literature review on direct payments

5.1 Background

Many European countries offer some form of payment scheme whereby disabled people can receive money to buy social services instead of receiving services arranged by the state (Glasby and Littlechild, 2002:58, Leece 2004c; Keigher, 1999; Askheim, 2005; Lundsgaard, 2005). Direct payments (DP) were introduced in the UK in 1996 as a means of enabling local authorities to make cash payments to social service users in lieu of directly provided services, where such payments would be cost-effective (Glasby and Littlechild, 2002). Recipients of DP typically employ a personal assistant (PA), either directly or through an agency, giving the service user greater choice over which individual supports them, at what times the service is provided, and what the service comprises.

The earlier Independent Living Fund (ILF), which was similar to DP in many ways, had proved popular with users, fundamentally shifting power away from professionals, but was too costly for a government wanting to limit public expenditure. DP were initially only available to adults aged under 65, but in 2000 were extended to older people, carers, people with parental responsibility for disabled children, and disabled young people. Since April 2003, councils have had a duty to make DP to individuals who consent to and are able to manage them, rather than a duty just to offer DP (Department of Health, 2004b, 2004c). DP can only currently be used instead of social care services (Glasby and Hasler, 2004).

5.2 Evidence base

The following sources were searched, generally using the keywords "direct payment". In some of the early searching, "service broker" was also searched for, but this generated few references, and it was omitted from later searches. This means that evidence from other models such as service brokerage has not been considered by this review.

- Caredata, the electronic library for social care (255 references found).
- CSA Social Sciences (220 references found).
- HMIC (220 references found).
- BIDS/IBSS (41 references found).
- Individual websites: www.jrf.org.uk, www.nimhe.org.uk, www.dh.gov.uk, www.psi.org.uk, www.adss.org.uk.
- Social Work abstracts (six references found).
- British Library (two relevant articles found).

- ASLIB Index to theses (keyword "DP") found two theses, one of which was relevant, but the author has published an article covering similar ground.
- DARE (no relevant articles found).
- Digital dissertations (no relevant articles found).
- Department of Health research register (five projects found). The results of two projects had been reported in articles already found by the search. The contacts for the other projects were contacted by e-mail, requesting information and any results.

Finally, there was a search for articles citing key articles or with related reference lists – Web of Science – Social Sciences database.

Over 450 unique references were found through the search. Over 55 references were obtained in full.

5.3 Benefits

DP are generally well regarded by service users because of the flexibility, choice and control they offer (Commission for Social Care Inspection, 2004; Glendinning *et al.*, 2000a; Stainton and Boyce, 2004; Carmichael and Brown, 2002; Dawson, 2000; HASCAS, 2004; Witcher *et al.*, 2000; Lundsgaard, 2005). Older people and people with mental health problems receiving DP have reported feeling happier, more motivated and having an improved quality of life (Clark *et al.*, 2004; HASCAS, 2004). Researchers in a pan-European study concluded that DP were a positive development (Pijl, 2000:56–7, cited by Glasby and Littlechild, 2002:58–9). There may however be some difficulties in the relationship between users and workers (see below). Zarb and Nadash (1994) observed that people receiving DP placed more emphasis than other service users on organisational aspects of service, such as timeliness and convenience.

DP for disabled people may be more cost-effective than direct service provision (Zarb and Nadash, 1994; Dawson, 2000), mainly due to lower administrative overheads, as the service users themselves do much of the administration. Zarb and Nadash (1994) also suggest that 'mixed' arrangements combining services and payments are both more costly and less efficient than either the payments option or services on their own. There may also however be a presumption among many that 'bulk' purchase is more efficient than individual purchasing (Commission for Social Care Inspection, 2004). The overall view in a review of DP in European countries was that DP are at least as expensive as directly provided services, although the response was mixed (Halloran, 1998). A more recent study suggests they can give quality benefits at similar cost to other modes of service provision, provided they are suitably targeted (Lundsgaard, 2005).

There may be benefits for people from ethnic or other minority groups. Clark *et al.* (2004), for example, state that DP enabled Somali older people to employ PAs who shared their language (Clark and Spafford, 2002). DP may also play a key role in ongoing improvement of assessments, making them more focused on needs rather than services (Lyon, 2005).

5.4 Market effects

There is little evidence about whether DP acts as a mechanism for improving services overall, and Perri 6 (2003) suggests that DP may have had only a marginal effect, partly because the scale of DP take-up has been relatively small (see below). It has been claimed that the development of DP has enabled Gateshead Council to significantly change the nature of services (Commission for Social Care Inspection, 2004), and another study felt that DP might drive up the general quality of community support (Joseph Rowntree Foundation, 2000; Hasler, personal communication). The growth of a new independent 'care market' appears to have been stimulated by DP service developments in Germany, Austria, Netherlands and France and to a lesser extent in Sweden and Denmark, where local authority providers may be preferred, because of a positive attitude towards public services (Halloran, 1998).

There are concerns, summarised by Spandler (2004) that at a community or system level DP may distract from:

- investing in welfare services – overall levels of funding are important;
- developing services that can better meet the needs of groups of people who have similar difficulties;
- developing 'culturally appropriate' communal services;
- understanding the wider structural context in which oppression is experienced;
- developing 'self-help' movements.

The service users who are most dissatisfied with existing services and who are most likely to campaign for improvements may be more likely to take up DP, with potential loss of stimulus for service improvement. Thus DP may lead to inequalities, or perhaps heighten existing ones, between users who wish to pursue individual solutions, and those who want to use provided services (Lyon, 2005). There is also a danger that the availability of DP as an 'alternative' that people can choose may be used by local authorities to justify avoiding development of other services (Lyon, 2005).

5.5 Issues

A study of DP across Europe identified some issues (Pijl, 2000:56–7, cited by Glasby and Littlechild, 2002:58–9) including:

- cost containment;
- quality of the services purchased;
- welfare of care givers – low pay, job insecurity, lack of training;
- opposition from trades unions and formal service providers.

These and other issues with DP have often expressed themselves in slow take-up of DP.

5.5.1 Take-up

DP are not the best option for everyone. Some people will still want to use directly provided services as long as they are of good quality (Joseph Rowntree Foundation, 2000). In the context of younger disabled people, where care is complex and care managers are responsive to users' needs, then neither users nor staff see a need for a direct payment (Social Services Inspectorate, 2000). Nevertheless, the take-up of DP has been slow, particularly among groups outside of the initial focus on disabled people, i.e. older people, people with mental health problems, and people with learning difficulties (Social Services Inspectorate, 2000; Jordan, 2004; Bainbridge and Ricketts, 2003; Joseph Rowntree Foundation, 1999a, 1999b; Ridley and Jones, 2003; Zarb and Nadash, 1994; Riddell *et al.*, 2005).

Among older people, take-up appears to be relatively slow in the UK compared with other European countries (Leece, 2004c). DP have been particularly under-utilized by minority ethnic users (Vernon, 2002, cited by Pearson, 2004). It may also be that the middle classes are disproportionately benefiting from DP (Clark *et al.*, 2004; Leece, 2004a, cited by Leece 2004b), perhaps due to access having been at the discretion of care managers (Perri 6, 2003), or, in Sweden, individuals having to positively ask for a DP (Askheim, 2005).

Barriers to take-up include (Commission for Social Care Inspection, 2004):

- low staff awareness of DP and what they are intended to achieve;
- restrictive or patronising attitudes about the capabilities of people who might use a DP and a reluctance to devolve power to them;
- inadequate or patchy advocacy and support services;
- inconsistencies between the intention of the legislation and local practice, perhaps because of a lack of clear national guidelines on how to operate DP;
- unnecessary, over-bureaucratic paperwork;
- problems in recruiting, employing, retaining and developing PAs and ensuring quality.

5.5.2 Staff awareness and attitudes

Glasby and Littlechild conclude that the attitude of frontline workers is crucial, and they may fail to provide support and information if, for example, they are suspicious about the implications for their work, or they are set conflicting priorities such as enabling choice and controlling costs (Glasby and Littlechild, 2002:137). DP have worked best in local authorities where a supportive local authority infrastructure is combined with both an understanding of the principles of independent living and a commitment to partnership with users (Joseph Rowntree Foundation, 2004a). But research suggests that many staff/organisations have tended to be reluctant to give more control to users, and that staff education and training is the primary means to addressing this.

Pressures for local authorities to develop DP schemes draw on two discourses: market and social justice (Pearson, 2000), and while this linkage of discourses is powerful in many respects, it also has tensions. Resistance to developing DP schemes in Scotland has in part been due to fears of this being part of a drive to privatise services (Pearson, 2000, 2004). There have also been concerns about workers in existing mental health services not being needed any more, and a reduction in the power of care coordinators (Ridley and Jones, 2003; Newbigging and Lowe, 2005).

Training and practice development for staff was felt to be needed, providing accurate information and an opportunity to explore concerns (Newbigging and Lowe, 2005). Stainton found that social workers, while not fully embracing the need to relinquish control over some aspects of care management, seemed to accept that they needed to work more in partnership with clients (Stainton, 2002). Education and training for social workers would help, but structural conflicts of interest appeared to be the main barrier to greater control for DP users.

Clark and Spafford found varying levels of willingness among care managers to give more control to service users, partly reflecting debates about professional identity, and partly tensions in the role of care management between empowering users and controlling costs. (Clark and Spafford, 2002). They suggest education and training for staff, about social models of aging and disability, and their links to DP, with service users being involved in the training. (Clark *et al.*, 2004) also report that DP are yet to become part of the culture of care management. That staff knowledge and attitudes are hindering take-up of DP is a common concern (Jordan, 2004). Staff training was the most often suggested solution to this.

5.5.3 Information and support services

Actual experience has revealed little support or encouragement to older people to consider DP options (Bainbridge and Ricketts, 2003). The way in which care managers promoted a scheme similar to DP to different older people varied: the older people had little or no understanding of what they had been offered (Clark and Spafford, 2002). Many agencies had not adapted to the needs of users with learning difficulties (Joseph Rowntree Foundation 2004b).

DP has worked best where there has been good information and support for users and staff (Paiva and Davies, 2005; Davidson and Luckhurst, 2002), developed with involvement of users. Support services have been crucial in enabling older people to use DP (Clark *et al.*, 2004). This is also the case for people with disabilities (Stainton and Boyce, 2004), with the fact of support services that are staffed by disabled people giving enhanced quality. For mental health services, support workers have been identified as one of the main factors supporting implementation of DP (HASCAS, 2004). Where there are DP facilitators in addition to social workers, take-up of DP appears to be higher (Social Services Inspectorate, 2002), and users prefer support to be provided independently (Commission for Social Care Inspection, 2004; Ridley and Jones, 2003).

Information needs to be ‘personalised’, address individual needs, be straightforward and be presented in a variety of formats (Maglajlic *et al.*, 2000). It should use real-life examples to demonstrate how DP can be used, their potential impact, and how to access support (Newbigging and Lowe, 2005).

People with learning difficulties need the same sort of information as other people, but may need this to be provided in different ways (e.g. written information may be less useful; Joseph Rowntree Foundation 2004b). Ways of helping people with learning difficulties make informed choices include providing accessible information, giving people time, reducing the formalities, respecting the ways in which people communicate, lessening the pressures and enabling people to make decisions in their own, familiar environment (Department of Health, 2004b). People with learning difficulties could also play an important role in informing others with learning difficulties (Joseph Rowntree Foundation, 2004b; Department of Health, 2004b).

5.5.4 Bureaucracy

Various aspects of DP are bureaucratic and complex (Carmichael and Brown, 2002; Department of Health and Cabinet Office, 2005), including Criminal Records Bureau checks, opening bank accounts and lack of detailed authoritative guidance. People may be put off DP, and recipients may not all make ’appropriate’ checks on the staff they employ, and this may lead to maltreatment (Department of Health and Cabinet Office, 2005).

5.5.5 Employing personal assistants

Many recipients of DP employ a PA, either directly or through an agency. PAs have been recruited mainly through advertisements or word of mouth via friends or other disabled people (Glendinning *et al.*, 2000a; Stainton and Boyce, 2004; Dawson, 2000). Many PAs are already known to users, either as paid carers, friends or neighbours (Stainton and Boyce, 2004), and there is some evidence of ‘poaching’ PAs from other employers (Glendinning *et al.*, 2000a). In the USA, Keigher (1999) found that some clients had known their worker prior to receiving care from them, typically for a long time. Black clients and workers were more likely to have known each other previously than white clients and workers; and subsidised clients were more likely to have known their worker than private-pay clients.

Many DP users in two studies had experienced difficulty recruiting suitable staff, with advertisements producing few suitable applicants (Glendinning *et al.*, 2000a; Carmichael and Brown, 2002). Maglajlic *et al.* (2000) report that finding appropriate staff can be a lengthy process. HASCAS (2004) reports some difficulties in recruiting PAs at times, due to low pay rates, and in a survey of authorities in Scotland, difficulty recruiting PAs was experienced in most, particularly rural ones, partly linked to low rates of pay (Witcher *et al.*, 2000). Glendinning *et al.* (2000a) states that restrictions imposed by some DP schemes made it impossible for users to offer good terms of employment. In a survey of English local authorities, about 10% of respondents said that difficulty in recruiting PAs was limiting take-up of DP (Jordan, 2004). Those users with the most extensive needs were least attractive to prospective employees. Only one study was found where it was reported that most people had little difficulty recruiting staff (Dawson, 2000).

Some service users prefer to use an agency because they do not then have the responsibilities of being an employer (Glendinning *et al.*, 2000a), but may be dissatisfied with the quality of the PA (Glendinning *et al.*, 2000a; Morris, 2004). Glendinning *et al.* (2000a) found that directly employing PAs provided greater continuity of care than either conventional home care services, or care agency staff, and this continuity was valued both by users and by PAs. Warm, friendly relationships develop (Leece, 2004a, cited by Leece 2004b), but this can lead to users developing a sense of obligation towards their PAs, and thus being less able to control the help they receive, especially as there may be a lack of clear statements of PA roles and responsibilities (Glendinning *et al.*, 2000a). Conversely, PAs may work unpaid hours (Leece, 2004a, cited by Leece 2004b). Some users have experienced problems where staff have not respected the boundary between work and friendship (Stainton and Boyce, 2004), and conversely there may also be inappropriate behaviour from employers (Keigher, 1999). Both users and PAs struggled to avoid the exploitation which could occur on either side.

PAs may feel isolated and lack development opportunities (Glendinning *et al.*, 2000a), although for a minority of PAs in one study, the role was a stepping stone to other things (Keigher, 1999). There are concerns in various European countries that there could be future dangers for both service users and PAs from an unregulated home care market based on an untrained, fragmented and vulnerable work force (Halloran, 1998). Four streams of literature, from the new right, from the disability lobbies, from feminists and from welfare pluralists, see payments for care as potentially transformative (Ungerson, 1997). Three of the streams are generally positive, but the feminist stream is concerned about the potential reinforcement of caring work being women's work. It may be that the impact of DP is overstated; an adequate understanding of the implications for citizens, carers and users is yet to be developed.

5.5.6 Monitoring quality

Social workers have reported finding it more difficult to monitor the care packages of DP users (Stainton, 2002), with much being taken on trust. This was viewed as positive by some social workers, and negative by others. How the quality of services accessed through DP should be monitored is said not to be easy to resolve, given that a key purpose is to promote service user independence (Halloran, 1998).

5.6 Implications for health care

Knowledge arising from DP may be relevant to health care in two ways:

1 directly, as DP might be extended into health care;

2 by analogy with the choose and book initiative, whereby take-up of DP corresponds to a patient making a choice of hospital, rather than the

decision being made by their GP; selection of a PA is analogous to choosing a particular hospital.

Drawing on the experience of DP, the Government has recently proposed (Prime Minister's Strategy Unit, 2005) that there should be a progressive move to 'individual budgets for disabled people, drawing together the services to which they are entitled and giving them greater choice over the mix of support they receive in the form of cash and/or direct provision of services'. Some options will be piloted first, to consider questions such as cost-effectiveness, availability of a range of services, circumstances where individual budgets are appropriate, support requirements and ensuring equitable treatment for people who cannot manage a budget. The aim is for a national rollout by 2012, resources permitting.

While this strategy does not appear to include NHS resources as part of the individual budgets, it has been reported (Cozens, 2004; Harding, 2005) that DP is being considered as a model for offering choice and control to NHS patients, such as people with chronic conditions. The Association of Directors of Social Services (ADSS) Local Government Association *et al.* (2004) has recommended making DP more flexible so that they cover continuing health care for long-term conditions, accompanied by appropriate shifts of resources from the NHS to local authorities (Local Government Association *et al.*, 2004).

Even though free NHS services may be available, some people in receipt of DP purchase such help from their PA because of the greater independence and control this gives (Glendinning *et al.*, 2000b), although other research did not find examples of this (Stainton and Boyce, 2004). Users had some concerns about equity if the DP scheme were extended to health care, although these concerns could be outweighed in areas where they felt users could make better use of NHS resources (Glendinning *et al.*, 2000b). Glasby and Hasler (2004) suggest a gradual extension into health care, particularly when health and social care are working in integrated settings, in tandem with careful evaluation and consideration of necessary policy changes.

Similarly, Cozens (2004) argues that to avoid services being 'patchy, volatile and provider-led', DP should, if at all, only be introduced gradually into health care, in conjunction with a strategic build up of diversity of service provision. The Commission for Social Care Inspection (2004) recommends that the Government carries out further detailed study into the practicality of DP for NHS services for people who use DP and have inter-related health and social care needs.

In drawing any conclusions about what the experience of DP might imply for choice in health care, the many differences between the social and health care sectors need to be borne in mind. This is particularly the case when considering the choose and book initiative; DP in health care is more similar. These differences include the following.

- There has been historically a much greater role for the voluntary and private sectors in social care provision.
- Social care is devolved to local authorities, so there may be scope for greater diversity of approach than in the NHS (although individual

primary care trusts (PCTs), GP practices and GPs may well approach issues in very different ways).

- DP concerns an ongoing relationship between a service user and services, whereas choose and book is more episodic, contact with hospital services possibly being limited to one or two occasions.
- In DP the user generally enters into a contract with the service provider, and handles the financial arrangements, whereas in choose and book the relevant contract will be between a PCT or GP commissioner and a hospital.
- Payment by results means that costs to purchasers will not vary between providers in choose and book, whereas in social care, costs are of great concern.
- The criteria for social care users being offered the option of DP have left much to the discretion of social workers and local authorities, whereas the criteria for offering choose and book appear to be more ‘objective’.
- DP is regarded as a means of user empowerment, emphasising rights and social justice, whereas this has not been a particular emphasis in the development of choose and book.
- The care manager role in DP is most closely analogous to the GP role in choose and book, but their powers and their relationships with users/patients and services are very different.

With regard to extending DP to health care, the evidence found in this review suggests that there could be potential benefits to some service users. Careful consideration should be given to the model of DP used and the investment in it, with a view to the following.

- Giving DP recipients greater control over services at an individual level.
- Stimulating ongoing service development, both with regard to services purchased through DP and other related services. This should not be limited to market mechanisms, but also include user involvement in planning and service development.
- Meeting the information and support needs of DP recipients and PAs.
- Enabling access to quality services by ethnic minority and other potentially disadvantaged groups, whether in receipt of DP or not.
- Keeping costs under control, while not disadvantaging DP recipients or PAs.
- Providing sufficient information, training and support for GPs and other NHS and social care staff.
- Minimising bureaucracy.
- Enabling service quality to be monitored sufficiently.
- Addressing any barriers from the different ways in which health and social care services are organised and funded.
- Monitoring and reporting on the above.

With regard to choose and book, the analogy with DP suggests the importance of:

- information and support for patients and for GPs, with clear national guidance;
- safeguarding the interests of ethnic minority and other potentially disadvantaged groups;
- allowing time for people to make decisions;
- monitoring and reporting on the above.

5.7 Implications for research

Possible topics for future research include the following.

- Which sections of society benefit disproportionately from choice, and what ways might inequalities be reduced? (see Leece, 2004a, cited by Leece 2004b; Newbigging and Lowe, 2005; HASCAS, 2004; Riddell *et al.*, 2005).
- How can patients best participate in assessing and monitoring service quality? (see Halloran, 1998).
- Action research/pilot projects on extending DP into health care. (see Commission for Social Care Inspection, 2004).
- Comparison of different models of DP and their applicability to UK health care.
- How having choice affects the relative importance that patients give to different aspects of service quality. (see Zarb and Nadash, 1994).

Appendix 6 Literature on choice in primary and secondary education

6.1 Policy background

In 1988 a new Education Reform Act was introduced in the UK. It was explicitly aimed at enabling open enrolment and greater choice for families outside their catchment areas by offering them an opportunity to apply for popular schools. Academic ability was discontinued in many areas of the country and replaced by 'free choice', which was linked to per-capita funding of schools.

Underlying policy objectives were not dissimilar to those introduced via choice in health care as choice was expected to induce competition and drive up standards of education. It was also explicitly expected that choice would improve equity by extending a privilege of choice that was only available to the affluent and articulate while promoting social mobility. But choice was also seen as a good of its own value which was presumed to be highly popular among the users. The main principles underpinning education policy have been largely unchanged since the 1988 Education Reform Act and there is a body of evidence evaluating the uptake of the reforms and their effects on those who choose and those who do not.

6.2 Do families like choice of schools?

School choice appears popular with parents, local education authorities, schools and the general public (Flatley *et al.*, 2001; Whitty *et al.*, 1998, Gorard *et al.*, 2002). However, the effects appear to be marginal, with the vast majority of parents choosing local schools. Therefore segregation and social stratification that was feared as a result of the reforms' introduction was less than expected. The positive effects were also not as significant as it was hoped according to some, possibly because of the pre-existing inequities (Taylor, 2002; Gorard, 2000), although this view is not uniformly supported either (Bradley *et al.*, 2000; Burgess *et al.*, 2004). Other researchers think that choice in state schools has resulted in sorting by both socio-economic status of the parents and by the students' ability (Bradley and Taylor, 2002; Burgess *et al.*, 2004). Proponents of choice argue that choice enables patients to select schools with better academic outcomes which provides benefits to individual pupils (Hoxby, 2003) as well as collective benefits (Hughes, 2004). Taylor argues that on the whole geography of education remains an under-researched area, particularly in light of major transformations in education provision over the last two decades (Taylor, 2001a).

However, Burgess *et al.*, in their review of economic evidence on choice of education and health, cite Ladd, who argues that parents' perception of school quality is partly dependent on the socio-economic status of the school body, which in turn affects choices by creating an 'uneven playing field' of school choice (Ladd, 2002, cited by Burgess *et al.*, 2005). They also identify a number of preconditions and constraints determining the exercise and outcomes of choice. Choice of schools was found to be dependent on the flexibility of supply and the nature of vouchers where they were used (e.g. the USA).

With regard to the nature of schools, particularly local schools, selective, fee-paying, voluntary aided and grant-maintained schools are all associated with higher sorting of pupils by ability whether in the UK or elsewhere (Williams and Rossiter, 2004). This is often a result of high popularity of the 'good' schools who can introduce different selection criteria to enable them to choose the pupils. Gorard *et al.* argue that schools in the UK have introduced wide variations in their admission criteria after different re-organisation and rationalisation programmes thus having a consequence for increased segregation in the situation where demand frequently outstrips supply (Gorard *et al.*, 2003). Burgess *et al.* on the other hand suggest that supply has been subject to strict Government regulations creating conditions that impede rather then facilitate choice (Burgess *et al.*, 2005). The latter study also compares the UK with the US evidence where choice seems to have improved access for certain groups of less-advantaged children through introducing pro-active policies in form of well-designed, targeted vouchers (Hoxby, 2003).

Burgess *et al.* define information about schools' performance as a prerequisite for parents to make informed choices about schools (Burgess *et al.*, 2005). However, choices made by parents are not constraint-free and information contained in performance measures is used by both parents and school teachers (Propper and Wilson, 2003) but the latter are slightly more sensitive in their responses (Wilson, 2004). Research suggests also that this does not necessarily lead to improvements in outcomes because schools can manipulate outcomes (Burgess *et al.*, 2005) by either increasing raw output or improving measured performance by altering their intake (Propper and Wilson, 2003; Wilson, 2004). Therefore the information on performance has to be seen in the context of what information it is trying to elicit and what objective it is trying to fulfil (Burgess *et al.*, 2005).

Research evidence presented in this section has, in addition to choice per se, various implications for both equity and outcomes. It is referred to here to point out the difficulty in examining and measuring parents' willingness to exercise choice under various constraints imposed by the way choice is implemented and by other constraints to access (i.e. purely geographical constraints in rural areas).

6.3 Choice and efficiency

Efficiency in education is very difficult to assess because readily measurable outcomes such as results achieved in national examinations may not reflect efficiency while more substantive results such as equipment with life skills are long term and very difficult to measure. On the whole however, results of studies of efficiency of the UK education system over time are either stable or show slight improvement. Schagen and Morrison, who measured GCSE results between 1994 and 1996 found that they improved between 1994 and 1996 and that then in 1996 they decreased again (Schagen and Morrison, 1998).

Burgess *et al.* differentiate between raw score and value-added performance measures, arguing for the latter as the best indicators for schools' effectiveness (Burgess *et al.*, 2005). However, they also state that it is difficult to predict what might be the consequences for productivity, pointing at some gains from exercising choice, which are not uniform across different groups of students or choice programmes, and stressing rather the importance of contestability on increased productivity, particularly in the USA.

In the UK, although parents use performance indicators to inform their choices, this does not automatically translate in schools achieving better outcomes because schools are able to alter their raw intake and the results are also sensitive to measures used (Propper and Wilson, 2003; Wilson, 2004). As a result they may seem to improve measured performance but not the actual outcomes. Schools are also judged as more or less efficient depending on their attendance rate and their proportion of GCSE A*–C grades in exams. Studies by Bradley *et al.* and Bradley and Taylor found a small positive relation between competition and relative efficiency (Bradley *et al.*, 2000; Bradley and Taylor, 2002); however, some other studies use different measures to disprove it (Burgess *et al.*, 2005).

6.4 Choice and equity

Although reforms in education in the UK were aimed at reducing inequality of access to good public schooling (due to the Education Reform Act 1988), the view as to whether this has been achieved are at best mixed. The evidence available suggests that families from higher socio-economic groups are more likely to be knowledgeable and exercise choice, and several studies suggest that cultural and material resources are a clear advantage in the educational market place (Dustman, 2004; Reay and Lucey, 2003; Carol and Walford, 1996; Bradford, 1991). The ability of wealthier people to move into desirable areas, so-called 'selection by mortgage', has led to a paradox of wealthier parents in some places campaigning for 'so called comprehensive reform that never happened' (Ball *et al.*, 1996).

Almost a decade after introduction of reforms in the UK, choice by catchment area for popular schools remained almost unchanged. If anything, social homogeneity was even strengthened (Gewirtz *et al.*, 1995; Gibson and Asthana, 2000; Hatcher, 1998), while poorer families outside the catchment area do not want to risk rejection and settle for their own local school (Carrol and Walford, 1996). Also, Bagley and Woods found that children with special educational needs were marginalised and devalued in the UK because of pressure on academic achievement (Bagley and Woods, 1998).

The evidence from the USA seems to lend even stronger support to these findings. The evidence from the USA supports UK findings about children with learning disabilities where a voucher system is found to create inequities for those children who usually end up on the bottom tier of the education system (Lens and Gibelman, 2002). Thus a voucher system when coupled with an ability to choose from public and private schools is in effect seen as a public subsidy that may not necessarily benefit those who are less advantaged (Ladd, 2002). Under a private-choice model public funds are transferred directly to the consumer to purchase education on the open private market.

However, there are also findings from well-designed empirical studies in the USA that contradict these views. For example Hoxby suggests that the less advantaged black pupils benefited from a targeted voucher system (Hoxby 2000; Hoxby 2003). She argues that flexibility of schools to respond to demand, and the availability of uniform and universal vouchers, should prevent selection by ability, which is an equivalent to 'cream-skimming' or selection of low-risk patients in health care. There is also an alternative view arguing that choice had resulted in relatively insignificant inequity because the education market was already inequitable (Gorard and Fitz, 1998; Gordon *et al.*, 2002), highly stratified and inequitable before the introduction of the reforms (Taylor, 2001b).

Studies from other countries such as New Zealand seem to suggest that market has led to more socio-economic and educational polarisation (Ladd, 2003; Ladd and Fiske, 2001), and choice has led to more social stratification in primary education in Sweden (Blomqvist, 2004). Similarly, Rossiter and Williams (2004) cite various studies from Chile to conclude that parental choice has resulted in reduced equity. This is because the uptake of choice of private schools by classes with lower socio-economic status was constrained by income, transportation costs and other factors, even when vouchers were introduced. There is also a negative effect of parental choice of state schools in non-metropolitan areas and segregation of pupils by both class and ability (Williams and Rossiter, 2004). Nechyba examines the impact of income on school sorting that reaches counterintuitive conclusions in that a pure state system results in higher sorting of pupils by ability than private schooling (Nechyba, 2003). On the other hand, various authors conclude that a range of vigorous reform efforts over the past decade and a half have, whatever their successes, failed to resolve some seemingly intractable problems in the schooling of disadvantaged groups and of schools in disadvantaged areas (Bell, 2003; Milliband, 2003; OECD, 2001).

6.5 Choice and quality

It is very difficult to ascertain whether choice improves quality in education because outcomes in education are notoriously difficult to evaluate as they are either long-term or poorly represented by existing performance indicators. In addition there are many other factors which may confound studies of the outcomes of reform, one of which may be more lenient marking (Gorard and Taylor, 2002), as well as deficiencies or changes in the assessment process (Williams and Rossiter, 2004).

The problem of quality measurement in education is that knowledge is not a static commodity and there are problems involved in comparability over time and among schools. The most commonly accepted proxy outcome would be to examine the results in terms of educational attainment. However, these are also used to determine performance and efficiency. Over the period choice was introduced in the UK, there seems that the gap in educational attainment between different social groups measured as achievement in exams (Williams and Rossiter, 2004); however, it is uncertain whether it can be attributed to the working of the market or other factors (Le Grand, 2004; Gorard and Taylor, 2002).

6.6 What is needed to implement choice in education?

As summarised by Burgess *et al*.'s (2005) review of economic evidence there are several preconditions for choice to produce its benefits.

- A successful choice policy would improve standards for most school children but gains of the working class might lead to losses of middle classes (through falling prices of property).
- The key to successful school policy is flexibility of supply. If greater choice is universal it should not leads to segregation or 'sorting' which currently comes by residence or ability.
- The role of children's peer groups is important in determining the effects of school choice, and the quality of peer groups may influence parents' choices and the capacity of school to generate good exam results.

The Labour Government can be seen as having embraced the quasi-market with a similar enthusiasm to that of its Conservative predecessors although it has tended to emphasise social inclusion as opposed to competition (West and Pennell, 2002). While it has attempted to soften the edges of the quasi-market it has not tackled some of its major deficiencies such as the power of schools who are their own admission authorities to distort the admissions process.

Furthermore, there is an important issue of information. Burgess *et al.* define information about schools' performance as a pre-requisite for parents to make informed choices about schools (Burgess *et al.*, 2005). However, choices made by parents are not constraint-free and information contained in performance measures is used by both parents and school teachers (Propper and Wilson, 2003) but the latter slightly more sensitive in their responses (Wilson, 2004). Research suggests also that this does not necessarily lead to improvements in outcomes because schools can either manipulate outcomes (Burgess *et al.*, 2005) by increasing raw output or improve measured performance by altering their intake (Propper and Wilson, 2003; Wilson, 2004). Therefore the information on performance has to be seen in the context of what information it is trying to elicit and what objective it tries to fulfil (Burgess *et al.*, 2005). Bradford argues for a need to introduce adjustments to the performance indicators to account for the effects of the local environment and perhaps parental choice itself, as well as prior attainment and social class (Bradford, 1991).

Finally, a pointed out by Rossiter and Williams in their comparative review of international evidence given specific policy conditions (flexibility of supply and excess capacity), school choice can have a 'levelling up' effect on the performance and efficiency of the state schools (Rossiter and Williams, 2004). As there is no consistent evidence that choice leads inevitably to higher polarisation between best and worst, segregation of children by ability is a reality but it may produce higher outcomes for the less advantaged. Thus it might need to be dissociated from educational outcomes as there are trade-offs involved between the two values.

6.7 Implications for health care

There are several important similarities between education and health and therefore useful lessons to be learned. Similarities extend to the common pedigree of the reforms, their content and their almost simultaneous introduction with the quasi-market health care reforms in the late 1980s in the UK. Thus in both cases choice and competition among schools and hospitals is expected to improve performance and 'exit' rather than 'voice' to use Hirschman's terminology (Hirschman, 1970) promoted through choice mechanism. Apart from underpinnings of common policy the similarities extend to the importance of co-production functions, equity considerations implied by comprehensive evidence available and high costs involved in obtaining information and negotiating access. Longer and uninterrupted path of reforms in the UK and elsewhere might have produced more coherent and consistent results, and therefore more comprehensive and possibly also better research findings.

However, there are also a number of important differences, which limit the relevance of the transfer of findings from education to experience in health care. First is the central role of agency specificity in education with parents choosing on behalf of the pupils, which is much more limited in health care. Secondly, cream-skimming in form of selection made on the basis of academic ability is 'institutionalised' in education system in the UK, which so far is far from being a reality in health care. Furthermore, there is more scope for 'selecting by mortgage' and choosing to live in more desirable residential areas for the mobile middle class than in health care. Finally, schooling in its present form involves complex issues of relations between the state and Church in both the UK and USA while health care provision in the UK is almost solely public, with few private providers operating.

However, there are policy assumptions underlying school choice, which do not seem to hold in reality (Perri 6), therefore disabling policy effectiveness. A core assumption is that there will be competition among schools, which is not necessarily the case (Perri, 6) as it turns out it is often the parents (and pupils by extension) that compete for a place in a 'good' or desirable school, in effect schools choosing the pupil. Following from this assumption is the next premise that schools will compete on outcomes which will then serve as a good indicator of their performance. This might not be the case for at least two reasons, because it disregards the effects of social geography (Nechyba, 1999; 2003) and results of national exams are questionable indicators of school performance (Wilson, 2004). The other assumption is that private schools will force public schools to enhance their competitive position and to provide a better 'product', which again is not necessarily the reality (Burgess *et al.*, 2005). Finally, there is an unfounded belief that there will be no cream-skimming while the evidence suggests otherwise (Perri 6, 2003).

The assumptions are not dissimilar to issues of outcome performance measurement that bedevil health care, with arbitrariness of targets being widely criticised (Propper and Wilson, 2003; Wilson, 2004; Burgess *et al.*, 2005) but also more generally the issue of over-reliance on tangible and thus measurable indicators as opposed to potentially more meaningful but less measurable ones. However, important dissimilarities between education and health care need to be taken into account, such as the peculiarities involved in choice of school that can be applied up to the capacity of the school, after which the school chooses the pupils. The other important and education-specific issue is the importance of parental background, which is strongly related to pupils' secondary choice: there is a strong association between class and educational choice and subsequent educational achievement (Dustman, 2004), which in turn disaffects later social mobility in life.

However, the experience of education is an important lesson for health, and with an appropriate (or rather inappropriate) incentive structure, it is easy to see how adverse selection procedures could operate in the NHS. This is perhaps most likely if the market comes to contain multiple private, for-profit providers, when the population's attachment and resulting responsibility associated with the current NHS might be lost.

The second main point of comparison is whether competition between schools has increased standards in education. As with health, the issue is complex because choice and competition is only one of a range of factors at play. However, it is probably fair to say that choice in education has produced both winners and losers among schools and parents, a somewhat similar conclusion to that on the impact of choice on quality of health care. Introducing choice, either for individual patients or as part of a competitive market, cannot be relied upon to improve quality on its own.

Research evidence from choice in education presented in this report indicates various negative and some positive implications for both equity and quality outcomes. It also suggests that it is difficult to examine and measure parents' willingness to exercise choice under various constraints imposed by the way choice is implemented, and by other constraints to access (i.e. purely geographical constraints in rural areas).

6.8 Implications for research

Education is possibly the best researched area of public policy where introduction of choice has been evaluated in different settings. Although there is plenty of evidence from different countries, there is little comparative research among sectors such as education and health or education (with an exception of Greener, 2003a, 2005), health and social care (e.g. Blomqvist (2004) in Sweden and Fotaki and Boyd (2005) in the UK and Sweden). There are several important points of comparison between education and health and therefore useful lessons to be learned.

Similarities extend to the common pedigree of the reforms, their content and their almost simultaneous introduction with the quasi-market health care reforms of the late 1980s in the UK. In both cases, choice and competition among schools and hospitals were expected to improve performance.

However, cream-skimming in the form of selection made on the basis of academic ability is institutionalised in the education system in the UK, but forms no part of the plans for the NHS. In education, there is more scope for 'selecting by mortgage' and choosing to live in a more desirable residential area for the mobile middle class than in health care. Selection is therefore much more prominent in education than in health, where risk–averse selection would be the corollary.

Potential areas of comparative research could include:

- identifying reasons for higher acceptance of inequalities that are present in education and residential care as compared with health care;
- identifying how users can best participate in assessing and monitoring service quality.

Appendix 7 Literature review on individual treatment choices

7.1 How individuals make choices in health care

This appendix looks in more detail at how individuals make choices in order to draw conclusions on what might be the impact of patient choice on individuals' behaviour but also how factors that influence individual decision-making may influence the outcome of the policy itself.

For individual patients to exercise choice they have to make decisions about their health care and to make decisions they need information to reduce uncertainty and risk, and also to maximise the benefit that results from decision-making. Section 4.5 (in the main report) described the importance of information and factors that enable or limit the use of information in choosing primary care and specialist provider. Thus it is not surprising that many of the papers identified about individual choice were also about information. Based on the issues raised through the papers we classified papers into the following categories.

- Those concerned with information, perceptions, communication and relationships that patients have with health care professionals. As many papers on decision aids emerged, a separate subsection was created for these.
- Those concerned with the process of individuals making choices and the individual and personal factors that influence them.

7.2 Information, perceptions, communication and relationships

Information allows a better understanding and a greater involvement in the decision-making process and allows patients to make choices if they wish (Coulter, 2002). Health policy in the UK emphasises the importance of patient informed choice with regard to all treatments. The Patient Charter states that patients have the right to be given a clear explanation of any treatment proposed, including any risks or alternatives, before they decide whether to agree to the treatment (Department of Health, 1991).

This reflects the increasing recommendation that it is unethical for individuals not to be informed of the consequences of medical interventions as well as the belief that informed choices are associated with better patient outcomes than uninformed choices (Johnston and Vogele, 1993). Physicians assist patients in their decision-making competency by providing them with information and as many patients identify physicians as their main source of information, communication between physicians and patients would also seem to be of great importance. Hence several papers that emerged from our literature search were about communication and relationships between doctors and patients.

There were five key messages to emerge from the papers on information, communication, and relationships. These were:

1 patients are not fully informed;

2 patients want information more than responsibility for decision-making about their treatment or care;

3 patients' and health care professionals' perceptions of decision-making and information of professionals vary from the reality;

4 what patients and health care professionals want from their relationships differs;

5 there is a need to improve efforts of information gathering and communication.

7.2.1 Patients are not fully informed

There are very few measures of whether patient choice is informed. For example, in a review of measures assessing the involvement of patients in shared decision-making (Elwyn and Edwards, 2001) only one measure of informed choice was found (Braddock *et al.*, 2002, cited by Elwyn and Edwards, 2001). Many decisions can be seen as uniformed choice as not enough information was available or sought.

Marteau *et al.* (2001) provide evidence that not all patients are fully informed. They took their definition of informed choice ('…that is based on relevant knowledge, consistent with the decision-maker's values and behaviourally implemented…') as the basis for developing a measure of informed choice. This measure was used to assess informed choice in deciding whether to undergo a screening test for prenatal screening for Down's syndrome (Marteau *et al.*, 2001). They found that 24/42 women who were offered this choice made various types of uninformed choices. They also report that knowledge of the test varied between women. They suggest that it is becoming increasingly necessary to be able to assess the extent to which choices are informed. A measure such as this may also be of value to other choices patients face.

Markham and Smith suggest that preoperative fasting is one area of health care where patients may want to exercise choice and yet information needs are dealt with very poorly (Markham and Smith, 2003). In their survey they investigated the length of fast recommended before routine general anaesthesia, the explanation and the evidence for this. Only half of the information leaflets recommending fasting promoted the up-to-date recommendations. Omitting fasting times or avoiding mentioning fasting at all gives hospital staff leeway to vary fasting times to their beliefs or preferences. If evidence is not available to patients, they are unable to challenge the prolonged fasts and are not able to exercise choice. This demonstrates information leaflets being available but not giving the relevant information. This finding is in agreement with another study by Coulter *et al.* carried out in the late 1990s where written information in several different specialities that was provided to patients was found to be out of date, inappropriate and poor (Coulter *et al.*, 1998).

The findings of this research confirmed that the majority of patients wanted information about treatment options, even if they did not wish to be involved in decision-making about their treatments; but they often did not receive it (Coulter *et al.*, 1998). The study also acknowledged that the quality of written information provided was quite poor when measured against the patients' expectations and needs. There was, for example, very little information on a treatment's risks and side effects; the coverage of treatment options and effectiveness was incomplete or missed out altogether; and uncertainties were ignored or glossed over (Coulter *et al.*, 1998).

In the review mentioned above, carried out by Entwistle *et al.* (1998), it is consistently reported that many patients in the UK currently do not receive as much information as they would like to from health professionals, but that this does not always correlate with preferences for involvement in decision-making. In the arthritis study discussed above (Hudak *et al.*, 2002), the patients did not know that they had a treatable condition. Granted this was an awkward situation for the physicians to initiate conversations, which would need to challenge the patients' wellness beliefs, but nevertheless the patients were uninformed and informing them that they have a treatable condition is the responsibility of the health care professional.

Furthermore, Ford *et al.* (2003a, 2003b) also identified gaps between patients' preferences for information and involvement in decisions in the UK General practice setting. Between a quarter and a third of patients reported receiving less information than they desired, particularly in relation to the risks and benefits of treatment options. Regarding decision-making roles achieved, patients varied in terms of whether they preferred a doctor-led, shared or patient-led decision-making model, and three-fifths of patients felt that the style of the consultation actually matched their preference.

Those patients who preferred a more paternalistic or doctor-led style of consultation and decision-making were more likely to have their preferences met. However, overall these findings are consistent with those of other settings in demonstrating substantial proportions of patients for whom the experiences and expectations of health care are not promoting or enabling the exercise of choice. They do suggest that some at least of the apparent barrier is modifiable, principally through continuing professional development and training initiatives to address communication skills, competences (attitudes and approaches) and competencies (specific skills and steps).

7.2.2 Patients want information more than responsibility for decision-making about their treatment or care

It has been argued that even patients who do not want to make final decisions want information (Blanchard *et al.*, 1988; Beisecker and Beisecker, 1990). This emerged as a main theme from the literature on information, communication, and relationships. Fifteen out of 20 women with cancer wanted as much information as possible (Henman *et al.*, 2002). Some wanted it to make decisions but most wanted it to assist them in coping by feeling in control, reducing anxiety, changing behaviour to take better care of themselves and enable them to make predictions for the future even if this involved bad news. In addition, some women used the information that they sought to assess their doctor's expertise.

Another study exploring the information needs for a sample of people with colorectal cancer (*n*=48) was carried out by Beaver *et al.* (1999) in the UK. Their study replicated the methods of a larger study carried out for women with breast cancer (*n*=150) and they compared and contrasted the findings for both disease groups. They found that both groups of patients appeared to have the same information needs despite the differences in decision-making role preferences as active or passive. Both groups prioritised needing information about cure, spread of disease and treatment options and the similarities in information needs. The similarity in information needs of the two disease groups has implications for health care professionals providing information to people with cancer.

It was also found in a review of evidence-informed patient choice by Entwistle *et al.* that the majority of patients value being given information about the effectiveness of treatment options (Entwistle *et al.*, 1998). Degner *et al.* (1997) carried out a study investigating the information needs and decisional preferences in women with breast cancer. They found that despite wide variation in decisional preferences, most patients desire information (Degner *et al.*, 1997). The most highly ranked types of information were related to knowing about chances of cure and spread of disease. Women younger than 50 years rated information about physical and sexual attractiveness as more important than did older women; women older than 70 years rated information about self-care as more important than did younger women; and women who had a positive family history of breast cancer rated information about family risk as more important than did other women. These identified priorities for information could provide an empirical basis to guide communication with women seeking care for breast cancer.

7.2.3 Patients' and health care professionals' perceptions of decision-making and information of professionals vary from the reality

Whether and how to use prescription medications are among the most common and important choices in which patients can participate. Thus Markoul *et al.* (1995) investigated how physicians and patients communicate and make decisions about prescribed medications and how they perceived this process and the congruence between these perceptions and actual communication. They found that GPs overestimated the extent to which they elicited patients' opinions about medication, discussed risks and benefits of medication, and discussed patients' ability to follow treatment plans. In this study GPs only initiated discussion of patients' ability to follow treatment plans in 4.8% of the 923 videotaped consultations.

Markoul *et al.* (1995) also found discrepancies between patients' perceptions and the actual consultations. In fact in this study 24.3% of patients either moderately or strongly agreed that their physician fully explained the risks of the particular medication when there was actually no mention of the side effects, precautions or risks. The patient questionnaires were administered right after the consultation, making it very unlikely that patients had forgotten what had taken place (Markoul *et al.*, 1995)

This is in agreement with other findings. For instance, Waitzkin (1984) carried out a literature review of doctor–patient communication. He also found that doctors tend to underestimate patients' desire for information and to misperceive the process of giving information to patients (Waitzkin, 1984).

Discrepancies between perceptions of and actual consultation can affect the impact of patient choice on individual health outcomes. If physicians do not share information with their patients it is highly unlikely that patients will be able to make competent decisions and be able to take full advantage of patient choice, although as Markoul *et al.* (1995) point out that these patients may well leave the consultation with the illusion of being fully informed and competent in their decision-making. It is suggested that improving decision-making in primary care may require changing the nature of the relationship between GP and patient in which patients play a more active role in the decision-making, which GPs may find difficult (Markoul *et al.*, 1995).

A similar finding was established by England and Evans who found wide variation in perceptions of patients who had all been invited to take control over a decision about cardiovascular risk management (England and Evans, 1992). The amount of control they perceived they had in this situation was related to their beliefs about how much control they had over their health in general. Conversely others experienced a sense of personal control even though treatment decisions were still substantially influenced by external factors, such as results from health assessment checks. Again this supports the notion that some patients could be under an illusion that they have fully participated in their management decisions when they have not. England and Evans recommend that physicians should be aware that some people may not perceive much control despite being invited to participate and that they may require extra encouragement.

Divergence in perceptions arose again in two other studies, which found that for many patients the concept of choice about the treatment was absent. Henman *et al.* carried out a qualitative study about the decision-making of women with cancer, relationships with physicians and the information they desired (Henman *et al.*, 2002). Some of these women perceived that there was no decision to be made, as extension of life was their main concern, thus they had to undergo treatment. Therefore, slight differences in chemotherapy regimes were not important to them. This underlines the importance of establishing patient priorities and concerns before embarking on discussions about treatment.

Similarly, in another qualitative study carried out by Hudak *et al.*, which explored decisions about surgical treatment, total joint arthroplasty (TJA), it was found that some elderly people seemed to perceive that a treatment decision was not needed (Hudak *et al.*, 2002). This was in part due to the patients believing that the arthritis was not a disease or condition but just part of normal aging. It implies that consideration of how information is processed and understood is needed, especially with subgroups such as older people. This study is discussed further below with reference to patients' beliefs.

7.2.4 What patients and health care professionals want from their relationships differs

Green *et al.* (2003) carried out a study to investigate clinical decision-making in pain management. They found that responses varied on the basis of the type of pain and gender of the patient. Physicians were more likely to provide optimal treatment for men with acute postoperative or cancer pain. The physicians here reported lesser goals for relief of chronic pain when compared to acute and cancer pain. Physicians in this study reported that they would like patients to be more forthcoming about their pain complaints. Lower goals for chronic pain relief may lead to the under-treatment of chronic pain. This study demonstrates that the provision of adequate pain management may be influenced by patient characteristics such as whether or not patients explain their pain to their doctor and physician (Green *et al.*, 2003). As mentioned above, the review by Entwistle *et al.* pointed out that patients consistently report that they do not receive as much information as they would like to from health professionals (Entwistle *et al.*, 1998). A qualitative study exploring the participation in decision-making of patients (*n*=74) who attended consultations in five clinical areas in the UK showed that people interpret statements about their own and health professionals' roles in decision-making in very diverse ways. It reinforced concerns about the validity of the usual responses to the control preferences scale, which is a measure used to identify the roles people have played in decision-making (Entwistle *et al.*, 2004).

Henman *et al.* found that while risk of reoccurrence, life expectancy, side effects and quality of life was reported as influencing their decisions, at least as much emphasis was placed on their personal relationships with their specialists (Henman *et al.*, 2002). When asked what they considered critical about their relationships with specialists they said that feeling: that the doctor cared for, respected and understood them; that they could have trust and confidence in the doctor; that the doctor gave them enough time; that they would be listened to; and that the doctor would be open and honest. If these things were present they would accept the recommendation of the doctor and leave the doctor to make the decision and they would be confident they would receive the right treatment.

Henman *et al.* cite Cassell, who argued that a sick person is qualitatively different from the well person, physically, emotionally and cognitively (Cassell, 1993, cited in Henman *et al.*, 2002), and Degner and Sloan, who argued that the general public are different from actual patients, e.g. 59% patients versus 36% of non-patient public would prefer to leave treatment decision-making to the doctors (Degner and Sloan, 1992, cited in Henman *et al.*, 2002). At a time when physically unwell, overwhelmed with anxiety, many patients appear to sanction a degree of paternalism if the relationship between their doctor and themselves is satisfactory. Both groups of individuals seem to want better communication within this relationship.

Hamann *et al.* (2004) carried out a qualitative, cross-sectional study with equal numbers of psychiatrists in private practice and public psychiatric hospitals (*n*=100) in Munich, investigating prescribing of antipsychotic drugs for 200 patients. It was found that older physicians were up to five times more likely to prescribe first-generation antipsychotics even though guidelines recommended the second-generation antipsychotics. The study points out the need for investigating physicians' attitudes to prescribing. While some patients may want to take part in these decisions, many will still expect their physician to make the judgments for them.

7.2.5 There is a need to improve efforts to improve information gathering and communication

One area where lack of information has been particularly questioned is in post-mastectomy breast reconstruction. Thus Finlayson *et al.* carried out a study to determine whether specific preoperative counselling could increase the likelihood of a woman choosing a post-mastectomy breast reconstruction (Finlayson *et al.*, 2001). Breast reconstruction is as important as mastectomy, which although is very effective for local control of malignancy can cause physical disfigurement that can be terrifying for a woman who is at the same time coming to terms with her diagnosis of breast cancer. As a group only 20% of women undergoing mastectomy also chose reconstruction. When stratified by age women over 60 years were the least interested in breast reconstruction. Low reconstruction rates in this study seem to reflect patients actually choosing not to have reconstruction rather than lack of information (Finlayson *et al.*, 2001).

Coaching has also been used to try and improve participation and information gathering. Greenfield *et al.* (1988) developed an intervention designed to increase the involvement of patients in medical decision-making. A rigorous randomised trial was conducted to compare this intervention with standard educational materials. Analysis of audiotapes of the visits to the physician showed the experimental patients were twice as effective as controls in eliciting information from the physician. Experimental patients reported significantly fewer function limitations. The authors conclude that the intervention is feasible and that it changes patient behaviour, improves blood sugar control, and decreases functional limitations (Greenfield *et al.*, 1988).

Oliver *et al.* carried out a study to evaluate the effect of an individualized education and coaching intervention on pain-related knowledge among outpatients with cancer-related pain (Oliver *et al.*, 2001). At follow-up, average pain severity improved significantly more among experimental-group patients than among control patients. Compared with the provision of standard educational materials and counselling, a brief individualised education and coaching intervention for outpatients with cancer-related pain was associated with improvement in average pain levels. Larger studies are needed to validate these effects and elucidate their mechanisms.

One area where it has been particularly difficult to promote patient choice is in consultations with children. Traditionally children have been 'mute players' in patient choice, leaving decisions to be made by their parents and their physicians. But Kaplan has argued that this is not good especially if they have a chronic illness, as it is they who have to live with their disease for the rest of their lives. She says the best way is to negotiate treatments between children, their parents and their physicians (Kaplan, 1999). At present it is a computer-based coaching programme for children with diabetes and the irritable bowel syndrome that uses animated icons to drive children through decision-making algorithms.

As well as coaching and counselling, many decision aids have also been developed to improve the quality of information patients have and to aid the decision-making process. These are discussed below.

7.3 Decision aids

Over the last decade, the development of decision-support material for patients, also called patient decision aids, has seen a significant growth; many health providers want to purchase and implement these tools across a range of clinical conditions – yet this same interest also highlights a lack of agreed standards for their development and evaluation, an issue which is being addressed by an international collaboration (Elwyn *et al.*, 2006). The interest in decision-support material emerged initially from a research community (O'Connor *et al.*, 1999). In 1999 there were approximately 10 decision aids known to the Cochrane database managed in Ottawa, Canada, by Professor Annette O'Connor. Enthusiasm for developing decision support of this type has increased in tandem with the parallel interest in shared decision-making (Charles *et al.*, 1997; Elwyn *et al.*, 2000, 2004). It is estimated that over 500 patient decision aids have been developed by 2005, the majority by researchers and associated developers.

The interest in this technology has arisen out of the understanding that some decisions require careful deliberation about options, which can either be about treatments or about other issues, such as having investigations or undergoing screening procedures. In these circumstances, shared decision-making describes a process of interacting with patients who wish to be involved in arriving at an informed choice, a choice which has taken both personal values and deliberation about context, and other factors that impinge on decision-making into account.

Evidence-based medicine and patient choice have developed as a response to what has been perceived as excessive authority given in traditional medicine to physicians and other health care professionals. Evidence-based medicine promotes the authority being given to the evidence for a particular intervention rather than the physician and patient choice stresses patients playing a central role in decisions about their health care. Thus providing 'evidence-based' information to patients should help people to make effective, informed choices reflecting their values. Different patients have different values and the best intervention for one patient may not be the best choice for another facing a similar clinical situation. Therefore patient values must be factored into the decision (Entwistle *et al.*, 1998).

Patient decision support (known as either patient decision aids or tools) typically have three common elements:

- they present information about options and the probabilities of the associated benefits and harms of those options;
- they enable individuals to consider their personal values with regard to the decisions that they face and
- they guide individuals in a decision process (O'Connor *et al.*, 2004a).

Information is typically obtained from rigorous sources such as Cochrane Collaboration systematic reviews. These decision support interventions are designed to supplement rather than replace interactions between patient and practitioners. They have used many delivery methods including print, video and audio. There is a trend for the tools to become interactive, digitalised and available on the Internet (Evans *et al.*, 2004).

Evidence detailing the impact of patient decision aids on a range of outcomes is available in other publications (O'Connor *et al.*, 2004b). To summarise, these interventions consistently improve knowledge and enable patients to have more realistic expectations about the outcomes of treatments and other procedures. Widely used outcomes include: perceived involvement, satisfaction with decision-making, agreement with values, anxiety and decisional conflict. In the great majority of empirical studies to date, these outcomes have changed in a positive direction without increasing patient anxiety (O'Connor *et al.*, 2004b). As the use of decision aids increases, evidence emerges about the elements contained in them, e.g. how to convey risk probabilities.

Evidence-based health care has become accepted as the basis for good clinical practice and increasingly every effort is being made to implement it (Sackett *et al.*, 1996). Evidence-based patient choice, defined as offering patients research-based information and the opportunity to participate in decisions about their treatment and care, has not yet reached this stage (Edwards *et al.*, 2001a). Yet Holmes-Rovner *et al.* have argued that the concept is fundamental to high-quality patient care (Holmes-Rovner *et al.*, 2001). They suggest that patient choice modules could be added to systematic reviews and other assessments of health technology and that these modules would help patient involvement in decision-making. In addition, these modules would also be key data sources for developers of decision aids (Holmes-Rovner *et al.*, 2001). They suggest that the modules would act as templates for decision aids and would typically provide information on the condition, treatment options, and for each treatment option they would provide information on the process, outcomes and probabilities of benefits and harms, and some value trade off the treatments.

Other simpler technologies can be used as well. O'Caithain *et al.* (2002) used a cluster randomised control trial to investigate whether 10 leaflets (produced by the Midwives Information and Resource Service and the NHS Centre for Reviews and Dissemination) summarising evidence on 10 decisions women face in pregnancy and childbirth led to informed choice and increased knowledge, satisfaction with information, satisfaction with the way choices were made and discussion with health care professionals. Twelve of the 15 large maternity units in Wales took part, involving 6452/10 070 women (a 64% response rate; O'Caithain *et al.*, 2002). The intervention group received

10 pairs of leaflets (a women's leaflet giving information on benefits and risks of options available and professional's leaflet with references for the research on which recommendations were based and references could be accessed via midwives). The control group continued with usual care. After intervention both groups reported a very slight increase in informed choice (only 6% rise in intervention group and 2% rise in control group).

The leaflets did not help to improve choice in this study. However, there were some problems with the study design and there was also a weak definition of 'informed choice': it was a simple self-report measure in a questionnaire, which asked 'have you had enough information and discussion with midwives and doctors to make a choice?' Nevertheless, the study shows that even print-based aids, when used consistently, can make an impact on decision processes.

However, researchers point out that incorporating decision aids into routine practice in busy medical interactions is a difficult exercise and that to move to offering patients significant amounts of information about treatment choices may require revising appointment systems to allow time for shared decision-making (Edwards *et al.*, 2003). These tools are becoming available on the Internet.

This migration to a new medium raises its own set of questions (Edwards *et al.*, 2003), not least about the so-called digital divide that occurs between socio-economic gradients. It is clear that how decision aids are to be implemented into existing clinical practice is an area that requires more research. The NHS has the opportunity to provide high-quality patient information and decision aids through outlets such as NHS Direct online with the potential to enhance patient care through enhanced patient choice. One recent example of this type of decision aid is one produced by a group in Cardiff University (Prosdex; www.prosdex.org.uk) developed for men facing a decision whether or not to take the prostatic screening antigen test.

This is an example of a class of decision aids that have been called interactive health communication applications (IHCAs). A systematic review of IHCAs for people with chronic disease concluded that the evaluations of these interventions revealed a mixture of outcomes. They state that individuals with chronic diseases have multiple needs, which include information about their illness and various treatment options, social support, support with making decisions and help with achieving behaviour change, such as changes in lifestyle. IHCAs were found to improve knowledge of the users and led to an increase in self-reported social support. There was however no evidence that outcomes such as user self-efficacy had been increased, or that their health behaviours and outcomes had been modified (Murray *et al.*, 2001).

Although there has been a significant growth in the development of decision aids, there is still uncertainty about how they should be used. Charles and colleagues have noted that although multiple goals have been identified for these tools, there remains a lack of clarity about the assumptions that underpin their design and mechanism of action (Charles *et al.*, 2005). The authors suggest that further work needs to be done about the context in which these tools are used, that the goals have to be clarified and therefore the mechanisms by which these tools are assumed to operate, and how they are implemented, needs to be considered in more depth.

Given the interest in funding their development and as yet lack of uptake in actual clinical practice, the questions raised by Charles point to an area that needs debate. Gafni *et al.* examined the issue of *agency* in the individual health care encounter or consultation (Gafni *et al.*, 1998). Gafni approaches this as a health economist, and develops the other seminal papers by the same authors addressing shared decision-making in its clinical context and from sociological perspectives (Charles *et al.*, 1999, 1997).

Gafni *et al.* note that it is likely to be more feasible 'to design contracts' to encourage physicians to transfer knowledge to patients than to motivate physicians to find out their patients' utility functions (Gafni *et al.*, 1998). This may be in the privately funded health care system that they are more familiar with (North America), but applies equally to issues of professional development and education as well. However, a number of barriers persist (lack of time, cultural attitudes, etc.; see below), indicating that even this model is far from straightforward (Holmes-Rovner *et al.*, 2001).

Gabe *et al.* (2004) explored the issue of patient partnership in paediatric (child health) clinics. They note that any investigation of partnership needs to take account of the organisational and legal setting in which the health care encounters take place (Gabe *et al.*, 2004). Furthermore the beliefs and agendas that all parties bring to the encounter are important. Clearly in paediatrics there are the child's and parents' beliefs and agendas, as well as the clinician's, hence the title of the article, Three to tango, developing the earlier title by Charles *et al*., Two to tango – at least (Charles *et al.*, 1997).

It is relatively straightforward to conceptualise the difference between this and more usual health care encounters between a clinician and an adult. There should be little difficulty in envisaging how the same approaches to shared decision-making, involvement, choice, etc., can be operationalised. However, this extra layer of complexity means there is inevitably a further layer of difficulty that may make it less likely, and thus restrict choice in the reality of usual health care encounters in this special context. The particular issue of research to explore and understand decision-making in this context is raised, including using a range of methods to help children at home to review their involvement in decision-making in the clinic.

Ford *et al.* described the concept and potential structure of an 'evidence-based patient choice consultation' (Ford *et al.*, 2003a, 2003b). This drew on the earlier monograph by Hope (1996) on evidence-based patient choice and an edited book of the same title but integrating it with the shared decision-making developments (Elwyn and Edwards, 2001). Ford *et al.* summarised the trends in health care (patient choice, involving patients, preferences for information, etc.) and explored with a variety of professionals and lay people about what they thought an evidence-based consultation ought to comprise.

They explored how issues of integrating research information and the decision-making process could be integrated with 'conventional' models of consulting, including addressing patients' perspectives, the doctor–patient relationship, etc. There were general views that evidence-based information regarding diagnosis and treatment options should be shared with patients during a consultation. Importantly however, there were no specific suggestions as to how this should be achieved in practice (Ford *et al.*, 2003a, 2003b). This is concordant with the earlier texts cited, in particular the book by Elwyn and Edwards in which some detail is mapped out for implementation of shared decision-making, even risk communication strategies, but the further step of accessing and integrating evidence itself remains a challenge (Elwyn and Edwards, 2001).

7.4 Individual and personal factors that influence patients' decisions and choices

Several personal and individual factors have been found to influence a patient's choice. These include:

- patient's beliefs, values, and expectations;
- personal characteristics (gender, age and race) and long life experience of real or perceived discrimination;
- previous experience of health care (witnessing unsuccessful treatment);
- trading-off different aspects of treatment.

7.4.1 Beliefs, values and expectations

One study, which demonstrates patients' beliefs affecting choice, was carried out by Gordon, who investigated patients' decisions for treatment at end-stage renal disease (ESRD; Gordon, 2001). Gordon argues that kidney transplantation is the treatment of choice because it offers a longer life span and a better quality of life than haemodialysis and that it is also more cost-effective. Seventy-three percent of the patients who did not choose transplantation in this study stated that they did not want to be 'cut on' as one of their main reasons. This had different ethno-medical meanings for different people depending on their beliefs. Their concerns were all grounded in their own personal or social life experiences. These people were all Afro-American.

This study demonstrates the need for dialysis professionals to be informed of factors influencing patients' treatment decisions and to try and understand patients' cultural and ethnic concerns about health. The theory of reasoned action (discussed above) would explain these as salient beliefs held by a person to determine that person's attitude towards a behaviour (in this case getting a transplant). The intention determines behaviour, which in this case is to not go on the list for a transplant but to continue to have dialysis.

The results of Gordon's study are congruent with other studies about kidney transplant. Ayanian *et al.* found that black patients were less likely than white patients to want a kidney transplant (Ayanian *et al.*, 1999, cited in Gordon, 2001). Holley *et al.* showed that strong religious beliefs were associated with the decision not to be put on the list for transplant (Holley *et al.*, 1996, cited in Gordon, 2001). Gordon (2001) explains that patients sustain ethno-medical beliefs about health, the body and transplantation, which inform their treatment decision-making.

Similarly in other studies, cultural beliefs have been found to have a profound influence on decisions regarding treatment. Kravitz and Melnikow reviewed 12 papers, which came out of a Medical Research Council conference about patient preference regarding treatment (Kravitz and Melnikow, 2001). They say that patient choice involves decisions that are complicated, going way beyond the uncertainty of scientific evidence. They depend on values people hold, attitudes to risk and family and cultural beliefs. Some south-east Asian cultures, for example, consider surgery to give rise to continuous imbalance, causing the person to be physically incomplete in the next incarnation (Fadiman, 1997, cited by Kravitz and Melnikow, 2001).

Navajo patients and families believe that direct information about risks from a procedure or a diagnosis is harmful and that talking about death can actually accelerate its onset (Carrese and Rhodes, 1995, cited by Kravitz and Melnikow, 2001). Kravitz and Melnikow recommend training doctors and coaching patient to improve communication and using more decision aids. They conclude that patients do want to be involved in or at least be informed about health care decisions but at the moment more attention needs to be paid to the realities of clinical practice. There may not be enough time in consultations for doctors and patients to learn from each other. Practical tools are needed from research to help this communication.

These cultural beliefs could be explained by the theory of reasoned action as the person’s subjective norm. For example, if most people in the culture the person is living in believe that surgery gives rise to continuous imbalance, then it is reasonable to assume that the person would perceive that most people who are important to them would think that they should not perform the behaviour in question (i.e. getting surgery). This would be their subjective norm and this would (together with the person’s attitude) determine their behavioural intention, which in turn would determine their behaviour.

Another study, which found that individual beliefs influenced patients’ health care decision-making, was carried out by Howell-White (1997). She investigated the influence of a woman’s definition of childbirth on choosing a birth attendant. She found that women who defined childbirth as ‘risky’ and ‘medical’ and requiring technical intervention were more likely to select an obstetrician. Most women who selected a midwife characterised childbirth as a natural normal event, which, she reports, is consistent with findings from other studies (e.g. Aaronson, 1987; Annandale, 1988; Cunningham, 1993; Klee, 1986, all cited in Howell-White, 1997). The desire to avoid intervention illustrates the belief that unnecessary interventions could also be considered potentially risky.

This supports the fact that risk can have multiple meanings as people also consider the risks involved with particular interventions, such as continual foetal monitoring giving rise to having to undergo Caesarian section. Howell-White points out that some women chose midwives but on hospital grounds and that they represented a compromise of natural and medical as they chose midwives for a personal experience but also liked having the technology and medical staff available (Howell-White, 1997). The women who chose medical childbirth perceived a higher degree of risk in childbirth. The prevailing concern of these women was the potential for complications. Also these women did not acknowledge the potential risk involved in an intervention related to childbirth. This continuum of beliefs could provide useful insight into childbirth decision-making. Depending on women's childbirth beliefs, they consider one type of care to be more appropriate than another, demonstrating again that individual beliefs affect patients' choices.

In Hudak *et al.*'s study (discussed above), exploring how elderly people made decisions about surgical treatment, TJA in Toronto, Canada, they found that for some of the participants it involved a long, ongoing deliberation, some hoping the condition would get better and that a decision would never need to be made (Hudak *et al.*, 2002). They reported three beliefs and views held by participants, which influenced their decisions, such as many older people believing that arthritis is not a disease or illness but just part of normal aging and that they needed to be in constant pain and almost unable to move before they considered themselves as a TJA candidate. Thirdly some believed that if they required or would benefit from TJA their physicians would advise it. Patient choice can only take place if discussions about treatment options occur.

Chen *et al.* (2003) carried out a study investigating decisions of whether to enter a hospice program or to continue with a traditional hospital approach of patients with advanced cancer in Florida, USA, with a life expectancy of less than 1 year (Chen *et al.*, 2003). The study demonstrates how the values of the patient influence their treatment decision. They found that patients receiving hospice care were significantly older, less educated, and had more people in their households. Hospice patients had more co-morbid conditions and worse activities of daily living scores than non-hospice patients. Families largely made the final decision to enter hospice (42%), followed by patients themselves (28%) and physicians (27%). Hospice patients were more realistic about their disease course than hospital patients (more than one-third of hospital patients believed they would be cured or improve). Patients' understanding of their prognoses affected their perceptions of the course of their disease. This study shows that patients who decide to enter a hospice were more likely to agree to sacrifice length of life for a better quality of life and supports the notion already discussed above that an individual's values influence the decision-making process about health care.

Donovan *et al.* assessed preferences for salvage therapy or palliative care among 81 ovarian cancer patients receiving first-line chemotherapy and 75 non-cancer controls (Donovan *et al.*, 2002). They found that compared to controls, ovarian cancer patients overwhelmingly preferred salvage therapy: quantity of life was of primary importance. Few were willing to compromise the chance that survival might be prolonged. They report that 25% of patients never considered stopping their chemotherapy, upholding their preference for salvage therapy even when the median survival period was less than 1 week. For these women the quantity of life was valued much more highly than the quality of their life. These women were willing to tolerate the toxicity of chemotherapy in expectation of some therapeutic benefit. In both groups, preference was not related to age, marital status, number of children or employment status.

On average, patients' switch from salvage therapy to palliative care was not associated with life satisfaction, quality of life or psychological or spiritual well-being in either group. The majority of women, independent of a cancer diagnosis, indicated a desire for continuing aggressive treatment, despite poor outcomes.

The values people hold will be explained by social judgement theory as cues that have to be weighted and then integrated to make their decisions about treatment. For instance quality of life and quantity of life are both cues that go into making a treatment decision. The women in the above study (Donovan *et al.*, 2002), who never considered stopping their chemotherapy, upholding their preference for salvage therapy even when the median survival period was less than 1 week, obviously weighted the quantity of life cue much more heavily than the quality of life cue. In contrast, the cancer patients in the Chen *et al.* (2003) study who went into hospices and agreed to sacrifice length of life for a better quality of life put a higher weighting on the quality of life cue than they did on the quantity of life cue.

Mastaglia and Kristjanson carried out a descriptive study to investigate factors that influenced women’s decisions for choice of surgery in breast cancer in Western Australia (Mastaglia and Kristjanson, 2001). They found that for both those choosing modified radical mastectomy (MRM) and those choosing breast-conserving treatment (BCT), equivalence of long-term survival was an important factor. However, for those choosing BCT long-term survival was the most important factor, but not for those choosing MRM. For the BCT group the surgeon’s preference was an important influencing factor (Mastaglia and Kristjanson, 2001). For the MRM group avoiding further surgery played an important role in decision-making. More than half the women wanted the decision to be their own and 36% wanted to share the decision-making.

There was a significant association between the women’s role preference and her GP as an information source (i.e. for those who wanted to control the decision themselves the GP was reported as an important source of information). Those in the BCT group preferred a more active role in the decision-making. Rural women were more likely to select MRM instead of BCT as opposed to urban women. This could be due to lack of radiotherapy centres in rural areas, which may have influenced decision-making. These authors point out that other researchers have found a similar trend.

Expectations were found to influence decisions in a study carried out by Hodgkin (1996). He examined patients' choice of hospital in relation to specialised services offered in the case of cardiac catheterisation. The structure of health insurance in the USA was such that price of services did not influence patients’ choice of hospitals. Therefore they have been competing on non-price attributes only. One of these is hospitals’ mix of specialist services. This can cause expensive duplication of facilities and overuse of costly procedures. These have been studied prior to this study but Hodgkin argues that until his study, little attention had been paid to how patients chose hospital. He found that patients did not appear to treat specialist services as an indication of quality. Although availability of cardiac catheterisation has a strong, significant effect on the choice of hospital, the effect appears to be confined to those patients who expect to need the service as their diagnoses indicate some probability of needing the service. However it was an urban area where he carried out with a greater choice of hospital and the results may not replicate to price competitive markets.

Barone *et al.* (2004) describe how the characteristics of US men undergoing vasectomies do not reflect the diversity of the population. Some groups of the population are accessing vasectomy, but others are not. Kuiper *et al.* (1997) noted a rapid decline in contraceptive implant use among teenage girls, a group for whom the implant method is advocated as safe and effective. They examined how information networks, including media influences, have an important effect on the choices people make in their health care.

7.4.2 Race, gender and discrimination

Patient choice in ESRD was also investigated by Klassen *et al.* with patients who met transplant criteria (Klassen *et al.*, 2002). This study found that perception of discrimination and response to it predicted list access to cadaveric transplant. The authors point out that in 1997 African-American ESRD patients made up 46% of patients getting dialysis but only 18% of those living with functioning transplants. They found that 20% of patients did not want the treatment modality they were receiving. Listed patients were younger, male and more highly educated than non-listed patients. There was no statistically significant difference in disease cause, time since onset or health status. Women, older patients and patients with previous experience of race discrimination were less likely to be on the waiting list.

Perception of racial discrimination and response to it were found to predict list access more strongly than race itself. African-Americans were more likely to have received racial discrimination than whites; women were more likely than men to report having experienced sex discrimination. Women were more likely to accept it as a factor of life. African-Americans reported that they were more vulnerable to discrimination when they sought care in unfamiliar settings as opposed to familiar settings, such as the haemodialysis centres. For example, they reported difficulty seeing relatives as the transplants took place in a centre that was a 3-hour drive away and in one centre a patient's wife was not allowed in with him when she had driven him there and was asked to wait in the car.

Lifetime experience of any type of discrimination was negatively associated with wanting a transplant, but patients reporting only racial discrimination as opposed to sex only or sex and race were significantly less likely to be listed. Regardless of race or sex, patients whose coping strategy was to accept discrimination were less likely to be listed than those who attempted to change the situation. Related to this, two beliefs were also identified as being predictors of whether or not a patient would desire a transplant. People who believed that the system for allocating organs 'was probably as fair as possible' and those who thought 'those who are well off or had connections received organs more rapidly' were both less likely to want a transplant. Klassen *et al.* interpreted these seemingly contradictory beliefs as representing "fatalism" believing a fairer system of allocating organs is not achievable (Klassen *et al.*, 2002).

For those patients who wanted to remain on dialysis partly because they were satisfied with their treatment but also because they don't desire transplant, and if their lack of desire stems from social inequalities, then such inequality should be addressed. These people are more passive about discrimination, thus it is important that they have access to culturally competent providers to discuss transplantation. They also point out that it must be acknowledged, that 'the cumulative effect of negative experience over life becomes a prism through which choices are viewed' (Klassen *et al.*, 2002:815).

Another paper looked at the influence of patient race on decision-making (Di Caccavo *et al.*, 2000). Their study investigated decision-making in primary care in response to psychological complaints. They report that there is a well-established psychiatric literature, which finds a consistently higher frequency of schizophrenia and other affective psychoses observed in African-Caribbean populations compared to Asian and white groups. As GPs are usually the first point of contact for psychological complaints Di Caccavo *et al.* asked 18 GPs in the UK to complete a vignette task. The vignettes were constructed using the *Diagnostic and Statistical Manual of Medical Disorders* (American Psychiatric Association, 1994).

They found that diagnoses were most accurate in the case of depression whereas psychoses were almost equally likely to be interpreted as depression or anxiety. For the vignettes that presented anxiety, the GPs diagnoses for white patients were almost all correct (82.3%). For Asian patients, GPs were just as likely to diagnose a physical problem, as they were to correctly diagnose anxiety. GPs were also less likely to correctly diagnose anxiety for African-Caribbean patients. Di Caccavo *et al.* suggest that GPs' assumptions about racial groups and patients' own style of presentation may explain differentials in diagnoses of symptoms (Di Caccavo *et al.*, 2000). Presentation styles of different racial groups need further exploration using naturalistic methods of observation. The importance of patient race as we have already seen (above in the case of ESRD) is not exclusive to diagnostic decision-making in psychiatry. Without correct diagnoses these patients will not be able to exercise patient choice.

Greiner *et al.* (2003) examined racial/ethnic variations in rates of hospice use in the last year of life in a national cohort to identify individual characteristics associated with hospice use. They found that African-Americans were 40% less likely to use a hospice than whites (Greiner *et al.*, 2003). The negative relationship between African-Americans and hospice use was unaffected when controlled for sex, education, marital status, existence of a living will, income and access to health care. Furthermore these findings suggest that economics, education and access to care are not the primary reasons for African-Americans using hospices less frequently than whites.

The authors suggest that there may be other important causes, such as different care preferences, and the lack of necessary hospice knowledge to seek out or accept hospice care. They also suggest it could be that different health care providers and health care systems contribute to these disparities through differential treatment based on racial/ethnic stereotyping or discrimination. Expanding literature on racial disparities shows that systemic and individual discrimination can drive care patterns and could cause the hospice care differences shown in this study. If this is the case it could take some time before high-quality end-of-life care will be a reality for minorities.

Di Caccavo and Reid (1998) report that previous research has shown that GPs perceive or diagnose men and women differently. A number of studies indicate a bias for women's symptoms to be attributed to emotional illness rather than organically based problems (Di Caccavo and Reid, 1998). Such findings have tended to be explained in terms of stereotypes. Although there is evidence that suggests patients can evoke strong feelings in their doctors, little attention has been given to the potential influence of GPs' attitudes towards the patients on their decision-making. Di Caccavo and Reid (1998) found that GPs' attitudes were differentially associated with management decisions for male and female patients.

When GPs reported feeling negatively or neutrally about patients presenting with psychological complaints, they were more likely to prescribe drugs for women, while men were given health advice or referrals to other clinical services. Yet when GPs felt positively about patients this pattern was reversed. They argue that the strength of attitude of GPs may govern whether gender stereotypes actually enter into the decision-making. These attitudes could be based on personal factors such as personality of the patient or the way the person communicates with the GP (Di Caccavo and Reid, 1998).

Equally these attitudes could be the response to patient demands for referrals to other clinical services, as suggested by the large literature that exists on the so-called heart sink patients. Heart sink patients refer to patients who evoke in their doctors 'an overwhelming mixture of exasperation, defeat, and plain dislike' (e.g. O'Dowd, 1988, cited by Di Caccavo and Reid, 1998). Corney suggests that heart sink patients typically present frequently with very few symptoms with no apparent organic cause and demand referral to other clinical services (Corney 1988, cited by Di Caccavo and Reid, 1998). With time pressure, litigation fear and judgement uncertainty inherent in general practice, it seems that unless patients elicit a more positive response in GPs, GPs will be more likely to rely on gender stereotypes in the treatment decision-making process. This paper again implies that there are reasons for patients and doctors to learn to communicate more effectively.

The above study findings could demonstrate the principles of fast and frugal heuristics. For example, GPs may rely on stereotypes in certain situations (when there is time pressure and they have a neutral or negative attitude toward the patient) to economise on the mental processing needed.

However, a study discussed above (Chen *et al.*, 2003) examined decisions about location of care – in this case hospices or non-hospice care for palliative care. As mentioned above, hospice patients were more likely to be older, less educated and from larger households. They had more co-morbid conditions, and poorer functional health status. The former characteristics could suggest that certain features were leading clinicians not to offer the same opportunities to decide about location of care (often a key aspect of palliative care) to some groups of patients although these aspects could be modified through professional education and training initiatives. However, the latter characteristics may suggest that bio-medical aspects are important in restricting the opportunity for choice (it may be less feasible to stay at home with other co-morbid conditions), and therefore that the limitations on choice are not in fact modifiable.

7.4.3 Witnessing unsuccessful treatments

The Gordon study (discussed above in relation to patient beliefs), which investigated patients' decisions for treatment of ESRD, also found that witnessing unsuccessful patients was a big deterrent from choosing to have a transplant (Gordon, 2001). Fifty-three percent of the patients who decided not to go for screening to get a transplant in this study reported that they were strongly influenced by knowing and/or seeing unsuccessful recipients returning to dialysis or by hearing that they had died. However, when a patient leaves the centre and has a successful transplant they don't get to know about it, as the patient has no need to return to the haemodialysis centre.

These findings are consistent with the findings of other studies (e.g. Gallagher *et al.*, 1998 and Orona *et al.*, 1994, cited in Gordon, 2001). Successful transplant recipients could visit the dialysis centres then those who could choose transplants could get a more balanced view of transplantation (i.e. give them living proof of the viability of transplants). Again patients are simplifying information processing to make decisions and patients will not go for a transplant because they have seen or heard about unsuccessful recipients. Also because the patient knows an unsuccessful recipient they make the decision not to have a transplant because the same thing may happen to him/her, even though they probably know there would be many successful recipients out there somewhere.

Charles *et al.* conducted interviews with 20 women with early-stage breast cancer attending a regional cancer centre in south-western Ontario, Canada, to explore treatment decision-making (Charles *et al.*, 1998). They found that some women assessed their chances of survival by assuming that their prognosis would be similar to a highly selected reference group of individuals personally known to them who also had cancer. Several patients assessed their risk by recalling other people who had died of the disease. For some it was difficult to think about chemotherapy as a reasonable treatment option because when they had been visiting friends or relatives who also had cancer they saw other patients suffering and dying while on this treatment. These comparisons resulted in a negative outlook and Charles *et al.* (1998) point out that this experience demonstrates the 'availability bias' (Tversky and Kahneman, 1973). In other words they assessed their probability of survival based on their personal knowledge of an acquaintance who had already died of cancer rather than on probabilities of risk.

It seems that patients are not blank slates upon which scientific information can merely be stamped. Rather, patients bring their own beliefs, values and everyday experiences to treatment decision-making tasks. These beliefs and values serve as filters through which scientific information is translated, made understandable and given personal meaning.

7.4.4 Trading-off different aspects of treatment

Discrete choice experiments on attitudes to choice suggest that patients are willing to exercise choice of provider and that they are also willing to trade-off different aspects of treatment against perceived benefits (Sculpher *et al.*, 2004). For example, in their study of discrete choice of 129 men with non-metastatic cancer men's preferences for, and trade-offs between, different attributes associated with treatment, life expectancy and out-of-pocket expenses, Sculpher *et al.* found that men were willing to contemplate trading-off life expectancy to be relieved of the burden of side effects such as limitations in physical energy, but the preferences of older men were not the same as the younger ones (Sculpher *et al.*, 2004).

Also, the willingness of patients to trade-off aspects of treatment against perceived gains was also demonstrated in some of the previously discussed studies, such as the Chen *et al.* study, where cancer patients who decided to enter a hospice were making trade-offs between quantity of life and quality of life (Chen *et al.*, 2003). In this study, patients who decided to enter a hospice traded length of life for a better quality of life. Conversely, in the Donovan *et al.* study ovarian cancer patients traded-off quality of life for the chance of survival being prolonged and thus overwhelmingly preferred salvage therapy to palliative care even when this meant only very short prolongation of life (Donovan *et al.*, 2002).

Ryan and Fernando (2003) carried out a test based on the comparison of preferences for three different goods (a supermarket, dentist consultation and bowel-cancer-screening programme) to examine the assumptions of complete preferences within health care. Their results, however, did not provide sufficient evidence to support the hypothesis that individuals have well-defined preferences for any choice they are presented with. Authors pointed out that further research is required before these results could be generalised.

7.5 Type and severity of the condition

Entwistle *et al.* do say that uncertainty, discomfort and incapacity associated with being acutely and severely ill may make it hard for patients to behave as consumers (Entwistle *et al.*, 1998). On the other hand, people living with chronic illness who are highly informed about their condition might be particularly keen to contribute to treatment decision-making. West developed a framework to compare decision-making in relation to chronic and acute conditions (West, 2000). She concluded that decision-making is often driven and constrained by the overwhelming impact of acute medical problems on all aspects of the individual's life. This made the patient dependent upon the expertise of the physician in providing all therapeutic options which was very different from chronic conditions where patients were increasingly knowledgeable and had to take multiple and repetitive decisions, with variable outcomes, about how they will live their lives.

However, it was known that the seriousness of the disease was negatively associated with patients' willingness to participate in medical decisions (Cassileth *et al.*, 1980), but the latter was positively associated with educational status (Deber, 1994; Deber *et al.*, 1996). Waldenström and Nilsson (1993), who looked into 1527 pregnant women's preferences in choosing alternative maternity care in the Stockholm area, also found that age, educational and professional status were crucial in this process.

7.6 Methodological issues

There are a number of studies that have examined methodological issues for research on patient choice and involvement in decision-making. In particular there are studies looking at patients' preferences for a decision-making role, or perceptions of actual roles in a decision about treatment or care. The most frequently used 'tool' is the card-sort method proposed by Degner and Sloan in which patients or participants in research choose from five scenarios of decision-making, ranging from entirely clinician-led ('paternalistic') to entirely patient-led ('informed choice'; Degner and Sloan, 1992). In general these studies show that patients have higher preferences for information than for involvement in decision-making per se, but also that preferences vary according to context. Context variation includes acute or chronic illness episodes, more serious or less serious type of illness, and actual versus hypothetical, potential or future decisions. People express greater preferences for involvement in decision-making in the chronic situation, and in the hypothetical than the actual decisions.

However, difficulties have been encountered in these papers. For example, Entwistle *et al.* (2001) examined the responses women gave to measures of the involvement in decision-making about hysterectomy surgery, compared with the descriptions they gave in qualitative interviews (narrative). Significant mis-match was evident between the responses given to questionnaire summaries and the understandings gained from narrative exploration of the same issues (Entwistle *et al.*, 2001).

A similar issue was identified by Hooper *et al.* (2005). These authors examined doctors' and patients' reports of consultations in British Armed Forces medical centres, focusing on actual activities (prescriptions, tests, referrals) and perceptions of unmet expectations. There was poor agreement on the actual activities themselves that had occurred. Unsurprisingly therefore, there were also differences in the perceived unmet expectations. Of note, however, the prevalence of perceived unmet patient expectations was higher among the doctors than the patients themselves. This suggests that these doctors were to some extent at least in tune with the notion of expectations, whether met or unmet, consistent with current communication skills training for clinicians. However, the discrepancies between doctor and patient reports illustrate the methodological difficulties in undertaking research in the domains of communication, autonomy and choice.

Research on patient involvement is still very much required to clarify the nature and potential of choice in the individual health care encounter ('micro-level') but these findings suggest the need for foundation methodological research first, in order to have the tools to explore it with validity. This must address our understanding of the key features of shared decision-making, choice (real or perceived) and involvement, and then go on to develop valid measures that enable research on the topics across a variety of settings and contexts.

Appendix 8 Data tables: details of papers reviewed

Table A1 Systematising the evidence of impact of choice in health care: efficiency, equity and quality

Authors and publication	**Description of study**	**Summary of findings**
Allen, P and Riemer-Hommel, P. (2006). What are 'third way' governments learning? health care consumers, choice and quality in England and Germany. *Health Policy*, 76(2): 202–212.	The paper examines how consumer information is related to attempts to improve quality of health care in England and Germany. It traces the changes between the first and second electoral terms of respective 'third way' governments. Both systems attempt to give users' information but the question is how information can be used. The paper proposes a theoretical policy analysis and uses evidence available to argue whether and how information can be used to promote choice in non-market health systems.	A degree of convergence can be observed concerning the amount of choice permitted to consumers. In the case of England, the amount of choice consumers have is gradually increasing, while in Germany, attempts are being made to restrict the wide choice of providers in order to cap expenditure. It concludes that simply providing information (USA) or choice for patients (Germany) does not seem to improve quality of care, in combination with financial incentives, it might be useful.
Anell, A. (1995). Implementing planned markets in health services: the Swedish case. In R. Saltman, and C. van Otter (Eds) *Implementing Planned Markets in Health Care*. Buckingham, Open University Press, Chapter 9: 209–226.	Chapter describes several trends in public competition models implemented in different county councils, and evaluates their consistency	The key finding in all models is about inconsistency in simultaneous development towards increased freedom of choice for individuals as well as

Authors and publication	Description of study	Summary of findings
	and effectiveness in meeting the stated policy goals.	the establishment of sub-country purchasers responsible for health services for their populations. Information on alternatives and therefore choice was found to be insufficient. The incentive structure of the county councils was found to give reforms many multiple and occasionally also mutually exclusive objectives. They consider promotion of individual choice as an important objective - at the same time there is a pressure that structural changes in health care system should not be too extensive.
Anell, A. (1996). The monopolistic integrated model and health care reform: the Swedish experience. *Health Policy.* 37, 1, 19–33.	This article reviews internal markets in the Swedish health-care sector, describes driving forces behind reforms, and analyses the limitations of reforms implemented within a monopolistic integrated health-care model. The study discusses incentives within Swedish county councils, and of how they have influenced reforms in the direction of more choices for consumers and a separation between purchasers and providers.	It is argued that the current incentives, in combination with criticism against county council activities in the early 1990s, account for the present inconsistencies as regards reforms. The article maintains that a weak form of separation between purchasers and providers will lead to distorted incentives, restricting innovative behaviour and structural change. In conclusion, introduction of the the internal market into Swedish monopolistic integrated health-care is said to rest on shaky ground.
Anell, A. and Svarvår, P. (1993). *Reformed County Council Model.*	Evaluation of the initial results	Freedom of choice for patients

Authors and publication	**Description of study**	**Summary of findings**
Survey and analysis of organisational reforms in Swedish health care sector. Lund: The Swedish Institute for Health Economics.	of organisational reforms in Sweden.	was quite significant in the areas with a high concentration of specialist facilities, which in some cases extended even across the boundaries of county councils, as was the case in Western Sweden. They nonetheless concluded that patients seemed to be making little use of it, as they preferred to be referred within their neighbourhoods.
Anell, A., Rosén, P., Hjortsberg, C. (1997). Choice and participation in the health services: a survey of preferences among Swedish residents. *Health Policy.* 40, 2, 157–168.	The study looks at individual and group preferences of Swedish residents concerning the demand for choices, and whether there is any dependence on age, education and place of living. 2000 randomly selected respondents from four counties in Sweden were sent a questionnaire. Response rate was 68%. Questionnaire looked at the demand for free-choice of provider and participation in medical decision-making. Four types of choices were investigated: choice of primary-care physician, choice of hospital, choice of specialist at the hospital, and choice of treatment initiative using Likert scale.	There are similarities but also important differences among different resident groups. Preferences seem to vary significantly depending on the age and education level. The elderly and less educated are less likely to opt for choices of treatment. On the other hand, the elderly are three times more likely to opt for choice of primary care physician. Younger and more educated are more likely to want to choose hospital and treatment while women are twice as likely to want choice of hospital when compared to men.

Authors and publication	Description of study	Summary of findings
Anessi-Pessina, E., Cantu, E., and Joninii, C. (2004). Phasing out market mechanisms in the Italian National Health Service. *Public Money & Management*. 24, 309–316.	Italy - Documentary analysis, key informant interviews, utilization and funding data to explore quasi-market mechanisms impact and evolution since 1997.	Despite desire to move towards markets, only 1 region (Lombardy) actively pursuing marketisation. Regions generally have been trying to mitigate the effects of quasi-markets and now increasingly 'governing' them since extension in choice has been accompanied by increasing financial deficits due in part to activity related DRG type funding and private sector (more expensive) providers. Some desirable results, including a shift from ordinary to same-day hospitalizations and a reduction in length of stay, particularly in the private sector.
Appleby, J. and Dixon, J. (2004). Editorial: Patient Choice in the NHS', *British Medical Journal*. 329, 61–62 (10th July). http://bmj.mbjjournals.com/ cgi/reprint/329/7457/61.pdf	Policy commentary. The Chief Economist and the Policy Director of the King's Fund discuss the Labour government's and Conservative opposition's policies on patient choice.	Both policies, they argue, are unclear as to how patient choice will work in practice and narrow on their scope of choice. Uncertainties exist about how powerful an incentive mechanism patient choice is to be allowed to be, how will equality of opportunity of choice be ensured or defined, and how will popular hospitals to ration their services given short term restrictions on capacity.
Appleby, J. Harrison, A, Dewar, S. (2003a). Editorial: Patients choosing their hospital, *British Medical Journal*, 326, 407–08. http://bmj.bmjjournals.com/	Policy commentary. The Chief Economist and the senior team of the Patient discuss choice policies introduced into the	Choice policies they argue are similar to the experience of Sweden and Denmark in the 1990s as they are driven by

Authors and publication	**Description of study**	**Summary of findings**
cgi/content/full/326/7386/407	NHS and point at various trade-offs involved in choice and equity and the nature of the changes that choice will bring about.	reducing waiting lists, but will result in more changes. In the NHS specialists will increasingly have to face up to the prospect of losing "their" patients and control over their waiting lists while hospitals will need to be reimbursed for the work they do. Equity and individual choice are in fundamental conflict.
Appleby, J, Harrison, A, and Devlin, N. (2003b). What is the real cost of more patient choice. London, King's Fund Publishing.	Discussion paper uses evidence on the extent of patient choice in the NHS to raise questions about the limitations of choice in the NHS, desirability of different types of choice, likely benefits and costs involved in patient choice in the NHS. It also asks questions about choice in relation to public involvement, and hypothesises whether choice will succeed in the NHS.	It concludes by pointing out different limitations to choice that exist in each system, different factors that determine individual choices including personal valuation of one's own health, perception of risk and various personal characteristics of users. A full commitment to choice involves choice between services and not only among providers. Choice is likely to be expensive and may have negative equity implications as Coronary Heart Disease project. The conclusion is that current policy is more likely to put more pressure on providers rather than to extend choice.

Authors and publication	**Description of study**	**Summary of findings**
Audit Commission (2004). *Choice in public services*. Audit Commission, London.	The report draws upon the results of an Audit Commission-commissioned MORI study of just over 1,000 British adults during July of 2004. 8 issues were selected including choice of school for children with special needs, choice in support for the elderly, choice of school, choice of payment method for council tax, more choice subjects in GCSE, choice of ways residents contact the council, council tenants' choice of which property they live in and their choice of housing service management.	It suggests that people want choice because they believe that the resulting competition will improve services, but that they're not necessarily prepared to pay more. There is also a clear hierarchy of choices that were important to the majority of users with choice of school for children with special needs, choice in support for the elderly, choice of school coming at the top of the list. Analysis would appear to suggest that, generally, the least privileged in society were most supportive of the need for greater choice; the very people who should benefit most and whom current political debate has suggested are least likely to take advantage of new choices.
Baker, R (2005). Continuity of care: patients' and carers' views and choices in their use of primary care services. http://www.sdo.lshtm.ac.uk/continuityofcare.htm	The study examines the hypothesis that not all types of people have the same attitudes to continuity of care, using quantitative (questionnaire) and qualitative methods to interview 75–100 patients and carers recruited from local GP practices.	Different groups of patients and carers take different views of the continuity of care, and make different choices under different circumstances. Patients do want to be able to choose which GP they see, and they want to be able to choose whether to see a GP or a nurse when they consult in primary care.
Bentley, J.M. and Nash, D.B. (1998) How Pennsylvania hospitals have responded to publicly released reports on coronary artery bypass graft surgery. *Joint Commission*	See entry for Marshall *et al.* (2000), which reviewed this study	

Authors and publication	**Description of study**	**Summary of findings**
Journal for Quality Improvement, 40–49.		
Bergman, S.E. (1998). Swedish models of health care reform: a review and assessment. *International Journal of Health Planning and Management.* 13, 91–106.	The study reviews the evidence to evaluate different solutions sought in the various county councils to improve efficiency and effectiveness. In about one third of these county councils some sort of purchaser-provider models have been introduced.	Emerging evaluation reports claim that the models have succeeded in improving efficiency; making the system more patient-oriented; and enhancing cost-consciousness. However, there are also problems with more difficulties in controlling costs, and with inadequate remuneration systems.
Besley T, Hall J, Preston I. (1999). The demand for private health insurance: do waiting lists matter? *Journal of Public Economics*. 72, 155–181.	The study examines why in spite of government dominance in financing health care in many countries, the private health care sector remains important, although most public provision is heavily subsidized, and in many cases free, at source. It looks at British Social Attitude survey data, and builds a model to examine individual's willingness to pay for services in relation to waiting time, seen as a proxy for quality of care in the NHS.	The study shows that longer waiting lists for NHS treatment are associated with greater purchases of private health insurance. Britain's National Health Service fails to drive out the private sector because it suffers from certain inflexibilities. Individuals see long waiting lists, which are seen as proxy for quality of services provided by the public sector, which influences their decision to insure privately.
Beusekom I, Tönshoff S, de Vries H, Spreng C, Keeler EB (2004). *Possibility or Utopia? Consumer Choice in Health Care: a Literature Review.* Prepared for Bertelsmann Foundation. Santa Monica, RAND Corporation.	Literature review on consumer choice in several countries with predominant focus on the social insurance model (mostly Germany). It starts with the broader health economics	It concludes that even in the systems where consumers must make choices of alternate treatments, providers and insurance schemes, they have poor information about these

Authors and publication	Description of study	Summary of findings
	paradigm that focuses on the uncertainty of the consumer. The review focus is on the choice of providers and insurance companies.	choices, and therefore information at present has little effect in practice. Consumer choice leads to changes in the health care market that affects different actors and maybe resisted by other actors, but there is little evidence on its impact on wider economy or society in general.
Blomqvist, P. (2004). The choice revolution: privatization of Swedish welfare services in the 1990s. *Social Policy and Administration*. 38, 2, 139–55.	Swedish welfare state has been and is still undergoing a transforming process manifested in an increased reliance on market mechanisms such as choice and opening to competing private actors. Public welfare services have been transformed by introducing user choice and opening them up to competition from private providers in the 1990s.	As a result, the share of private provision grew, both within the health-care and primary education systems as well as within social service provision. This resulted in a socially segregating dynamic, prompted by the introduction of "consumer choice". The study argues that the reforms of the public welfare service sector in the 1990s, risks losing one of its main characteristics: the belief in and institutional support for social egalitarianism.
Broder, MS., Simon, LP, Brook, RH. (2004). Surgical quality: review of Californian measures. *British Medical Journal*, 328, 152–3.	The study examines the adequacy of publicly reported data about surgical quality in California, the most populous state in the United States with more surgery done than in any other state. Surgical procedures are those invasive	18 organisations that reported 333 measures of health care quality were identified. The most often reported outcome was death in hospital and major complication rate, which was reported for 11 different procedures. These procedures

Authors and publication	**Description of study**	**Summary of findings**
	procedures listed by the National Center for Health Statistics. Survey of all organisations and collected data about publicly reported quality measures including procedures covered, risk adjustment method from 1998, and new measures planned for release by 2005.	comprise 11.6% of the Californian total. For 88% of surgical patients in California, no publicly reported information exists. These patients must rely on indirect measures, such as academic affiliation, to assess quality. Even consumers who have conditions for which data are reported face difficulties in using these limited data.
Brouwer W, van Exel J, Hermans B and Stoop A. (2003). Should I or should I go? Waiting lists and cross-border care in the Netherlands. *Health Policy.* 63, 289–298.	The study looks at the implications of Smits–Peerbooms ruling of the European Court of Justice which explicitly mentions undue delay as a legitimisation for cross-border care within the EU. In the Netherlands, waiting times are well above the norm set by several health care parties as well as maximally acceptable waiting times elicited in patients. The study examines the consequences of the ruling for Dutch patients, and examines whether they are willing to travel abroad.	Although the consequences of the rulings in the case of Smits–Peerbooms may be substantial, especially in legal terms, it is not expected that many Dutch patients will be crossing the border for health care any time soon. Increasing possibilities for cross-border care in Europe seem to be confined especially to those health care systems which experience long waiting lists (often systems that restrict supply rather than demand)., even those living in border regions. Patients seem to prefer longer waiting in the Netherlands over shorter waiting by going abroad. In addition, mobility of patients within the Netherlands is very modest.

Authors and publication	Description of study	Summary of findings
Burden, R (1998) Vulnerable consumer groups: Quantification and analysis. Heynes: Office of Fair Trading.	This empirical research based on analysis of the 1994/95 General Household Survey aims to determine the membership sizes of seven groups of consumers which are commonly assumed to be vulnerable in some respects, and to evaluate to which extent those memberships overlap. By doing so, the paper seeks to identify and quantify groups of consumers which may be particularly vulnerable because they belong to several of the vulnerable groups simultaneously.	Only 30.3% of the total population of Great Britain featured in none of the seven identified vulnerable groups (low income, with limiting longstanding illness -17%, elderly – under one fifth, with no formal educational qualifications, unemployed, young, ethnic minorities) or a combination of those (13.7%). In total, 40% of the elderly suffered from limiting longstanding illness, 32% were on low incomes and 1.3% were members of ethnic minorities.
Burge P, Devlin N, Appleby J, Rohr C, Grant J. (2004). Do patients always prefer quicker treatment? A discrete choice analysis of patients' stated preferences in the London Patient Choice Project. *Applied Health Economics and Health Policy*, 3, 4, 1983–194.	Paper analyses data extracted from London Patient Choice Project (LPCP) on patients waiting around 6 months for elective procedures of choice of treatment at an alternative NHS or private hospital, or treatment at an overseas hospital. The paper investigates patients' responses with regard to the following: -what are the factors that patients consider when deciding whether to accept choice offered;	30% of respondents consistently choose their 'current' over the 'alternative' hospital. All the attributes and levels examined in the experiment were found to exhibit a significant influence on patients' likelihood of opting for an alternative provider, in the expected direction. Age, education and income had important effect on the 'uptake' of choice. This may have equity implications because certain groups such as the elderly, those on lower incomes and of lower socio-

Authors and publication	**Description of study**	**Summary of findings**
	-relative weight placed on each of those factors (i.e. what are the trade-offs involved) -existence of any systematic differences; between subgroups of patients (in terms of their personal, health and socio-economic characteristics) in their responses to choice. Patients' preferences are elicited using discrete choice experiment. 2114 patients are recruited prior to being offered their choice between hospitals and are presented with seven hypothetical choices via self-completed questionnaire.	economic status may be less predisposed to accept choice. Also other factors in addition to the length of waiting time such as reputation of the alternative hospital play an important role in affecting these choices, raising the issue of information provision on quality and reputation that could/should be made available to inform choices.
Burge P, Devlin N, Appleby J, Rohr C, Grant J. (2005). *London Patient Choice Project evaluation. A model of patients' choices of hospital from stated and revealed* preference *choice data.* Prepared for the London Patient Choice Project Team, Department of Health. Santa Monica: RAND Coropration.	One of the four evaluations of the London Patient Choice Project (LPCP) established to improve choices for patients who are clinically eligible for treatment and have been waiting for it beyond a defined target that was commissioned by the Department of Health. The study looks at: -what are the factors that patients consider when deciding whether to accept the choices offered;	Patients are less likely to opt for treatment at an alternative provider if they are older (>60); if they have low education levels; if they have family commitments, and if their income is <£10, 000 p.a. Also a poor or unknown reputation of the alternative hospital is associated with patients overall being less likely to opt for quicker treatment; this was stronger for those with income at <£10, 000 p.a. Transport arrangements were overall important but more so for

Authors and publication	**Description of study**	**Summary of findings**
	-weight placed on each of those factors; -systematic differences between sub-groups of patients in terms how they respond to choice, and what are the characteristics of those who opt for quicker treatment. Stated preference data on hypothetical choices were obtained from LPCP participants via discrete choice experiment while revealed preference data that indicate the choices that were actually made by patients were obtained in the course of the project. Model has been estimated simultaneously using both complementing datasets.	parents or guardians of children. Results suggest important implications for equity. The stated as opposed to revealed preference indicate that 30% and 35% decided to stay in home hospital respectively while 55% switched between choosing alternative and staying in home hospital when hypothetical choices were offered. In the event 65% of patients chose to move to an alternative hospital. Revealed preferences indicate that age is positively associated with tendency of patients to stay at their local hospital; men are more likely to decide to move than women and larger numbers of patients are more likely to opt for alternative provider within ophthalmology whereas those requiring gynaecological procedures will stay at their local hospital in larger numbers.
Burgess S, Propper C and Wilson D. (2005). *Choice. Will more choice improve the outcomes in education and health care? The evidence from economic research.* Centre for Market and Public Organisation, University of Bristol. Bristol: CMPO, University of Bristol.	The report reviews the economic evidence mostly from the UK but also from elsewhere, about the effect of choice in education and health. It provides a conceptual framework built around the definition of choice (what), act of choice (what from) and	Here we present the findings of extending choice for health while findings on education are presented in Table A5. Key findings from economic evidence are: - choice will extend competition between hospitals but if hospitals react to competition by merging,

Authors and publication	Description of study	Summary of findings
	actors (who), outlining constraints and limitations of choice.	the benefits might be reduced. - policies that increase choice will result in changes in patterns of treatment. Certain activities will become profitable while others will be loss-making. Also choice may prove more costly for some patients than others.
Burström, B. (2002). Increasing inequalities in health care utilisation across income groups in Sweden during the 1990s. *Health Policy.* 62, 2, 117–29.	The study examines the changes in patterns of health care utilisation across income groups during the 1990s using the Swedish Survey of Living Conditions 1988/89 and 1996/97, employing face-to-face interviews with a random sample, representative of the Swedish population aged 16 years and over. The data set used in the present study includes 10,578 men and 9900 women aged 25–84 years. The non-response rate in the surveys has been slowly increasing from 16.9% in 1979 to 20% in 1997. The non-response rate increases with age, and is higher among urban residents and among persons with no earned income. Age standardised prevalence rates and adjusted odds ratios for utilisation were calculated	The study is based on secondary analysis of self-reports of utilisation of health care, obtained from household interview data. Results suggest a possible increase in inequalities in utilisation of health services, to the disadvantage of low income groups. An inverse income gradient which was not evident in 1988/89 appeared in 1996/97 in having needed but not sought medical care. In multivariate analyses, urban residents had higher rates of contact with a doctor than did residents of other areas, but there was no difference for the other measures. Further specific studies are warranted to monitor emerging inequalities in access to and utilisation of health care in Sweden, in view of changes in the provision of services, in treatment practices and of user fees, which have taken place during the

Authors and publication	**Description of study**	**Summary of findings**
	for the whole sample and among persons with limiting longstanding illness, by income quintiles.	1990s.
Calnan M and Gabe (2001). From consumerism to partnership? Britain's National Health Service at the turn of the century. *International Journal of Health Services* 31, 1, 119–131.	A theoretical study examining the role of consumerism in UK health policy during the 1990s including quasi-markets, creation of the new managerialism, and new organisational structures set under the New Labour government. It considers the consequences of these changes for the users of health care and for citizenship rights, in particular the extent to which the changes have empowered these users and citizens. Draws on various evidence mostly from the UK.	The paper concludes that although the access to the NHS is still based on need rather than price, the right to the equitable provision has been challenged by development of the two-tier system under the GP fundholding scheme, and by widening of the geographical disparities under the internal market making choice of doctor dependent on user's area of residence. The new managerialism has changed the power relationship between health professionals and managers in favour of the latter but it has not empowered users (even if they are more likely to complain when things go wrong). Finally, users' decreasing trust in health care professionals has not necessarily translated into their higher desire for taking on responsibility and more involvement in decision-making.
Cant S and Calnan M. (1992). Using private health insurance. A study of lay decisions to seek professional medical help. *Sociology or Health & Illness* 14, 1, 39–56.	A two stage study using postal questionnaire to identify the groups for in-depth qualitative interviews to examine the decision-making process	The study informs the theoretical debate about health-seeking behaviour, in particular the usefulness of the notion of choice and 'shopping around' in the

Authors and publication	Description of study	Summary of findings
	associated with the use of private insurance. The focus was on the criteria respondents draw on to decide when to use the private health sector and when not to. The sample of 3060 men aged between 35–55 in relatively high income groups, was selected for the questionnaire. 55% response rate reported. Small random samples of the following were selected for interviews.	health care market. It is concluded that users of health care services do exhibit a reasoned approach in deciding between different medical settings, although, due to lack of knowledge and passivity the final decision is usually made by their general practitioner.
Cellini, R, Pignataro, G, and Rizzo, I. (2000). Competition and efficiency in health care: An analysis of the Italian case. *International Tax and Public Finance*, 7, 5 03–519.	Empirical data to assess the relationship between technical efficiency and its determinants in Italy. Index of technical inefficiency is constructed by means of Data Envelopment Analysis (DEA) and a regression analysis used to analyse relationship between efficiency and competition.	Competition is not a value per se, its effects on hospitals' performance are affected by the rules governing the health system.
Charny, M, Klein, R, Lewis, PA, Tipping, GK. (1990). Britain's new market model of General Practice: do consumers know enough to make it work?. *Health Policy.* 14, 243–252.	The paper evaluates the proposals for introducing primary health care market model in the early 1990s. It argues that reforms assume that patients will be active consumers searching out those general practices which best meet their needs. One key assumption of this strategy is	The results suggest that British consumers lack the knowledge needed to make market-style choices and that, more generally, policy-makers applying the market model to health care should explicitly address the problem of how to create a better informed public.

Authors and publication	**Description of study**	**Summary of findings**
	tested that patients have the information required to make such choices by analysing data generated by a survey of the health beliefs and practices of 4266 people.	
Chernew, M. and Scanlon, DP. (1998). Health plan report cards and insurance choice. *Inquiry-the Journal of Health Care Organization Provision and Financing*. 35, 9–22.	USA - analysis of relationship between comparative health plan report card ratings and employee choice.	Some evidence that report card ratings related to enrolment choices, but the relationship is not uniform. Individuals also choose plans based on attributes from other sources and often weighting place on report ratings is low. Performance data is less influential than the underlying plan traits individuals observe from other sources.
Chernew, M, Gowrisankaran, G, McLaughlin, C. and Gibson, T. (2004). Quality and employers' choice of health plans. *Journal of Health Economics*, 23, 471–492.	USA - Quantitative assessment of influence of health plan performance (as reflected in publicly available performance data sets), in choice of health plans offered by large employers (n=17) to their employees.	Mixed results, though with some evidence of positive relationship between performance data and plan being offered. Other plan characteristics such as more established, non-profit, and affiliated with national chains important.
Chuang, KH, Covinsky, KE, Sands, LP, Fortinsky, RH, Palmer, RM, and Landefeld, CS. (2003). Diagnosis-related group-adjusted hospital costs are higher in older medical patients with lower functional status. *Journal of the American Geriatrics Society*, 51, 1729–1734	USA - comparison of hospital costs between older medical patients with lower and higher functional status.	Hospital costs were higher in patients dependent in Activities of Daily Living Scores (ADLs) on admission than in patients independent in ADLs on admission ($5,300 vs $4,060, P<.01). Mean hospital costs remained higher in ADL-dependent patients than in

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		ADL-independent patients in an analysis that adjusted for DRG weight ($5,240 vs $4,140, P<.01), and in multivariate analyses adjusting for age, race, sex, Charlson comorbidity score, acute physiology and chronic health evaluation score, and admission from a nursing home.
Cookson, R and Dawson, D. (2006). Hospital competition and patient choice in publicly funded health care. In EM. Jones (ed) *The Elgar Companion to Health Economics* Part IV Organisation of Health Care Markets. Oxon: Edward Elgar Publishing.	International review of evidence on the effects of competition and choice on quality and waiting times, efficiency of hospital care, and geographical equity of access with particular focus on the UK and US literature. Conceptual framework for understanding hospital competition and limitations involved is offered.	The paper differentiates between imperfect competition with no price regulation and non-price competition under fixed price regulation drawing on the US market experience. It quotes US evidence of how payers-driven price competition reduced price, costs and excess capacity after the introduction of the managed care. However, the impact of competition on quality is more mixed. Vigorous competition for fixed price (Medicare) patients is associated with higher mortality rates while increased competition for HMO patients (negotiated contracts is associated with reduced mortality rates following acute myocardial infarction in the USA. In the UK the impact of competition under quasi-market reforms seems to be more negative for the same condition.

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		However, internal market in England brought some efficiency gains manifested as reduced hospital prices and reduced waiting times for non-emergency treatments, reduced referral rates and one-off reduction in prescribing costs.
Coulter, A. and Magee, H. (2003). *The European Patient of the Future.* Buckingham: Open University Press. Chapter 11: 117–229.	A cross-national study looking into different aspects of patients' experience and expectations from health care in the UK, Switzerland, Sweden, Italy, Slovenia, Germany, Spain and Poland using telephone interviews with app. 1000 of respondents in each of the eight countries as a primary method of investigation. Willingness to choose a primary care doctor, specialist doctor or hospital were investigated in addition to other aspects of choice such as willingness to be involved in decision-making, and possession of sufficient information to make choices.	79% of patients in the UK thought they should have free choice of hospital specialist and 87% thought they should be able to choose their GP. The overwhelming majority of people in all countries wanted to choose their provider but only in Spain and Switzerland was there satisfaction with the amount of choice offered. This demand was particularly high among younger and more educated people but was slightly lower for those with a university degree. The demand for choice of provider was exceptionally high everywhere except Sweden where the majority wanted to choose a primary care doctor but only 31% wanted choice of specialist and 54% wanted free choice of hospital. The shared decision-making model was the most popular as 51% of respondents in all

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		countries opted for it. Overall younger and more educated were in favour of involvement in decision-making. Overall less than half of respondents said they had sufficient information to make an informed choice of primary care doctor, and the proportion was even less for specialists or hospitals.
Coulter, A. Entwistle, V. and Gilbert, D. (1998). *Informing patients. An assessment of the quality of patient information materials*. London, Kings Fund Publishing.	Materials on several conditions including low back pain, cataract, depression, glue ear, high cholesterol, hip replacement, infertility, menorrhagia, prostate enlargement, stroke rehabilitation were collected from self-help groups and the voluntary sector, Health Authorities and trusts, professional organisations and commercial sources. They were then assessed via focus groups of patients, and academic specialists.	This study showed that the majority of patients wanted information about treatment options, even if they did not wish to be involved in decision-making about their treatment, and other studies have shown that patients in the UK frequently do not receive as much information as they would like to from health professionals.
Coulter A, Le Maistre N, Henderson L. (2005). *Patients' experience of choosing where to undergo surgical treatment. Evaluation of the London Patient Choice scheme.* Oxford, Picker Institute. www.pickereurope.org	One of the four evaluations of the London Patient Choice Project (LPCP), focused on patients' experience of the scheme. It explores a) patients' reactions to the offer of the hospital choice and	Most of those on a waiting list (82%) responded positively when asked whether they would consider treatment at an alternative hospital, with somewhat higher preference expressed by those in paid

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	which factors influenced their decisions on where to have the treatment b) to compare uptake between different social groups c) to identify patients' requirements for information and practical support and d) to compare the experiences of those treated at their home hospitals and those who opted to go elsewhere for their surgery. Completed questionnaires were received from 2,144 out of 1,839 sent the *Before Surgery* questionnaire (response rate 54%) and from 977 out of 1,839 sent the *After Surgery* questionnaire (response rate 53%). In addition, 27 interviews were conducted with patients awaiting surgery and 24 with patients who had completed treatment and their carers.	employment, higher education and above average income. Factors influencing this decision included perceived urgency of treatment, the likely quality of care and facilities in different hospitals, transport arrangements, convenience for themselves and their relatives. Practical considerations were stronger for those in less advantaged groups. Less than 32% apparently eligible for the scheme were offered choice and the reasons for this are unclear, and 67% of those offered choice made use of it. There was no evidence of inequalities of access or uptake by social class, educational attainment, income or ethnic group. However, uptake was influenced by the level of pain experienced while waiting and the reputation of the home hospital. When choosing, patients looked at the location of the hospital, the length of wait, travel arrangements and convenience for family and friends. The support received from Patient Care Advisers (PCAs) was highly regarded and free transport

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		attracted high satisfaction ratings. One in three patients were not happy with information on alternative hospitals.
Council for Public Health and Health Care (2004) *The preferences of health customers in Europe.* Zoetermeer, The Netherlands, Council for Public Health and Health Care.	An exploration of the concept of customer in different health systems in Europe with focus on social health insurance systems, which are compared with the UK. By presenting different systems the report attempts to highlight the differences of consumer notion in health care and other services and outlines conditions under which this shift may happen. The study carried out telephone surveys in each country asking patients what were their preferences and what importance they attached to the following: -the choices patients wished to enjoy in different stages of the health care process -the wishes and preferences of customers with regard to innovation -attitudes to undergoing treatment in another country	Key conclusions are: there is no developed notion of customer in health care in ay of the systems examined but there are clear differences between Belgian, German, Dutch and British consumers. the challenges health systems face are similar and there is a scope for convergence in the consumer development. there is a correlation between the structure of health care system, the organisation of the services provided, and the way patient is able to approach health providers. If customers are offered options they are likely to value it more highly If customers are offered options of going to a specialist or GP they may not opt for the former Despite exiting personal contributions (excess) patients are willing to pay for the services they value. Only Dutch patients want more choice than they have, they are in favour of innovation they are

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		prepared to pay for it.
Dalmau-Matarrodona, E. and Puig-Junoy, J. (1998). Market structure and hospital efficiency: Evaluating potential effects of deregulation in a national health service. *Review of Industrial Organization*, 13, 447–466.	Catalonia, Spain. Empirical data to estimate relationship between market concentration and technical efficiency. Index of technical inefficiency is constructed by means of Data Envelopment Analysis (DEA) and a regression analysis used to analyse relationship between efficiency and competition.	The number of competitors in the market contributes positively to technical efficiency. Other factors influencing technical efficiency include ownership, market structure and regulation.
Dawson, D., Jacobs, R., Martin, S. and Smith, P. (2004). *Evaluation of the London Choice Project: System wide impacts, Final Report. A report to the London Patient Choice Project*. Centre for Health Economics, University of York, September 2004.	One of the four evaluations of the Patient London Choice Project (LPCP) running from 2002–2004, commissioned by the Department of Health, which present system-wide impact of this pilot. It is concerned with examining the difference LPCP and its incentives made to underlying changes in choice, capacity, activity and waiting time. To partly control for these non-choice effects, choices two crude control groups were used (one of which compared changes in all England excluding London, and the other compared developments in other metropolitan areas and in London). Data derived from the routine Department of Health quarterly returns on	The results differed by speciality but there were important reductions in the variation in mean waiting times in London in all three specialities. For London trusts in ophthalmology there was marginally statistically significant reduction in waiting times relative to other English conurbations and the rest of England for both exporting trusts (by approximately 3 weeks relative to both comparator groups) but also for importing trusts. For orthopaedics the similar trend followed as in ophthalmology only the reduction for exporting trusts was by approximately 1 week relative to both comparators. Gains of patients at originating trusts do not appear to have been at the expense of patients at receiving trusts. In general

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	Trust referrals, activity and waiting times for both outpatients and inpatients. Three specialties within trusts were used as units of analysis (ophthalmology, orthopaedics, general surgery), and summary measure of mean waiting time for both inpatient and outpatient by speciality were applied. Econometric technique is employed to compare change in waiting times for groups of London trusts before and after the LPCP with changes in waiting times in the two above mentioned comparator groups. Also a hypothesis as to whether the introduction of choice regime would alter the behaviour of GPs and consultants in terms of their propensity to refer patients for treatment was tested using data from 1995 to March 2004.	surgery there was no significant difference between London and the comparator groups of Trusts. Gains of patients at originating trusts do not appear to have been at the expense of patients at receiving trusts. Nor was the improvement at originating trusts statistically significant relative to comparators while waiting times fell at recipient trusts they fell significantly faster at the comparator groups. Hospital Episode Statistics (HES) indicate that LPCP procedures in ophthalmology may account for between 61% and 73% of specialty activity while for general surgery this was only between 21% to 27%. There is low estimated elasticity of GP referrals to change in waiting times although it differs by speciality (higher in ophthalmology and insignificant in orthopaedics). There is no change in consultants’ decision behaviour to admit more patients in London in relation to other parts of the country for ophthalmology and there may even be a negative relation between falling waiting times and patients admitted for orthopaedics.

Authors and publication	**Description of study**	**Summary of findings**
Dawson, D., Jacobs, R., Martin, S., Smith, P. (2005). The London Choice Project: the impact on waiting times. Paper presented in European Health Policy Group, Cologne, Germany 21–22 April 2005.	Empirical study using data derived from the routine Department of Health quarterly returns on Trust referrals, activity and waiting times for both outpatients and inpatients for ophthalmology and orthopaedics. The aim was to measure reduction in waiting times in the London Patient Choice Project large-scale pilot that offered choice of alternative hospital to 15,000 patients in relation to other areas of the country, and in relation to hospitals in London who did not offer choice.	The study report small but significant reduction in waiting times in London relative to other areas where there was not patient choice, the main effect of the choice regime was to produce convergence of mean waiting times within London. Convergence was achieved by bringing waiting times at the hospitals with high waiting times down to the levels that prevailed in hospitals with low waiting times. The study argues that this represented a clear improvement in equity of access, which is an important objective of the NHS. However, the paper contends that this improvement will not necessarily hold with the national roll-out of choice because the favourable financial incentives for the recipient trusts will cease to apply from 2004/2005 throughout the country.
Diederichsen, F. (1995). Market reforms in healthcare and sustainability of the welfare state: lessons from Sweden. *Health Policy*, 32,141–53.	The study looks at how reforms introduced in some counties during the 1990s, focussing on a purchaser-provider split and fee-for-service payment of providers, influenced equity and efficiency of service delivery. He argues that loyalty to the	Reforms have increased productivity sharply, increased utilization even among the groups that previously were 'pressed out' and reduced waiting lists. Increased efficiency however, threatens equity in some specific aspects. Fee-for-service payment means increased production and

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	system (through taxation) was threatened in a situation where cost-containment policies were applied while equity principles were still a strong priority.	so far even increased costs. It is argued that if they are to be met with increased private financing, rather than with present tax financing, it will bring the risk of inequities. Also inequities in health care can be related to the way it deals with inequalities in health due to inequalities in living conditions or inequalities in living conditions due to ill health.
Dixon A., Le Grand, J., Henderson, J. Murray, P., and Poteliakhoff E. (2003). *Is the NHS equitable? A review of the evidence.* London School of Economics, Health and Social Care Discussion Series DP1, London, London School of Economics.	The paper reviews the evidence from micro-studies and macro-studies to answer the question whether the NHS is inequitable, what form the inequity takes and what could be its principal causes. The definition adopted regards observed inequalities in utilisation as proxies for inequalities in access.	There is strong evidence that lower socio-economic groups use services in relation to need than higher ones from many studies of specific NHS services. Potential barriers to access include: lack of suitable transport and restrictions on time, superior connections and communications by middle class patients, and severity of illness and the need to seek medical treatment.
Dixon, J., and Glennerster, H. (1995). What do we know about fund-holding in General Practice?. *British Medical Journal.* 311, 727–730.	Review of evidence on GP fundholders with regard to its technical and allocative efficiency, control of drug prescription, referral rates to hospitals and shifts from secondary to primary care and underspending by fundholders. It also examines transactions	- Fund-holders have curbed prescribing costs, given leverage to improve hospital services; they have also reduced waiting times - Fund-holders may receive more money than non-fund-holders - The impact of fund-holding on quality, equity and transaction costs is unknown.

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	costs and distribution of funds to fundholders.	
Dowling, B. (1997), Effect on fund-holding on the waiting times: database study. *British Medical Journal.* 315, 290–92.	To determine whether fundholding patients have shorter waiting times for surgery than non-fundholding patients and to establish if any such differences resulted from practices attaining fundholding status. Comparison of waiting times of fundholding and non-fundholding patients for elective surgery covered by the fundholding scheme at four providers over four years in West Sussex.	Patients of fundholding practices had significantly shorter waiting times than those of non-fundholders for all four providers and over all four years. Waiting times for patients did not fall until the year that the practices joined the scheme. Fundholding shortens waiting times but this may be because purchasing of elective surgery is best done at a practice level or because fundholding practices are funded overgenerously.
Dranove, D, Kessler, D., McClellan, M, and Satterthwaite, M. (2003). Is more information better? The effects of "Report cards" on health care providers. *Journal of Political Economy*, 111, 555–588.	USA - before and after comparison with control states where no performance data released, focusing on elderly heart attack patients and all patients receiving CABG from 1987 to 1994.	Report cards result in better patient matching (i.e. enabling sicker patients to choose higher quality hospitals), resulting in a gain in social welfare. However, the study also identified an impact in terms of selection behaviour by providers, with a shift in the illness severity of patients receiving CABG surgery, but not in illness severity of AMI patients. Sicker patients experienced higher rates of readmission with heart failure and higher rates of AMI and expenditure overall increased.
Dusheiko M, Gravelle H, Jacobs R. (2004). The effect of practice budgets on patient waiting times: allowing for selection bias'. *Health*	The study argues that comparison of waiting times	The estimated effect of fundholding status was to

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Economics, 13, 941–958.	between fundholding and non-fundholding practices are potentially confounded by selection bias as fundholding was voluntary. It therefore estimates the effect of a practice's fundholding status on the waiting times of its patients using both cross-sectional methods (OLS, propensity score, instrumental variables, Heckman selection correction and Heckman heterogenous effects estimators) and difference in differences methodologies to correct for selection bias.	significantly reduce the waiting times for chargeable admissions of the patients of fundholders by 4.1–6.6% (or 4–7 days) with the instrumental variables and Heckman selection correction estimators yielding the highest estimates. We also find that patients of fundholding practices had shorter waits (by 3.7% or 2 days) for non-chargeable elective admissions, suggesting that fundholders were able to obtain shorter waits for all types of elective admissions.
Dziuban, SW, Mcilduff, JB, Miller, SJ, and Dalcol, RH. (1994). How a New-York cardiac-surgery program uses outcomes data. *Annals of Thoracic Surgery*. 58, 1871–1876.	See entry for Marshall *et al.* (2000), which reviewed this study	
Edgman Levitan, S. and Cleary, PD. (1996). What information do consumers want and need? *Health Affairs*. 15, 42–56.	See entry for Marshall *et al.* (2000), which reviewed this study	
Ellwood, S. (1997). The response of fund-holding doctors to the market. London, CIMA.	Empirical study of the influence of price and quality on 35 GP fundholding referral patterns in the West Midlands.	There are a few changes in referral patterns even though the potential savings from changing were high.
Farley, DO, Elliott, MN, Short, PF, Damiano,P., Kanouse, DE, and Hays, RD. (2002a). Effect of CAHPS performance information on health plan choices by Iowa Medicaid beneficiaries. *Medical Care Research and Review* 59, 319–336.	USA - new Medicaid cases randomly assigned to experimental or control groups. The former received a consumer health plan performance report and the control group did not.	No effects of performance information on HMO choices were found for the total sample. However, it did affect plan choice in an earlier laboratory experiment.

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Farley, DO, Short, PF, Elliott, MN, Kanouse, DE, Brown, JA., and Hays, RD. (2002b) Effects of CAHPS health plan performance information on plan choices by New Jersey Medicaid beneficiaries. *Health Services Research*, 37, 985–1007.	USA - new Medicaid cases randomly assigned to experimental or control groups. The former received a consumer health plan performance report and the control group did not.	No effects of performance information on HMO choices were found for the total sample. The subset of cases who read the report and did not choose this dominant relatively low scoring HMO chose HMOs with higher scores, on average, than did those in an equivalent control group.
Feachem, RGA, Sekhri, NK, White, KL, Dixon, J., Berwick, DM, and Enthoven, AC. (2002). Getting more for their dollar: a comparison of the NHS with California's Kaiser Permanente Commentary: Funding is not the only factor Commentary: Same price, better care Commentary: Competition made them do it. *British Medical Journal*, 324, 135–143.	USA and UK comparison: compare the costs and performance of the NHS with those of an integrated system for financing and delivery of health services (Kaiser Permanente) in California. Adjusted costs of the two systems and their performance were compared with respect to inputs, use, access to services, responsiveness, and limited quality indicators.	Per capita costs of the two systems, adjusted for differences in benefits, special activities, population characteristics, and the cost environment, were similar to within 10%. Kaiser members experience more comprehensive and convenient primary care services and much more rapid access to specialist services and hospital admissions. Age adjusted rates of use of acute hospital services in Kaiser were one third of those in the NHS.
Ferlie, E., Freeman, G., McDonnell, J., Petsoulas, C, Rundle-Smith., S. (2006), 'Introducing choice in the public services: some supply side issues', *Public Money and Management*, 26(1): 62-72	Report findings from a recent study of a Choice experiment in NHS London (2002–2004), considers implications for policy and practice as well as the change management literature. It examines how supply side issues were affected under the new incentive system and in particular how speedily a	The overall conclusion is that in some cases, high volume Diagnostic and Treatment Centres (DTCs) emerged as a major service innovation. More specific conclusions are: *-Capacity Creation* Even with the strong incentives available in London Choice, the supply side response was patchy and narrow

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	substantial additional capacity, can (or cannot) be produced when incentivised to do so. Qualitative methods, namely comparative case studies where the organisation is the focus of analysis were used. The case studies were undertaken in three waves. After each wave, we reviewed completed case studies to identify themes in an iterative manner.	(DTC based). Some Trusts were reluctant to declare significant new capacity. Some of the new capacity was in reality pre-existing and simply relabelled for Choice. -NHS and Private Sector Providers: Relations between the NHS and private sector providers have been confined to short term 'spot contracts'. These tensions were apparent even though it exhibited rapid capacity creation. *-Choice and continuity of care.* London Choice implied two breaks in clinical continuity: between assessment and the operation and between operation and follow up (this will not necessarily be true as Choice is extended to the point of referral, although issues about follow up remain). 'Shopping around' for better opportunities under Choice works best for simple procedures (cataracts), less well for orthopaedic operations and is least appropriate for general surgical procedures where boundaries are fuzzy.
Ferlie, E., Freeman, G., McDonnell, J., Petsoulas, C., Rundle-Smith., S. (2004) *NHS London Choice Project evaluation. Organisational process strand. Final Report. Findings and key learning points.*	One of the four evaluations of the Patient London Choice Project (LPCP) running from	There were several learning points identified. On a system level there was need for some

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Centre for Public Services Organisations, Royal Holloway, University of London. London: Centre for Public Services Organisations.	2002–2004, commissioned by the Department of Health. It investigates organisational behaviours associated with the introduction of LPCP, identifies and comments on change management issues, and assesses the extent of organisational and managerial learning to derive key organisational learning points for the future. This report takes an overview of seven individual case studies comprising a mixture of Originating Trusts (OTs) and Receiving Trusts (RTs), and is based on qualitative and comparative methods, using the organisational process analysis. The organisation is the focus of analysis. Each case study included up to 16 semi structured interviews with a range of clinical, nursing, managerial and other personnel who were involved in LPCP either operationally or strategically (total 89). The response of the organisation to LPCP is tracked in relation to a set of high volume tracer conditions (ENT; general surgery; orthopaedics and ophthalmology) where LPCP	coordinating capacity at SHA level in relation to forecasting, inter-organisational diplomacy and systems thinking. There are some concerns about the variable managerial capacity of PCTs to perform these complex tasks. There might be important implications of the growing use of the private sector. On an organisational level: culture and the role of local context were about trusts' variation in terms of innovative and risk taking culture which was supportive of choice and had a powerful influence on organisational behaviour. Another conclusion was that incentives around Choice had to be strong in order to influence organisational behaviour and the willingness to declare new capacity quickly. Clinical as well as managerial support for LPCP was important. Knowledge management, 'learning about learning and change management' remain key themes which should inform the development of further Choice policies on an organisational level. Learning points on the contracting process were about

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	was in operation. A sweep of interviews with personnel in Strategic Health Authorities and Primary Care Trusts focusing on organisational learning and commissioner development issues (subtotal of 24) was also undertaken.	LPCP providing relatively generous incentives that successfully encouraged RTs to bid for and take on extra work that reduced London wide waiting lists in the chosen specialties. The contracting process in LPCP offered rapid negotiation from a single point whereas individual PCTs are so small as to lead to fragmentation of contracting process for large providers, whether NHS or private sector.
Forrest, E. (2004). The right to choose. *Health Service Journal*, 114, 24–25.	The concept of choice in health care provision is not applied to mental health as much as other areas. A framework for patient choice in various aspects of the mental health services is scheduled for Spring 2005.	There is patient demand for choice in access to psychological therapies, in selection of a keyworker, and in the use of advance treatment directives.
Forsberg, E, Axelsson, R. and Arnetz B. (2001a). Effects of performance-based reimbursement on the professional autonomy and power of physicians and the quality of care. *International Journal of Health Planning and Management.* 16, 297–310.	The key question addressed in this study is whether performance-based reimbursement in health care affects the professional power and autonomy of physicians, and if so, whether this has any consequences for the quality of care. This cohort study examines the period 1994–98 in 11 Swedish county councils. Four hundred and eighteen physicians were studied in	The results show that professional power and autonomy are considered to be very limited in all councils, and that they have decreased during the period studied. Professional autonomy is, however, more limited in Stockholm. The limitations in Stockholm are more related to financial considerations, whereas the limitations in the other councils are more due to guidelines and lists of

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	Stockholm County Council, which has a performance-based reimbursement system, and in ten councils without such a system.	recommended drugs. Professional autonomy and power were found to be important determinants for quality of care, and the physicians in Stockholm estimated the quality of care lower than their colleagues in the ten other councils. Thus, our study suggests that the performance-based reimbursement system might fail to reach the desired results due to its negative impact on professional power and autonomy.
Forsberg, E., Axelsson. R. and Arnetz, B. (2001b). Financial incentives in health care. The impact of performance-based reimbursement. *Health Policy*, 58, 243–62.	The key question addressed in this study is whether performance-based reimbursement (PBR) is a useful way to create the right incentive for efficiency improvements in health care. In this 4-year prospective cohort study, physicians in one council with PBR and in ten councils without such a system were studied.	The results of this study indicate that PBR, compared to an annual budget system, creates a different incentive, an 'inner incentive' which may be stronger than the external incentive of financial pressures. PBR may result in a greater cost awareness and shorter average length of stay, but it may also lead to negative effects on the quality of care. A strong cost awareness was found to be a negative predictor of quality of care indicating that it is a difficult balancing act to maintain cost considerations at a 'good' level in order to retain the benefits of cost awareness

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		without adversely impacting quality of care.
Fotaki, M. (1999). The impact of the market oriented reforms on information and choice. Case study of cataract surgery in Outer London and County Council of Stockholm. *Social Science and Medicine*, 48, 1415–32.	Cataract surgery is used as a case study to trace the impact of competition among providers on choice and information. Qualitative research methods were employed to record the perception of changes in their type and amount as it was given to both purchasers and patients. A set of open ended and standardised questionnaires was used to elicit the views of all actors involved. Four study sites from Outer London representing the diversity of responses and a large provider of eye services to Stockholm County Council were selected.	The analysis of the data showed that the quasi-market reforms have resulted in a change of attitude of providers. Some improvements in the amount and type of information given to purchasers and patients could also be detected, although as far as direct users were concerned, the demand has not been fully satisfied. However, the impact on choice available to patients and purchasers alike seemed to be adverse, an effect that was particularly strong in the UK case.
Fotaki, M. (2001). The impact of the market oriented reforms in the UK and Sweden. Case study of cataract surgery. Unpublished thesis. London: University of London.	The thesis used cataract surgery as a case study to trace the impact of competition among providers and the separation of purchasers' functions from the former on the set of selected indicators: choice, information, quality, responsiveness and efficiency in the UK and Sweden. Qualitative research methods	Quasi-market reforms have resulted in a change of the attitude of secondary providers, which had some positive influence on quality of care expressed in reduction of waiting times. However, the impact on choice available to patients and purchasers alike seemed to be adverse, an effect that was particularly strong in the UK case and which was precisely the

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	were employed to record the perception of changes of those indicators for patients, primary care providers, eye surgeons, managers and purchasers. Open ended and standardised questionnaires were used and were then compared with figures on prices for service obtained from hospital registers and waiting times obtained from league tables.	opposite of what reforms proclaimed. This was partly a result of disincentives introduced by the reforms but it also reflected the ambivalence that patients had towards enacting their choices.
Fowles, JB, Kind, EA, Braun, BL. and Knutson, DJ. (2000). Consumer responses to health plan report cards in two markets. *Medical Care*, 38, 469–481.	USA - survey to compare consumer responses to report cards in 2 markets, to determine how personal characteristics relate to exposure, and to assess the perceived helpfulness of the report cards.	Employees who used patient survey information in their plan decision were more likely to remember seeing the report card (odds ratio [OR], 4.85), to read it intensely (OR, 2.84), and to find it helpful in learning about plan quality (OR, 3.04) and deciding whether to stay or switch plans (OR, 2.64).
Gage, H. and Rickman, N. (2000). *Patient choice and primary care*. Department of Economics, University of Surrey. Surrey: University of Surrey.	A policy polemic based on the review of the evidence on the effects of the GP fundholding under quasi-market reforms and the reversal of the patient choice policy under Labour in 1997.	Argues that patient choice is the key to patient empowerment in the health care arena, and that the recent reforms (introduction of the PGCs in 1997) at the primary care level have reduced patients' choice with potentially adverse impact on quality of care.
Gandhi IG, Parle JV, Greenfield SM and Gould S. (1997). A qualitative investigation into why patients change their GPs. *Family Practice.* 14, 1, 49–57.	Qualitative investigation experiences. In depth interviews with 24 patients	The decision was in most cases multi-factorial. Interviews yielded more detailed and richer accounts

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	were conducted to determine why they had changed their previous doctor. Letters describing the process of change were received from a further 17 patients. Analysis was performed using standard qualitative techniques.	than letters. For interviewees, rudeness or the attitude of the doctor was the commonest reason. Overall, 19 different reasons were identified of which the largest single category was accessibility, closely followed by attitudinal problems. Clinical issues and personal characteristics of the doctor were less common. The majority of those responding by letter gave only one reason, usually distance.
Garpenby, P. (1997) Implementing quality programmes in three Swedish county councils: the views of politicians, managers and doctors. *Health Policy*, 39, 195–206.	This article deals with quality assurance within the Swedish health care system at the regional and local levels. It examines changes in Swedish health care in recent years with respect to increased freedom of choice for the individual, the purchaser-provider split and new forms of financial reimbursement that have affected quality assurance. 35 interviews are conducted in 1995 with health care politicians, health care administrators, hospital directors and clinical department heads in three Swedish county councils.	The article concludes that indirect incentives can be very strong factors in affecting care providers' active interest in quality assurance. This interest is aroused when providers feel they are in competition in that the number of patients decreases, or in that their activities are being called into question, such as in the form of discussions about possible structural changes in the county council.
Gerdtham, UG, Rehnberg, C. and Tambour, M. (1999). The impact of internal markets on health care efficiency: evidence from health care	Sweden compares technical efficiency when hospital services	The introduction of an internal market improves health care

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reforms in Sweden. *Applied Economics*, 31, 935–945.	are provided by county councils with internal markets and output-based reimbursement with provision by county councils with budget reimbursement, by estimating technical efficiency using data envelopment analysis and multiple regression.	efficiency. Potential savings in costs due to a hypothetical switch from budget based allocation to an output based allocation is about 13%. County councils with a nonsocialist political majority are relatively more efficient than those with a socialist regime and that large county councils are more efficient than small county councils.
Glennerster, H. (1996). Competition and equity in health care: the UK experience. *International Journal of Quality in Health Care.* 10, 5, 403–410	The paper uses the example competition in the NHS under quasi-market to review briefly the theoretical literature on the subject and to predict its effects on health care quality. It looks at the impact of these reforms, in particular GP fundholding in its various forms and GP commissioning, on quality of care and hypothesises about the outcomes under the changes proposed by Labour government in 1997.	The evidence suggests that there was little overall change for good or bad as a result of the reforms. The changes that did occur had an impact on speed of treatment, patient convenience and choice, but medical quality was largely unaffected. These benefits were reaped, by the more competitive agents-the family doctors or GPs.
Glennerster, H, Matsaganis, M, Owens, P. (1994). GP Fundholding: Wild Card or Winning Hand?. In R. Robinson and J. Le Grand (Eds). *Evaluating the NHS Reforms*. London, King's Fund Publishing.	Various reform issues in nationwide sample: ten 1st wave, one 2nd wave and sixteen 3rd wave fundholding practices were interviewed.	Tangible efficiency gains by leverage on hospitals and practice innovations offset by poor budg *et al.*location mechanism. Justifiable fears of equity losses.
Goldstein, E. and Fyock, J. (2001). Reporting of CAHPS (R) quality information to Medicare beneficiaries. *Health Services Research*, 36, 477–488.	USA - Fourteen focus groups of beneficiaries and State Health Insurance Assistance Program	Getting the care they need quickly, having access to specialists, and communicating well with doctors

Authors and publication	Description of study	Summary of findings
	counselors, more than 200 cognitive interviews, and 122 mall- intercept interviews to determine which performance measures to report to Medicare beneficiaries, how beneficiaries and information intermediaries interpret different formats for presenting information, and how beneficiaries have reacted to the performance information included in the annual mailing to beneficiaries.	were more important to consumers than non-medical characteristics of plans, most of whom had problems interpreting quality information. Many misinterpreted star charts, and while bar charts appear easier to read, many beneficiaries still had trouble interpreting the information on these charts. Most beneficiaries did not consider quality information important to them and most were unaware of the availability of performance information.
Gosden, T., Torgerson, D. (1997) 'The effect of fund-holding on prescribing and referral costs: a review of the evidence', *Health Policy* 40:103–114	The paper reviews all the available quantitative evaluative evidence of the effects of (partial) fundholding on general practice. A total of 17 published quantitative studies were found of which 13 were reviewed. These studies examined the impact of fundholding only with regard to prescribing and referral behaviour.	The results of these studies indicate that fundholders appeared to: constrain their prescribing and referral costs increase their generic prescribing rate not inflate their costs prior to joining the scheme The review did not find high quality evidence evaluating fundholding referral behaviour while there was a relative abundance of research comparing prescription patterns.
Gowrisankaran, G. and Town, R. (2003). Competition, payers and hospital quality. *Health Services Research*. 38, 1403–21.	The objectives was to estimate the effects of competition for both Medicare and HMO patients on the quality decisions of hospitals in	The study finds that an increase in the degree of competition for health maintenance organization (HMO) patients is associated with a decrease in risk-adjusted

Authors and publication	Description of study	Summary of findings
	Southern California. Data source: secondary discharge data from the Office of Statewide Health Planning and Development for the State of California for the period 1989–1993. Outcome variables are the risk-adjusted hospital mortality rates for pneumonia (estimated by the authors) and acute myocardial infarction (AMI) (reported by the state of California). Measures of competition are constructed for each hospital and payer type, and are formulated to mitigate the possibility of endogeneity bias. The relationships between risk-adjusted mortality and the different competition measures are estimated using ordinary least squares.	hospital mortality rates. Conversely, an increase in competition for Medicare enrollees is associated with an increase in risk-adjusted mortality rates for hospitals. In conjunction with previous research, it indicates that increasing competition for HMO patients appears to reduce prices and save lives and hence appears to improve welfare. However, increases in competition for Medicare appear to reduce quality and may reduce welfare. Increasing competition has little net effect on hospital quality in our sample.
Gravelle H, Smith PC, Xavier A. (2003). Waiting lists and waiting times: a model of the market for elective surgery. *Oxford Economic Papers.* 55, 1, 81–103.	The study uses a simple dynamic model of the demand and supply for elective surgery in the UK National Health Service in which waiting time acts as the prime indicator of performance. The model is tested using a panel of quarterly data for 123 English health authorities over an	Supply is increasing and demand is decreasing in measures of the previous period waiting time. The results imply that health care systems which are rationed by waiting do respond to indicators of waiting times. The paper adds to other research and confirms that public sector systems respond to important aspects of

Authors and publication	Description of study	Summary of findings
	eight-year period.	reported performance.
Ham, C., York, N, Sutch, S. and Shaw, R. (2003). Hospital bed utilisation in the NHS, Kaiser Permanente, and the US Medicare programme: analysis of routine data. *Brutish Medical Journal*. 327, 1257.	USA and UK comparison (following Feachem *et al.*'s findings): Analysis of routinely available data from 2000 and 2001 on inpatient admissions, lengths of stay, and bed days in populations aged over 65 for 11 leading causes of use of acute beds to compare the utilisation of hospital beds in the NHS in England, Kaiser Permanente in California, and the Medicare programme in the United States and California.	Bed day use in the NHS for the 11 leading causes is three and a half times that of Kaiser's standardised rate, almost twice that of the Medicare California's standardised rate, and more than 50% higher than the standardised rate in Medicare in the United States. Kaiser achieves these results through a combination of low admission rates and relatively short stays. The lower use of bed days in Medicare in California compared with Medicare in the United States suggests there is a 'California effect' as well as a 'Kaiser effect' in hospital utilisation.
Hann M; Gravelle H; (2004). The maldistribution of general practitioners in England and Wales. *1974–2003 British Journal of General Practice.* 54, 894 -898.	To estimate levels of maldistribution across family health service authorities over the period 1994–2003 and to examine the long-term trend in maldistribution from 1974–2003.Annual snapshots from the GP census were used. One hundred 2001 'frozen' health authorities in England and Wales for 1994–2003 and 98 family health service authorities for 1974–1995. Ratios of GPs to raw and need-	Maldistribution of GPs as measured by the Gini coefficient and Atkinson index increased from the mid-1980s to 2003, but the decile ratio showed little change over the entire 1974–2003 period. Unrestricted GP principals and equivalents were more equitably distributed than other types of GP. It concludes that 20% increase in the number of unrestricted GPs between 1985 and 2003 did not lead to a more equal distribution.

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	adjusted populations were calculated for each health authority for each year using four methods of need adjustment. Three summary measures of maldistribution across health authorities in the GP to population ratio — the decile ratio, the Gini coefficient, and the Atkinson index — were calculated for each year.	
Hannan, EL, Kilburn, H, Racz, M, Shields, E. and Chassin, MR. (1994). Improving the outcomes of coronary-artery bypass-surgery in New-York-State. *Jama-Journal of the American Medical Association*. 271, 761–766.	See entry for Marshall *et al.* (2000), which reviewed this study	
Hannan, EL, Sarrazin, MSV, Doran, DR. and Rosenthal, GE. (2003). Provider profiling and quality improvement efforts in coronary artery bypass graft surgery - The effect on short-term mortality among Medicare beneficiaries. *Medical Care*. 41, 1164–1172.	USA - Compares CABG mortality rates and changes in CABG mortality rates in regions with quality improvement/public dissemination efforts with the remainder of the country.	Public dissemination of outcomes data/formal region-wide quality improvement initiatives appear to be associated with lower risk-adjusted mortality rates for CABG surgery.
Hanning, M. (1996). Maximum waiting time guarantee - an attempt to reduce waiting lists in Sweden. *Health Policy.* 36, 1, 17–35.	This article describes the background and the introduction of the guarantee, and discusses some of the major results during the first 2 years. Generally, waiting lists decreased substantially during 1991 and 1992. By the end of 1992 only a few departments were unable to serve patients within 3 months. During 1993	The overall successful result, in terms of waiting lists and waiting times, seems to have been achieved mainly by increased production, improved administration of the waiting lists, and a change in attitudes toward waiting lists. The expectation that the guarantee would lead to a more even use of resources across the country has not been

Authors and publication	**Description of study**	**Summary of findings**
	the reduction in the waiting lists ceased, and waiting lists for some procedures showed a tendency to increase by the end of the year.	realised since it appears that hospital departments chose to expand their own activities rather than use the new opportunity offered by the guarantee to refer patients to other hospitals.
Hanning, M and Spånberg, U. (2000). Maximum waiting time – a threat to clinical freedom? implementation of a policy to reduce waiting times. *Health Policy*. 52, 15–32.	The study examines the reasons behind limited success of waiting list guarantee in Sweden. Three questions are addressed: Did the implementers understand the intentions and the goals of the reform? Were they able to fulfil the guarantee? And, did they approve of the initiative? The study subjects were chief physicians at the hospital departments involved with the guarantee. Their attitudes towards the policy were ascertained by two surveys. Other material, such as statistics on waiting times, was also used.	The study shows that the physicians approved of the guarantee initially. The measures taken in the first years were effective and did not conflict with earlier practice. However, increased demand in combination with economic restraints necessitated new priorities among patient groups. These changes of clinical practice did not coincide with the physicians' professional values and hence they became more critical to the initiative and finally chose to abandon the intentions in the guarantee.
Harris, C., Scrivener, G. (1996). Fund-holders' prescribing costs: the first five years. *British Medical Journal.* 313, 1531–1534.	Objectives: To determine whether the first five waves of English fundholding practices have reduced their prescribing costs relative to non-fundholding practices, and the duration of any reduction achieved. Design: Analysis of item and cost data for all	Absolute prescribing costs increased over the six years, by 66% in the continuing non-fundholders and by 56–59% for fundholders. Successive waves of fundholders showed a similar pattern of change: a small relative reduction in the pre-fundholding year, maximum

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	general practices in England in the six years from April 1990 to March 1996. The practices of each of the first five waves were identified at the Prescription Pricing Authority. Setting: All general practices in England. Main outcome measures: Changes and rates of change in net ingredient cost per prescribing unit, and changes in number of items per prescribing unit in fundholding practices, before and after fundholding, relative to continuing non-fundholders.	relative reduction in the first year, and a declining relative reduction in the second and third years. After this, their increases in costs were largely similar to those of non-fundholders. The number of items dispensed remained stable over the six years in all groups.
Health Link (2004). *Taking the soundings. A patient and public involvement in the London Patient Choice Project.* London, Health Link. www.health-link.org.uk	50 organisations working with 'hard to reach' groups were approached to examine their views on Patient Choice. 13 organisations facilitated its involvement with carers, older people, disabled people, families with sick and disabled children, faith communities, ethnic minority groups, mental health service users, care home residents, young people, homeless people and those living in poverty. 90 people took part in framework survey comprising range of involvement methods (face to	Participants were generally enthusiastic about Patient Choice, particularly choice of appointment date and time, many were sceptical about whether the NHS could deliver it. In particular concerns were raised about: access ranging from how to get to the hospital to waiting times for the procedure; quality covering performance such as mortality rates and cancelled operations as well as information about the environment (e.g. disabled access), staff (e.g. dementia skills of nurses) and processes (e.g.

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	face or telephone semi-structured interviews and self-administered survey forms).	numbers of visitors allowed, communication with GPs); policy (e.g. parent allowed in the recovery room); subjective and attitude (e.g. quality of nursing care, respect and dignity). Information in accessible form for all groups with diverse needs and personal support for some user groups was seen as a crucial aspect if choice policy is to redress rather than to aggravate the existing disadvantage. Concerns were expressed that *Choose and Book* might exclude those who need treatment most often.
Hibbard, JH. and Jewett, JJ. (1997). Will quality report cards help consumers? *Health Affairs*. 16, 218–228.	USA - Content analysis from focus group transcripts and survey data regarding report card contents - n=104 publicly insured participants.	Comprehension of quality information is strongly related to salience, since comprehension drives salience. Deciding what should appear in report cards and what is salient to consumers will be an iterative one in which consumers' interests in quality information evolve along with their understanding of the health care environment.
Hibbard, JH., Jewett, JJ, Legnini, MW. and Tusler, M. (1997). Choosing a health plan: Do large employers use the data? *Health Affairs*. 16, 172–180.	USA - interviews with representatives of thirty-three large employers that purchase for 1.8 million covered lives to	Purchasers are not always aware of clinical outcomes data and the measures do not meet their decision-making needs. Further,

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	examine how large employers use performance information, including clinical outcomes, in purchasing decisions.	the variety and amount of performance information to process for purchasing decisions is a barrier to effective decision-making. Some mis-interpret the data or believe that quality monitoring can be left to others.
Hibbard, JH., Harris-Kojetin, L, Mullin, P, Lubalin, J. and Garfinkel, S. (2000). Increasing the impact of health plan report cards by addressing consumers' concerns. *Health Affairs*. 19, 138–143.	USA - controlled experimental design to examine the effect of reframing the health plan choice decision to one that emphasizes protecting oneself from possible risk.	Framing the health plan decision using a risk message has a consistent and significant positive impact on how consumers comprehend, value, and weight comparative performance information.
Hibbard, JH, Stockard, J. and Tusler, M. (2003). Does publicizing hospital performance stimulate quality improvement efforts?. *Health Affair*s. 22, 84–94.	USA - Experimental design for 3 groups of Wisconsin hospitals - 1 public release, 1 private report and 1 no report regarding their performance. Before and 9 months after comparison.	Making performance information public appears to stimulate quality improvement activities in areas where performance is reported to be low.
Higgins, J and Wiles, R. (1992). Study of patients who choose private health-care for treatment. *British Journal of General Practice.* 42, 361, 326–329.	The aim of the study was to discover which groups of people chose private health care and why. It also examined how patients exercised choice in a market situation and how well informed they were when they did so. A questionnaire survey carried out in 1991 in Wessex regional health authority of a sample of private patients having inpatient treatment in	The most common reason for choosing private care was to avoid long waiting lists (61.5%) although they did not know how long the wait might be. The majority (71.2%) had decided to use private health care before consulting their GP but their choice of consultant and hospital was influenced by their GP's advice. Although the respondents were active and well informed consumers in relation to some

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	eight independent hospitals, and in pay beds in three NHS hospitals. A total of 649 patients replied (response rate 60.7%), and 60 respondents to the questionnaire were also interviewed. The questionnaire asked about the role and influence of GPs in patients' decisions to use private health care.	aspects of their care, they had very limited knowledge of the options available to them or of the likely cost of the treatment (61.9% did not know in advance how much their treatment would cost).
Howie, J, Heaney, D, Maxwell, M. (1995). Evaluating care of patients reporting pain in fund-holding practices. *British Medical Journal*. 309, 705–710.	A survey of a total of 2329 patients in six Scottish practices in 1990 and another 2005 in 1992 after the practices had become fundholders. The study focused on patients who had particular health problems and used a measure of patient satisfaction/enablement - the extent to which patients feel that the practice enables them to look after themselves when coping with health problems.	There was a significant decrease in satisfaction/enablement scores for fundholding patients with pain, skin problems and digestive problems, as well as for patients in general, between 1990 and 1992. There was no change in consultation length after the practices became fundholders.

Authors and publication	**Description of study**	**Summary of findings**
Hsu, J., Schmittdiel, J, Krupat, E, Stein, T, Thom, D, Fireman, B. and Selby, J. (2003). Patient choice - A Randomized Controlled Trial of provider selection. *Journal of General Internal Medicine*. 18, 319–325.	USA - Randomized controlled trial of provision of telephone or web-based provider-specific information to aid in the selection of a primary care provider (PCP), n= 3274, > 30 years old, PCP retired immediately prior to study.	Intervention subjects were more likely to perceive that they chose their PCP (78% vs 22%; P<.001), to retain their PCP at 1 year (93% vs 69%; P<.001), and to report greater overall satisfaction with the <LF>PCP (67% vs 57%; P<.01), compared to control subjects who were assigned to a PCP. The intervention subjects also reported greater trust in their PCP on most measures, but these differences did not remain statistically significant after adjustments for patient age, gender, ethnicity, education, and health status.
Hughes, M. (2004). *Enabling Choice. A report to the Local Government Association.* School of Public Policy, Birmingham, University of Birmingham.	The report provides four contributions on choice in different areas of public service: Parental choice in Schools Patient Choice in the NHS Choice based lettings in social housing Choice in social care Each contribution in this report considers choice in terms of current debates in each of the public services drawing on the evidence available. These debates follow a common framework that is concerned with: the purpose of service,	We report the results on Patient Choice in the NHS here. Parental choice in Schools is reported in Table A5 and choice in social care in Tables A3 and A4 respectively. Choice in social housing is not reviewed in this project. The study contends that the policy question is not whether to offer choice but how to extend patient choices, how to meet the costs, how to manage the risks and how to minimise the unintended or unacceptable consequences. The next innovation in policy arena is choice of provider rather than the choice of treatment. Patients

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	the range of choice, the exercise of choice, the framework of choice, support for choice, the values of choice, the costs of choice and the judgment of choice.	currently show inertia in their choice of GP. New initiatives in patient choice are likely to focus on the secondary care for some time. Examination of the assumptions involved in the use of patients choice to promote a variety of policy goals leads to case for rather careful management of the expectations of individual patients, the taxpayers, the media, and the policy-makers themselves.
Isroliwala, S, Wainwright C, Sehdev, K (2004). *A Local view of factors influencing patient choice in the NHS. Health Management Research Group*. Cranfield University. Bedfordshire, Cranfield University.	Report based on qualitative and quantitative research with the sample of GPs practicing in mid and north Bedfordshire and the surrounding counties. Concerned with teasing out factors influencing patient choice but there is no empirical data on revealed preferences (actual choices made) under choice policies. Only stated preference (hypothetical answers).	Most GPs (78%) refer most patients (90%) to local hospitals. If offered more choice 68% GPs happy with existing providers. GP advice has big influence on choice.
Ito, H. and Sugawara, H. (2005). Relationship between accreditation scores and the public disclosure of accreditation reports: a cross sectional study. *Quality and Safety in Health Care*. 14, 87–92.	Japan - A cross sectional study examining the association between accreditation scores and the public disclosure of accreditation reports.	Accreditation scores were positively related to the public disclosure of hospital accreditation reports. Scores for patient focused care and efforts to meet community needs were significantly higher in actively disclosing hospitals than in non-disclosing hospitals. Among the

Authors and publication	**Description of study**	**Summary of findings**
		large hospitals, scores for safety management were significantly higher in hospitals advocating disclosure than in non-disclosing hospitals.
Jewett, JJ. and Hibbard, JH. (1996). Comprehension of quality care indicators: Differences among privately insured, publicly insured, and uninsured. *Health Care Financing Review*. 18, 75–94.	See entry for Marshall *et al.* (2000), which reviewed this study	
Jones, D, Lester, C and West, R. (1994). Monitoring changes in health service for older people. In R. Robinson, R. and J. Le Grand (Eds). *Evaluating the NHS Reforms*. London, King's Fund Publishing.	A study, conducted at an early stage of the implementation of the reforms examined the choices and information, participation in decision-making, communication between the elderly and staff in the UK. The two studies were undertaken in health authorities in South Wales with random sample of 1,500 patients in before (1990) and after the introduction periods (1992) (n=3,000) in the community study, and 2, 400 in the hospital study. Postal questionnaire was a key method used, supplemented by interviews in the community study.	High response rate was achieved in both studies (94% in the community study and hospital study 89% and 85%). The vast majority of patients had not been offered any choices and the information provided by GPs was very low. Most patients were treated in hospitals in their health authorities and when they were offered alternatives they did not have sufficient understanding what this entailed for them. The study concluded that some improvement in information provision had appeared without differentiating whether this concerned fund-holders' or non fund-holders' patients.
Kalda R, Põlluste K, Lember M (2003). Patient Satisfaction with care associated with personal choice of physician. *Health Policy.* 64, 55–62.	The study evaluates whether choosing one's own primary care doctor is associated with patients' satisfaction with primary health care. A cross-	Overall 68% of respondents have been listed with their personal physician. Their overall satisfaction levels with the physician as well as satisfaction

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	sectional study of random sample of Estonian population (n=997) using pre-categorised questionnaire.	with several other aspects of primary care were significantly higher compared with those of unregistered respondents. Although some other factors (practice size, patients' age and health status) also influenced patients' satisfaction, presence of a personal physician appeared the most important predictor of high satisfaction with physician's punctuality and understanding, effectiveness of prescribed therapy, clarity of explanations given by the physician as well as overall satisfaction with the physician.
Kerrison, S. Corney, R. (1998). Private provision of 'outreach' clinics to fund-holding general practices in England. *Journal of Health Services Research and Policy.* 3, 20–22.	Private provision of outreach clinics in fundholding practices.	Considerable private provision of fundholding outreach clinics. No mechanism for monitoring the impact of it on the quality and cost of services provided.

Authors and publication	**Description of study**	**Summary of findings**
Knutson, DJ, Kind, EA, Fowles,JB. and Adlis, S. (1998). Impact of report cards on employees: A natural experiment. *Health Care Financing Review*. 20, 5–27.	USA - before and after survey of two groups of Minnesota State employees, one of which received a report card and one that did not.	Authors looked for report card effects on relative changes in the employees' knowledge of health plan benefits and their ratings of quality and cost attributes, as well as their plan choice, rates of switching plans, and willingness to pay higher premiums. The only report card effect found was an increase in perceived knowledge for employees with single coverage.
Lang, S, Wainwright, C, Sehdev, K. (2004b). *PCT commissioning under Patient Choice: Implications for Bedford Hospital.* Health Management Research Group, Cranfield University. Bedfordshire, Cranfield University.	This report reflects a snapshot of the situation at a particular point in time. Therefore the conclusions are based on two evaluations of pilot schemes; one for choice at the point of referral and one for choice at six months. There are also remarks about limited choice based on small pilots as opposed to planned choice policies.	Choice at the point of referral pilot, all electives - 4 months from October 2003 Ease of access was a major influence on choice (56%) followed by reputation of hospital (47%) and quality of care (43%). Waiting time was the fourth factor influencing 34% of patients. For judging 'quality of care' people cited factors such as knowing people who were unhappy with a provider or information from family and/or friends. Only 8% used the website and only 4% contacted the call centre. Most patients chose their local hospital.

Authors and publication	**Description of study**	**Summary of findings**
		CHD Choice at 6 months pilot Younger patients were more likely to take-up choice (61% vs. 55% for over 60s).
Le Maistre, N, Reeves, R, Coulter, A. (2003). *Patients' experience of CHD choice*. Oxford, Picker Institute.	Evaluation of patients' experience who had been on the waiting list for heart surgery for six months or more and were offered choice of alternative hospital within Coronary Heart Disease (CHD) Choice scheme. An 8 page questionnaire was distributed to 4,330 patients who had recently undergone heart surgery. Patients were eligible for the survey if they had been on a list at one of 24 participating NHS trusts and had waited for their operation for at least six months. Most patients on the list were offered treatment but some were excluded because of the severity of their medical condition. Response rate was 79.2%.	Three quarters of patients were offered choice of an alternative hospital of which half took up the offer. Of those not offered a choice more than a third have been given admission date by their home hospital by the time they heard about the scheme; one in five were not well enough to travel. Elderly were slightly more likely to remain on the waiting list. The reputation of the alternative hospital was the most important factor influencing patients' decisions but speed of treatment was also important. More than a third of patients made their decisions on their own but the remainder sought the advice of the Primary Care Adviser (PCAs), a doctor at their home hospital and family or friends.
Longo, DR, Land, G, Schramm, W, Fraas, J, Hoskins, B. and Howell, V. (1997). Consumer reports in health care - Do they make a difference in patient care? *Jama-Journal of the American Medical Association*. 278, 1579–1584.	See entry for Marshall *et al.* (2000), which reviewed this study	
Luce, JM, Thiel, GD, Holland, MR, Swig, L, Currin, SA. and Luft, HS. (1996). Use of risk-adjusted outcome data for quality improvement by public hospitals. *Western Journal of Medicine*. 164, 410–414.	See entry for Marshall *et al.* (2000), which reviewed this study	

Authors and publication	**Description of study**	**Summary of findings**
Magee, H, Davis, LJ. and Coulter, A. (2003). Public views on healthcare performance indicators and patient choice. *Journal of the Royal Society of Medicine*. 96, 338–342.	UK - 6 English locations, focus groups to investigate the views of patients and members of the public on publication of information about the performance of health care providers.	Participants felt that independent monitoring of health care performance is necessary, but they were ambivalent about the value of performance indicators and hospital rankings. They tended to distrust government information and preferred the presentational style of 'Dr Foster', a commercial information provider, because it gave more detailed locally relevant information. Many participants felt the NHS did not offer much scope for choice of provider.
Mahon, A., Wilkin, D. and Whitehouse, C. (1994). Choice of hospital for elective surgery referral: GPs and patients' views. in R. Robinson, and J. Le Grand (Eds). *Evaluating the NHS Reforms*, London, King's Fund Publishing Institute.	Patient choice of hospital examined in before and after study. Aspects of choice offered to patients by their GPs, patients' perceptions of choice, and the factors involved in choice, and GPs experience of choice. Survey of patients before and after the introduction of the fundholding (app. 1,850 in each case) in five hospitals in the North West, and a survey with app. 300 GPs and interviews with GPs (n=19).	43% response rate from patients in each of the two stages of the study. Response rate for GPs survey was 58% and 57% respectively. Despite high satisfaction levels many patients would have liked more choice of hospital and information about consultants and hospitals they could have gone to. The overall conclusion is that the level of patient's choice for hospital remains low and reforms have had very little impact on increase of choice. GPs played a central role in choosing hospital with proximity and convenience were the main the factors that influence their decisions.

Authors and publication	**Description of study**	**Summary of findings**
Mannion, R. (2005). *Practice – based budgeting: lessons from the past; prospects for the future.* Report to the Department of Health. York, Centre for Health Economics, University of York.	Report synthesises the available evidence regarding the impact of previous models of practice level budgeting with the aim of exploring the implications of these findings for the design and evaluation of current approaches to practice based budgeting in the NHS. 'Hand' search of the key published evidence was relied upon rather than a systematic review covering all of the available literature complemented by consultation with a number of academics and senior practitioners/policy-makers with expertise in the primary care commissioning.	Key findings of the review are: Practice level budgeting/commissioning has taken a variety of forms in the NHS, including, standard GP fundholding (GPFH) GPFH had lower elective referral and admission rates and reduced waiting times for non-emergency treatment. They also had improved coordination of primary, intermediate and community support services and curbing the rise in prescribing costs. However, alongside these positive effects there is evidence that devolved budgets may induce a range of adverse outcomes for patients and local health economies, including: -reduced patient satisfaction -increased management and transaction costs and worsened the inequities of access.

Authors and publication	**Description of study**	**Summary of findings**
Mannion, R. and Goddard, M. (2003). Public disclosure of comparative clinical performance data: lessons from the Scottish experience. *Journal of Evaluation in Clinical Practice*. 9, 277–286.	UK, Scotland - Interviews with hospital staff at all levels of the organization (n=56) and other stakeholders (e.g. Health Boards), plus questionnaire to Health Councils to assess impact of public disclosure of comparative clinical performance data.	Indicators rarely used by any of the stakeholder groups. Reasons include poor dissemination within hospitals, credibility of indicators information and lack of incentives.
Marshall, MN. and Romano, PS. (2005). Impact of reporting hospital performance. *Quality and Safety in Health Care*. 14, 77–78.	Commentary.	Highlights the need for more rigorous designs exploring the relationship between public reporting of performance data and performance.
Marshall, MN, Shekelle, PG, Leatherman, S. and Brook, RH. (2000). The public release of performance data: What do we expect to gain? A Review of the evidence. *JAMA: The Journal of the American Medical Association*. 283, 1866–1874.	USA – Literature review to summarize the empirical evidence concerning public disclosure of performance data, relate the results to the potential gains, and identify areas requiring further research.	Consumers and purchasers rarely search out the information and do not understand or trust it; it has a small, although increasing, impact on their decision-making. Physicians are skeptical about such data and only a small proportion makes use of it. Hospitals appear to be most responsive to the data and in a limited number of studies, the publication of performance data has been associated with an improvement in health outcomes.

Patient choice and the organisation and delivery of health services

Authors and publication	**Description of study**	**Summary of findings**
Marshall, MN, Hiscock, J, and Sibbald, B. (2002). Attitudes to the public release of comparative information on the quality of general practice care: qualitative study. *British Medical Journal*, 325, 1278–1281.	UK - North West England. Focus groups (Participants 35 service users, 24 general practitioners, and 18 clinical governance leads) using mock quality report cards as prompts for discussion.	Attitudes were strongly influenced by experience of comparative reports from other sectors-for example, school league tables. Service users distrusted what they saw as the political motivation driving the initiative, expressed a desire to 'protect' their practices from political and managerial interference, and were uneasy about practices being encouraged to compete against each other. General practitioners focused on the unfairness of drawing comparisons from current data and the risks of 'gaming' the results.
Maynard, A. (2003). What are the costs and benefits of patient choice? *British Journal of Health Care Management.* 9, 2003, 362–364.	Discusses whether the patient choice initiative will improve NHS efficiency and help reduce health inequalities between social classes.	Concludes by outlining the potential conflicts between choice and efficiency, and puts forward a proposal that choice in connection with other policies should be used to promote cost-effective procedures.

Authors and publication	**Description of study**	**Summary of findings**
McCormick, D, Himmelstein, DU, Woolhandler, S, Wolfe, SM. and Bor, DH. (2002). Relationship between low quality-of-care scores and HMO's subsequent public disclosure of quality-of-care scores. *Jama-Journal of the American Medical Association*. 288, 1484–1490.	USA - Retrospective cohort study of administrative and quality-of-care data on HMOs from the National Committee for Quality Assurance (NCQA) annual Quality Compass databases for 1997, 1998 and 1999, including Health Plan Employer Data and information Set (HEDIS) quality scores.	Of the 329 HMOs that publicly disclosed HEDIS scores in 1997, 161 plans (49%) withdrew from public disclosure in 1998. Of the 292 HMOs that disclosed their scores in 1998 (including 130 newly participating plans), 67 plans (23%) withdrew from public disclosure in 1999. Plans whose scores ranked in the lowest-quality tertile were much more likely than plans ranking in the highest-quality tertile to withdraw from public disclosure in 1998 (odds ratio [OR], 3.6; 95% confidence interval [CI], 2.1–7.0) and 1999 (OR, 5.7; 95% Cl, 2.7–17.7).
Mennemeyer, ST, Morrisey, MA, and Howard, LZ. (1997). Death and reputation: How consumers acted upon HCFA mortality information. *Inquiry-the Journal of Health Care Organization Provision and Financing*. 34, 117–128.	See entry for Marshall *et al.* (2000), which reviewed this study	
MORI (2003). *Patient Choice in Birmingham, Solihull, and The Black Country*. London, MORI.	Report present main findings of qualitative and quantitative research conducted by the MORI Social Research Institute on behalf of Birmingham, Solihull, and The Black Country Authority in September 2003. The study examined public views of currently available choices, the demand for choices, attitudes towards choice, trade-offs involved and practicalities involved in choice , support	Key findings are: Knowledge about the choice initiative is low among public is low with middle class people knowing more than working class people (10% versus 6%). Choice is not highest priority for the public as they do not see it as means to an end but there is positive attitude to it in principle. Despite support for the principle of choice there are concerns around its practical introduction

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	and communication needed to exercise it. A total of 1, 208 telephone interviews were carried out and 13 focus groups were conducted across local PCTs, which included hard to access groups. It also explored doctors' and consultants' views on demand and supply issues involved in choice. 200 of telephone interviews were carried out which were supplemented by fieldwork.	(e.g. how much assistance will be available, to 'fear of outsiders'). Patients mostly want choice of hospital, choice of consultant, GP appointment (date and time), but there are marked differences by class, age, ethnicity. Only 55 are not prepared to travel beyond their local hospital. Only a minority of people feel able to make choice of hospital unaided (15%), and most people (62%) want advice and information. GPs are most trusted professionals in the UK (95% trusts GPs versus 20% for government ministers).
MORI (2004) MORI (2004) Public perceptions and patient experience of the NHS: Winter 2004 Tracking survey summary report. Report submitted to the Department of Health. http://www.dh.gov.uk/assetRoot/04/11/81/09/04118109.pdf	Report present main findings of a Winter 2004 survey conducted among the general public the MORI Social Research Institute, initially conducted in 2000 and followed up in 2001. A national sample of 1000 provides a check on a public sentiment with regard to; a)overall perceptions of the role the NHS and funding preferences, b)reported use of and perceptions of, specific areas in the NHS, c)priorities for	Satisfaction is high with most measures consistent with findings from Spring 2004. Key aspects are: a) satisfaction with running the NHS overall (62%) b) satisfaction with GP services remains high 87% c) satisfaction with AandE 70%, outpatient services high levels 85% d) increased satisfaction with inpatient services from 82% in Spring to 92% and Walk-In clinics

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	spending and perceptions of key priorities and d)information sources they hear about the NHS and their reliability.	from 73% to 85%.
Mukamel, DB, Weimer, DL, Zwanziger, J, Gorthy, SFH. and Mushlin, AI. (2004). Quality report cards, selection of cardiac surgeons, and racial disparities: A study of the publication of the New York State Cardiac Surgery Reports. *Inquiry-the Journal of Health Care Organization Provision and Financing* 41, 435–446.	USA - revealed preference comparing selection of cardiac surgeons in 1991 (pre-report publication) and 1992 (post-report publication).	Information about a surgeon's quality published in the reports influences selection directly and diminishes the importance of surgeon experience and price as signals for quality. Selection of surgeons for black patients is as sensitive to the published information as is the selection for white patients, although choice is sensitive to income and education suggesting that those who are capable of accessing and using information gain at the expense of the rest.
Mythen, M. and Coffey. T. (2004). Fighting Shy. *Health Service Journal.* 114,18–19.	The article discusses how the patient choice agenda can be made to work at the level of the GP consultation.	Exploiting the GP consultation to empower patients requires: - GPs to "buy in" to the potential of increased patient power to improve health; -steps to engage those who do not want choice; -equipping the GPs with information about the relative expertise and experience of consultants; -development of personalised consultations;

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		- better information for patients.
National Audit Office (2005). *Patient Choice at the Point of GP Referral.* London, National Audit Office. TSO.	A survey of GP opinions by NAO investigated knowledge of the Choose and Book among GPs in England (n=1,500).	A quarter of primary care trusts are forecasting that they will miss the target of offering all patients a choice of 4–5 providers of elective procedures by December 2005. The report identifies low clinical engagement with the choice agenda as the key risk to the delivery of the target. 61% of GPs feel either negative or "a little negative" about being able to deliver the choice agenda due to lack of capacity, increase in workload, greater consultation length and fears that existing health inequalities will be exacerbated. On present plans, only 60–70% of the NHS will have "choose and book" or e-booking facilities in place by December 2005. This means that choice will have to be delivered in a less efficient way.
National Consumer Council (2003). *Expectations of public services. Consumer concerns 2003.* London, National Consumer Council.	See entry under Policy Commission on Public Services (2004).	
Newton J, Fraser M, Robinson J, Wainwright D. (1993). Fundholding in Northern Region: the first year. *British Medical Journal.* 306, 375–378.	Review of fundholding in Northern Region: 19 GPs in 10 fundholding practices.	Greater responsiveness of hospital consultants. No change in patient choice. Extra staff taken on and high administration time. Uncertainty of making savings

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		year on year.
Page, B. (2004). What they really want. *Health Service Journal.* 8th April, www.hsj.co.uk.	MORI Director discusses findings of research it carried out on behalf of the Commission of Health Improvement, and its own surveys on perceptions of users of public services, the NHS, in particular.	Key findings are: - There is little correlation between star ratings, mortality and waiting times, and perception of care. -There is strong link between how well people rate their quality of life and perception of their local council but in terms of health deprivation matters much less in terms of affecting patients' views than it does in terms of overall public attitudes. -What matters most is the ethnic mix. The more ethnically diverse an area is, the more patients are likely to be negative about their treatment.
Peckham, S. (2004). What choice implies for primary care. *British Journal of Health Care Management.* 10, 210–213.	There is an increasing emphasis on developing patient choice in primary care. While the main emphasis is on NHS primary care and the increasingly important role of pharmacists, dentists and opticians, there has also been a growth in the use of complementary and alternative medicine, some of which is funded.	Such developments blur traditional boundaries and create new management problems for primary care.
Pedersen, KM. (2002). *Reforming decentralised integrated health*	Conceptual and theoretical	The scheme suggests that overall

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systems: Theory and the case of the Norwegian reform. Working Paper 2002:7. Health Economics Research Programme, University of Oslo. Oslo: University of Oslo.	scheme is proposed for analysing decentralised integrated health care systems of Northern Europe using the ideas of fiscal federalism, principal-agent thinking, and discrete structural alternatives from new institutional economics thinking in addition to public competition model conceptualised by Saltman and van Otter. The scheme is used to analyse driving forces behind the reforms and the prediction of effects. Norway is an example that follows the opposite (decentralisation to centralisation) path and is discussed in more detail.	there is no *a priori* reason to expect large improvements in efficiency but neither should one expect to get things worse. Many effects depend, however, crucially, on a) the financing of the system that will be put in place in 2002 or 2003 and b) whether the political and management culture will change as a result of reforms.
Perri, 6. (2003). Giving consumers of British public services more choice: what can be learnt from recent history?. *Journal of Social Policy.* 32, 2, 239–70.	The article identifies policy goals for introducing choice in several public sectors (school choice, nursery vouchers, higher education, choice of GP, choice of consultant, choice of treatment, DP, community care and social rented housing), and reviews how they were achieved using available evidence. It also identifies problems and unintended side-effects, including distributional problems, inefficiencies and	Although few would oppose choice for consumers on general principle, designing policies to support greater individual choice presents government with both technical challenges and conflicts of values. It might be possible to incrementally raise satisfaction, and some improvements in efficiency can be achieved but the objective of responsiveness might be more difficult to attain. To achieve equitable outcomes and avoid adverse selection or segregation on the basis of

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	one type of political risk. Findings are presented in two tables while lessons are drawn in discussion section.	ascribed characteristics requires substantial investment. Experience of the last 15 years in implementing extended consumer choice should be taken into account.
Policy Commission on Public Services (2004). *Making public services personal: A new contract for public services.* Independent Policy Commission on Public Services report to the National Consumer Council. The London, Policy Commission on Public Services.	In December 2002 National Consumer Council set an independent Policy Commission on Public Services to examine the current delivery of services to consumers and to try to answer three overarching questions: what is the relationship between choice and equity? what is the relationship between consumer and citizen? are consumers' expectations of public services changing? The Commission used the reference of four specific public services: primary health care, personal social services, secondary education and physical urban regeneration. Two sets of consumer consultations: quantitative fieldwork with 104 opinion formers and 1,028 members of the public, four consultative	Users are in favour of more personalised services and see the scope for extending choice to make services more responsive to users' needs. There are also some reasonably stringent conditions that have to be met if choice is to achieve the aims of government policy. There is a need to distinguish between different types of choices (e.g. economic and non-economic choices), and to acknowledge the limits of choice (e.g. where the individual interest is in conflict with the public interest). Both choice and voice should be used to rebalance services from being provider orientated to being more user orientated. Citizenship is not 'one fit all' concept. Public values should be used as a guide to the pursuit of the public interest through complementary voice and choice mechanisms.

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	workshops, and stakeholder meetings took place.	
Policy Unit (2004). *Choice in public services. A Policy Unit survey of the topic.* London, Policy Unit.	This paper traces the development of government policy with regard to choice in public services, reviews the literature, highlights key findings, and provides basis on which to build further work.	A review and internal document produced for information purposes. Poses a series of questions about the nature and feasibility of choice in public service provision.
Propper, C., Söderlund, N. (1998). Competition in the NHS internal market: an overview of its effects on hospital prices and costs. *Health Economics.* 7, 187–197.	Synthesis of both the theory underlying the introduction of competition into the NHS, and the limited existing evidence on whether competition affects the prices posted by sellers of medical services, and the cost of producing these services.	The results indicate high levels of price variability, widespread disregard for average cost pricing rules and some indication that competition had some effects on prices. It appears that lower prices may be offered to smaller purchasers, such as General Practice Fund Holders (GPFH). This effect of competition on price was mirrored, with delay, in hospital costs.
Propper, C. and Burgess, C. Green, C. (2004). Does competition between hospitals improve the quality of care? Hospital death rates and the NHS internal market. *Journal of Public Economics.* 88, 7–8, 1247–72.	Payer-driven competition has been widely advocated as a means of increasing efficiency in health care markets. The 1990s reforms to the UK health service followed this path. The study examines whether competition led to better outcomes for patients, as measured by death rates after treatment following heart attacks.	The study finds that the relationship between competition and quality of care appears to be negative. Greater competition is associated with higher death rates, controlling for patient mix and other observed characteristics of the hospital and the catchment area for its patients. However, the estimated impact of competition is small.

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	The study uses data that until 1999 were not publicly available in any form on hospital level death rates.	
Propper, C, Croxson, B. and Shearer A. (2002) Waiting times for hospital admissions: the impact of GP fundholding. *Journal of Health Economics.* 21, 2, 227–52.	The study uses a difference in differences methodology to examine the impact of the GP fundholder initiative on hospital waiting times for over 100,000 elective hospital admissions in the one health authority over a period of four years (1993–1997). The analysis looked whether fundholders secured faster treatment for their patients, and whether they were able to obtain faster treatment for all procedures or only those they paid for directly.	GPFH secured faster treatment for their patients only for the procedures they were able to pay for because hospital were interested in additional income from marginal fundholders giving hospital managers a direct financial incentive to reduce waiting times in particular areas but there were no spill-over effects for other patients or other procedures. The authors conclude that the results are consistent with fundholding generating an inequitable ‘two tier’ system’as some GPFH patients had shorter waits than other patients. However, the overall average waits were not significantly less than those of non fundholders.
Public Administration Select Committee, House of Commons (2005). *Choice, voice and public services*. London, The Stationery Office Limited.	The report examines whether greater choice is an effective instrument for promoting quality, responsiveness, efficiency and equity in public services.	It concludes that in many cases choice is more effective than alternatives, such as voice mechanisms. However, it should not be assumed that extending user choice is an option for all public services, or that it is the principal determinant of reform. The traditional “voice” mechanisms continue to have an

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		important role to play in shaping the development of our health services. Patient choice introduces powerful new mechanisms for patients to express their preferences and to drive up standards of care.
Rankin, J. (2005). *A good choice for mental health.* Report to the Institute for Public Policy Research. London, IPPR.	The paper considers patient choice in relation to mental choice policies. It offers an assessment of mental health users' choices or the lack of choices in recovery options and outlines the core principles for promoting choice in mental health, as well as the conditions necessary to support choice in practice.	Critique of the current patient choice policy with its lack of focus on mental health is offered first. Principles are proposed to guide choice in mental health and shift from the past assumption that mental health service users are unable to make choices. Choice can be expressed in individual and collective terms; it is seen as an aspect of personalised responsive care and as a right of health and social care users that extends beyond those areas. Two recommendations are made to achieve this: GPs should not be the sole gate keepers into the services, and different types of worker based support should be available in community organisations. People should be entrusted their own personal budgets, adapted from the current practice of DP.
Robinson, S. and Brodie, M. (1997). Understanding the quality challenge for health	See entry for Marshall *et al.* (2000), which reviewed	

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consumers: The Kaiser/AHCPR survey. *Joint Commission Journal on Quality Improvement*. 23, 239–244.	this study	
Rodwin, VG and Le Pen, C. (2004). Health care reform in France: The birth of state-led managed care. *New England Journal of Medicine* 351, 22, 2259–2262.	The paper uses French health care system to discuss whether it is possible to achieve the balance among solidarity, liberalism, and pluralism while health care costs are kept under control and the cherished features of the present system are sustained.	It concludes that French health system has reached a turning point that should interest clinicians and policymakers in the United States, for the current reform represents the French response to a fundamental question. The birth of state-led managed care in France has clarified the challenge ahead by posing a challenge as to whether France can adapt the NHI system to technological and economic change without provoking insurmountable opposition from the medical profession.
Romano, PS. and Mutter, R. (2004). The evolving science of quality measurement for hospitals: implications for studies of competition and consolidation. [Review] [102 refs]. *International Journal of Health Care Finance & Economics.* 4, 2, 131–57.	USA – Review article focusing on research investigating relationship between quality and competition.	Literature on competition and quality is relatively young, subject to confounders, focused on limited spectrum of outcome measures, fails to use clinical data systems for risk-adjustment and findings have been inconsistent. Research applying more quality measures to broader sets of conditions and procedures is required.

Authors and publication	Description of study	Summary of findings
Romano, PS. and Zhou, H. (2004). Do well-publicized risk-adjusted outcomes reports affect hospital volume? *Medical Care*. 42, 367–377.	USA - time-series analysis exploring whether hospitals recognized as performance outliers experience volume changes after publication of a report card. Secondary objectives were to test whether favorable outliers attract more patients with related conditions, or from outside their catchment areas; and whether disadvantaged groups are less responsive to report cards.	In California, low-mortality and high-mortality outliers did not experience changes in AMI volume, but low- complication outliers for lumbar diskectomy experienced slightly increased volume. In New York, low- mortality outliers experienced significantly increased CABG volume in the first month after publication, whereas high-mortality outliers experienced decreased volume in the second month. Volume effects were modest, transient, and largely limited to white Medicare patients in New York.
Rosen, R. (2004). Lifetime commitment. *Health Service Journal.* 114, 222–23.	Discusses patient choice in the context of chronic illness. Patients with chronic illnesses typically require different levels of care at different times.	Choice in this context must include respect for patients' personal values and lifestyles, as well as choice of provider. Article concludes by considering the limits of choice.
Rosén, P, Anell, A, and Hjortsberg, C. (2001). Patients' views on choice and participation in primary health care. *Health Policy.* 55, 2,121–128.	In order to identify individual preferences for choice and shared decision-making a survey was conducted among 1543 primary care patients in 13 general practices in the south of Sweden with mixed socio-economic criteria of the area. A total of 3784 questionnaires were distributed; response rate was 42%. As suggested by earlier	Results show both similarities and differences in attitudes among young and old patient groups, and differences could be explained by combination of life-cycle effects, cohort effects and expectations ensuing from the need for future health care contacts. Results also show that young patients with chronic diseases and high number of earlier physician visits show

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	work, special preference was paid to the strong link between patient preference and age.	similar preferences to the elderly in choosing their primary care doctor. Well- educated elderly also exhibit preferences closer to those of the younger respondents.
Rosenau, PV. and Linder, SH. (2003). Two decades of research comparing for-profit and nonprofit health provider performance in the United States. *Social Science Quarterly*. 84, 219–241.	USA - systematic review of 179 assessments of performance differences between private for-profit and private nonprofit U.S. health care providers on four performance criteria (access, quality, cost/efficiency, and/or amount of charity care) published since 1980.	Overall, the nonprofits were judged superior 59 % of the time, the for-profits superior only 12 % of the time, and for the rest (29 %), no difference was found or results were mixed.
Rosenthal,GE, Hammar, PJ, Way, LE, Shipley, SA, Miller, J, Wojtala, B., Miller, J. and Harper, DL. (1998). Using hospital performance data in quality improvement: the Cleveland Health Quality Choice experience. *Joint Commission Journal of Quality Improvement.* 24, 7, 347–369.	See entry for Marshall *et al.* (2000), which reviewed this study	
Salisbury, CJ (1989). How do people choose their doctor?. *British Medical Journal*, 299, 608–610.	See entry for Wearne, 1998.	
Scanlon, DP, Chernew, M, and Lave, JR. (1997). Consumer health plan choice: Current knowledge and future directions. *Annual Review of Public Health*. 18, 507–528.	USA - review summarizes state of knowledge about how individuals make choices among health plans and outlines an agenda for future research.	Health plan choice requires better understanding of how plan attributes other than price influence plan choice, how other variables such as health status interact with plan attributes in the decision-making process, and how specific populations differ from one another in terms of the sensitivity of their health plan choices to these different types of variables.

Authors and publication	**Description of study**	**Summary of findings**
Scanlon, DP, Chernew, M, McLaughlin, C. and Solon, G. (2002). The impact of health plan report cards on managed care enrollment. *Journal of Health Economics*, 21, 19–41.	USA - revealed preference to assess impact of release of health plan performance ratings on employee health plan choice.	Employees are less likely to enroll in plans requiring relatively high out-of-pocket contributions. Individuals avoid health plans with many below average ratings, but are not attracted strongly to plans with many superior ratings. Report card may have more impact if identifies 'bad' rather than 'good' performers.
Schauffler, HH. and Mordavsky, JK. (2001). Consumer reports in health care: Do they make a difference? *Annual Review of Public Health*. 22, 69–89.	USA - review is to evaluate the evidence on the impact of consumer report cards on the behavior of consumers, providers, and purchasers.	Consumer report cards do not make a difference in decision-making, improvement of quality, or competition. Consumers desire information that is provider specific and may be more likely to use information on rates of errors and adverse outcomes. Purchasers may be in a better position to understand and use information about health plan quality to select high-quality plans to offer consumers and to design premium contributions to steer consumers, through price, to the highest-quality plans.
Schneider, EC. and Epstein, A.M. (1996). Influence of cardiac-surgery performance reports on referral practices and access to care - A survey of cardiovascular specialists. *New England Journal of Medicine*. 335, 251–256.	See entry for Marshall *et al.* (2000), which reviewed this study	

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Schneider, EC. and Epstein, AM. (1998). Use of public performance reports: A survey of patients undergoing cardiac surgery. *JAMA: The Journal of the American Medical Association*. 279, 1638–1642.	USA - Telephone survey to examine the awareness and use of a statewide consumer guide that provides risk-adjusted, in-hospital mortality ratings of hospitals that provide cardiac surgery.	Only 12% of patients surveyed reported awareness of a prominent report on cardiac surgery mortality before undergoing cardiac surgery. Fewer than 1% knew the correct rating of their surgeon or hospital and reported that it had a moderate or major impact on their selection of provider.
Schoen, C, Osborn, R., Huynh, PT., Doty, M, Davis, K, Zapert, K. and Peugh, J (2004). Primary care and health system performance: Adults experiences in five countries, *Health Affairs.* W4–487–403 [PMID: 15513956. Last accessed 27th September 2005.	This paper reports on a 2004 survey of primary care experiences among adults in Australia, Canada, New Zealand, the United Kingdom, and the United States. A comparative study looking into perceptions of adults about primary care and health system performance using data from Commonwealth Fund International Health Policy Survey in five countries compares patients' satisfaction with choice of doctors with the USA and among each other.	The survey finds shortfalls in delivery of safe, effective, timely, or patient-centered care, with variations among countries. Failures to communicate, to engage patients, or to promote health are widespread. It finds levels of satisfaction with choice highest in New Zealand and the UK and lowest in Canada when compared to the USA with Australia positioned somewhat lower but still higher than the USA. A similar trend was observed for the values of least satisfied patients with New Zealand and UK having lowest and Canada highest percentages. Contrasts across countries point to the potential to improve performance and to learn from international initiatives.
Schultz, J, Call, KT, Feldman, R. and Christianson, J. (2001). Do employees use report cards to assess health care provider systems?.	USA - telephone survey to investigate consumers' use of report cards that provide	Consumers who changed to a new provider group are more likely to use report card information and

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Health Services Research. 36, 509–530.	information on service quality and satisfaction at the provider group level.	find it helpful, consumers employed in large firms are less likely to use the report card, and families who use information from their own health care experiences are less likely to find the report card helpful. In addition, individuals who changed to a new provider group are more likely to find the selection decision difficult.
Schwartz, H. (1994). Public choice theory and public choices: Bureaucrats and state reorganisation in Australia, Denmark, New Zealand, and Sweden in the 1980s. *Administration* and *Society.* 26, 1, 48–77.	A comparative analysis of the rationale market oriented reforms in four countries that introduced separation of policy making from production of welfare by introducing market disciplines and competition. The argument was that fiscal bureaucrats afraid of raising fiscal deficits and public debt thus sought to control what they saw as rent seeking behaviour and agents abuse of principles in the public sector. Departing from premises of the public choice theory, they sought to control future behaviour in the public sector by changing the incentive structures workers and agency managers faced.	The conclusion is that even if public choice premises about agents' motivation were not true, the reforms introduced changed the pattern of spending and reduced budget deficits in all countries, shifted users' perceptions of quality introducing conditions for 'exit' from the market, and possibly also imposed disciplines on other public servants.
Short, PF, McCormack, L, Hibbard, J, Shaul, JA, Harris-Kojetin, L, Fox, MH, Damiano, P, Uhrig, JD. and Cleary, P.D. (2002). Similarities and	USA - survey exploring similarities and differences in how different groups of	Choosing a plan was more difficult for Medicare and Medicaid recipients than for the privately

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differences in choosing health plans. *Medical Care*. 40, 289–302.	consumers choose health plans.	insured. Medicaid recipients cared most about convenience and access, whereas the privately insured emphasized providers and costs. Most consumers spent less than 30 minutes looking at performance reports.
Siciliani, L. (2005). Does more choice reduce waiting times?. *Health Economics.* 14, 1, 17–23.	This paper develops a model of the supply of elective treatments within a duopolistic market structure where patients can be referred to the hospital with the lowest waiting times. We investigate the effect of a higher degree of substitutability among the two hospitals on equilibrium supply, waiting time and the size of the waiting list. The degree of substitutability is interpreted as the degree of choice or the extent to which patients can switch from one hospital to the other.	The study shows that the greater the degree of substitutability among hospitals, the lower is the supply and the higher the waiting time. The effect on waiting list size is ambiguous. This result holds either when the hospital is remunerated with a fixed budget or with activity-based funding. However, the reduction in supply and the increase in waiting time generated by higher substitutability are higher when hospitals are remunerated with fixed budgets. The main implication of the model is that, under certain assumptions, policies aimed at increasing provider choice may fail to reduce waiting times.
Siciliani, L and Hurst, J. (2004). Tackling excessive waiting times for elective surgery: a comparative analysis of policies in 12 OECD countries. *Health Policy.* 72, 201–215.	The paper compares policies to tackle excessive waiting times for elective surgery in 12 OECD countries. It divides and reviews supply and demand side policies that have been used to reduce or manage	It is found that waiting times may be reduced by acting on the supply of or on the demand for surgery (or both). On the supply side, the evidence suggests that both capacity and financial incentives towards productivity

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	waiting times. It groups the evidence of how different policies have worked thematically according to whether they fall into two large groups.	can play an important role. On the demand side, inducing a raising of clinical thresholds may reduce waiting times but may also provoke tensions between clinicians and policy-makers. Preliminary evidence also suggests that an increase in private insurance coverage may reduce waiting times. They conclude that policies introducing unconditional maximum waiting time guarantees more recently in England were effective but they may have also been achieved at the expense of clinical prioritisation.
Silverman, E. and Skinner, J. (2004). Medicare upcoding and hospital ownership. *Journal of Health Economics*. 23, 369–389.	USA - Claims data for 4 respiratory disease DRGs to examine effects of hospital ownership (for vs not-for-profit) on DRG upcoding.	Between 1989 and 1996, the percentage point share of the most generous DRG for pneumonia and respiratory infections rose by 10 points among not-for-profit hospitals, 23 points among for-profit hospitals, and 37 points in hospitals converting to for-profit status. Not-for-profit upcoding was also higher in markets with a larger for-profit hospital share.
Smith, R and Wilton, P. (1998). General Practice fund-holding: progress to date, *British Journal of General Practice.* 48, 1253–1257.	Review of the published evidence of the extent to which internal market objectives such as cost-containment and cost-	In terms of achieving cost-containment and cost-effectiveness there is mixed evidence. In some areas such as prescribing, there is clear

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	effectiveness, quality of care, and patient choice and empowerment have been achieved during the period they operated.	evidence of cost-saving but the effect on reduction or changes in referrals is unclear. Even gains in prescribing could have been achieved at substantially higher administrative and transaction costs. Procedural aspects of quality might have improved but there is no impact on outcomes. Choice of secondary providers by GP has improved but little progress has been made to increase consumer choice and empowerment.
Söderlund, N, Csba, I, Gray, A, Milne, R, Raftery, J. (1997). 'Impact of the NHS reforms on English hospital productivity: an analysis of the first three years'. *British Medical Journal.* 315, 1126–29.	The objective was to evaluate the effect of purchaser mix, market competition, and trust status on hospital productivity within the NHS internal market. Methods: Hospital cost and activity data were taken from routinely collected data for acute NHS hospitals in England for 1991–2 to 1993–4. Cross sectional and longitudinal regression methods were used to estimate the effect of trust status, competition, and purchaser mix on average hospital costs per inpatient, after adjusting for outpatient activity levels, casemix,	Real productivity gains were apparent across the study period for NHS hospitals on average. Casemix adjustment drastically improved cross sectional comparisons between hospitals. Gaining trust status and increasing host district purchaser share were associated with productivity increases after adjustment for casemix, regional salary differences, and hospital size and scope. Hospitals that became trusts during the study period were on average less productive at the beginning of the period than those that did not, and there were no significant productivity differences between

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	teaching activity, regional salary variation, hospital size, scale of activity, and scope of cases treated.	trust waves at the end of the period in 1993–4. Market concentration was not associated with productivity differences.
Spånberg-Winbald, U (2003). *From decision to practice. The role of the physician in implementing patient choice in Swedish health care.* Unpublished PhD thesis. University of Uppsala, Sweden.	The aim of the thesis has been to investigate the physicians' role in bringing the policies into effect. In order to examine attitudes, knowledge and behaviour among the physicians a questionnaire was sent out to 960 physicians in Stockholm County Council. The results show that only a minority of the physicians, on a regular basis, help patients choose a health care provider by giving them information and letting them choose where they want to be referred. The next question was to explain why physicians did not encourage patients to choose care provider.	A case study in Stockholm County Council showed that from a formal perspective there was no conflict between national and locally governed rules. However, knowledge about local rules concerning these policies was poor among the physicians in general. Physicians who were more knowledgeable about the policies were more prone to assist patients to choose health care provider at hospital level. Finally, it was shown that a majority of the physicians experienced no conflict between the policies and their day-to-day clinical decision-making. However, physicians who felt professionally threatened by the policies were less willing to inform patients about patient choice. To summarize, a decade later, still only a minority of physicians act in accordance with the political intentions. This could explain why so many patients are still unaware of their right to choose hospital.

Authors and publication	**Description of study**	**Summary of findings**
Spranca, M, Kanouse, DE, Elliott, M, Short, PF, Farley, DO. and Hays, RD. (2000). Do consumer reports of health plan quality affect health plan selection?. *Health Services Research*. 35, 933–947.	USA - fractional factorial experiment. Consumers reviewed materials on four hypothetical health plans and selected one to learn whether consumer reports of health plan quality can affect health plan selection.	In the absence of performance information, 86 % of consumers preferred plans that covered more services, even though they cost more. When information was provided, consumers shifted to less expensive plans covering fewer services if ratings identified those plans as higher quality (59 % of consumers preferred plans covering more services). Consumer choices were unaffected when ratings identified the more expensive plans covering more services as higher quality (89 % of consumers preferred plans covering more services).
Street, A. and Jacobs, R. (2002). Relative performance evaluation of the English acute hospital sector. *Applied Economics*. 34, 1109–1119.	UK - The English Department of Health has undertaken relative performance evaluation in comparing the unit costs of acute hospitals using ordinary least squares (OLS) methods. This paper questions the official interpretation of the OLS residuals by re-estimating efficiency.	English acute hospitals exhibit less in efficiency than is implied by official estimates.
Talbot-Smith, A, Gnani, S, Pollock, AM. and Gray, DP. (2004). Questioning the claims from Kaiser. *British Journal of General Practice*, 54, 415–421.	USA UK comparison: Detailed re-examination of the data and methods used and consideration of the 82 letters responding to the Feachem *et al.* 2002 article to assess accuracy of	US population younger, healthier and more affluent. Costing methods incorrect and use of performance measures selective and comparison of universal with selective coverage system means Feachem *et al.* (2002)'s results are

Authors and publication	**Description of study**	**Summary of findings**
	comparison and conclusions.	flawed and conclusions erroneous.
Taylor, R. Pringle, M. and Coupland, C. (2004). *Implications of offering 'Patient Choice' for routine adult surgical referrals.* Report submitted to the Department of Health, University of Nottingham and Dr Foster.	Empirical study that assesses the feasibility of offering choice of referral pathway in general practice consultations to patients needing routine referral for surgery. Designed as a randomised controlled trial, clustered by practices followed by a descriptive trial of sustainability. Undertaken in three Strategic Health Authorities areas in England: Trent, Norfolk, Suffolk and Cambridgeshire, and Dorset and Somerset. 116 general practitioners in 38 practices were recruited; 75 were randomised to the intervention arm and 75 to the control arm; with 593 patients recruited, 309 in the intervention arm, 215 in the control arm, and 69 in the sustainability follow on phase. Of 48 general practices originally recruited, 38 agreed to participate in the study and of 166 GPs originally recruited, 116 took part in the study.	Of patients who were offered choice of referral 81% of the case made choices themselves as compared to 37% of the control group. Of participating GP practices only 22% offered choice to patients 'most of the time' and 75% 'some of the time', and that 65% of them had a positive attitude to choice. The study also estimated that GP consultation time in case choice of referral was offered, increased only by 36 seconds, which was not statistically significant but there was a statistically significant difference of 1.6 minutes in the mean time of the consultation in intervention as compared to the control group. Patients considered ease of access and quality of care as more important than waiting times in making their choices. No change in the referral pathways was shown with most patients still opting for their local hospital.
Vrangbæk, K. and Bech, M. (2004). County level responses to the introduction of DRG rates for "extended choice" hospital patients in Denmark. *Health Policy.* 67, 25–37.	The Danish case provides interesting lessons because patients' free choice has been	There was limited impact of DRG rates and low uptake of choice because it went against the

Authors and publication	Description of study	Summary of findings
	in effect since 1993. This paper explores the responses at the supply side after the introduction of DRG rates for extended choice patients in the Danish hospital system in 2000. The main question is whether the introduction of DRG rates and the resulting changes in incentives have affected county management of health care.	established county-based governance system, which traditionally has emphasised budget control, co-operation and equity, and also choice incentives were not particularly strong.
Waldenström, U. and Nilsson, C. (1993). Characteristics of women choosing birth center care. *Acta Obstetrica and Gynaecologica Scandinavia.* 72,180–188.	A study looking into 1527 pregnant women preferences in choosing alternative maternity care in the Stockholm area.	Age, educational and professional status were crucial in this process.
Wearne, S. (1998) How patients choose a GP and do patients use directories to in form their decisions?. *Family Practice.* 15(3), 259–260.	Piloted questionnaire distributed among the staff and all patients registered with a GP practice between July-December 2005.	Of 80 completed questionnaires only 2 respondents decided to change GP because they were not satisfied with the service. Patients rarely chose to change GP practice because of dissatisfaction with it. Convenience and reputation are the most important factor for choosing a GP. Patients use often informal sources of information. The study confirms earlier findings from Salisbury *et al.*, 1989.
Which? (2005) *Which choice? Health*. London: Which?	Which? has produced a report about choice and health exploring pros and cons of the	What people want is good health care services flexible to the needs of those using them, over and

Authors and publication	**Description of study**	**Summary of findings**
	Government choice agenda. It reviews the evidence from recent studies, government commissioned and other surveys and polls, in addition to findings from its own surveys conducted in 2004 and its more recent qualitative research on choices in health care conducted in 2005. The 2005 survey reported in this research used several groups of patients to discuss consumers/patients perceptions, knowledge, attitudes and experiences of 'choice in health care' from various locations in England that included urban, suburban and rural locations. The groups comprised: 14 groups and 6 depths, 8 groups of 'patients' and 6 groups of 'well' people, 2 depths with parents, 2 depths with carers and 2 depths with 'patients'.	above the choice of providers. More specifically: 85% believed that access to a good GP was more important than the Government giving them more GPs to choose from 89% agreed that access to a good hospital was more important than the Government giving them hospitals to choose between. 74% agreed that patients should be able to choose an appointment time that is convenient to them. Report also highlights that people are unaware of the choices available, and feel ill equipped or lack the knowledge of how to make choices about the clinical side of the treatment. Good information and support is needed particularly for those with poorest health so they are not disadvantaged by choice.
Whitehead, M, Gustafsson, RA, Diderichsen, F. (1997). Why is Sweden rethinking its NHS style reforms?. *British Medical Journal*, 315, 935–39.	The paper discusses the origins and main features of the Swedish reforms, examine the subsequent developments which have led to a rethink, and consider what other countries can learn from this experience.	Key points: The 1990s reforms of the British NHS stimulated similar market-style changes in Sweden. In the largest county, Stockholm, problems started to surface almost immediately, requiring a series of modifications.

Authors and publication	Description of study	Summary of findings
	Interviews with senior politicians and policy-makers in Stockholm County are carried out, as well as analysis official policy documents and empirical analysis of activity and cost data is performed.	By 1996 a rethink was evident; as a result, there was a swing towards cooperation and away from competition. Financial factors behind the rethink included a loss of cost control and problems with productivity incentives. Concerns about maintaining equity and trust within the system were also decisive in the rethink.
Wiles, R. and Higgins, J. (1996). Doctor-patients relationships in the private sector: patients' perceptions. *Sociology of Health and Illness.* 18: 3, 341–56.	Using data collected from a study of private patients, an analysis of patients' interpretations of their relationships with their doctors was undertaken. The study argues that challenges have resulted in moves away from traditional paternalistic relationships. As a result of their market position, private patients as a group might be expected to be most advanced in bringing about change in the doctor-patient relationship.	The patients' accounts indicated that relationships contained elements of both mutuality and consumerism. The features of the interaction, the organisation of health care in the private sector and the power of the medical profession are used to explain how these relationships develop. It is argued that there are tensions that exist in reality between the principles underlying each model which constrain relationships between doctors and patients moving too far in the direction of either consumerism or mutuality.
Williams, J and Rossiter A. (2004). *Choice: the evidence. The operation of choice systems in practice: national and international evidence.* London, The Social Market Foundation.	The report reviews comprehensive evidence from introducing market mechanisms and patients'	Key findings are: There is a clear division between high patients' uptake of choice in pilots in London and elsewhere

Authors and publication	Description of study	Summary of findings
	choice into primary and mostly secondary care systems in the UK, Scandinavia, New Zealand, and USA. It provides a solid account of the impact of choice of hospitals from international comparative perspective. However, the evidence on patient choice is much less thorough and much less extensive when compared with the evidence on schools that the report also provides (see Table A5).	where the uptake has been fairly low. This could be due to the support offered to patients in LPCP. Female, elderly, less educated, guardians of under 18s and those with low incomes were less likely to choose. Care became more responsive and quality improved both under quasi-markets in the 1990s and in LPCP as the waiting times decreased. In other countries with low uptake waiting times have not decreased. There is no research on long term cost of introducing patient choice.

Table A2 Systematising the evidence of impact of choice in health care: choice of individual treatments

Authors and publication	Description of study	Summary of findings
Barone, M. A., Johnson, C. H., Luick, M. A., Teutonico, D. L., and Magnani, R. J. (2004). Characteristics of men receiving vasectomies in the United States, 1998–1999. *Perspectives on Sexual and Reproductive Health*, Vol 36, Number 1, p27–33	A nationwide, practice-based survey of 719 men receiving vasectomies was conducted between July 1998 and June 1999, to identify the characteristics of men choosing vasectomy.	The characteristics of US men undergoing vasectomies do not reflect the diversity of the population. Some groups of the population are accessing vasectomy, but others are not.
Beaver, K., Bogg, J., and Luker, K. A. (1999) Decision-making role preferences and information needs: A comparison of colorectal and breast cancer. *Health Expectations*, 2, 266–276.	A cross-sectional design involving structured interviews. The main variables investigated were decision-making preference (using a decisional role preference card sort), perceived decisional role and information need (using an information needs questionnaire). Carried out in Liverpool and Manchester, North West, UK. This study was with the colorectal sample (n=48) and compared these results with the results of another study of breast cancer patients (n=150).	The majority (78%) of the colorectal cancer patients preferred to play a passive role in decision-making in contrast to 52% of women with breast cancer in previous work. 80% of the colorectal sample and 61% of the women with breast cancer perceived that the doctor had made treatment decisions. Priority information needs for both groups related to cure, spread of disease and treatment options. The 2 most striking findings from the comparison of the 2 disease groups relate to the differences in decision-making role preferences and the similarities in information needs. The similar information needs of the 2 disease groups has implications for h/c professionals providing information to people with cancer.
Beaver, K., Luker, K.A., Owens, R.G., Leinster, S.J., Degner, L.F. (1996) Treatment decision making in women diagnosed with breast cancer, *Cancer Nursing* 19 (1): 8–19	The purpose of this study was to explore the hypothesis that women with breast cancer had specific preferences about the degree of control they wanted over treatment decision-making. One hundred	The majority of the newly diagnosed women preferred to play a passive role in treatment decision-making, leaving the decision-making responsibility to their physician, whereas the benign control group preferred a collaborative role in which

Authors and publication	Description of study	Summary of findings
	fifty women, newly diagnosed with breast cancer, were interviewed and their preferences for participation in treatment decision-making were established using a measurement tool designed to elicit decision-making preferences. Two hundred women with benign breast disease served as a descriptive comparison group. Unfolding theory provided a means of analysing the data so that the degree of control preferred by each woman could be established.	joint decisions could be made between the patient and the physician. The implications of the results for patient participation are discussed.
Charles, C., Redko, C., Whelan, T., Gafni, A., And Reyno, L. (1998). Doing nothing is no choice: lay constructions of treatment decision-making among women. *Social Science and Medicine*, 47, 3. pp. 347–354.	A qualitative study carried out in a regional cancer centre in Southwestern Ontario. Open-ended personal interviews with 20 women with early stage breast cancer.	They found that some women assessed their chances of survival by assuming that their prognosis would be similar to a highly selected reference group of individuals personally known to them who also had cancer. Several patients assessed their risk by recalling other people who had died of the disease. For some it was difficult to think about chemotherapy as a treatment option because they recalled suffering and dying of others on this treatment.
Chen, W., Haley, W. E., Robinson, B.E., and Schonwetter, R. S. (2003). Decisions for hospice care in patients with advanced cancer. *Journal of American Geriatric Society*, Vol 51: pp.789–797	A cross-sectional study using structured interviews in Tampa, Florida, USA. 1 community based hospice and 3 University based teaching hospitals. 234 cancer patients with a life expectancy of less than 1 year.	Patients receiving hospice care were significantly older, less educated, and had more people in their households and were more realistic about their disease course than hospital patients. Patients' understanding of their prognoses affected their perceptions of the course of their disease. This study shows that patients who decide to enter a hospice were more likely to agree to sacrifice length of life for a better quality of life and supports the notion already discussed above that an individuals' values influence the decision-making process about health care. The health care community may better meet the end-of-life care needs of advanced cancer

Authors and publication	Description of study	Summary of findings
		patients through enhanced communication with patients and families, including providing accurate prognoses and better understanding of patients' preferences and values. Hospice care has the potential for offering quality end of life while also reducing medical costs. Future research is needed to identify interventions that can facilitate successful and accurate communication about prognosis, hospice and palliative care at critical times for decision-making.
Davies, S., Laker, S., and Ellis, L. (1997). Promoting autonomy and independence for older people within nursing practice: a literature review. *Journal of Advanced Nursing*, 26, pp.408–417.	A literature review carried out in Sheffield, UK. Included 90 references.	The ability to make quite small decisions about their day to day activities can make a significant difference to older people’s sense of control. They argue that a wealth of research conducted over a wide range of settings has demonstrated the importance of adequate information in promoting patient recovery and that this should form a fundamental principle of care delivery.
Degner, L. F., and Sloan, J. A. (1992). Decision making during serious illness: What role do Patients really want to play? *Journal of Clinical Epidemiology*, 45, 9, pp 941–950	Two surveys were conducted to determine what roles people actually want to assume in selecting cancer treatments. 436 newly diagnosed cancer patients and 482 members of the general public participated. Card sort procedures were used to elicit preferences which described five potential roles in decision-making.	The majority (59%) of patients wanted physicians to make treatment decisions on their behalf, but 64% of the public thought they would want to select their own treatment if they developed cancer. Findings suggested that the impact of being diagnosed with a life-threatening illness may influence preferences to participate.

Authors and publication	**Description of study**	**Summary of findings**
Degner, L. F., Kristjanson, L. J., Bowman, D., Sloan, J. A., Carriere, K. C., O'Neil, J., Bilodeau, B., Watson, P., and Mueller, B. (1997). Information needs and decisional preferences in women with breast cancer. *JAMA*; 277(18), pp.1485–92.	A cross sectional survey carried out in 2 tertiary and 2 community hospital oncology clinics, in Winnipeg, Canada. 1012 women completed the survey.	Despite wide variation in decisional preferences, most patients desire information. The 2 most highly ranked types of information were related to knowing about chances of cure and spread of disease. In this study 22% of 1012 women wanted to select their own treatment and 44% wanted to share the decision-making with their doctors.
Di Caccavo, A., and Fraser Reid, F. (1998). The influence of attitudes toward male and female patients on treatment decisions in General Practice.. Sex Roles, Vol. 38, Nos. 7/8	Checklists were completed after 115 GP consultations and then analysed in UK General Practice. 23 GPs completed checklists after 115 GP consultations featuring psychological presentations. These were then analysed.	GPs' attitudes were differentially associated with management decisions for male and female patients. When GPs reported feeling negatively or neutrally about patients presenting with psychological complaints, they were more likely to prescribe drugs for women, while men were given health advice or referrals to other clinical services. Yet when GPs felt positively about patients this pattern was reversed. They argue that the strength of attitude of GPs may govern whether gender stereotypes enter into the decision-making. This paper again implies that there is reason for patients and doctors to learn to communicate more effectively.
Di Caccavo, A., Fazal-Short, N., and Moss, T. P. (2000) Primary Care decision making in response to psychological complaints: The influence of patient race. *Journal of Community & Applied Social Psychology*, 10: 63–67	A vignette task carried out in General Practice in the Birmingham area of the UK. 18 GPs completed the vignette task. The vignettes were constructed using the Diagnostic and Statistical Manual of Medical Disorders (APA, 1994). There were 3 sets of 6 vignettes.	They found that diagnoses were most accurate in the case of depression whereas psychoses were almost equally likely to be interpreted as anxiety, depression, or anxiety. For the vignettes that presented anxiety, the GPs' diagnoses for white patients were almost all correct (82.3%). For Asian patients, GPs were just as likely to diagnose a physical problem, as they were to correctly diagnose anxiety. GPs were also less likely to correctly diagnose anxiety for African Carribeans. GPs diagnoses of depression and psychoses did not differ according to racial groups of patients. Di Caccavo *et al.* suggest that GPs' assumptions about racial groups

Authors and publication	**Description of study**	**Summary of findings**
		and patients' own style of presentation may explain differentials in diagnoses of symptoms. Presentation styles of different racial groups need further exploration using naturalistic methods of observation. Without correct diagnoses these patients will not be able to exercise patient choice.
Divshali-Luft, S. (1991). *Personal* treatment selection and the psychological wellbeing of women with primary breast cancer. G5f M.Phil. Thesis, Newcastle upon Tyne, 41–8100.	A study using both qualitative and quantitative methods was carried out in Newcastle General Hospital Oncology Unit, UK. 103 consecutive patients referred to the unit for breast abnormalities between March 1988 and February 1989. They were interviewed and assessed using semi-structured and structured questionnaires and three rating scales.	The main criterion for choice was the perceived efficacy of a particular treatment. The best predictor of patients' well-adjustment was adequate support. Making a choice by itself could not predict patients' successful coping. Results suggested that it is sufficient guided information and professional support given to patients at all stages, both prior to the diagnosis and the treatment and rehabilitation period, that enhances the patients' quality of life and their psychological well being.
Donovan, K. A., Greene, PG., Shuster, JL, Partridge,EE, and Tucker, D.C. (2002). Treatment preferences in recurrent ovarian cancer. *Gynecologic Oncology*, 86: 200–211.	A cross-sectional study with women recently diagnosed with ovarian cancer and non-cancer controls, in Alabama, USA. All participants completed at least 4 questionnaires. The study also used a decision board task to assess preferences for salvage therapy or palliative care among 81 ovarian cancer patients receiving first-line chemotherapy and 75 non-cancer controls.	They found that compared to non-cancer controls, ovarian cancer patients overwhelmingly preferred salvage therapy; quantity of life was of primary importance. These women were willing to tolerate the toxicity of chemotherapy in expectation of some therapeutic benefit. In both groups, preference was not related to age, marital status, number of children, or employment status. For ovarian cancer patients the quality of their life was of secondary importance to their desire to prolong life.
England S, and Evans J. (1992). Patients' choices and perceptions after an invitation to participate In treatment decisions. Social Science and Medicine 34(11): 1217–1225.	A questionnaire study carried out in a Cardiac Risk Management (CRM) clinic, Australia. 143 patients in a CRM clinic were given a pre-decision, health control and a perceived decisional control questionnaire.	They found wide variation in the perceptions of patients about how much control they had over the treatment decision when in fact all the patients had all been invited to take control over a decision about CRM. The amount of control the patients perceived they had in this situation was related to their beliefs about how much control they had over their health in

Authors and publication	Description of study	Summary of findings
		general. There were a few patients whose management choices were substantially constrained by external factors, but some of these reported perceiving a sense of personal control even though treatment decisions were forced. This study again implies that patients' perceptions play an important role in decision-making and that physicians should be aware that some people may not perceive much control despite being invited to participate and that they may require extra encouragement.
Entwistle V A., Sheldon T A., Sowden A,. Watt I S. (1998). Evidence-informed patient choice. *International Journal of Technology Assessment In Health Care*, 14:2 212–225.	A literature review carried out in the UK, involving 63 references.	The majority of patients value being given information and it is consistently reported that many patients in the UK do not receive as much information as they would like to from health professionals. A wide range of role preferences is seen within sampled populations, making it difficult to predict role preferences from demographic information, symptom distress levels, or stage of disease etc. Some studies suggest that psychological outcomes may be better on average among people who were given a choice about their treatment than those who were not. But these results may not replicate across different settings and patient groups. They point to several reasons why people may not want to get involved in decisions about their health care. Some have argued that if a patient wants to leave decision-making responsibility up to a health professional, then the health professional should respect that as a choice on the part of the patient and make the decision, guided by what is known of the patient's values. On the other hand, it has been argued that patients should be expected to share the responsibility for decision-making and therefore should be encouraged to think about the options and

Authors and publication	**Description of study**	**Summary of findings**
		express a preference.
Entwistle, V. A., Skea, Z. C., and O'Donnell, M. T. (2001). Decisions about treatment: interpretations of two measures of control by women having a hysterectomy *Social Science Medicine*, 53: 721–732.	They explored the validity of 2 measures used to classify patients' roles on decision-making about their health care. Twenty women who had recently had hysterectomies described their treatment decision-making in their own words and then picked role descriptions from the 2 measures.	Discrepancies occurred between their own narratives and the role descriptions suggesting that there are problems with the validity of some currently used measures of patients' participation in decision-making in health care. They argue that attention needs to be paid to the key features of participation in decision-making and measures should be developed that can distinguish between them.
Entwistle' V. A., Watt, I. S., Gilhooly, K., Bugge, C., Haites, N., and Walker, A. E. (2004). Assessing patients' participation and quality of decision-making: insights from a study of routine practice in diverse settings. *Patient Education and Counselling*, 55: 105–113.	A qualitative study exploring patients' participation in decision-making, in the UK. 74 participants who attended consultations in five clinical areas completed structured measures of decision-making and discussed their responses during interviews.	The study showed that people interpret statements about their own and health professionals' roles in decision-making in very diverse ways. It reinforced concerns about the validity of the usual responses to the control preferences scale (a measure used to identify the roles people have played in decision-making). The study suggests that the scale overestimates the number of people who engage in shared decision-making. In practice, attempts to elicit reports of decisions faced and made by patients might be facilitated by use of a structured set of questions and interviews instead of usual measures of participation to encourage people to describe in meaningful ways the options considered and selected.
Finlayson, C. A., MacDermott, T. A., and Arya, J. (2001). Can specific preoperative counselling increase the likelihood a woman will choose post mastectomy breast reconstruction? *The American Journal of Surgery*, 182, pp.649–653	Prospective study carried out in Colorado USA. 106 women with breast cancer who were specifically educated about reconstruction.	As a group only 20% of women undergoing mastectomy also chose reconstruction. When stratified by age women over 60 years are the least interested in breast reconstruction. Low reconstruction rates in this study seem to reflect patients actually choosing not to have reconstruction rather than lack of information and /or access to services.
Ford, S., Schofield, and Hope, T. (2003a). What are the ingredients	This qualitative study used semi-structured interviews to identify the	All respondents placed importance on doctors and patients being well informed and appraised of the

Authors and publication	**Description of study**	**Summary of findings**
for a successful evidence-based patient choice consultation?: A qualitative study. *Social Science and Medicine*, 56, pp.589–602.	elements and skills required for a successful evidenced based patient choice (EBPC) consultation to occur. The purposefully selected sample from the UK included 11 GPs, 10 hospital doctors, 5 practice nurses, 11 academics, and 8 lay people.	latest available medical evidence. There was a general view that evidence-based information regarding diagnosis and treatment options should be shared with patients during a consultation. However, there were no questions of how this might be achieved in practice. Participants' opinions relating to which model of decision-making should be adopted ranged from favouring an informed choice model, to decision-making being shared equally. Similarly, there was no clear view on how much guidance a doctor should offer a patient during decision-making.
Ford, S., Schofield, T., and Hope, T. (2003b). Are patients' decision-making preferences being met? *Health Expectations*, 6: 72–80	They used post consultation, patient preference and enablement questionnaires to investigate the information and decision-making expectations of general practice patients. Thirteen GPs volunteered to take part in Oxfordshire, UK and 171 patients completed the questionnaire.	The decision-making preferences of general practice patients tend to vary. However, there was a substantial mismatch between the stated preferences of patients for the role they wanted to have in decision-making and what they felt actually took place in their consultation. Thus it remains a challenge for doctors to match their consultation style to the decision-making preferences of individual patients.
Gabe, J., Olumide, G., and Bury, M. (2004). 'It takes three to tango': a framework for understanding patient partnership in paediatric clinics. *Social Science and Medicine*, 59: 1071–1079.	This paper considers recent ideas about partnership in medical encounters and the extent to which they are applicable to children. The paper goes on to develop a framework for understanding patient-partnership issues taking account of the organisational and legal setting as well as the beliefs and agendas that all parties bring to the medical encounter.	They argue that these matters require study outside as well as inside the clinic, through the use of a range of methods, including those that help children at home review their involvement in decision-making in the clinic.
Gafni, A., Charles, C., And Whelan, T. (1998). The Physician-Patient Encounter: The physician as a perfect agent for the patient *versus*	They discuss ‘agency’ with reference to the implementation of 2 treatment decision-making models in patient choice. These are 1) the physician as the	They argue that the approach of transferring information to the patient is easier (but not easy) and, hence, more feasible than transferring each patient's preferences to the physician in each medical

Authors and publication	Description of study	Summary of findings
the informed treatment decision-making model. *Social Science and Medicine*, 47(3): 347–354.	perfect agent for the patient and 2) the informed treatment decision-making models. They argue that the choice of model depends on the ease of implementation (e.g. is it simpler to transfer patient's preferences to doctors or to transfer technical knowledge to patients?). Also the choice of treatment decision-making model is likely to have an impact on the type of incentives or regulations (i.e., contracts) needed to promote the chosen model.	encounter and that it is more feasible to design contracts to motivate physicians to transfer information to patients than to design contracts to motivate physicians to find out their patients' utility functions. They also discuss current realities of clinical practice and their potential implications for the way that economists model physician-patient clinical encounters.
Gordon, E. J. (2001) Patients' decisions for treatment at end-stage renal disease and their implications for access to transplantation. *Social Science and Medicine*, 53: 971–987.	An ethnographic study over 18 months, 1997–98, using both quantitative and qualitative methods in 5 free standing and 2 hospital-based haemodialysis facilities in North East Ohio (US). It used mixed purposive sampling and had 79 participants. Semi-structured interviews – each participant interviewed 3 times over three months and also used card sort. Multiple methods used including content analysis.	Most common reasons for not choosing a transplant were, doing well on dialysis, fear of being 'cut on' from a transplant, and knowing other patients whose transplants had failed. People not wanting to be 'cut on' had different ethnomedical meanings for different people. Dialysis professionals should be informed of factors influencing patients' treatment decisions and should understand patients' cultural and ethnic concerns about health. Successful transplant recipients should visit the dialysis centres so those who could choose transplants could get a more balanced view of transplantation.
Green CR, Wheeler JRC, LaPorte F. (2003). Clinical decision making in pain management: Contributions of physician and patient characteristics to variations in practice. *The Journal of Pain*, 4(1): 29–39.	Prospective Cohort Study Mail Survey Michigan, USA. 63% primary care physicians, 36% speciality physicians 368 physicians - Mail Survey, 9 Case Vignettes.	In investigating decision-making in pain management, they found that responses varied on the basis of the type of pain and gender of the patient. Physicians were more likely to provide optimal treatment for men with acute postoperative or cancer pain. Physicians here reported lesser goals for relief of chronic pain when compared to acute and

Authors and publication	**Description of study**	**Summary of findings**
		cancer pain and reported that they would like patients to be more forthcoming about their pain complaints. Lower goals for chronic pain relief may lead to the under-treatment of chronic pain. Patients need to tell physicians of their pain concerns. Again this study shows that there is scope here for the training of patients to communicate better in order to improve health care.
Greenfield, S., Kaplan, S. H., Ware, J. E. Jr., Yano, E. M., Frank, H. J. (1998). Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *Journal of General and Internal Medicine*, 3(5): 448–57.	A randomized trial carried out in two university hospital clinics, California, Los Angeles. 33 experimental patients, 26 controls.	Analysis of audiotapes of the visits to the physician showed the experimental patients were twice as effective as controls in eliciting information from the physician. Experimental patients reported significantly fewer function limitations.
Greiner, K. A., Perera, S., and Ahluwalia, J. S. (2003). Hospice usage by minorities in the last year of life: Results from the national mortality followback survey. *JAGS*, 51, pp.970–978.	Secondary analysis of 1993 National Mortality Followback Survey Hospice Care, USA. Data from 23000 deceased individuals used.	African Americans were found to use hospices 40% less frequently than white. Logistic models revealed that the presence of a LW diminished the negative relationship between African Americans and hospice use, but it remained significant. Furthermore these findings suggest that economic, educational, and access to care are not the primary reasons for explanations for African Americans lower frequency of hospice use than Whites. It is suggest that different health care providers and health care systems could contribute to these disparities through differential treatment based on racial/ethnic stereotyping or discrimination. Discrimination in health care provision needs further study and health care needs to be provided in a socially and culturally sensitive manner.

Authors and publication	Description of study	Summary of findings
Guadagnoli, E., and Ward, P. (1998). Patient participation in decision-making. *Social Science and Medicine*, 47, 3, pp.329–339.	A literature review carried out in the USA. Reviews 14 studies on patient desire for participation in medical care and reviews 15 studies on the effect of participation on outcomes. Some of the studies in the review had methodological flaws although authors point these out.	This study concludes that not all patients are ready to make medical choices. Some benefits detected from patients making their own treatment choices. Implies that physicians should endeavour to engage patients to participate at varying degrees They propose using a model of behaviour change to differentiate patients on the basis of "readiness" to participate in decision-making. Interventions should vary depending on their readiness.
Hamann J, Langer B, Leucht S, Busch R, Kissling W. (2004). Medical decision making in antipsychotic Drug Choice for Schizophrenia. *American Journal of Psychiatry*; 16, pp.1301–1304.	A qualitative – cross sectional study carried out in Munich, Germany, with 50 psychiatrists in private practice and 50 in psychiatric hospitals. 100 interviews undertaken about antipsychotic drug choice for 200 patients with schizophrenia.	There was a trend for older patients, or patients with a longer course of illness to be more likely to be prescribed first-generation antipsychotics. Conversely patients who expressed a wish for or against a certain antipsychotic compound or patients who had a bad experience using them were more likely to receive 2nd generation compound. However, the only variable that could significantly predict prescription was a physician characteristic, specifically the age of the physician. Older physicians were up to five times more likely to prescribe first-generation antipsychotics even though guidelines recommended the second generation antipsychotics. Physicians' judgments need more investigation as many patients still want the physician to make the judgment while others might want to share the decision-making.
Henman, M. J., Butow, P. N., Brown, R. F., Boyle, F. and. Tattersall, M. H. N. (2002). Lay constructions of decision-making In cancer. *Psycho-Oncology*, 11, pp.295–306.	Qualitative study with 20 women having a telephone interview after 1st consultation. Recruited until informational redundancy was achieved. It took place in Australia, in 4 teaching hospitals in Sydney and 2 regional hospitals in New South Wales.	Extension of life was the main concern and so women felt there was no choice, they had to take treatment to reduce risk. 15 of the 20 women with cancer wanted as much information as possible but 50% wanted a passive role in decision-making. While risk of reoccurrence, life expectancy, side effects and quality of life was reported as influencing their decisions, at

Authors and publication	**Description of study**	**Summary of findings**
		least as much emphasis was placed on their personal relationships with their specialists. The results from this study suggest that health care professionals need to ask patients what role they want to play in the decision-making as soon as possible and an individualised approach should then be used.
Hodgkin, D. (1996). Specialized service offerings and patients' choice of hospital: The case of cardiac catheterisation. *Journal of Health Economics*, 15 pp.305–332	Secondary data analysis carried out in MA, USA. The data source was the state of New Hampshire's Uniform Hospital Discharge Data sets from 1985 to 1991.	Hodgkin found that patients did not appear to treating specialist services as an indication of quality. Although availability of cardiac catheterization has a strong, significant effect on the choice of hospital, the effect appears to be confined to those patients who expect to need the service as their diagnoses indicate some probability of needing the service. However it was an urban area where he carried out with a greater choice of hospital and the results may not replicate to price competitive markets.
Holmes-Rovner, M., Llewellyn-Thomas, H., Entwistle, V., Coulter, A., O'Connor, A., and Rovner, D., R. (2001). Patient choice modules for summaries of clinical effectiveness: a proposal. *British Medical Journal*, 322, pp.664–667.	Education and Debate in UK	They discuss issues around the education of patients being important but is it realistic in a 15-minute visit to a general practitioner or even a 45-minute consultation with a specialist? Perhaps decision aids could help patients to be more informed before they arrive at the appointment, so that time could be saved in explanation. However the physician would still need to know they were making an informed choice.
Hope, T. (2002). Evidence-based patient choice and psychiatry. *Evidence Based Mental Health*; 5; pp.100–101.	Debate in EBHM notebook. UK.	Hope discusses the issue of Psychiatry being a particularly difficult area to promote evidence based patient choice as mental illness can affect understanding and decision-making. But he argues that patient choice is good in itself even if it leads to poorer health. He points out that the most challenging situation that psychiatrists face is when the mental illness affects a patient's values but not

Authors and publication	**Description of study**	**Summary of findings**
		their intellectual values. Examples of such illnesses are mild to moderate depression, mild manic illness, and anorexia.
Howell-White, S. (1997). Choosing a birth attendant: The influence of a woman's childbirth definition. *Social Science and Medicine*, 45, 6, pp.925–936.	Multiple methods used, including postal questionnaire and interviews, in this prospective study carried out in the USA with a Health Maintenance Organisation (HMO) in New Jersey. A convenience sample of 193 pregnant women from self selected HMO participants (all were more affluent than the general population).	Most women who selected a midwife, characterised childbirth as a natural normal event – the desire for a more personal experience overrode the possibility that complications would arise. Some of these women said that they did not want to be hooked up to technology, which may inhibit the natural course of childbirth, illustrating that interventions could also be considered risky. This supports the fact that risk can have multiple meanings. Future studies to consider this dual definition of risk when studying providers. Illustrates that care choices are related to knowledge, experience and one's beliefs, and if women are informed about alternative providers, they may select them and an increase in their usage would have important implications for workforce supply and organisation.
Hudak, P. L., Clark, J., Hawker, G. A., Coyte, P. C., Mahomed, N. N., Reder, H. J., Wright, J. G. (2002) 'You're perfect for the procedure! why don't you want It?' Elderly arthritis patients' unwillingness to consider total joint arthroplasty surgery: A qualitative study. *Medical Decision Making*: 22:272–278.	Qualitative Study using in depth interviews in Toronto, Ontario. Interviews carried out with 17 patients identified as potential candidates for Total Joint Arthroplasty Surgery (TJA) who were unwilling to undergo the procedure.	Some elderly people seemed to perceive that a treatment decision was not needed, due in part to the patients believing that the arthritis was not a disease or condition but just part of normal aging. A lot of participants spoke about the arthritis being "not bad enough" and "not being at that point yet", many thought they needed to be in constant pain and almost unable to move before they considered themselves as a TJA candidate. Some believed that if they required or would benefit from TJA their physicians would advise it. Consideration of how information is processed and understood is needed, especially with subgroups such as the elderly. Shared decision-making can only occur if a discussion about treatment options occurs. If an elderly person assumes either that arthritis is not a disease

Authors and publication	Description of study	Summary of findings
		requiring treatment or that he/she is not a candidate for TJA, a discussion about treatment may never occur. This could raise the question whose role or right is it to challenge patients' views about arthritis being a normal part of aging?
Kaplan, S. H. (1999). Coaching Children To Participate in Healthcare Decision-making. *The Quality Letter Perspective.*	An Interview with S H Kaplan by Q L Perspective. Boston, USA.	Traditionally children have been "mute players" in patient choice, leaving decisions to be made by their parents and their physicians. But Kaplan (1999) has argued that this is not good especially if they have a chronic illness, as it is they who have to live with their disease for the rest of their lives. She developed and tested a coaching program for adults with chronic diseases to improve physician and patient communication. She reports that it worked and improved health outcomes.
Klassen AC, Hall AG, Saksvig B, Curbow B, Klassen DK, (2002). Relationship between Patients Perceptions of Disadvantage and Discrimination and Listing for Kidney Transplantation. *American Journal of Public Health*, 92, 5, pp.811–817.	Multiple methods were used and scales were developed and multivariate analyses used to build models. Purposeful sampling was used and they recruited all transplant eligible African Americans and white patients aged 21–70 from 3 Maryland haemodialysis dialysis centres during 96 and 97. Patients with co morbidities, severe mental illness and homelessness, were excluded. Of 297 receiving dialysis in the 3 units, 132 were eligible and approached and of these 114 were interviewed. Maryland USA.	20% of participants did not want the treatment modality they were receiving. African Americans were more vulnerable to discrimination when they sought care in unfamiliar settings. Regardless of race or sex, patients whose coping strategy was to accept discrimination were less likely to be listed than those who attempted to change the situation. Lifetime experience of any type of discrimination was negatively associated with wanting a kidney transplant. Those who believed that a fairer system of allocating organs is not achievable were less likely to want a transplant. Patients wanting to remain on dialysis are in part because they are satisfied with their treatment but also because they don't desire a transplant. If lack of desire stems from social inequalities it should be addressed. Providers should combat disadvantage by changing behaviours.

Authors and publication	**Description of study**	**Summary of findings**
Kravitz, R. L., and Melniko, J. (2001). Engaging patients in medical decision making. *British Medical Journal*; 323, pp.584–585.	A review carried out in the UK. Cites 12 articles.	They say that patient choice involves decisions that are complicated going way beyond the uncertainty of scientific evidence. They depend on values people hold, attitudes to risk and family and cultural beliefs. They conclude that patients do want to be involved in or at least be informed about health care decisions but at the moment more attention needs to be paid to the realities of clinical practice. There is just not enough time in consultations to fully explain everything and educate the patient. Practical tools are needed from research to help doctors and patients learn from each other.
Kuiper, H., Miller, S., Martinez, E., Loeb, L., and Darney, P. (1997). Urban adolescent females' views on the implant and contraceptive decision-making: A double paradox. *Family Planning Perspectives*, 29, pp.167–172.	Focus groups and in-depth interviews were used to explore reasons for the decline in popularity of the contraceptive implant in a clinic based sample of 41 ethnically diverse, urban, sexually active adolescents, a group for whom the implant method is advocated as safe and effective.	They examined how information networks, including media influences, have an important effect on the choices people make in their health care. The study suggests that contextual influences are important, whether explained by system barriers, the influence of information sources, or access to information and choices among individuals.

Patient choice and the organisation and delivery of health services

Authors and publication	**Description of study**	**Summary of findings**
Lees, A., Scott, N., Scott, S. N., McDonald, S., and Campbell, C. (2002). Deciding on how NHS money is spent: a survey of general public and medical views. *Health Expectations*, 5, 47–54.	Postal Questionnaire carried out in Scotland, UK. They sent out a questionnaire to public and clinicians to see how much the priorities of the public and clinicians mirror those of the PSI and to examine any differences between the 2 groups. Purposive sampling involving the public and 314 GPs and 189 hospital consultants in Argyle and Clyde (Scotland in 1999). Questionnaire sent out in March 1999 to 2472 individuals, reminder letter and questionnaire a month later. Response rate 55% overall; (51% for public and 71% for clinicians).	Public thought lottery should provide extra money to NHS while clinicians thought it should come from higher taxes on cigarettes and alcohol. Opinion divided on giving less priority to those who contributed to their own illness e.g. smokers. On PSI it was reported that: much greater importance should be given to h/c that improves health or quality of life rather than cost, or to government or local health board policies; it is very important that NHS money is spent on preventative h/c and care, which tries to help patients have a better quality of life; it is very important that the same h/c is available for everyone; less important to spend NHS money on making h/c environments pleasant for patients. Consideration of public and clinician opinion suggests that a revised PSI should place greater weight on benefits to patients and lower weight on cost of h/c.
Luker, K, Beaver, K, Leinster, JS, Owens, R. G, Degner, FL, Sloan, JA. (1995). The information needs and sources of information for women with breast cancer. *Journal of Advanced Nursing*. 22, pp.134–141.	The aim of the study was to explore what particular types of information were important to women newly diagnosed with breast cancer; to enable nurses and other health care professionals to utilize their time as effectively as possible and provide a high-quality service to individuals in their care. Women with breast cancer (a mean of 2–5 weeks from diagnosis) were interviewed and asked to compare items of information. The items of information were presented in pairs and the women stated a preference for one item in that pair. Thirty-six pairs were presented in total.	Information about the likelihood of cure, the spread of the disease and treatment options were perceived as the most important items of information at the time of diagnosis. Other information needs, in order of descending priority, included information about the risk to family, side-effects of treatments, impact on family, self-care, effect on social life and sexual attractiveness. Profiles of information needs were produced to take account of differences in age, level of education and social class. The use of the profile as a clinical reference guide to assist nurses and others to provide targeted information to individuals is discussed.

Authors and publication	**Description of study**	**Summary of findings**
Luker, K., Beaver, K., Leinster, J.S., Owens, R. G. (1996) Meaning of illness for women with breast cancer *Journal of Advanced Nursing*, 23, 1194- 1201.	This study involved assessing meaning of illness for a group of women with breast cancer at two points in time, the time of diagnosis and a mean of 21 months from diagnosis. The eight meanings of illness devised by Lipowski were depicted by the following words: challenge, enemy, punishment, loss, strategy, relief, weakness and value.	The most popular choice of meaning for the women was challenge, although some women's choices indicated that maladaptive coping strategies were being used. The implications of the study for nurses and other health care professionals are discussed.
Margalith, I., and Shapiro, A. (1997). Anxiety And Patient Participation In Clinical Decision-Making: The Case Of Patients With Uretheral Calculi. *Social Science Medicine*, 45, 3, pp.419–427.	Questionnaires and interviews were used in this study carried out in Jerusalem, Israel. The sample contained 96 patients referred to urology clinic for removal of a ureteral calculus. First 54 to arrive at the clinic formed the control group and the next 42 experimental. Subjects' anxiety level (using (StAI) (Spielberger *et al.* 1970)) was compared within each group 3 times. Perception of receipt of information and participation in clinical decision-making, coping style (using Shannan's Sentence Completion Test, (Shannan *et al.*, 1970)) educational level (using a split of 0–11 years and 12+ years of schooling), and knowledge about treatment alternatives were also measured	Decreases in anxiety were found among patients who were not asked to participate in the decision-making process, those who perceived that they did not participate in decision-making, those who perceived that they had received information, those with a lower educational level who perceived that they had received information and among higher educated patients who perceived that they participated in clinical decision-making. Anxiety also declined among patients with a passive coping style who perceived that they had either received information or had participated in the decision-making process. The results suggest that anxiety of patients is likely to decline when they perceive that they have been given relevant information but not necessarily when they actually participate in decision-making. Patient participation may not have the same effect on every patient and the therapeutic approach needs to be tailored to patient characteristics. Emphasis could be placed on both providing information and enhancing patients' perception of receiving such information when giving patients' choices in clinical decision-making.
Markham, R., and Smith, A. (2003).	A survey of patient information leaflets in	Out of 51 leaflets about general anaesthesia in adults

Authors and publication	Description of study	Summary of findings
Limits to patient choice: example from anaesthesia. *British Medical Journal*; 326, pp.863–864.	267 Anaesthetic departments in the UK. It was not clearly stated how they selected these departments.	only 27 mentioned fasting. Only 14 recommended fasting periods in agreement with the latest research evidence. 8 did not specify a fasting period. 18 explained why fasting was necessary but none of them quoted any research evidence to support the times recommended. Omitting fasting times or avoiding mentioning fasting at all gives hospital staff leeway to vary fasting times to their beliefs or preferences. If evidence is not available to patients, they are unable to challenge the prolonged fasts and are not able to exercise choice. This is an example of information leaflets being available but not giving the relevant information.
Markoul G., Arnston P., and Schofield, T. (1995) Health Promotion in Primary Care: Physician-Patient Communication and Decision-Making about Prescription Medicines. *Social Science and Medicine*, 41, 9, pp.1241–1454.	An observational study using 5 methods of data collection. Video analysis of consultations, patient questionnaire, medical record review, telephone interviews with patients, and doctor questionnaire. GP practices in Oxford, England. 271 GP consultations observed.	GPs overestimated the extent to which they elicited patients' opinions about medication, discussed risks and benefits of medication, and discussed patients' ability to follow treatment plans. Discrepancies also occurred between patients' perceptions and the actual consultations. In fact in this study 24.3% of patients either moderately or strongly agreed that their physician fully explained the risks of the particular medication when there was actually no mention of the side effects, precautions or risks in the videotaped consultations. Furthermore, the patient questionnaires were administered right after the consultation. Improving patients' choices about medication may require more discussion about the benefits, risks and for physicians to elicit more information from the patients about their ability to follow choices.
Marteau, T. M., Dormandy, E., and Michie, S. (2001). A measure of informed choice. *Health*	A test of a newly developed measure of informed choice was carried out in the UK. They used questionnaires and interviews with women in Antenatal	They found that 18/42 women who were offered this choice made informed choices, where as 24 made various types of uninformed choices. They say that 15 of the women had poor knowledge of the

Authors and publication	Description of study	Summary of findings
Expectations, 4, pp.99–108.	departments who were offered a screening test for Downs syndrome. 66 women awaiting their first antenatal clinic appointment.	screening test and 15 had behaviour that was not consistent with their attitudes about the test (i.e. 11 took the test while having a negative attitude towards the test and 4 did not have the test despite a positive attitude towards the test). They suggest that as plans are underway for a large expansion in screening programmes in the UK, it is becoming increasingly necessary to be able to assess the extent to which choices for screening are informed. A measure such as this may also be of value to other choices patients face.
Mastaglia B. and Kristjanson L.J. (2001). Factors influencing women's decisions for choice of surgery for Stage I and Stage II breast cancer in Western Australia, *Journal of Advanced Nursing* 35,6, pp.836–847.	A descriptive correlational study carried out in Western Australia. Sample included 175 women with Stage I and II breast cancer, The study used questionnaires on demographic information and 2 scales (The Factor List and MHLC scale).	7.9% of women wanted to play a passive role. More than half the women wanted the decision to be their own and 36% wanted to share the decision-making. There was a significant association between the women’s role preference and her GP as an information source (i.e. in those who wanted to control the decision themselves the GP was reported as an important source of information). Health professionals should be aware that women vary in their preferred decision-making roles and should elicit these early so that they can have their desired control. Health professionals should be aware that influencing factors can be different depending on what values they hold and they should also try to support their informational needs. Access to support and choice may be limited due to restricted medical services in the country areas.

Authors and publication	**Description of study**	**Summary of findings**
Murray, E., Davis, H., See Tai, S., Coulter, A., Gray, A., and Haines, A (2001). Randomised Control Trial of an interactive multi-media decision aid for benign prostatic hypertrophy in primary care. *British Medical Journal*, 323, 7311. pp.493.	An RCT carried out in the UK –12 general practices in Oxford and Chilterns and 2 general practices in London and Harrow. Between Jan 1996 and Sept 1998. Sampling – opportunistic but then randomised into intervention and control groups.	Decisional conflict was reduced in the intervention group (which had an interactive multi-media program), measured this using "O'Connor AM Validation of a decisional conflict scale" which indicated reduced uncertainty about the decision. Patients in the intervention group took a more active role in the decision-making process. Anxiety was less in the intervention group than in the control group (measured using the Speilberger state trait anxiety inventory short form). Patients want more information about their condition and treatment options. Decision aids like this could provide them with this information.
O'Caithain A, Walters SJ, Nicholl JP, Thomas KJ, Kirkham M. (2002) Use of evidence based leaflets to promote informed choice in maternity care: randomised controlled trial in everyday practice. *British Medical Journal*, pp.324; pp.643-	Cluster randomised control trial carried out in 12 of the 15 large maternity units in Wales. 6452/10070 women (64% response rate). There may have been some problems with this study. Not all women in the intervention group reported that they had had both leaflets, some women in the control group may have received the same leaflets. The study relied on a simple self report measure in the questionnaire.	They investigated whether leaflets (produced by The Midwives Information and Resource Service and the NHS Centre for Reviews and Dissemination - leaflets summarising evidence on 10 decisions women face in pregnancy and childbirth) led to informed choice and increased knowledge, satisfaction with information, satisfaction with the way choices were made and discussion with health care professionals. The leaflets did not really help to improve choice in this study. They conclude that perhaps decision aids can be effective but only under certain circumstances.
Oliver, J. W., Kravitz, R. L., Kaplan , S. H., and Meyers, F. J. (2001). Individualized Patient Education and Coaching to Improve Pain Control Among Cancer Outpatients, *Journal of Clinical Oncology*, 19, 8, pp.2206–2212.	A randomized controlled trial of patients at two oncology clinics, California, USA. English-speaking cancer patients (18 to 75 years old) with moderate pain over the past 2 weeks were randomly assigned to the experimental (n = 34) or control group (n = 33).	After coaching average pain severity improved significantly more among experimental group patients than among control patients. Compared with provision of standard educational materials and counselling, a brief individualized education and coaching intervention for outpatients with cancer-related pain was associated with improvement in average pain levels.

Authors and publication	Description of study	Summary of findings
Ryan, M and Fernando M (2003). Contingent valuation: revisiting the axiom of completeness in health care. *Health Economics* 12, 4, pp.295–307.	The paper reports the results of a discrete choice experiment carried out to examine the assumptions of complete preferences within health care. The tests carried out are based on the comparison of preferences for three different goods for which three different levels of formed preferences are expected: a supermarket, dentist consultation, and bowel cancer screening.	The results do not provide sufficient evidence to support the hypothesis that individuals have well defined preferences for any choice they are presented with. Further research is required before these results are generalised.
Ryan, M, McIntosh, E, Dean, T and Old, P. (2000). Trade-offs between location and waiting times in the provision of health care: the case of elective surgery on the Isle of Wight. *Journal of Public Health Medicine*. 22, pp.202–210.	This study considered the technique of discrete choice conjoint analysis (DCCA) for eliciting community views regarding the importance of reducing waiting times. It aimed to establish whether residents living on the Isle of Wight are prepared to travel to the mainland for elective surgery where waiting times are shorter but travel costs may be greater, and, further, if residents are willing to travel, what reduction in waiting time and increase in travel costs would be acceptable. DCCA questionnaire was sent to a random sample of 1000 individuals.	Seventy-eight per cent of respondents were willing to travel to the mainland for elective surgery. Of these, 48 per cent always chose the mainland and 30 per cent traded between island and mainland, depending on the levels of waiting time and travel costs. Whereas 'traders' preferred the Isle of Wight, they would forgo their preferred location if waiting times were reduced by at least 3.9 months, and they were willing to pay over £12 for a 1 month reduction in waiting time. Different combinations of waiting time reductions and travel cost increases that were acceptable to traders were estimated.
Sculpher, M., Manca, A., Abbott, J., Fountain, J., Mason, S., Garry, R. (2004), 'Patients' preferences for the management of non-metastatic prostate cancer: discreet choice experiment', *British Medical Journal* 328, pp.134-137.	A study of discrete choice of 129 men with non-metastatic cancer, men's preferences for, and trade-offs between, different attributes associated with treatment, life expectancy, and out of pocket expenses.	The study found that men were willing to contemplate trading-off life expectancy to be relieved of the burden of side effects such as limitations in physical energy but the preferences of older men were not the same as the younger ones.
Waitzkin, H. (1984). Doctor-patient	Literature Review carried out in New	Doctors tend to underestimate patients' desire for

Authors and publication	Description of study	Summary of findings
communication. Clinical implications of social scientific research. *JAMA.* 2, 252(17), pp.2441–6.	Mexico, USA. A review of the social science literature on doctor-patient communication, with emphasis on its implications for medical education and clinical practice.	information and to misperceive the process of information giving. Training programs and standards of clinical practice should emphasize that improved doctor-patient communication is both desirable and possible.

Table A3 Systematising the evidence of impact of choice in social care: choice of residential care home

Author and publication	**Description of study**	**Summary of findings**
Auken, S.V. (1992) Nursing home selection: replication, decision recency and strategic implications. *Health Marketing Quarterly*, 10, 185–208.	Postal survey of individuals responsible for nursing home placements with a nursing home chain, presumed to be in the USA. 674 useable responses were obtained (50%).	Proximity to the family was most often regarded as important in selecting a nursing home, followed by quality of nursing care and cleanliness. Advertising aimed at potential residents and their families had minimal effect. The experience of others was the most common information source when developing a shortlist of homes, followed by a physician's referral. 31% of residents/families evaluated only a single nursing home.
Bell, J. (1996) Decision making in nursing home placement. *Journal of Women & Aging*, 8, 45–60.	Taped semi-structured interviews with 16 family decision makers living in rural areas of the USA about a recent decision to place an older person in a nursing home. Tapes were transcribed and read by a panel of experts to identify key issues.	Cleanliness (absence of odours) and proximity of the home to the family were among the greatest concerns of families making nursing home placement decisions. Family looked for staff to appreciate the elder as a person. What staff considered to be minor details were very visible signs of an impersonal institutional setting for the families. Families did not consider the quality of the home with regard to licensure, standards, staffing or other credentials. Families felt they had "muddled through" alone, although support and information was sought through informal social networks.
Castle, N.G. (2003) Searching for and selecting a nursing facility. *Medical Care Research & Review*, 60, 223–247	Examined factors associated with both the search for and selection of a nursing facility. Structured interviews with 306 residents aged 65+ and resident for 90 days or less in one of 42 licensed nursing facilities in Pennsylvania and New Jersey. Family members were also interviewed.	Location was the most important factor in choosing a nursing home, followed by quality, particularly cleanliness, and price. Family members' most important source of information was advertising; residents' most important source of information was a friend. Residents and family members did not visit many homes. They were more likely to be very satisfied with the nursing home they had chosen if

		they: had spent a greater than average time looking for a home had visited the home were not hospitalised when making the choice had previously considered long-term care were less highly educated (i.e. up to 12th grade).
Cheek, J. and Ballantyne, A. (2001) Moving them on and in: the process of searching for and selecting an aged care facility. *Qualitative Health Research*, 11, 221–237	Semi-structured face-to-face interviews with 12 residents and 20 sponsors from a purposive sample of 25 families from South Australia, where a family member had been within the last 90 days admitted to an aged care facility upon discharge from an acute hospital.	People reported spending as much as an hour a day for 26 days telephoning homes and visiting up to 25 homes. This was stressful and said to have a negative effect on family relations. Participants consistently reported an inability to determine who they should contact for information.
Davies, S. and Nolan, M. (2003) 'Making the best of things': relatives' experiences of decisions about care-home entry. *Ageing and Society*, 23, 429–450.	Study aimed to provide new insights into the experience of care-home placement and to generate knowledge to inform practice. Data were collected in 37 semi-structured interviews involving 48 people from 36 families who had assisted a close relative to move into a nursing home. Participants were a convenience sample from nursing homes in Sheffield. The time since admission ranged from 3 weeks to 8 years, although most occurred within the previous 2 years.	Relatives felt under pressure, out of control, and that they were working in opposition to health and social care staff. Relatives expressed a particular need for information and advice about alternatives to long-term care, financial issues, appropriate levels of care, and activities in a home. They also craved meaningful information about what constitutes a 'quality home'. Those who did receive adequate support and information experienced a far more positive transition. Personal recommendation, especially from a health or social care professional was highly valued. When assessing homes, relatives tried to balance various factors such as travel distance, cost and the availability of activities. Other repeatedly mentioned aspects included: absence of odour, good décor and comfortable furnishings, and the intangible 'feel' of the home.
Fotaki, M. and Boyd, A. (2005) From Plan to Market: a comparison of health and old age care policies in the UK and	5 case studies where single older people attempted to survey the market.	Due to a variety of factors, quasi-markets in social care do not appear to have increased quality or efficiency in the UK or in Sweden, but to have

Sweden. *Public Money and Management*, 25(4), 237–243.		produced the following results: Increasing provision by the private sector Less diversity of supply Local authorities constraining individual choices, due to financial pressures Increasing central regulation No reduction in bureaucracy No demonstrated increase in quality Some increased responsiveness for relatively "strong" clients Politicians have struggled to "let go" Public expenditure has risen Public trust has declined
Green, B., Peardon, J., Raymond, G., and Watkins, C. (2005) Case studies of elderly consumers choosing a residential care home (Annex H). In Office of Fair Trading (2005) Care homes for older people in the UK: A market study. London: Office of Fair Trading.	5 case studies where single older people attempted to survey the market.	Care homes took a kindly, but limited interest in the individual older person. No suggestion was made to any older person that other types of accommodation might be more suitable for them. Most brochures relied on generalities, printing few specifics about the service that could be checked, such as staff/resident ratios, or staff training and qualifications.
Hill, C.J. (2001) Determinant attributes in nursing home choice: profiling attribute segments. *Health Marketing Quarterly*, 19, 73–88.	177 people from 10 states in the USA who had inquired about one or more nursing homes were surveyed by telephone. Respondents were asked to rate the importance of various nursing home attributes, and the extent to which they perceived the nursing homes they had considered, to be different on each of these attributes.	Nursing home attributes that were perceived to be both important and to differ between homes were (in order): cleanliness, location, reputation, competent/caring staff, bed availability and comfort of rooms. Taking account of perceived differences between homes increases the salience of location and decreases the salience of competent/caring staff. Different attributes may determine choice for decision-makers who only consider one nursing home.

Jenkins, M. (2005) Care homes mystery shopping (Annex G). In Office of Fair Trading (2005) Care homes for older people in the UK: A market study. London: Office of Fair Trading.	A mystery shopping survey was conducted to determine availability of care home places, how easy it is to obtain information on a range of issues and adequacy and transparency of fees and contracts/terms of business. Randomly selected sampling points generated samples of care homes for older people, from which 725 in-depth investigations (375 using an Authority funded scenario; 350 using a self funded scenario), were carried out by mystery shop transactors. An additional 1527 care homes were contacted solely to ascertain availability of places.	46% of homes across the UK had a vacancy. Most service details, apart from top up fees, were readily obtainable from homes with an initial telephone call. The amount provided spontaneously, rather than being asked for, varied by subject matter. Few mystery shop transactors were told about the care home's inspection report. Of those that were, half were informed it is available upon request. It is difficult to gauge how well literature reflects the care homes themselves; for example, small care homes producing short form literature may not be best representing themselves.
Jenkins, M. and Gibson, J. (2005) Survey of older people in care homes (Annex F). In Office of Fair Trading (2005) Care homes for older people in the UK: A market study. London: Office of Fair Trading.	Aimed to establish: whether or not older people, and their relatives, feel they are put under pressure when selecting a care home; the extent to which, once in a care home, they are reluctant to move; price transparency; and availability and clarity of contracts in relation to fees. Interviews were conducted, between 13 September and 25 October 2004, with 658 residents, where possible with their relative present, acting as a supporter. Lists of care homes from local authorities across the UK were sampled in proportion to the population of the Authority, giving a total of 1,279 care homes. Interviewers randomly selected from 1 to 4 residents from the homes that were not ineligible, had taken part in piloting of the interviews, or refused to take part, until the quota of interviews was complete. Interviews	Satisfaction levels among care home residents were high, and practically everyone (95%) would recommend their current care home to a friend. Most people moving into a care home have not considered alternatives, such as care at home. Location was the single most important reason for choice of home – particularly being near family (44%), but also being in the area where they used to live (20%) or near to friends (8%). Other important considerations are: availability – only one available/ there was a room free when I needed one (31%) reputation/ recommendation of home (27%) knew someone there (14%). In the majority of cases, family were involved in the decision-making process to choose a particular home – either solely (37%) or jointly with the resident (37%). 18% of residents claimed they had made the decision alone. A minority of residents said they felt under pressure to choose quickly, or would have liked a little more time. 26% of care home residents made no visit, either to the home they subsequently

	thus took place in 234 homes. 2 questionnaires were used, one for recent residents (243) (up to 6 months in their current home) and one for longer term residents (415) (have lived in their current home for at least a year). Interviews among recent residents also covered choosing a care home.	moved into or to any other, 41% visited just their current home, and a third visited more than one. Family and social services are the main sources of information and advice about care homes in an area. 23% of those who did not receive guidance would have liked help. Homes that are part of a chain are more likely to give residents brochures, information and contracts than homes run by smaller providers, and large homes (more often part of a chain) are more likely than small ones to provide such a range of information. Only 17% of residents felt they had had a wide choice of home, and 43% said their choice was limited or very limited. 59% of residents considered only one home, while 12% considered four or more homes. When residents chose the home on their own, 77% considered only one home.
Lawrence, F.C., Moser, E.B., Prawitz, A.D., and Collier, M.W. (1998) Helpfulness of information sources in the selection of a nursing home. *Psychological Reports*, 83, 1217–1218.	A questionnaire was posted to 1,342 "responsible parties" of residents from a random sample of 16 nursing homes, stratified by regions within a southern state in the USA. 857 usable questionnaires were returned (65% response rate). Respondents ranked 14 information sources on a 5-point scale of helpfulness.	Families selecting a nursing home found visits and personal investigation, as well as information from a variety of people (nursing home personnel, word-of-mouth from friends and family, other visitors, social workers, doctors etc.), more helpful than printed materials.
Macknick, F.J. (1998) Two takes on facility marketing. *Nursing Homes Long Term Care Management*, Oct, 47, 70.	Insights from "mystery shopping" on the admissions performance of nursing homes across the USA, undertaken by a consultancy firm.	Recommends that nursing homes take more time with people making inquiries: be friendly, listen to concerns and needs, and introduce key caregivers and residents. Follow up with a thank you letter and phonecall. "Anyone following these steps will almost certainly receive the admission".
Nolan, M. and Dellasega, C. (2000) 'I really feel I've let him down': supporting family carers during long-term care placement for elders. *Journal of Advanced*	Interviews with family carers who had placed a relative in one of 13 nursing homes in single small geographical areas in the USA and UK within the previous 4 weeks. 54 carers in the USA and 48 in the UK were interviewed. The	Many placement decisions were "expert driven". With regard to exploration and information, carers generally were far better served in the USA. The UK sample members were more likely to feel under pressure to select a home quickly, had less

Nursing, 31, 759–767.	interview containing both structured and unstructured sections. The structured part comprised the Placement Response Scale instrument, which considers carers' experience of placement in three phases: events leading up to the admission; events during the admission; and events after the admission.	information on which to base a decision, had less professional assistance and had fewer opportunities to discuss their feelings. In both countries, however, there were limited opportunities for both the carers and the older persons to visit homes and to select the ones that they really wanted.
Nolan, M., Walker, G., Nolan, J., Williams, S., Poland, F., and Curran, M. (1996) Entry to care: positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing*, 24, 265–274.	Draws on 4 studies: An evaluation of an educational programme for the staff of a new form of sheltered tenant housing scheme for older people in Wales – 15 tenants were interviewed. An evaluation of a new community care assessment procedure in a large county in the Midlands, England – older people and their carers involved in 20 admissions were interviewed. An evaluation of the introduction of community care in a largely rural county in Wales – interviews with older people and their carers from 30 recent admissions to either a nursing or residential home. The extent to which annual inspection reports produced by the inspection unit of the social services department of a Welsh county could be improved in order to make them more 'user-friendly' - interviews with older people and carers who had recently been involved in 12 admissions to residential care.	Admissions to care were characterised by four 'ideal types', which have been named: the positive choice, the rationalized alternative, the discredited option, and the fait accompli. Older people and their carers had few if any criteria upon which to select a home when the eventuality arose. Those individuals who had some criteria in mind based these upon personal knowledge or experience of local homes or local reputation.
Office of Fair Trading (2005) Care homes for older people in the UK: A market study.	Looks at how well the care homes market serves people over 65 in the UK. The study included various elements, some of which are reported on in more detail elsewhere in this table:	Found cause for concern in the areas of: Information about moving into a home – there is a lack of awareness among older people and their representatives about sources of information. Authority obligations – there is confusion about what

	A review of the literature on consumer behaviour and care homes (Williams, 2005). A survey of older people living in care homes to get their experiences of moving into and living in care homes for older people (Jenkins and Gibson, 2005) A survey of care homes to establish sound factual information about care homes and their business strategies with regard to issues such as information provision, contracts, complaints handling, and relationship with their Authority. A mystery shopping exercise to gauge how easy it is for older people and their representatives to obtain key information from care homes, including contracts and prices (Jenkins, 2005). Also a test of the experiences of older people looking for a care home without any support from relatives or others (Green *et al.*, 2005). A survey of Authorities across the UK to clarify their behaviour in this market, their support of older people and their relationship with care homes, asking questions ranging from information provision over data collection to commissioning strategies. A variety of stakeholders were also consulted.	advice and support Authorities should be providing. Price transparency – there is a lack of timely, accessible information about fees and services. Contracts – a large number are potentially unfair. Many are unnecessarily complex or unclear. Access to making complaints – low awareness of how to complain, and a lack of support for complainants.
Prawitz, A., Lawrence, F., Draughn, P., and Wozniak, P. (1991) Relationships between steps taken in selecting a nursing home and consumers' satisfaction. *Psychological Reports*, 69, 404–406.	Postal questionnaire to 1,028 families of the residents of 7 nursing homes in the southern USA. 411 (40%) were returned. Satisfaction was measured on a 5-point Likert scale.	Satisfaction with a nursing home among families of residents was greater if they had more time to make the decision, and had used this to investigate all the homes in an area before selecting one.
Prawitz, A.D., Lawrence, F.C.,	A subsample of "responsible parties" from the	Families ranked quality of care as the most

Draughn, P.S., and Wozniak, P.J. (1994) Criteria Families Use to Select Nursing Homes. *Journal of Family and Economic Issues*, 15(1), 37–51.	411 families responding to the survey reported by Prawitz *et al.* (1991). The data used was from the 231 respondents who had ranked all 9 of the nursing home characteristics as instructed.	important characteristic of nursing homes, followed by appearance of building and grounds (e.g. clean, free from odour, pleasant décor), and atmosphere (e.g. friendliness of staff and other patients, homelike feeling). But the researchers questioned whether quality of care is the dominant factor in the final choice, and suggested that location might be a key limit to choice.
Reed, J., Cook, G., Sullivan, A., and Burridge, C. (2003) Making a move: care-home residents' experiences of relocation. *Ageing and Society*, 23, 225–241.	Focus groups and individual interviews with staff and residents, and a case note audit of 255 records, from 8 care homes in 2 local authorities in the North East of England. 10 homes were selected according to 5 characteristics regarded as important to the study, but 2 withdrew. 32 staff participated and 12 residents.	Residents were able to make choices when they were: aware of their rights and choices; able to communicate and debate these choices with others; and able to access and evaluate information about the options.
Reed, J. and Morgan, D. (1999) Discharging older people from hospital to care homes: implications for nursing. *Journal of Advanced Nursing*, 29, 819–825.	Individual interviews with older people and family members, and focus groups and individual interviews with care home and hospital staff. Patients had been recently discharged from a large acute hospital in the North East of England to the independent sector within 10 miles of Newcastle. Of 48 patients identified, 20 were able and willing to participate. 17 interviews were held with "significant others". Case notes were also examined. 23 staff participated in 7 focus groups, 1 staff member was interviewed, and 6 provided written responses to a questionnaire.	The older people did not seem to expect to exercise much choice over the home they moved to. The choice of home was delegated to family members or social workers. Their ideas about care homes had been vague and based on snippets of information gathered from friends, acquaintances and the media. Family members did not consider themselves to be informed consumers. Hospital nurses had no standardised approach to dealing with the process.
Reed, J., Roskell Payton, V., and Bond, S. (1998a) The importance of place for older people moving into care homes. *Social Science & Medicine*, 46, 859–867.	139 interviews with 46 older people from 6 care homes in a single English local authority area, which contained 2 small towns and a number of small villages. The homes were regarded as being of a high standard by local inspectors. There was a sequence of interviews	For many participants the process was not one of making a decision at a general level and then looking for a particular home, but of deciding straightaway to move into a specific home that they knew about or were familiar with. Those participants who claimed familiarity with specific homes often did so

	which followed each person through the process of moving into care homes, beginning with loosely structured interviews before the move, and three subsequent to it, ending when the research participant had been in the care home approximately six months. The emphasis of the interviews was on developing life histories and personal narratives of residents.	on the basis of what seemed very tenuous information, such as having driven past a home on the way to work or having known the village when a child. Some participants chose homes because of their closeness to amenities or public transport routes and in doing so took account of their current life-style and social networks. None of the participants had moved more than 10 miles from their domestic home, but nevertheless this was seen by them as moving out of the area.
Roberts, K. (2001) Across the health-social care divide: elderly people as active users of health care and social care. *Health & Social Care in the Community*, 9, 100–107.	A postal questionnaire to elderly people (70 years and over), returning to a private address on discharge from one district general hospital. The questionnaire related to the extent to which they had played an active role. 262 questionnaires were returned (50%). Semi-structured interviews were carried out with 30 respondents, purposively sampled on the basis of age, gender and household composition.	Respondents with the least need or wish for statutory care were found to be in the strongest position in terms of choice. They were able to refuse services, that is, choose not to receive them. The active role played by service users in the social care sector, however, does not appear easily transferable to health care provision due to a number of factors. These include the monopoly provision of health care, the specialised nature of health care, the lack of direct purchasing power by service users and the difficulty in making the link between perceived need and appropriate service delivery.
Rodgers, B.L. (1997) Family members' experiences with the nursing home placement of an older adult. *Applied Nursing Research*, 10, 57–63.	9 family members of older people placed in nursing homes in southeastern Wisconsin, USA, were interviewed within 1 month of relocation of the older person to a nursing home. A reflexive journal was maintained throughout data collection and analysis.	Families were concerned with quality of care, but did not know what features indicated quality, and felt inadequately prepared to make an appropriate selection. For most, the general impression of the facility gained on a personal visit, especially with regard to "cleanliness" was the deciding factor. Because of the difficulty in visiting homes, people narrowed the list of possibilities provided by social services, based on anecdotal reports and personal experience.
Sales, A.E., Hedrick, S.C., Sullivan, J., Gray, S.L., Curtis, M., and Tornatore, J. (2005)	A prospective cohort design targeting all persons entering community residential care settings in a three county area in western	External ratings of the overall pleasantness of a facility appear to be associated with choice. How a residential care facility looks, smells, and feels may

Factors affecting choice of community residential care setting. *Journal of Aging & Health*, 17, 190–206.	Washington, USA, between April and December 1998 on Medicaid or state funding. 249 residents were interviewed in person at enrolment. Also interviewed were 237 informal caregivers, 184 owners or managers, and 115 staff providing most hands-on care to these residents.	be a factor in whether it is chosen as a place to live.
Shemwell, D., J. and Yavas, U. (1997). Congregate care facility selection: A conjoint approach. *Health Marketing Quarterly*, 14(4), 109–120	Interviewed 42 adults in a Southeastern city who were recently involved or were in the process of selecting a congregate care facility for a family member (i.e., a residential environment providing health, housekeeping, personal hygiene and transportation services to assist impaired but not seriously ill or chronically dysfunctional patients). This type of living arrangement is for people functioning at a relatively high level, but who are not able to stay at home for one reason or another. Respondents were asked to rank-order 10 profiles of facilities in terms of their desirability from 1 = best to 10 = worst. The profiles were based on 2 levels of 7 attributes: cost, quality of nursing care, physical facilities, extent of recreational activities, location, rehabilitation/therapy programs and staff attitude.	Staff attitude was the most important consideration of families choosing a congregate care facility, followed by location, and then quality of nursing care.
Smith, S.M. (1984) Family selection of long-term care services: it's not just the facility that's important. *Health Marketing Quarterly*, 1, 101–113.	Postal questionnaire survey of the "responsible person" for people enrolled in 6 long-term care facilities in a major western USA metropolitan area. 124 useable responses were received (41%).	Choices were frequently influenced by some knowledgeable "other". The selection process was a very short, but intense decision process. The average number of facilities visited, called or inquired about through the mail was 3.4. Respondents dissatisfied with current care differed from satisfied respondents: a smaller proportion believed that they spent adequate time in evaluating care facilities before making a decision; and a

		smaller proportion believed that they had been able to assess differences in the health care provided. Observable variables such as cleanliness were the most important aspects in the selection decision. Advertising aimed at decision makers had minimal effect.
Travis, S.S. and McAuley, W.J. (1998) Searches for a nursing home: Personal and situational factors. *Journal of Applied Gerontology*, 17, 352–370.	25 sponsors (81% response rate) of recently admitted nursing home residents were interviewed, selected from 150 respondents (78% response) to a telephone survey, identified with the help of 79 nursing homes in the eastern United States. Individuals were contacted within 90 days of having been placed on a waiting list for admission. Interview participants were selected to provide diversity across geographic locations in the state, rural and urban environments, sponsor-resident dyad types (e.g. adult child/parent, spouses, siblings, adult grandchild/grandparent, friend/friend), and ages of the residents. Interviews were transcribed.	None of the sponsors looked forward to or enjoyed their searches for an acceptable nursing facility. It is unlikely that any amount of education or intervention will change these affective elements of the process. However, with education and professional intervention, it may be possible to improve caregivers' perceived personal competence and reduce levels of stress associated with the process.
Tudor, R.K. and Carley, S.S. (1995) Time to choose. Consumers who make a snap decision about long-term care use different criteria from those who can afford to deliberate. *Journal of Health Care Marketing*, 15, 48–53.	Postal questionnaire survey of 472 people (79% response) in the USA who stated that they had either been involved in selecting a Long term health care facility for themselves or a significant other at some time in the past six months or anticipated doing so in the future. Respondents were asked to rate the importance of 29 criteria to their selection of facility, using a 5 point scale.	The most important attributes were competence and attitude of staff, cleanliness, and quality of physical care. "Gut-level" responses to a facility or its staff members could well be the basis of many decisions, especially when the decision maker feels he or she lacks the time or expertise needed for a cognitive judgment.
Unsworth, L., Dalley, G., Waller, M., Davies, T., Morton, R. (2004) Choice, power and performance: the need for information on care	Examines the performance of care homes for older people and for younger adults and children’s homes in relation to the National Minimum Standards on the provision of	25% of homes for older people met or exceeded the information standards. Of the other 75%, 51% were said to have almost met it, but 24% to have definitely failed it. Information currently provided by

services in England. London: The Stationery Office.	information. Based on data gathered during 2002/03, from inspections of 9,425 care homes for older people, where reports with valid information scores were available.	the care sector in England is often deficient.
Williams, J. (2005) Consumer behaviour and care homes - a literature assessment (Annex K). In Office of Fair Trading (2005) Care homes for older people in the UK: A market study. London: Office of Fair Trading.	Relevant literature was identified via bibliographic searches of The Social Science Citation Index, PsychInfo, PsycArticles, and AgeInfo databases. Keywords used included care/nursing/residential home(s), older/elderly people, consumer behaviour, choice/decision, admission/placement, adjustment, relocation/moving/transfer/transition, complaints/ redress/accountability and advocacy. The search focused on peer reviewed journal articles published in English reporting empirical research based in the United Kingdom, mainly published since 1993 when the community care reforms came into full effect. Research from other countries such as the United States was included where there is a considerable body of work or theory that has been drawn on widely in the UK literature.	There appears to be consensus about a number of features of the context in which older people and their relatives make choices about care homes: Some people lack information on which to base selection decisions and would value guidance on how to choose an individual home. People have low expectations of the care that will be provided by care homes. Decisions about moving to residential care are often made during a crisis. The decision to move to a care home is often 'expert driven'. Moves are often perceived as pressured and hurried. A significant proportion of older people report having little, or no choice about the home they move to, although this may be due to them having delegated the choice to a relative. Identifies a variety of factors that facilitate or impede the nature and level of consumer behaviour.
Williams, J., Netten, A. and Ware, P. (2003) The closure of care homes for older people: relatives' and residents' experiences and views of the closure process, Discussion Paper 2012/3, Personal Social Services Research Unit, University of Kent, Canterbury.	Part of a larger study that investigated the way in which independent care homes for older people are closed from the perspective of those involved. Interviews were conducted with people connected to 8 care home closures in 5 local authorities, with the homes closing for business related reasons in 2002. 10 residents and 28 relatives and informal carers linked to the case study home closures were interviewed. A further 7 relatives and informal carers with recent experience of a home	The value placed on personal recommendation has been identified Relatives and residents said that up-to-date and accurate vacancy information would be more useful than lists of all of the care homes in the area provided by social services. Relatives had not necessarily become experts in the process merely because they might have helped find the first home. Some seemed unaware of the information sources available.

	closure were also invited to take part via national and local carer associations and groups, and a local care home and day centre. The interview guides were chronologically organised, in order to encourage the interviewees to talk about their experience in their own words. All but one of the interviews were face to face, and all but 4 of the interviews were transcribed (the others were written up as field notes).	

Table A4 Systematising the evidence of impact of choice in social care: direct payments

Authors and publication	**Description of study**	**Summary of findings**
Askheim, O. P. (2005). Personal assistance - direct payments or alternative public service. Does it matter for the promotion of user control? *Disability & Society*, 20(3), 247–260	Compares models of personal assistance in the USA, UK, Sweden and Norway.	Argues that, though masked by phrases such as "user control" and "freedom to choose", there are paternalistic restrictions underlying DP in the UK. These have led to cuts, which harm the poorest and most vulnerable; and to strict control and audits. Different actors have different agendas for supporting DP, and it is important to look beyond the ideological "in-words" of policymakers.
Bainbridge, I. and Ricketts, A. (2003) Improving older people's services: an overview of performance. Social Services Inspectorate.	Information gathered by the Social Services Inspectorate from inspections and monitoring during the year 2002–03 to assess the progress made by councils in modernising and providing quality social services for older people. 15 councils were inspected.	DP schemes were only being enjoyed by very small numbers of older people. Identifies a variety of barriers to take-up.
Carmichael, A. and Brown, L. (2002) The Future Challenge for Direct Payments.	Evidence from a user-controlled Best Value Review of DP in Wiltshire.	Quality of life and autonomy (specifically, choice, control and flexibility) can improve through DP. Administrative, employment and banking aspects of DP are bureaucratic and complex. Recruiting and retaining good quality PAs is difficult.
Clark, H. and Spafford, J. (2002) Adapting to the Culture of User Control? *Social Work Education*, 21, 247–257.	43 in-depth interviews with 36 care managers and 6 team managers about their reactions to a pilot scheme similar to DP for older people in 1 local authority during 1999. Part of a larger evaluation.	The way in which care managers promoted the scheme to different older people varied: the older people had little or no understanding of what they had been offered. There were varying levels of willingness among care managers to give more control to service users, partly reflecting debates about

Authors and publication	Description of study	Summary of findings
		professional identity, and partly tensions in the role of care management between empowering users and controlling costs. The authors suggest education and training for staff is needed.
Clark, H., Gough, H. and Macfarlane, A. (2004). 'It pays dividends': Direct payments and older people. Bristol: The Policy Press	Research conducted between January 2002 and June 2003, examining how DP work for older people in 3 local authority areas. 41 older people participated in in-depth interviews in their own homes and/or in group discussions, as did 5 senior managers, 11 team managers, 32 care managers, and 10 DP support workers.	Older people receiving DP reported feeling happier, more motivated and having an improved quality of life than before. There was a positive impact upon their social, emotional and physical health. DP are yet to become part of the culture of care management. Support services were crucial in enabling older people to use DP.
Commission for Social Care Inspection (2004) Direct payments: what are the barriers?	Findings of a consultation event and follow-up policy seminar held in June 2004. The event was attended by 21 people in receipt of DP and 11 people who were direct payment workers, PAs or carers. The seminar was attended by 20 people: service users, national and local policy-makers, practitioners, researchers and social services managers, and was informed by a report of the 1st event.	DP are generally well regarded Barriers to take-up may include: low staff awareness restrictive attitudes about the capabilities of service users and a reluctance to devolve power limited advocacy and support services inconsistencies between the intention of the legislation and local practice over-bureaucratic paperwork recruitment and retention problems, and assuring quality Makes various recommendations, including further research into the practicality of DP for NHS services for some DP users.
Davidson, D. and Luckhurst, L. (2002) Making choices, taking control: Direct Payments and mental health service	Report of a conference held in February 2002, attended by over 50 survivors and users of the mental health system.	Mental health service users and staff need information and support to use DP.

Authors and publication	**Description of study**	**Summary of findings**
users/survivors. York, University of York.		
Dawson, C. (2000). Independent successes: implementing direct payments. York: Joseph Rowntree Foundation.	Monitoring of a pilot DP scheme in Norfolk, in 1998 and 1999. Research looked at the operation of the scheme, and take-up and effectiveness of DP. Interviews with recipients of DP (23), PAs and employees of the social services department and partners. Questionnaire survey of employers joining the scheme. 36 questionnaires were returned.	DP are a cost-effective means of service delivery when compared with similar support costs from in-house service provision and agency support. After two years, approximately 15 per cent of those eligible for DP in Norfolk had chosen this form of service provision. The strengths of the scheme included the perceived benefits from the perspectives of disabled employers. The scheme was not so effective in reaching out equitably to all who were eligible, or in changing the culture of service provision by offering an alternative provision for those in day or residential services.
Department of Health (2004) Direct choices: what councils need to make direct payments happen for people with learning disabilities.	Brings together existing information from a variety of sources, as well as using new information drawn directly from interviews with council direct payment staff, direct payment support groups and people currently using DP.	Suggests things to consider in order for information for people with learning disabilities to be effective.
Department of Health and the Cabinet Office (2005) Making a difference: direct payments. London.	To identify the existing burdens associated with the DP process, telephone interviews and meetings with local authorities and professional groups were conducted. 2 workshops were held with a total of 80 front line stakeholders from a range of local authorities, support groups and voluntary organisations. The workshops aimed to identify issues and practical solutions to the issues identified. A summary of all involvement and feedback was circulated to frontline staff to confirm that the right issues	Areas where staff considered unnecessary processes were burdensome included Criminal Records Bureau checks, opening bank accounts, and lack of detailed authoritative guidance.

Authors and publication	**Description of study**	**Summary of findings**
	and solutions had been captured.	
Glasby, J. and Hasler, F. (2004) A Healthy Option? Direct Payments and the implications for Health Care. A discussion document. Birmingham	Summary of key themes and issues from a private seminar in December 2004 for key stakeholders. The seminar was attended by around 20 participants from health and social care, academia, the disabled people's movement, policy implementation and the voluntary sector.	There is a desire to extend DP outside social care. A first step could be extension to small and relatively discrete areas of health (examples given). There was much less consensus about whether DP could work in wider health services.
Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K., and Tyrer, J. (2000a) New kinds of care, new kinds of relationships: how purchasing services affects relationships in giving and receiving personal assistance. *Health and Social Care in the Community*, 8, 201–211.	Study of 3 local authority areas: 42 interviews with users of DP aged 18–65 with complex needs; 3 focus group discussions with a total of 13 PAs. 27 completed postal questionnaires from disabled people in one of the 3 areas. Both interviews and the survey had high response rates. NB same data is reported by Glendinning *et al.* (2000b).	Direct payment users reported many benefits from employing their own PAs, including continuity of care and enhanced quality of life. A care agency may demand less of users, but is less beneficial. The close relationship between user and PA is key, but may make it hard to tackle any difficulties that arise.
Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K., and Tyrer, J. (2000b) Bridging the gap: using direct payments to purchase integrated care. *Health and Social Care in the Community*, 8, 192–200	Interviews with 42 users of DP aged 18–65 with complex needs, drawn from 3 local authority areas. NB same data is reported by Glendinning *et al.* (2000a).	Some direct payment users prefer to purchase help from their PAs, rather than using free NHS services, because of: the shortage of NHS services; health staff withdrawing a service, or delegating it to PAs; the greater independence and control. Users had some concerns about equity if DP were extended to health care, although these concerns could be outweighed in areas where they felt users could make better use of NHS resources (supply of equipment and consumables).
Halloran, J. (Ed) (1998) Towards a people's Europe: a report on the development of direct payments in 10 member states of the European Union. Brighton: European Social Network.	Review based on information supplied by directors of public services belonging to the Network, the National Centre for Independent Living in London, the European Network for Independent Living in Stockholm	DP may be at least as expensive as directly provided services, although the response was mixed. The growth of a new independent 'care market' appears to have been stimulated by DP service developments in some European countries, but there are concerns due to lack

Authors and publication	**Description of study**	**Summary of findings**
	and Age Concern.	of regulation and an untrained, fragmented and vulnerable work force. It is not easy to resolve how the quality of services accessed through DP should be monitored.
HASCAS (2004). Direct Payments, Independent Living and Mental Health: An Evaluation – Executive Summary. London: Health and Social Care Advisory Service.	An overview of a study of the National Pilot to implement DP in mental health. This took place across 5 local authority sites in England from February 2001 to July 2002. The evaluation took place in 2002–2003 during the last year of the pilot: semi-structured interviews with care co-ordinators, mental health service users who had DP agreed, local authority leads, members of the National Pilot team, staff from local support services, and focus group discussions with local steering groups; a 'quality of life' questionnaire was completed by direct payment recipients; quantitative data were collected on sources and outcome of referrals for DP, and on direct payment packages.	Perceived benefits included greater independence and flexibility in support arrangements and a positive impact on mental health A proactive, independent, sufficiently resourced DP support service was one of the main factors supporting implementation of DP. The willingness and ability of care co-ordinators to promote, support and enable service users to get DP was highly significant in taking forward or stalling progress and uptake. Most were still uncomfortable and had a variety of concerns about the direct payment process.
Jordan, C. (2004) Direct Payments in Action. London: SCOPE.	Survey to identify what social service departments saw as the barriers to using DP effectively, and what worked well. Questionnaires sent to all 150 directors of social services in England. 50% response rate.	Key factors identified: Staff training User involvement, and developing a user-led support scheme Adequate funding for a support scheme Addressing needs of specific client groups A strategic approach, with support at the highest management levels, to address barriers within social services to implementing DP.
Joseph Rowntree Foundation (1999a) People with learning difficulties and their	Findings from an eighteen-month information programme to inform as many people with	The implementation of DP for people with learning disabilities has been slow. Identifies

Authors and publication	**Description of study**	**Summary of findings**
access to direct payments schemes. York, Joseph Rowntree Foundation.	learning difficulties as possible about DP. The programme came into contact with over 1000 individuals and over 40 self-advocacy groups.	barriers and suggests various ways in which access might be improved.
Joseph Rowntree Foundation (1999b). Implementing direct payments for people with learning difficulties. Findings March 1999. York, Joseph Rowntree Foundation.	Case studies of how 3 local authorities were tackling the development of DP for people with learning difficulties. Meetings were also held with people with learning difficulties, their families and supporters, who were receiving individualised funding.	Measures local authorities were taking to maximise the potential for people with learning difficulties to make an informed choice included: providing accessible information, giving people time, reducing the formalities, respecting the ways in which people communicate, lessening the pressures and enabling people to make decisions in their own, familiar environment. A problem-solving approach and a culture of risk-taking are essential if local authorities are to successfully implement DP for people with learning difficulties. It seems that sometimes more effort is expended on preventing people from accessing DP than on solving problems and breaking down barriers.
Joseph Rowntree Foundation (2000) Implementation of the Community Care (Direct Payments) Act. Findings April 2000.]York, Joseph Rowntree Foundation.	A survey of local authority practice with regard to DP, carried out during June and July 1997. Completed questionnaires were received from 185 UK authorities (98% response rate). Also included consultations with people using and running schemes.	Support services are fundamental to a successful scheme. Local authorities key concerns: financial monitoring and review quality control assessing users' ability to manage payments provision of support and advice for users. Issues include lack of awareness and understanding about DP among care managers, and tensions between community care policies and the principles of independent living.

Authors and publication	**Description of study**	**Summary of findings**
Joseph Rowntree Foundation. (2004a) Developing direct payments in the North East of England. Findings June 2004. York, Joseph Rowntree Foundation.	Learning from a project to identify factors inhibiting take-up and to support local authorities in their development of direct payment schemes. A project worker worked with 3 local authorities over 10 months in the North East of England. DP users, local authority managers, support scheme co-ordinators, team managers, and social workers were consulted through a series of face-to-face interviews, questionnaires and information-sharing events and meetings.	DP worked best in local authorities where a supportive local authority infrastructure is combined with both an understanding of the principles of independent living and a commitment to partnership with users. The project identified various strategic and operational barriers to implementing DP, and some practical strategies to address them.
Joseph Rowntree Foundation (2004b). The importance and availability of peer support for people with learning difficulties accessing direct payments. Findings December 2004. York, Joseph Rowntree Foundation.	Interviews with 16 organisations between April 2003 and June 2004, either by telephone or face-to-face. These were: 1 Social Services Department; 3 self-advocacy groups; 6 Centres for Independent Living; 6 other support organisations run by disabled people.	Many agencies had not adapted to the needs of users with learning difficulties. People with learning difficulties need the same sort of information as other people, but may need this to be provided in a different way. People with learning difficulties could also play an important role in informing others with learning difficulties.
Keigher, S.M. (1999) The Limits of Consumer Directed Care as Public Policy in an Aging Society.	Interviews with 30 older disabled people, 18 carers and 41 workers whose services were purchased either privately or with financial support from a county council. A convenience sample from one mid-western community in the USA. Workers were interviewed twice. Fieldwork took place in 1996 and 1997.	At least 43% of the elders in the subsidized sample had known their worker previous to receiving care. Black clients and workers were more likely to have known each other previously than white clients and workers; and subsidised clients were more likely to have known their worker than private-pay clients. Highlights an issue of difficult clients who no one might want to work for.
Leece, J. (2004b) Money Talks, but What Does It Say? Direct Payments and the Commodification of Care. *Practice*, 16(3)	Incorporates early findings from a qualitative in-depth ongoing Ph.D. study in Staffordshire where 8 DP recipients and their PAs were	Warm, friendly, relationships develop between DP recipients and their PAs, with various benefits and drawbacks. Further research is

Authors and publication	Description of study	Summary of findings
September, 211–221.	interviewed separately: Leece, J. (2004a). Paying the piper and calling the tune? A study of the relationship between direct payment users and their PAs, ongoing Ph.D. study.	needed into whether the middle classes may be disproportionately benefiting from DP.
Leece, J. (2004c) Taking the money. *Working with Older People*, 8, 36–39.	Comparison of systems of DP in the UK with other countries.	Systems of DP exist throughout Europe, Australia, Canada and the United States. take-up of DP by older people appears to be slower than in other countries. Suggests some barriers, and ways of overcoming them.
Local Government Association, Association of Directors of Social Services, and the NHS Confederation (2004). Our future in our hands: putting people at the centre of social care. London.	Policy paper on achieving person-centred, pro-active and seamless adult social care services in England.	17 recommendations, including that DP should enable choice of social care and continuing health care for long-term conditions
Lundsgaard, J. (2005). Consumer Direction and Choice in Long-Term Care for Older Persons, Including Payments for Informal Care: How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability? Paris: OECD.	Review of different types of arrangements across OECD countries that allow home-care users more choice. Looks at outcomes in terms of flexibility, care quality, satisfaction and conditions for care givers.	Giving older persons a budget or cash to pay informal care givers can help tap into a wider pool of human resources where there are shortages of professional care workers. On the other hand, a functioning market for formal home-care services (or public supply of such services) is essential to allow relatives of older persons in need of care to maintain their attachment to the normal labour market.
Lyon, J. (2005). A systems approach to direct payments: a response to 'Friend or foe? Towards a critical assessment of direct payments'. *Critical Social Policy* Vol. 25(2): 240–252.	Reply to Spandler (2004). The author is a disabled person who receives community support services. She has experience of recruiting and managing PAs without actually being the legal employer. She has represented service users on contract management boards and has been involved in the development of domiciliary care,	DP should be seen as a component of, rather than a competitor to, the social care system. Unless analysis is done carefully, improvements due to better assessment processes, which determine how much care a person will receive, may be wrongly ascribed to DP. Nevertheless, DP may help to improve assessments. DP may lead to inequalities, or

Authors and publication	Description of study	Summary of findings
	supported living, and residential and day services for a large voluntary sector care provider.	perhaps heighten existing ones, between users who wish to pursue individual solutions, and those who want to use provided services.
Maglajlic, R., Brandon, D., and Given, D. (2000) Making direct payments a choice: a report on the research findings. Disability and Society, 15, 99–113.	Research in the London Borough of Tower Hamlets in 1997 and 1998. Semi-structured interviews were carried out with 10 users, 10 staff and 10 carers, from each of 3 user groups: people with learning difficulties, mental health survivors, and people with physical disabilities. Few of the interviewees had experience of DP, although a small number were receiving 3rd party payments.	Information for people with learning difficulties needs to be ’personalised’, address individual needs, be straightforward, and be presented in a variety of formats. Finding appropriate PAs can be a lengthy process.
Morris, J. (2004) 'One town for my body another for my mind': services for people with physical impairments and mental health support needs. York: Joseph Rowntree Foundation.	Responses from 83 people to a questionnaire published in a nationally available booklet on disabled people and mental health services. 25 of the respondents were interviewed (purposive sample to give a range of respondents).	PAs or agency workers funded by DP or people’s own resources were also very poorly rated: 70 % of 17 respondents said the service they received was either poor or very poor. This may be due to a lack of support.
Newbigging, K. and Lowe, J. (2005) Direct payments and mental health: new directions. York: Joseph Rowntree Foundation.	Learning from a project to promote the use of DP for people experiencing mental distress. 4 focus groups were held in different parts of England, each targeting a different group of people: service users; voluntary groups, self-help and advocacy groups; practitioners, particularly care coordinators and frontline workers; senior managers. A multi-stakeholder national implementation event then reflected on the key themes emerging from the focus groups. Telephone interviews with lead managers for DP in 5 selected local authorities were held.	Straightforward, accurate and accessible information is needed for service users, carers and professionals, particularly care co-ordinators. This information needs to be specific to mental health and use real life examples to demonstrate how DP can be used, their potential impact, and how to access support to pursue a direct payment. Training and practice development for staff is needed, providing accurate information and an opportunity to explore concerns. Makes 9 other recommendations to facilitate the implementation of DP.
Pearson, C. (2000) Money talks?	Document analysis and exploratory	Pressures for local authorities to develop direct

Authors and publication	**Description of study**	**Summary of findings**
Competing discourses in the implementation of direct payments. *Critical Social Policy*, 20, 459–477.	interviews with policy-makers were followed by more detailed semi-structured interviews with the major stake-holders involved in the planning and organization of DP in 2 local authorities, one in Scotland, one in England. Semi-structured interviews were conducted with 35 DP recipients, between November 1998 and May 1999.	payment schemes draw on two discourses: market and social justice. In both authorities studies, the market discourse became the main determinant of policy direction (pro-market in one authority, anti-market in the other).
Pearson, C. (2004) Keeping the Cash under Control: What's the Problem with Direct Payments in Scotland? *Disability & Society*, 19(1), 3–14.	Revisits the study reported in (Pearson, 2000).	Suspicion from social work practitioners, fearful of job losses, has meant that the option of a direct payment has not been adequately communicated to potential users. Central government and local authority planners need to promote change more enthusiastically and evenly.
Ridley, J. and Jones, L. (2003) Direct What? The Untapped Potential of Direct Payments to Mental Health Service Users. *Disability & Society*, 18(5), 643–658.	Qualitative research carried out in 2001 in 3 local authority areas in Scotland, chosen to represent rural, urban and mixed geographical areas, and including one operating an indirect payments scheme. A telephone survey of all local authorities in Scotland to establish how many mental health service users were receiving DP. 4 focus group discussions with 2 mental health service user groups, a support group for younger people with dementia, and a carers' group explored the idea of DP. 3 case studies including 23 interviews with managers, support organisations, advocacy organisations and service users.	There had been little progress with the implementation of DP over the last 2 years. Staff were concerned that if more people opted for DP, existing services might suffer, reducing choice for people not in receipt of DP. There was a need for a local support organisation, independent of service providers, to offer expertise on DP.
Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestley, M. and Mercer, G. (2005). The Development of Direct	Draws on data from the ESRC-funded project Disabled People and Direct Payments: A UK Comparative Perspective, which is being	Slow take-up across the UK, uptake of DP is quite low, with wide regional variation. In general, Labour controlled authorities have

Authors and publication	**Description of study**	**Summary of findings**
Payments in the UK: Implications for Social Justice. *Social Policy & Society* 4:1, 75–85	carried out by researchers at the Universities of Edinburgh, Glasgow and Leeds between 2004 and 2006. The research includes an analysis of policy and official statistics on uptake of DP, telephone interviews with local authority representatives throughout the UK and case studies of local authorities with different approaches.	failed to develop DP, whereas in Conservative controlled local authorities, particularly where there is a strong user-led support organisation, the number of direct payment recipients has increased markedly. DP have the potential to be used by local authorities to reinforce, rather than challenge, existing inequalities in the social recognition accorded to particular groups of disabled people.
Social Services Inspectorate (2000) New directions for independent living: inspection of independent living arrangements for younger disabled people. London: Department of Health.	Findings from inspections during 1999 in ten councils, chosen to be broadly representative of English councils. The inspections aimed to examine how councils promoted and supported independent living arrangements for younger disabled people aged 18–65, particularly through the introduction of DP.	Limited progress in implementing DP had been made by most councils. Some councils and staff are ambivalent. Users involved in DP schemes were more satisfied with their arrangements than those receiving only services directly arranged or provided by councils. Users perceived gains in flexibility, service reliability and feelings of control.
Spandler, H. (2004) Friend or foe? Towards a critical assessment of direct payments. *Critical Social Policy*, 24(2), 187–209.	Analytical article focusing on employment of PAs. Separates out "progressive" arguments both for and against DP from "reactionary" arguments, and explores the "progressive" arguments, in order to move beyond a polarised debate towards a critical assessment of the potential of DP.	DP are not clearly a 'consumerist' or a 'democratic' approach to social policy, but actually an example of the convergence of the two, a convergence that yields both problems and possibilities. While DP have brought benefits, care must be taken that they do not reproduce wider problems in welfare. Suggests some necessary conditions for DP to continue to be a progressive strategy.

Authors and publication	**Description of study**	**Summary of findings**
Stainton, T. (2002) Taking Rights Structurally: Disability, Rights and Social Worker Responses to Direct Payments. *British Journal of Social Work*, 32, 751–763.	A questionnaire survey of adult social work teams in two Welsh local authorities that jointly fund an independent living scheme (ILS). 88 responses were received (32%). A representative sample of 8 social workers, were interviewed across a range of teams (older people, learning disability, mental health, physical disability). 4 of the social workers had clients using DP. Interviews were held with key informants from the ILS and both authorities. 25 users were also interviewed, 23 of whom were receiving DP, and all of whom were under 65. The vast majority had physical impairments. The study was conducted between 1999 and 2001.	Individual social workers seemed to accept that they needed to work more in partnership with clients. Structural conflicts of interest for social workers appeared to be the main barrier to greater control for DP users. Social workers found it more difficult to monitor the care packages of DP recipients, with much being taken on trust.
Stainton, T. and Boyce, S. (2004) 'I Have Got My Life Back': Users' Experience of Direct Payments. *Disability & Society*, 19(5), 443–454.	Reports on the same data as Stainton (2002).	For most interviewees the experience of DP had been overwhelmingly positive, enabling them to exercise choice and control over the nature and timing of their assistance. Family carers enjoyed many of the same benefits from DP as users. For most users, the fact that the staff of the ILS are disabled people themselves made a crucial difference to the quality of the service they provided.
Ungerson, C. (1997) Social Politics and the Commodification of Care. *Social Politics*, Fall, 363–381.	Review article analysing the breakdown of the dualism of paid and unpaid work, particularly within the context of care.	4 streams of literature, from the new right, from the disability lobbies, from feminists, and from welfare pluralists, see payments for care as potentially transformative. 3 of the streams are generally positive, but the feminist stream is concerned about the potential reinforcement of caring work being women's work. It may be that the impact of DP is overstated; an adequate understanding of the implications for

Authors and publication	Description of study	Summary of findings
		citizens, carers and users is yet to be developed.
Witcher, S., Stalker, K., Roadburg, M. and Jones, C. (2000). Direct Payments: The Impact on Choice and Control for Disabled People. Edinburgh: The Scottish Executive Central Research Unit.	Research in 1999 and 2000. Structured telephone survey of unitary authorities in Scotland, to provide an overview of implementation of DP nationally. 31 out of 32 took part. 32 semi-structured interviews in 4 local authorities – a pilot authority and 3 contrasting authorities in terms of stage of implementation of DP, levels of support for recipients, and setting (urban, rural and small town). The interviewees were 4 social work managers, 4 care managers, 4 organisations of disabled people/voluntary organisations, 12 people receiving DP, and 7 people with PAs who were not direct payment recipients. When an initial analysis had been carried out, a respondent validation meeting was held to which the Research Panel and all who had participated in the study were invited. Participants were asked to comment on the interpretation and discuss the implications.	DP can have significant benefits for recipients, particularly choice and control. There can also be benefits for family members, social services and the community. DP can reduce reliance on family members, and enable recipients to play a more active role in family life, and in society. DP can lead to more efficient use of human and financial resources. Access to DP depends on the approach of individual care managers, partly due to the absence of clear policy and practice guidelines.
Zarb and Nadash, (1994). Cashing in on independence: Comparing the costs and benefits of cash and services. Derby: British Council of Organisations of Disabled People.	Interviews with 70 disabled people from 4 local authority areas in the Midlands, the South of England, and Inner and Outer London. 15 people had 80% or more of their support met through direct or inDP, 27 did not receive any payments, and 26 had their needs met through a mixture of payments and services. Budget data from the local authorities was used to calculate the costs of payments schemes and services.	DP for disabled people may be more cost-effective than direct service provision, mainly due to lower administrative overheads, as much of the administration is done by the service users themselves. 'Mixed' arrangements combining services and payments may be both more costly and less efficient than either the payments option or services on their own.

Table A5 Systematising the evidence of impact of choice in primary and secondary education

Title author and publication details	**Description of the study**	**Summary of findings**
Bagley. C. and Woods, PA. (1998) School choice, markets and special educational needs. *Disability and Society*, 13, 5, pp.763–783.	Locating the debate within a policy framework of school choice and special educational needs in England and Wales, the article investigates the ways in which schools competing within the educational marketplace perceive and respond to the needs of parents of special education needs students, and considers the perspectives, experiences and values of these parents relating to school choice. In focusing in-depth on one case study area the article draws on the qualitative findings of the Parental and School Choice Interaction (PASCI) study, a 3-year longitudinal investigation into the interaction between parental choice of school and school decision-making.	The findings reveal the pressures on senior school managers and the difficulties encountered by parents of special educational needs students and suggest that as schools working in a public-market increasingly 'privilege the academic' so the needs and preferences of parents, and students with special education needs are increasingly marginalised and devalued.
Bradford, M. (1991) School performance indicators, the local residential environment, and parental choice. *Environment and Planning,* 23, pp.319–332.	The study uses past and present research findings, to argue for a need to introduce adjustments to the performance indicators to account for the effects of the local environment and perhaps parental choice itself, as well as prior attainment and social class.	The study argues against the use of unadjusted national tests to be used as school performance indicators to monitor schools effectiveness, and to form basis on which parental school should operate. These indicators are one of the major mechanisms in the newly constructed education system by which schools will compete for pupils and resources, are thus seriously flawed. This is because they neglect the effects of social geography.
Bradley S and Taylor J (1998) the effect of	This paper investigates the relationship	The primary result is that there is a non-

School size on exam performance in secondary schools, *The Oxford Bulletin of Economics and Statistics*, 60, 3, pp. 291–324	between school size and the exam performance of school pupils in their final year of compulsory education. Previous studies of this relationship have been seriously constrained by lack of appropriate data, but the publication of the School Performance Tables for all publicly-funded schools in England since 1992 permits the construction and testing of a multivariate model which includes school size as one of the explanatory variables. After controlling for factors such as type of school, teaching inputs and eligibility for free school meals, the partial effects of school size on exam performance are estimated.	linear relationship (in the form of an inverted-U) between school size that maximizes the exam performance of schools is estimated to be about 1,200 for 11 16 schools and 1,500 for 11 18 schools. These estimates are considerably higher than the current mean size of schools.
Bradley S, Crouchley, R Millington J and Taylor J. (2000) Testing for quasi-market forces in secondary education, *The Oxford Bulletin of Economics and Statistics*, 62(3), pp.357–390.	This paper investigates the effect of introducing quasi-market forces into secondary education on the allocation of pupils between schools and on the exam performance of pupils. A unique database is used which covers all publicly-funded secondary schools in England over the period 1992 98.	The authors find several effects consistent with the operation of a quasi-market. Firstly, new admissions are found to be positively related to a school's own exam performance and negatively related to the exam performance of competing schools. Secondly, a school's growth in pupil numbers is positively related to its exam performance compared to its immediate competitors. Thirdly, there is strong evidence that schools experiencing an excess demand for places have responded by increasing their physical capacity. Fourthly, there is some evidence of an increase in the concentration of pupils from poor family backgrounds in those schools with the poorest exam performance of schools during 1992 98 can be attributed to the introduction of quasi-market forces.
Burgess S, Propper C and Wilson D. (2005)	The report reviews the economic evidence	The key findings on education are:

Choice. Will More Choice Improve the Outcomes in Education and Health Care? The Evidence from Economic Research. Centre for Market and Public Organisation, University of Bristol. Bristol: CMPO, University of Bristol.	mostly from the UK but also from elsewhere, about the effect of choice in education and health. It provides a conceptual framework built around the definition of choice (what), act of choice (what from) and actors (who), outlining constraints and limitations of choice.	a successful choice policy would improve standards for most school children but gains of working class might lead to losses of middle classes (through falling prices of property). The key to successful school policy is flexibility of supply. If greater choice is universal it should not leads to segregation or 'sorting' which currently comes by residence or ability. The role of children's peer groups is important in determining the effects of school choice, and the quality of peer groups may influence parents' choices and the capacity of school to generate good exam results.
Dustman, C. (2004) Parental background, secondary school track choice, and wages. *Oxford Economic Papers*, 56, pp.209–230.	In this paper, we use micro data to analyse the association between parents' education and profession, and secondary track school choice and subsequent career prospects of the child. Our analysis covers the last six decades in Germany, USA and the UK.	We demonstrate that parental background is strongly related to the secondary track choice of the child, and subsequent educational achievements. We find a slight convergence for individuals from different parental background over the last decades. We also find a positive trend for females to follow higher secondary school tracks, keeping parental background constant. The association between parental class and educational choice translates into substantial earnings differentials later in life.
Gibson. A, Asthana, S. (2000). Local Markets and the polarization of public-sector schools in England and Wales. *Transactions of the Institute of British Geographers.* 25, 3, pp.303–319.	This paper seeks to ass empirical weight to this debate whether the new government's goal was to 'overcome the spiral of disadvantage … passed from one generation to the next', can be achieved via market means despite long standing arguments concerning the socially-divisive	Arguing that recent analyses of aggregate levels of social stratification have masked polarization occurring at the local level, our analysis places schools in the context of the local markets within which they operate. This yields clear evidence that educational markets tend to exacerbate existing

	consequences of market forces in education.	differences between schools in terms of both their performance and social status. Notwithstanding the recent change of government, UK educational policy continues to stress school performance tables, parental choice and competition – reflecting an acceptance by New Labour of Tory notions concerning the role that market mechanisms play in improving school performance.
Gorard, S. (1998). Social movement in undeveloped markets: an apparent contradiction. *Educational Review.* 50, 3, pp.249–258.	This paper considers two aspects of the market reforms in secondary education on Wales since the Education Reform Act 1988: parental choice of schools and its impact on patterns of social segregation between schools. The data comes from tow separate projects – a study by survey and interview of school choice in 800 families and a study via secondary analysis of social segregation in 81 schools.	In Wales, school choice is not found to be as significant nor the market as developed as in England for a variety of geographical, economic and cultural reasons. If anything, the market in Wales appears to be pulling schools towards similarity rather than diversity. Schools in Wales are therefore moving towards less social segregation, while most commentators in England and Scotland are suggesting market reforms will lead to the opposite. Why this should be so is the main discussion point raised by this paper.
Gorard S, Fitz J. (1998). The more things change… The missing impact of marketisation?. *British Journal of Sociology of Education.* 19, 3, pp.365–376.	This paper uses longitudinal data from secondary schools in six of the new unitary authorities in South Wales – Cardiff, Swansea, Merthyr Tydfil, Bridgend, Caerphilly and Rhondda Cynon Taff local education authorities – to provide and empirical test of the academic debate concerning the likely effects of school choice on the social composition of differing schools.	Using several measures of segregation between schools, including a new one calculated from eligibility for free meals, the study concludes that the introduction of choice reforms for England and Wales in 1998 may have had a small but significant positive effect on the pre-existing social stratification between schools. In coming to this conclusion, the study inevitably raises questions about the findings generated by some previous qualitative studies of markets and choice in education.

Gorard, S and Taylor, C. (2002) Market forces and Standard in education; a preliminary consideration. *British Journal of Sociology of Education*, 23, 1, pp.5–18.	This paper considers the possible impact of market forces on educational attainment in secondary schools in England and Wales. One of the main arguments made by market advocates in favour of extending programmes of school choice was that this would drive up standards. However, despite 12 years of relevant experience in the UK, it remains very difficult to test this claim. This paper examines some practical difficulties before presenting three possible models for considering changes in educational standards over time.	The results are inconclusive, possibly even contradictory. The measures, such as GCSE and A levels, extending back to 1988 and beyond, have clearly increased in prevalence. In terms of these measures, students from state-funded education have also reduced the 'gap' relative to those from fee-paying institutions. However, it is not clear that either of these developments is market related. In addition, there is no evidence yet that these improvements indicate any breakage in the strong link between the socio-economic background of students and their school outcomes.
Gordon S, Taylor C, Fitz J. (2002). Does School choice lead to 'spirals of decline'?. *Journal of Education Policy.* 17, 3, pp.367–384.	This paper considers the notion of schools in a spiral of decline, in which less popular schools within a market system lose numbers and increase their proportion of socially disadvantaged pupils over time. The study looks at raw-score performance indicators to examine whether such a decline could quickly become a spiral, with disadvantage leading to poorer aggregated results, leading to less popularity and so on. Authors use data derived for all secondary schools in England from 1989 to 1999, to examine evidence for any increase in the existence of such schools.	There was little evidence found for any increase in the existence of such schools. Whether we consider falling rolls, closing schools, or special measures we find only one school, among 30 local education authorities considered in detail, that has both consistently falling rolls and increased social disadvantage. This one example may be due to market pressure, but we also authors present the suggestion that such irregular events happened prior to 1998 anyway. It is the case that the greatest increase in relative disadvantage in this school was from 1998 to 1999 (i.e. ten years after the Education Reform Act 1988), while its level of disadvantage as late as 1992 was only marginally higher than in 1989.
Hatcher. R. (1998). Class differentiation in education: rational choices?. *British Journal of Sociology of Education.* 19, 1, pp.5–24.	This paper examines the explanation of class differences in choices at transition or branching points in the system which is	Social class differentiation in education results not only from differences in academic ability and processes of

	offered by Rational Action Theory in the light of evidence from qualitative studies of educational transitions. It also explores the relationship of 'rational action' to Bourdieu's theory of cultural reproduction, with reference to some recent research into parental choice of school.	institutional differentiation but also processes of self selection of pupils, students and their parents in the progression through the school system and into higher education, training and employment. It concludes with a discussion of reconceptualised notion of 'rational action'.
Hoxby, C. (2000) Does competition among public schools benefit students and tax-payers? *American Economic Review* 90, pp.1209–1238	Tiebout choice among districts is the most powerful market force in American public education. Naive estimates of its effects are biased by endogenous district formation. Instruments are derived from the natural boundaries in a metropolitan area.	The results suggest that metropolitan areas with greater Tiebout choice have more productive public schools and less private schooling. Little of the effect of Tiebout choice works through its effect on household sorting. This finding may be explained by another finding: students are equally segregated by school in metropolitan areas with greater and lesser degrees of Tiebout choice among districts.
Hughes, M (2004) *Enabling Choice. A report to the Local Government Association.* School of Public Policy, University of Birmingham. Birmingham: University of Birmingham.	The report provides four contributions on choice in different areas of public service: Parental choice in Schools Patient Choice in the NHS Choice based lettings in social housing Choice in social care Each contribution in this report considers choice in terms of current debates in each of the public services drawing on the evidence available. These debates follow a common framework that is concerned with: the purpose of service, the range of choice, the exercise of choice, the framework of choice, support for choice, the values of choice, the costs of choice and the judgment of choice.	Key findings on education are: -'parents' choice' has turned schooling into commodity marketed to parents, rather than a public service for the benefit of the children. -as the key features of the quasi-markets introduced trough Education Act (1988) remain in place so do the undesirable effects such undermined social inclusion. - the research on the effects of 'quasi-markets' remains inconclusive. - there is little doubt however, that there is strong tendency for choice mechanisms to benefit the already advantaged, which present authorities with a major challenge.

Ladd, F. (2002) School vouchers: A critical view, *Journal of Economic Perspectives* 16(4) pp.3–24.	Ladd uses available evidence regarding school vouchers, including international data, to show that contrary to the claims of its proponents, a large-scale universal voucher program would not generate substantial gains in overall student achievement and that it could well be detrimental to many disadvantaged students.	School voucher programs are particularly controversial because they would permit parents to use public funds to secure education not only at public schools, but also at private schools.
Ladd, F. and Fiske, E. (2001) The uneven playing field of school choice: Evidence form New Zealand. *Journal of Policy Analysis and Management.* 20(1) pp.43-64.	New Zealand's 10-year experience with self-governing schools operating in a competitive environment provides new insights into school choice initiatives now being hotly debated in the United States with limited evidence. This article examines how New Zealand's system of parental choice of schools played out in that country's three major urban areas with particular emphasis on the sorting of students by ethnic and socioeconomic status.	
Lens, V and Gibelman, M (2002) School choice: how will children with disabilities fare? *The Social Policy Journal*, 13, pp.37–50.	The study examines the legal basis for special education services in the USA, and explores the extent to which the rights of children in private schools based system would be protected.	The authors conclude that serious questions of equity exist, with a disenfranchisement of children with special needs a likely consequence if vouchers are adopted on a broad scale.
Nechyba, T (1999) School finance induced migration patterns: The impact of private school vouchers, *Journal of Public Economic Theory* 1, 1, pp. 5–50.	This paper introduces a complex general equilibrium model of public school finance to analyse the impact of vouchers. In particular, the impact of vouchers in the context of different types of prevoucher educational finance systems is investigated.	The abstract model itself, is too complex to yield many analytic results. A computational counterpart to the model is therefore developed, calibrated to data, and utilized for policy experiments. It is found that migration patterns in general would cause vouchers to benefit public schools in poor communities while hurting public schools in

		wealthy communities.
Nechyba, T (2003) School finance, spatial income segregation and the nature of communities, *Journal of Urban Economics*, 54, 1, pp.61–88.	The study looks at the combination of a public system with a private school market to ascertain the least residential segregation as housing price distortions from the capitalization of the public system. The impact of vouchers and the sensitivity of results to alternative school production models is also investigated.	In a general equilibrium model that links school and housing markets, a purely public school system (regardless of the degree of centralization) results in substantially more spatial income segregation than a purely private system. However, the combination of a public system with a private school market yields the least residential segregation as housing price distortions from the capitalization of the public system generate incentives for middle and high income private school attendees to live with lower income public school attendees.
Parsons E, Chalkley B, Jones, A. (2000). School catchments and pupil movements: a case study in parental choice. *Educational Studies.* 26, 1, pp.33–48.	This paper, therefore, uses data provided by a case-study local education authority to examine the nature and scale of pupil flow across catchment boundaries. It does so by adopting a form of Geographical Information System as the principal research tool.	The results show over a third of Year 7 pupils moving to schools other than their catchment comprehensive. Interestingly, the inner-city catchments were the most permeable: by contrast, children in middle class and rural area were the least likely to enter schools outside their local area.
Reay, D and Lucey, H. (2003). The limits of 'choice': children an inner city schooling. *Sociology*, 37, 1, pp.121–142.	This paper attempts to retheorize school 'choice'; to begin to unpack dominant contemporary misconceptions through an examination of the 'choices' available to 454 inner city 10 and 11 year-olds engaging in the process of primary-secondary school transfer in England. The study argues that the prevalent focus within educational theorizing on 'choice' as a form of agency often masks the fact that 'choice' is a marker of economic privilege. It asserts that the more distant subjects are from economic necessity the more 'choice'	The majority of children in this research study had no 'choice' but to make a virtue out of necessity. They were forced to accept the least bad option. Particularly disadvantaged were the large numbers of refugees in the sample and those children, cutting across class and ethnicity, who chose 'against the grain'. Authors conclude that school 'choice' is an issue of power and constraint, of class and racial processes, although the possibilities of 'choice' cannot in any straightforward way be seen as conterminous with class positioning, implicating, as it does, both ethnicity and

	becomes a possibility.	fractions and differences within classes as well as between them.
Taylor, C. (2001a). The geography of choice and diversity in the 'new' secondary education market of England, *Area.* 33, 4, pp.368–381.	This paper reaffirms the position of a geographical approach to studying the education system by focussing on the differential impact of two major features of national policy reforms on secondary school admissions in England: the desire to enhance choice and diversity on the provision of schooling.	The geography of education remains an under-researched area, particularly in light of major transformations in education provision over the last two decades.
Taylor, C. (2001b). Hierarchies and 'local' markets: the geography of the livid market place in secondary education provision. *Journal of Education Policy*. 16, 3, pp.197–214.	While not providing a social class analysis of market competition this paper aims to build upon such work by introducing other factors that appear to be present in the education market place. In this paper market competition is considered along two broad dimensions. This first examines educational markets as spatial phenomenon. In the second empirical study of competition and markets in action is undertaken based on one year's transfer of pupils to secondary schools across six local education authorities, each with different geographies. The study proposes three key ways in which competition between schools can be classified.	The paper suggests that the education market place is, generally, hierarchical, and that the position of schools within these hierarchies is largely associated with their relative examination performances. The paper concludes by suggesting that the concept and subsequent identification of the 'local' markets is necessary before addressing issues such as the impact on school rolls and potential social segregation of intakes.
Taylor, C, Gorard, S. (2001). The role of residence in school segregation: placing the impact of parental choice in perspective. *Environment and Planning A*. 33, 10, pp.1829–1852.	The study examines many claims that the introduction of parental choice for schools in the United Kingdom would leave to further socioeconomic segregation between schools by reviewing the evidence available.	There is little evidence that segregation had actually emerged. Instead during the first half of the 1990s, in particular, the number of children living in poverty became more equally distributed between UK secondary schools. Part of the explanation for this lies with the prior arrangements for allocating children to schools, typically based upon designated catchment areas. The paper

		argues that the degree of residential segregation that exists in England ensured that schools were already highly segregated before the introduction of market reforms to education, and has continued to be the chief determinant or segregation since.
West A, Pennell, H. (2002). How new is new labour? The quasi market and English schools 1997 to 2001. *British Journal of Educational Studies.* 50, 2, 206–224.	This paper focuses on the reforms made to the quasi market in school-based education in England that occurred between May 1997 and May 2001. It discusses the changes that have taken place in relation to parental choice, admissions to schools, school diversity, funding and examination 'league tables'.	The Labour Government can be seen as having embraces the quasi-market with a similar enthusiasm to that of its Conservative predecessors although it has tended to emphasise social inclusion as opposed to competition. While it has attempted to soften the edges of the quasi-market it has not tackled some of its major deficiencies such as the power that schools have who are their own admission authorities have to distort the admissions process.
Williams, J and Rossiter A. (2004) Choice: the evidence. The operation of choice systems in practice: national and international evidence. London: The Social Market Foundation.	The report reviews comprehensive evidence from introducing market mechanisms and parental choice into primary and secondary education systems in the UK, Sweden, New Zealand, USA and Chile. It provides a very thorough account of the impact of choice in schools from international comparative perspective.	These are the key findings of the report: -given specific policy conditions (flexibility of supply and excess capacity), school choice can have a 'levelling up' effect on the performance and efficiency of the state schools. - there is no consistent evidence that choice leads inevitably to higher polarisation between best and worst - there is little evidence whether benefits outweigh the costs - new forms of provision have been present only in non-selective schools in the USA -activity in choosing tends to be skewed toward most advantage families and support is needed if all families are to benefit from

		choice. -segregation of children by ability is a reality but it may produce higher outcomes for the less advantaged. Thus it needs to be dissociated from educational outcomes as there are trade-offs involved between the two values.
Wilson, D. (2004) Which ranking? The impact of 'value added' measure of secondary school performance, Public Money and Management 24(1): 37–45.	This article analyses the impact of a value-added performance indicator (PI) on the rankings of secondary schools in the English league tables. School rankings are seen to be very sensitive to the type of PI employed, and the new value-added PI is likely to result in significant movements up and down the rankings. There is still scope for schools to try and game the system in order to improve their league table position. Value-added PIs reduce the incentives for schools to select their pupils, but the version currently employed in England may create an incentive for schools to distort effort away from those pupils at the top end of the distribution.	The value-added PI is shown to provide a more accurate measure of school performance. However, in order for parents to be effective drivers for improvement in the education market, it may also be necessary for the government to measure the impact of differential value-added across different student types.