

seminar briefing no2



THE UNIVERSITY
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PUBLIC INVOLVEMENT IN PRIORITY SETTING

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This OHE / HSMC briefing summarises the presentations and discussion at the seminar "Health economics approaches to public involvement in priority setting" held at the Health Services Management Centre, University of Birmingham on 3rd March 1999.

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Executive Summary

- International and UK experience illustrates the difficulty of involving the public in health care priority setting in ways that enable politicians, managers and doctors to incorporate public preferences into practical decision making.
- Many techniques for measuring public preferences fail to incorporate key concepts:
 - opportunity cost. What are people prepared to give up or have less of, in order to have more of something else? The public have to be asked to make trade-offs;
 - strength of preference. Satisfaction surveys, for example, do not reveal by how much one treatment or aspect of service is preferred to another;
 - a marginal approach. The public have to be asked questions that mirror the practical decisions that have to be made, otherwise their responses cannot be related to the issues faced by decision makers.
- Stated preference methods of measuring public preferences were initially used in the UK to inform pricing and investment decisions in public transport.
- Their use is now more widespread, because they replace the need for "gut feel" and judgement about public preferences about services where these cannot be directly observed. Up until now these methods have been used in health care only to focus on individual services, for example to measure trade-offs between waiting times for appointments and distance to travel.
- A study commissioned by East and North Hertfordshire Health Authority used stated preference methods to understand public preferences in priority setting, i.e. making a treatment available to one patient group at the expense of denying another treatment to another patient group.

- The results have to be interpreted with care but suggest that treatments for individual patients that cost more than £100,000 were rarely supported, whilst those costing below £70,000 were usually supported. The public did not always prefer choices that maximised health gain, sometimes preferring treatments that provided simply a good quality life.
- Stated preference methods often involve the use of qualitative research, to help identify the key issues of concern to the public, to pilot the types of questions to be asked, and, after the quantitative component of the study has been completed, to help the researchers understand and interpret the results.
- However, this assumes that preferences exist, are complete and are stable. It is likely that people's choices are partially constructed during the process of answering questions, which requires researchers to

ensure that people have time to reflect before answering questions. Qualitative research should be used to ensure that quantitative results are valid and that the underlying reasons for the trade-offs are understood.

- All attempts to involve the public in health care priority setting must accord the public respect. Whilst the views of the public will only ever be one of many criteria informing resource allocation, the results of research exercises involving the public must be seen to inform the decisions that are made. Stated preference methods, incorporating the effective use of qualitative research, offer an approach that can provide measured preferences in a way that directly addresses the decisions to be taken. This enables a direct link to be established between the views of the public and their impact on the decision making process.

INTRODUCTION TO PRIORITY SETTINGS

Adrian Towse

Adrian Towse introduced the seminar and argued that economics will make an increasingly important contribution to priority setting in health care in the near future. Until now, the most frequent input of economics to the priority setting process has been through appraisal of investment options and/or service reconfigurations. Health economists have been involved in the 'nitty-gritty' work of economic evaluation, i.e. in the measurement of incremental health gain relative to cost, but this is only a building block for the decisions that must be taken over which interventions to choose. Stated preference methods have been used in health care to elicit public preferences as between different attributes of a public service. However, they have focused on aspects other than health gain, for example the trade-off between waiting time and distance to travel. This seminar investigates the extent to which stated preference methods can contribute to an understanding of public preferences for one type of health care treatment to be made available to one patient group, as compared to another treatment to be delivered to a different patient group.

Any discussion of priority setting should start with definitions of the key terms. We can adopt Alan Williams' definition of rationing:

'...when someone is denied, or simply not offered, an intervention that everyone agrees would do them some good and which they would like to have'
(Williams, quoted in Maynard and Bloor, 1998).

We could add to this definition '*... or when someone experiences significant delay in getting access to such an intervention*'. The Williams definition, as amended, means that in the day to day experience of the health service, decisions about rationing in one form or another are being taken all the time.

Developments in the 'new NHS' will raise aspects of the priority setting agenda at several levels of the NHS:

- The National Institute for Clinical Excellence (NICE) will be explicitly looking at priorities, in the context of what else the health service can do with the money that might be spent on a new intervention.
- National Service Frameworks will be commissioned in an order which reflects the priorities given to tackling different diseases.
- Health Improvement Programmes will become local attempts to prioritise and to interpret National Service Frameworks and national priorities.

- Local decisions on commissioning services and local service reconfigurations are additional important priority setting activities.
- Waiting lists are currently the target of an initiative. The sustainable long term approach is to improve the NHS's ability to prioritise within lists, setting differential waiting time targets.
- The need for Primary Care Groups to live within local budgets will cement the need for improved priority setting in the 'new NHS', if we are to avoid the need for ad hoc rationing to make quick savings to achieve year-end budget targets.

"The health care sector is a monopoly public service, where the majority of the public do not have the option of 'exit' with which to express their preferences and so rely on 'voice'."

Adrian Towse

Should we involve the public?

Arguments have been put forward for and against public involvement in health care priority setting:

- The democratic deficit. Lack of elected representation means that decisions taken by local health managers and health authorities lack a mandate. Hence the need for local consultation. This misses the point. Locally elected councillors still hold public meetings and other forms of consultation to understand public views on particular issues.
- The utility of ignorance. This view holds that the public would prefer not to be involved in health care priority setting because there is a disutility from participating in a decision to deny someone treatment; yet the public know these decisions are being made, and are not expecting patients to be lined up in front of a public panel for them to make decisions on individual cases.
- The 'tyranny of the majority' argument holds that public involvement in priority setting may lead to a reduction in service provision for some groups of patients. However the role of public involvement is to inform decision making, not to enable managers and doctors to abdicate responsibility.
- The health care sector is a monopoly public service, where the majority of the public do not have the option of 'exit' with which to express their preferences and so rely on 'voice'. Towse believed this was the most important case for public participation.

In a review of public involvement in health care, Kneeshaw (1997) discussed the range of different methods that have been used so far, from opinion polls and satisfaction surveys to citizens' juries. These

methods have produced a range of findings as to public priorities. Some common themes that emerge are:

- Disagreement over the necessity of rationing.
- Significant differences between public priorities and professional priorities. For example, the public give greater priority to high technology medicine and professionals give greater priority to mental health.
- A strong view that final decisions are best left to doctors. The public want some involvement in setting the framework for decision making, and not in decisions about which named individuals are to receive care.
- The critical role of information and communication. In any consultation exercise there is a need to assess whether people have the information they need, whether they understand the tasks they are presented with, and whether the researchers correctly interpret the meaning of the responses obtained.

International experience on public involvement in priority setting provides mixed results. The Dunning Commission in the Netherlands and the National Medical Commission in Sweden are examples where agreement was reached on principles for priority setting, but there have been problems in operationalising these. Oregon has been the most renowned and most successful example of health care priority setting. A major feature of its success may well have been the contextual setting. All treatments were considered (presenting people with explicit lists) with the clear intention that practical trade-offs had to be made in order to achieve a community benefit of extended coverage (i.e. Medicaid coverage would be limited in scope but provided to a much large proportion of the population). Initiatives in New Zealand provide an example of explicit priority setting between patients within surgical waiting lists, but an attempt to define 'core services' was less successful.

International and UK experience illustrates the difficulty of involving the public in health care priority setting. Towse argued that, to be useable, public involvement had to involve choices that contained opportunity costs. Trade-offs had to mirror the choices politicians, managers and doctors had to make if they were to be of value. However, it cannot be forgotten that priority setting is a politically difficult and emotionally highly-charged policy area. We are looking for frameworks in which to make 'tragic choices'. The pendulum swing we see between different approaches may well arise from the desire of society to 'limit the destructive impact of tragic choices by choosing to mix approaches over time.' (Calabresi and Bobbit, in Locock, 1998)

'ECONOMIC' APPROACHES TO GETTING PUBLIC PREFERENCES

Mandy Ryan

Mandy Ryan argued that economics, as a discipline concerned with the allocation of scarce resources, embraced any instrument used to elicit public preferences to aid decision making. However, the use of economics in health care has been very quantitative, with a focus on instruments to provide numerical measures of benefit or utility. Although a wide range of public preference exercises have been carried out over time, from patient satisfaction surveys to stated preference methods, economists (Shackley and Ryan, 1995) have criticised many techniques as failing to take account of key concepts of opportunity cost, (i.e. we have to provide less of something if we want to provide more of something else), strength of preference (i.e. it is not enough to know that A is preferred to B, we have to know how much of B would be given up for some more of A) and the marginal approach (i.e. asking the public about the choices that actually have to be made). For example, satisfaction surveys may elicit aspects of service with higher and lower levels of satisfaction, but fail to capture people's strength of preference for improvements in each of these aspects.

Health economics has used three main approaches to elicit public preferences: (a) standard gamble and time trade-off techniques, to calculate quality-adjusted life years (QALYs); (b) willingness to pay techniques; and (c) conjoint analysis, which is also often called either 'stated preference' or 'discrete choice modelling'. All of these are based on the key premise that something is only of value if people are willing to give up something else for it: the QALY techniques involve the sacrifice of certainty or time, willingness to pay involves the sacrifice of money, and conjoint analysis

involves direct trade-off between aspects of health care.

The history of these approaches, in terms of their application to eliciting public preferences in health care, reflects debate about what is important to patients in the provision of health care, and especially of the importance of non-health outcomes (e.g. obtaining reassurance from a doctor) and process attributes (e.g. how long people wait and the distance they have to travel to get treated). Until the start of this decade, standard gamble and time trade-off were the two main economic techniques used to involve the public in decision making. In the early 1990s many economists argued that the pressing factors at health authority level were not only survival and quality of life, but also concerns about important non-health and process outcomes. Health services research had previously shown the last two to be important, but had no means of detailed measurement or valuation. Willingness to pay techniques, widely used in environmental economics and elsewhere, allow respondents to consider all relevant aspects of a health care intervention in their response. However, concerns over the effect of ability to pay on willingness to pay led to increased use of conjoint analysis as an alternative economic instrument that could go beyond health outcomes to incorporate non-health outcomes and process attributes of health care interventions. Conjoint analysis techniques have been widely used in market research and transport economics and have been recommended by a UK Treasury Working Group (Cave et al., 1993) as a technique for valuing changes in the quality of public services.

Box 1 **Benefit assessment in health economics**

A. Quality-adjusted life years (QALYs)

The QALY approach is based on the simple idea that the health benefit of health care programmes can be summarised as the survival benefit weighted to reflect the quality of life in that survival (Williams, 1985). The challenge within this has been how to measure quality of life. The two main methods used to estimate quality weights have been standard gamble and time trade-off techniques; other methods (e.g. visual analogue scales and magnitude estimation) are not widely used.

(i) Standard gamble

An individual is presented with a hypothetical choice between a certain outcome (B) or a gamble which may result in a better outcome (A) (with probability P) or a worse outcome (C) (with probability 1-P). The utility weight of health state B is given by the level of probability P* at which the individual is indifferent between a gamble and the certain outcome. A criticism of this technique arises from the known difficulties many people have understanding probabilities. The time trade-off

technique was developed in response to these concerns.

(ii) Time trade-off

An individual is presented with a hypothetical choice between living for a period T in less than perfect health (B) or living for a shorter time H in better health (A). The quality weight of health state B is given by the ratio H/T at the point where the individual is indifferent between the two alternatives. This technique was used with the EuroQol instrument to elicit UK general population preferences for health states (Dolan et al., 1995).

B. Willingness to pay (WTP)

WTP is based on the simple premise that the maximum amount of money an individual is willing to give up for a commodity is an indication of the value to them of that commodity. Individuals can take account of whatever characteristics of the health care intervention are important to them in deciding their maximum WTP. Four approaches have been developed to attempt to elicit maximum willingness to pay:

(i) Open-ended approach

An individual is asked how much they would be willing to pay for a given intervention. Open-ended questions have been criticised as too difficult to answer, as people are not used to being asked for their maximum WTP.

(ii) Bidding techniques

In an interview setting, an individual is asked whether they would pay £X for a given intervention. X is then bid up (down) until the individual says no (yes).

(iii) Payment card techniques

An individual is presented with a scale of monetary

amounts and asked to tick those they are willing to pay, cross those they are not, and circle the amount which represents the maximum they would pay. These are, in essence, an attempt to capture a bidding process in postal questionnaire form. They have worked well in health economics, and continue to be used.

(iv) Closed-ended questions

An individual is asked whether they would pay an amount £X for a given intervention. X is changed between respondent groups. Closed-ended methods were recommended in environmental economics as the preferred technique, although the empirical basis for this recommendation is limited and comparison of the use of these and payment card techniques in health economics is being investigated.

C. Stated preference or conjoint analysis

Stated preference or conjoint analysis is based in random utility theory. Techniques include ranking and rating exercises typically used in market research and discrete choice approaches used increasingly in transport and health economics. All techniques present an individual with scenarios defined in terms of a limited number of attributes deemed important to the intervention concerned; levels of attributes are varied across scenarios. The individual is asked to rank or rate scenarios, or to make a series of choices between scenario pairs. Individuals are not asked directly their maximum willingness to pay. Rather this (or benefit scores) can be calculated indirectly through statistical analysis to provide a measure of satisfaction or strength of preference. Figure 1 presents an example of one of the pairwise choices that people were asked to make in a study of preferences between different ways for providing in vitro fertilisation (IVF) services (Ryan, 1999).

Figure 1

Choice 1	Clinic A	Clinic B
Attitudes of staff towards you	Good	Good
Chance of taking home a baby	25%	25%
Continuity of contact with same staff	No	Yes
Time on waiting list for IVF attempt	18 months	18 months
Cost to you of IVF attempt	£1,500	£3,000
Follow-up support	No	No

Prefer Clinic A

Prefer Clinic B

Which clinic would you prefer?
(tick one box only)

Economic approaches can address two types of question: whether a service should be provided (or its scale changed), termed 'allocative efficiency' choices; and the way in which services should be provided,

"It is important to be sure that if you are going to invest time and money in eliciting public views, that you will be able to use this information to improve decision-making processes."

Mandy Ryan

termed 'technical efficiency' choices. Conjoint analysis has so far been used mainly to address the latter type of question, for example patient valuation of obstetrician- vs. midwife-led maternity care or of specialist nurse vis-à-vis consultant roles. Willingness to pay has also been used mainly to address technical efficiency questions, although one study attempted to apply willingness to pay to address an allocative efficiency question (Abel Olsen and Donaldson, 1998). QALYs have been used to address both types

of question, but looking only at health outcomes in order to do so.

It is important to be sure that if you are going to invest time and money in eliciting public views, that you will be able to use this information to improve decision-making processes. The three economic techniques outlined above all involve the key concepts of opportunity cost, strength of preference and the marginal approach, such that they can determine not only which options are preferred, at the margin but the strength of that preference. These techniques are very quantitative in nature, although there is much to be gained from using qualitative techniques as well. It is a fair criticism of economics that it is overly quantitative at the current time. Quantitative aspects are crucial, but the role of qualitative research and the need to combine both approaches has to be recognised. Conjoint analysis incorporates a mix of qualitative and quantitative approaches: the use of qualitative research in the first stages is critical to discover the appropriate set of attributes to include in choices; regression analysis is required to exploit the data generated by a conjoint analysis study; and there is scope for using qualitative research to investigate the validity of research findings.

STATED PREFERENCE METHODS FOR ELICITING VALUES

Rob Sheldon

Rob Sheldon provided more detail on the history, theory and practice of the stated preference approach (also known as the conjoint or trade-off method). Stated preference is a market research mechanism: a means of asking questions which provides a better understanding of the way in which people make choices. Rather than using direct questions, preferences are sought between packages of attributes, so making it more difficult for respondents to role play or answer strategically.

This method originated in the United States in the 1970s and was imported by UK economists to investigate price, journey time and frequency elasticities for British Rail. It became a common tool of transport economics in the 1980s, where it was subjected to substantial academic scrutiny, and subsequently became the recommended tool of several government bodies. The late 1980s and 1990s saw more widespread use of stated preference methods, both internationally and across sectors in the UK.

Certain aspects of stated preference methods can account for their popularity, in particular that they:

- replace the need for 'gut feel' and judgement over public preferences in sectors where these cannot be directly observed;
- replace and/or complement available data from revealed preference models (i.e. models that use data based on records of choices people made when using services), which can be expensive and inflexible, and from other approaches that have been used to explore preferences;
- come with heavyweight professional endorsement.

Stated preference methods are commonly used to address the question 'What are the priorities for resource allocation, and how do these differ by market segment?', but can also be used to investigate the worth of specific initiatives and/or the effect of such initiatives on public/consumer behaviour. Box 2 sets out an example.

Box 2 Stated preference task: example

Each participant is asked to complete a task, typically consisting of eight to ten choices. Each choice incorporates a number of attributes (typically four or five) of the good or service being investigated, presented within an overall package. The levels of some or all attributes vary between choices. Participants are asked to choose one option or the other in each of eight to ten different pairings and may be asked to give a strength for that preference (as below).

Car insurance example choice:

Option A

Pick up and ride to destination – within 50 miles

Loan car during repair – not supplied

Repair by approved manufacturer – yes

Annual premium – £375

Option B

Pick up and ride to destination – no service

Loan car during repair – own car standard

Repair by approved manufacturer – yes

Annual premium – £410

Which option do you prefer?

Definitely A

Probably A

Don't know

Probably B

Definitely B

Theoretical and design issues

Stated preference methods are an attempt to express the satisfaction or usefulness obtained from alternative patterns of resource allocation. The underlying economic theory is that of expected utility, where the technique aims to identify the factors entering the respondent's utility function, and the coefficients on these. To do so, an assumption of linearity is normally employed (i.e. the coefficients can measure how much of one attribute will be traded for more of another attribute), the technique then works by decomposing the elements of choice to estimate both the set of factors that are important to the respondent and the relative importance of each of these.

There are a range of issues involved in the practicalities of experimental design:

"stated preference methods...replace the need for 'gut feel' and judgement over public preferences in sectors where these cannot be directly observed"

Rob Sheldon

- what to include in the attribute set: it can be derived from client concerns, brainstorming with the client and/or the public, and/or from qualitative

research with the public;

- research setting: face-to-face interviews, telephone interviews, computerised tasks and self-completion questionnaires can all be used;
- number of tasks: whilst the number of tasks that any one individual can deal with is limited, especially when there are a large number of attributes, careful research design allows a large number of tasks to be covered given sufficient sample size by giving different sets of trade-offs to different sub-groups;
- complexity of task: whilst the public have been shown to be capable of completing complex exercises, task complexity has to be managed and will be affected by the specific nature and number of issues and participants involved;
- task design: software using fractional factorial design allows the number of choices to be minimised, with little loss of information on the interdependence of attributes. This is illustrated in Figure 2.

An important question in all of these studies is whom to ask. There is no scientific answer to this and there are arguments for using either representative samples of the public (as we are concerned with taxation-funded services) or service users (as the informed group on the services discussed). Choice of respondent group does appear to affect results, e.g. proxies' values over-estimate the impact of disease on quality of life when compared to patients' values. Stated preference methods have been used with the

Figure 2 Design task

1 Full factorial design

	Attribute 1	Attribute 2	Attribute 3
Alternative 1	1	1	1
Alternative 2	1	1	2
Alternative 3	1	2	1
Alternative 4	1	2	2
Alternative 5	2	1	1
Alternative 6	2	1	2
Alternative 7	2	2	1
Alternative 8	2	2	2

2 Fractional factorial design

	Attribute 1	Attribute 2	Attribute 3
Alternative 1	1	1	1
Alternative 2	1	2	2
Alternative 3	2	1	2
Alternative 4	2	2	1

Fractional design uses fewer alternatives, but at the cost of constraining the ability to look at all interactions.

Box 3 Case study: London Underground

London Underground has a large number of potential investment options. The broad objective of the organisation is to maximise net social benefit, subject to budgetary constraints, which distinguishes it from commercial organisations. Customer priorities feed into the process of determining which service improvements to make, both in a capital and an operational sense.

Stated preference methods were used to estimate the impact of different short and long term investment decisions on the objective of net social benefit. Two studies were carried out, in 1993 and 1996. Both studies used interviews with current service users; the latter included a focus on customers who experienced difficulties using the services.

The 1996 study identified 104 important attributes of service improvement. These were packaged first into 'train' and 'station' issues and then into issues concerning security, condition, environment, information, staffing, etc. Each participant was asked about only four of these attributes in a series of stated preference tasks. Attribute levels were selected to

reflect reality, e.g. the three levels for the graffiti attribute were: none, small patches, lots and/or offensive.

The London Underground study demonstrates how sufficient sample size allows a sizeable range of factors to be considered. As cost was one of the included attributes, outputs of the study included both preference orderings for all 104 attributes and monetary values of these. These results enable estimated costs and benefits of potential investment decisions to be built into a well-considered business and investment case.

This study now forms a fundamental part of the investment appraisal system for London Underground, the basis for both investment decisions and, in part, for management remuneration. The resultant model is coordinated with a monthly tracking study to determine whether investments achieve their anticipated effect. For the organisation, the study provides a method for prioritising improvements, with consistency of comparison, which is both widely applicable and which works in practice.

public, service users and clinicians. Preferences may well be as much a function of when you ask as how you ask or whom you ask, e.g. patients may rate process outcomes highly during treatment, but post-treatment, be only concerned with health outcome. Current evidence disputes this however, in that service attributes other than health outcome are valued similarly by current, past and potential service users (Ryan, 1999).

Stated preference methods are currently used in a range of different areas. A recent example of the use of stated preference methods to assess customer priorities for investment in London Underground is described in Box 3. Stated preference methods are currently being used to assess the impact of alternative road pricing policies for London. In environmental economics, stated preference methods have been used to investigate: amenity values placed upon

components of urban improvement schemes (e.g. the Royal Mile in Edinburgh); the utility benefit from improvements to road traffic nuisance and to air quality; public preferences for Areas of Scientific Interest, etc. In the utilities sector, stated preference methods are being used in a competitive framework to

investigate, for example, how people will switch energy supplier following deregulation. In the pharmaceutical industry, stated preference methods are used in drug development, for example to explore comparative valuations of different benefit and side effect profiles.

THE HERTFORDSHIRE CASE STUDY

Chris Heginbotham, Alison McCallum, Stirling Bryan, Tracy Roberts

The background, methods and results of an application of stated preference methods to health care resource allocation were presented by the research team, which comprised Chris Heginbotham, Alison McCallum, Stirling Bryan and Tracy Roberts. The wider context for this study is the desire of health authorities to attain the best health and mix of health care services for the local population, within the constraint of available resources. To do this, clear answers are needed to complex questions concerning the appropriate allocation of resources. One requirement for this is a better understanding of local attitudes to health care priority setting. Quantitative approaches are needed to complement the political and anecdotal information that is more widely available at the local level.

East and North Hertfordshire is a fairly 'average' health authority in population terms, but with a significant overspend, complex local service reconfiguration problems and high per capita usage of services. In this context, it is important to explore all ways to inform tough resource allocation decisions. The existing public involvement programme included focus groups, user consultation, cross-agency consultation, open meetings, information provision and the Hertfordshire Citizens Panel (a standing panel of 2,500 citizens who are asked questions relating to health and social services on a regular basis). The aim of the stated preference study (see Box 4) was to complement these to provide a more comprehensive approach to the resource allocation and priority setting process, and to explore any diversity of attitude by age, experience, socio-economic status, etc.

Practical lessons from the study

Designing and conducting the study produced tensions between the health authority's need for practical solutions, the researchers' desire for academic rigour and the polling organisation's commercial

approach. It was recognised from the start that the study hypothesis was overly simplistic, and that attributes would need to be further unpacked (into, for example, potential harms as well as benefits of treatment), such that the study should be seen as an initial investigation into public preferences, with the aim of raising questions for future research, rather than providing any definitive answers. It is important not to over-interpret data from studies such as these, despite a desire for information that can be used in decision frameworks. However, the Child B case, and others since, do show some face validity for the cost per treatment – willingness to pay relationship emerging from the study. The breakpoint at a per patient treatment cost of £70,000-100,000 corresponds to the area where health authorities face some of the most difficult decisions, especially when there is also low probability of the treatment being successful. Interventions with lower cost per individual are frequently provided, and those with higher cost rarely provided.

The clinical scenarios used were often concerned with rare conditions, or with interventions for which there is limited evidence of the treatment leading to survival or quality of life gains. This is typical of the resource allocation decisions that have to be made. Rare conditions raise conflicts between programmes and individuals, and we need to think about implications of priority setting choices for the overall balance of activities between: trying to improve population health; reduce premature death; prevent distress; minimise the impact of disability; and provide good palliative care; as well as for the distribution of benefits across the population. More understanding is required of why different socio-economic groups appear to make different choices about health care resource allocation: is this due to problems of understanding ('not speaking the same language'), of lay beliefs, or an effect of differences in personal and social experience of disease and of health care services?

Box 4 Case study: the East and North Hertfordshire study

The specific context for the study arose from discussion of the Child B case (Ham and Pickard, 1998). The health authority wished to investigate public preferences over choices where the number of people to be treated could be small, the chance of successful treatment low and the opportunity cost of resource use high. The hypothesis was that, whilst the public would support the provision of treatments with a low chance of success when the per patient costs were relatively low, there would be some threshold above which public preferences would dictate alternative use of health care resources.

The survey was based on a randomly selected sample of the health authority population, interviewed at home by professional interviewers with experience in health surveys (MORI). It was decided not to use the existing Citizens Panel as this offered little advantage in terms of research costs and constituted a sample with substantially more experience, and perhaps information, than the general population. The main research questions addressed were:

- When asked to consider health care priority setting questions, does the public respond in line with QALY maximisation?
- If not, what key aspects of health care programmes drive public responses to priority setting questions?

A secondary research question was:

- When asked to consider health care priority setting questions, do the responses of the public vary as the programme cost varies?

The attribute set included in the task design comprised: chance of treatment success; number of patients; survival; and quality of life. Between two and four levels per attribute resulted in 96 possible combinations. This was reduced by factorial design to 16 scenarios. Much time and effort was devoted to

forming realistic clinical scenarios that fitted each of the 16 programme options to better inform respondents about the options. However, after pilot study data showed that the provision of clinical examples had no impact on preference, these were not presented in the main study.

Each participant considered eight choices between alternative health care programmes. One such choice between Option I and Option G is set out below as an illustration. The notion of opportunity cost was ensured by having equal programme costs within each choice and by the implication that the programme not chosen would not be funded. The option of allowing the programme cost to vary within choices was rejected. Whilst it would have allowed an indirect calculation of willingness to pay, it would have enabled respondents to consistently choose the higher cost option without addressing where additional resources would be drawn from to fund it.

Of 1,762 people selected, 26% were not contactable and 22% refused to participate, providing a response rate of 52%. Respondent characteristics broadly matched those of the general health authority population. In the choices presented in the questionnaires, many respondents did not pursue QALY maximisation. This proportion varied from 7% to 67% depending on the choice; where this proportion was substantial, quality of life was a key factor (i.e. was higher in the option chosen). Analysis of response data to assess the sensitivity of choice to variation in attribute levels shows that, within the context of the study, people's choices are more sensitive to quality of life than to other attributes. Choice patterns appeared to vary systematically with programme cost, with expenditure of £20,000 seen as acceptable for single patients but higher patient numbers preferred at the two higher levels of programme cost.

<i>Example choice (showcard):</i>	Option I	Option G
Total cost	£500,000	£500,000
No. of individuals who will be treated	1	10
Chance of success	1 in 10	1 in 100
Survival if treatment successful	1 year	5 years
Quality of life if treatment successful	No problems performing usual activities, and will not be anxious or depressed	Some problems with performing usual activities, and will be moderately anxious or depressed
Survival with no treatment or unsuccessful treatment	a few weeks	a few weeks

A possible factor in the preferences that the study showed for options which maximised quality of life rather than overall QALYs, is a favouring of interventions which provide 'quite a good year' for the patients involved. An example of this would be surgery for Parkinson's disease, where successful treatment provides 'quite a good year' of life, as compared with that associated with the significant progression of the condition. This finding, if borne out by further research, has significant implications for the priority we accord rehabilitation and the treatment of disability.

"It will be useful for future work to focus on the high cost per patient (£70,000-£100,000) treatment issues, where there is likely to be the biggest benefit from improving the decision-making process"

Chris Heginbotham

The study team recognised the need for a comprehensive approach to both public involvement and decision-making, with due process, and built on an understanding of the interplay of factors involved in health care provision. Stated preference methods can form an important part of this approach. It needs to be recognised that such studies are methodologically complex, potentially expensive, raise issues of confidentiality for participants and of replicability and reliability for other health authorities,

and will often require extrapolation to fulfil the need for useable answers. Concerns raised over the ability of the public to understand the tasks presented, however, proved unfounded. The extent to which these results are generalisable will depend on the differences that may or may not emerge in public views between regions. The sample size allows the study to segment response data for East and North Hertfordshire and draw out the resource allocation implications of focusing on the preferences of different population sub-groups.

The study report will be distributed and the outcomes shared more widely. The results should be interpreted with caution and be seen as generating hypotheses for future research. The aim is to build on this work to develop a locality approach, involving a wider range of stakeholders including Primary Care Groups, Trusts, Community Health Councils, and patient groups. Evidence from studies such as this needs to be incorporated into the wider context alongside evidence from other public involvement research, and making the connections here is clearly difficult. The role of this type of research is seen as developing criteria or frameworks for future decision making, whereas information from patient groups may be used more to inform particular decisions. In this way, the study provides useful pointers towards issues that should be investigated further with the wider community, and those which less time could be spent on. In particular, it will be useful for future work to focus on the high cost per patient (£70,000-£100,000) treatment issues, where there is likely to be the biggest benefit from improving the decision-making process.

THE NEED FOR QUALITATIVE APPROACHES

Paul Dolan

Current research in health economics, and economics more widely, is based on the premise that preferences exist, that they are complete and that they are stable. Whilst this may be true for things we are used to purchasing, it may well not hold for new commodities where consultation with others, debate and consideration can have an important impact on our revealed preferences. Issues of the stability and consistency of preferences over time and across populations raise further questions about how to interpret the results from studies designed to elicit

stated preferences. There is a need for further research to investigate the extent to which we can rely upon responses gathered. Dolan presented some initial research into the nature of preferences and the role of qualitative approaches in investigating them.

If people's preferences are to play some role in priority setting, then we first need to address at least three important questions: firstly, what is the nature of those preferences; secondly, what are the best ways of eliciting these; and, having answered these questions,

what results arise from preference elicitation studies? The received wisdom amongst mainstream economists is that individuals behave as if they have well-defined and clearly articulated views or preferences over all the possible decision options they might face. The stated preference models of economics largely follow this paradigm, arguing that underlying preference functions can be 'tapped-into' by appropriate questions, such that to elicit true preferences we need only ensure that questions are clearly formulated and understood as intended.

This view is called into question by studies in a range of areas which have shown that seemingly subtle changes in question framing can change the stated preference of respondents, and that seemingly meaningful changes in question framing can have little impact on responses. One example of this is provided by two postal surveys which investigated the priority accorded to patient groups which differed in key characteristics: in one study 19% of respondents gave equal priority to patients aged 30 and those aged 60 and 20% gave equal priority to married and single patients; in another study the proportions of respondents giving equal priority in similar circumstances were 85% and 95% respectively. It is unlikely that differences between respondent samples could have accounted for such very different results, and far more likely that differences in the way in which questions were asked led to extreme variation in response.

The importance of framing effects suggests that we need to gain a better understanding of the cognitive processes that respondents use when answering these sorts of questions. To better understand these processes requires the collection and analysis of qualitative data. The possibility that people's preferences are at least partly constructed *during the process of elicitation* suggests that we should: (a) give people sufficient time and opportunity to think about what is being asked of them; and (b) allow them to reflect upon the implications of their responses. Too many quantitative studies have drawn inference from people's answers and predicted how people would act in other situations, but have not carried out the final research stage of going back to people with these inferences to see if they agree.

A qualitative study carried out by Dolan and Cookson provides an example of the results arising from preference elicitation studies that allow participants to consider and reflect upon their responses (see Box 5). The background to this study was the continuing debate over the appropriateness of allocating health care resources on the basis of the size of the health gain generated. Health economists have generally argued in favour of doing so, but others have argued that this leads to unacceptable discrimination against those with lower capacity to benefit. Rather than try to quantify precisely the extent to which people are

willing to trade off health gain for distributional and other considerations, the aim of this study was to elicit general qualitative information regarding the extent to which health gain matters vis-à-vis other things.

The fact that many respondents started with a horizontal equity concern for treating everybody equally (either through an unwillingness to discriminate on the basis of capacity to benefit and/or because of a concern for procedural principles/fair process) lends support to the founding principle of the NHS that there should be equal access to health care for all. A caveat, however, is that the formulation of questions in the study used equal priority as the 'default option', so that the tendency of respondents to treat groups equally may simply have been a demonstration of the desire not to make hard choices.

Most respondents were willing to trade off the principle of equality for vertical equity considerations (i.e. the unequal treatment of unequals) at some level, usually the point at which the size of gain to one group was no longer considered to be 'large enough'. Most seemed to base their decision on the endpoint levels of health rather than on the gain in health provided by treatment. The consensus view was thus that equality of access should prevail over the maximisation of benefits, subject to the outcome

"Since individual preferences rarely come well-articulated, we can get more accurate estimates when respondents have had the opportunity to think and reflect"

Paul Dolan

constraint that treatments are sufficiently effective. An important question for future research is therefore 'how effective do treatments have to be for the principle of equal access to apply?'

The tendency of respondents to include patient characteristics and other factors in their conceptualisation of abstract questions has serious implications for the findings of other studies, particularly postal questionnaires, in that findings may have more to do with these extraneous factors brought to bear than with factors thought by researchers to be responsible. For example, studies may opt to exclude disease context, on the basis that the research aims to inform generic resource allocation criteria. However, this leads into a wider debate on defining the set of legitimate or relevant aspects of health care programmes that should be considered. Qualitative research shows that people will bring a range of contextual factors to bear on abstract choices, some of which will be seen by decision-makers as legitimate

Box 5 Case study: York qualitative study

The study objective was to get a general sense of the underlying principles that people have when making trade-offs between health gain and other arguments. Focus groups were convened and moderated by the researchers. Group discussions were recorded so that insights could be gained into the cognitive processes that respondents used in order to arrive at their responses. 1,000 people on two York GP lists were invited to attend for two sessions of two hours each, for a payment of £30 (distributed at the end of the second session). 21% accepted, from among whom 72 were purposefully selected and invited to attend. Of these, 60 people attended, split into 10 separate focus groups.

The focus groups were asked to complete a series of tasks. In one exercise, respondents were asked to consider two groups of patients, both of which would benefit from treatment but by differing amounts or from different start-points. Only half of patients could be treated: respondents could opt to treat half of each group or all of the group standing to benefit most. Health benefits were expressed in terms of years survival (with and without treatment) or in terms of quality of life, expressed as a percentage of full health. It was left to participants to interpret these health states. Interpretation varied between individuals, although discussion within groups provided an idea of the understanding of fellow group members. Groups were then asked to 'draw the line' at the level of benefit to the lower-benefit patient group at which they would switch from giving equal priority to giving priority to health gain. The intention here was not to draw meaningful results from the exact location of switch-points, but rather from the general principles employed. Transcripts were coded for the number of times certain reasons for decisions were mentioned. These were divided into 'principles' – generalised rules for priority setting – and 'factors' – specific aspects of the situation presented in that question.

Initially, people were split broadly 50/50 between

those wanting to treat both groups equally and those wanting to give priority to the group that could gain most. Most respondents started from the premise that we want to treat people equally, with supporting principles including morality, equal valuation of life or simply avoiding choice. However, only three participants gave equal priority regardless of relative benefit; all others were willing, at some difference in health gain, to give priority to those who would gain most from treatment. Principles supporting unequal treatment of groups included priority for greater gain in survival, quality of life or health in general, and priority for life-saving conditions or avoiding disability. An important principle raised concerned priority according to threshold of endpoint or difference in health gain; where threshold was defined in either absolute (i.e. treat equally unless benefit to one group is 'meaningless') or relative terms.

The factors raised included health gain, health status of patients, age, additional benefits (e.g. costs of ongoing treatment) and additional health benefits. These demonstrate how respondents conceptualise abstract questions back into the contextual real world, even when they are explicitly told to ignore outside factors. Although the questions were seen as abstract, respondents made little use of real world examples and personal experience, and were willing to put themselves into the role of decision-maker.

In another task, participants were asked who they felt should make these kinds of decisions. This question was raised at the start of the first session and again at the end of the second session. On the first occasion, most people said that doctors should make these decisions, with some input from patients. On the second occasion, respondents were much more in favour of managers having an input, much less in favour of the public being involved and showed a realisation that choices are both complex and largely moral rather than medical. This is a similar finding to that emerging from Citizens Juries.

factors, and others as prejudices. It is hard to distinguish between legitimate and illegitimate factors, although the social, political and legal context of decision-making may make it easier. It is important to look both at the implications for resource allocation of including or excluding such factors, and at the acceptability to participants of a research approach that seeks to override certain views expressed because they use prejudice.

As with all group work, there is a danger that people's 'true' preferences are shaped by more articulate group members and/or the facilitator. Some evidence in Dolan's study of a 'group consensus effect' suggests that this could have happened, and the group environment may well have made respondents less willing to discuss issues of discrimination on the grounds of health gain. However, there was no evidence from the qualitative data that such group

effects were due to unthinking 'herd' behaviour. There was some sense of two respondent types in the focus groups: those who participated in order to air their own views; and those who participated to listen to the views of others.

Dolan's overall conclusion was that since individual preferences rarely come well-articulated, we can get

more accurate estimates when respondents have had the opportunity to think and reflect, and especially when they have had the opportunity to consider feedback on the implications of the choices they are making. We need to get behind the numbers generated by more simplistic quantitative methods, and to get a better understanding of what people mean by what they say.

Key Points from the Discussion

Qualitative and quantitative approaches to involving the public

It is not appropriate for economists alone to carry out the range of qualitative and quantitative research discussed above. Qualitative techniques are better done by, or at least alongside, other researchers, although all researchers, with appropriate training, are capable of carrying out both types of work. Qualitative work suffers from being time-consuming and from current journal reluctance to publish qualitative studies. This creates an inherent bias against the use of qualitative techniques among economists. As qualitative techniques usually carry substantial research costs, the richer data and better understanding of people's true preferences can usually only be gathered on small numbers of participants. There are also concerns that participants in qualitative research, through the very process of debate, discussion and reflection, cease to be a representative sample of the public.

The relative roles of qualitative and quantitative approaches will depend on the question being asked: complex issues of equity and priority require detailed understanding of preferences, whereas more straightforward questions, e.g. trade-offs between service location and waiting time, may be more appropriately researched by using quantitative, stated preference techniques.

The stated preference methods discussed today are not necessarily only quantitative techniques. They can involve in-depth face-to-face interviews, with a range of exercises to ensure respondents are as informed as possible before being presented with the more quantitative stated preference tasks. A distinction needs to be made between the extent to which people have a chance to think and reflect in any research exercise, and the extent to which this can be expressed

in a precise quantitative way. It is crucial to bring quantitative and qualitative techniques together, and it can be argued that the current balance of these in health economics is wrong, with too much quantitative work being carried out that has little meaning for NHS decision makers. It is crucial in the near term to prove the validity of conjoint analysis, as it is a new technique. Going back to people to validate study implications is one of the few ways in which external validation is possible in the health care setting.

Health authorities find the results of both quantitative and qualitative research useful, and both approaches have an important role to play in involving the public in health care decision making. Quantitative techniques are currently more favoured by researchers due to a lack of confidence in our ability to ensure that qualitative work is representative and bias-free. At the same time there is increased interest in, and recognition of the importance of, qualitative research. The dominant view at the moment would be to see the role of qualitative research as informing quantitative work, both to ensure that the right questions are asked and to ensure that responses are interpreted correctly. Quantitative studies can convince local practitioners that research can provide information above and beyond their own views on what their patients want. However, there appears to be much scope to merge the results of studies using quantitative methods with the vast amount of qualitative research that is currently being done at all levels of the NHS.

One concern raised by a mix of approaches is whether qualitative findings from a small group of a larger quantitative sample are generalisable to the full sample. However, previous work has not found such disagreements when implications have been taken

back to a sub-group of respondents, and such feedback was indeed found to help with the interpretation of quantitative results.

How important is public involvement?

All attempts to involve the public in health care priority setting must accord the public respect, in particular in providing clear aims of the research and clear expectations of a partnership approach. The views of the public will only ever be one of many criteria informing resource allocation decisions. There is a tendency to assume that decision-makers take all

perspectives into account, yet we need to address the critical question of the relative importance of the views of consumers (or the public) vis-à-vis other resource allocation criteria. For research involving the public to successfully continue, the results of these exercises need to be seen to inform decisions at the policy level. It is important to be clear with the public about what we are trying to do, why we are doing it and how it will feed into the wider policy arena. It is then equally important to ensure that such research does indeed feed into decision-making processes, so that the public do have incentives for engagement in future research.

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