

THE UNIVERSITY OF SHEFFIELD

**ELICITING USERS' VIEWS
OF THE PROCESSES OF HEALTH CARE:
A SCOPING STUDY**

**The School of Health and Related Research
&
CHePAS
Consumer Health Psychology at ScHARR**

ScHARR
**SCHOOL OF HEALTH AND
RELATED RESEARCH**

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ELICITING USERS' VIEWS OF PROCESSES OF HEALTH CARE: A SCOPING EXERCISE

EXECUTIVE SUMMARY

This report features our recommendations to the NCCSDO for future research on the methodologies used to elicit users' views of the processes of health care. It is based upon a three-month scoping exercise carried out between August and November 2000 at the University of Sheffield. This comprised of a review of the literature and in-depth interviews with key informants whose work has had a significant impact in this field. In addition the advice derived from a specially invited seminar of relevant experts, held at the NCCSDO in February 2001 has been incorporated into the report and its recommendations.

Why examine methodologies used to elicit users' views of the processes of health care?

Successive UK Governments have been concerned that the National Health Service be more responsive to the needs and views of the public and service users.

Government policy initiatives have placed increasing emphasis on the importance of the quality of patient experience and responding to patients' views of services. In addition there is recent guidance and expectation from the Department of Health for health service researchers to involve service users in their research.

Our methodology

The report describes the conduct and findings of the scoping exercise – both the interviews and the literature search. The interviews were conducted with 23 individuals who were either academic researchers, researchers working within the

health service or they represented user organisations in a research capacity. The literature search strategy employed multiple methods in an attempt to overcome the problem of poorly indexed methodology papers on electronic databases. This involved searching traditional electronic databases, more specialised databases and Internet sources covering grey literature, as well as citation searching and following up citations from reference lists. The team then examined the abstracts as part of the process of setting our operational definitions, inclusion and exclusion criteria and defining the essential tasks in the context of scoping the literature.

Inclusions and exclusions

We included processes of care such as access, availability, waiting time, location of service delivery, professionals' attitudes, communication, information, choice, involvement in decision-making, convenience, respect for dignity, privacy etc. We focussed primarily on health care, with some reference to the literature in social care. We focussed primarily on literature from the UK with only some reference to North American literature. While this area of inquiry, patient satisfaction studies in particular, has been well established in the USA, nevertheless it is conducted in a markedly different health care context. Any overlaps between methods and their effectiveness would need close scrutiny for their value in the National Health Service driven system and that task was judged to be beyond the scope of this exercise due to time constraints. We excluded quality of life measures because these are outcome measures and the focus of this study was processes of care; patient satisfaction because a Health Technology Assessment (HTA) systematic review of patient satisfaction is currently being undertaken; assessment of research instruments because of the timescale of the project and because an HTA systematic review of

eliciting public preferences covered such instruments; community development; consultation; literature from users' views in the areas of transport and business; observational research because although this can be used to understand processes of care it does not involve eliciting users' views.

Keeping the focus on methodologies

Our focus was on methodologies used to elicit users' views of the processes of care. However, during both our interviews with experts and our reading of the literature, we found that *involving users* in the development and assessment of health services and in the research process itself was an important issue. We could have chosen to ignore this and remain focused on the task of assessing methodologies. However, due to the strength of feeling from our expert interviewees and the coverage of this issue in the literature, we considered that involving users in the health service and in research should be considered alongside methodologies for assessing their views.

Findings

1. The results from both arms of this scoping exercise demonstrated the wide variety of methodologies currently employed by researchers in eliciting users' views of health care processes. These include a range of specifically qualitative methods (such as focus groups and in-depth interviews) and quantitative and mixed methods (such as surveys, health panels, rapid appraisal, citizens' juries, consensus methods and health economic techniques such as conjoint analysis and willingness to pay). The main methods reviewed here included both basic techniques (such as focus groups, interviews, conjoint analysis or questionnaire-based surveys) and

methodological approaches incorporating these techniques (such as rapid appraisal or deliberative polling). Brief descriptions of each of these can be found in Chapter One and a full description and discussion of the strengths and weaknesses of each can be found at the various relevant parts of the report. The contents page contains the details for individual methodologies.

2. Most of these methodologies have been put to effective use in some reported studies. There is however evidence across the majority of methods of poorly conducted research. Some of the reasons for this include poorly defined research aims, lack of understanding of the methods themselves on the part of the researchers, lack of analytical rigour in the analysis and reporting of findings and inadequate funding which has significantly impaired quality in many cases.
3. There was a re-assuring but perhaps not surprising overlap between the findings of the literature search and the interviews. That is that our evaluation of the quality and appropriateness of the methods used largely coincides with the views expressed by the experts.
4. There is a need to re-evaluate the way established methods, such as surveys and interviews, are being used and to ensure that appropriate ones are used for the group being researched and the context of care.
5. Newer or innovative methodologies, such as consensus groups, need to be examined further for what they may contribute particularly in the case of hard to assess groups or where the views of a particular group of users has been under-researched.

6. There are gaps in the research and evaluative skills of many who are required to elicit users' views. This is usually because there is a lack of training of health or social care practitioners and some research and development specialists in the agencies who are most likely to want to collect data on users' views. e.g. health care trusts, patient groups.
7. There are currently systematic reviews being undertaken within the area of users' views of the processes of health care. The most relevant are two HTA reviews currently being undertaken by R Crowe and M Ryan. The results of these need to be considered alongside the findings of this report when determining future research.

RECOMMENDATIONS

Primary methodological research

- i. Primary qualitative research should be undertaken to understand users' thought processes when completing quantitative techniques currently in use, in particular conjoint analysis, willingness to pay, and instruments to measure involvement in decision-making. As part of this qualitative research, researchers should assess how their findings can be incorporated into guidelines for undertaking these techniques, in particular whether in depth qualitative research is essential for every situation in which the technique is employed, or whether cognitive testing or extensive piloting be more appropriate. This is most important for conjoint analysis because this technique is

so useful for determining trade-offs people are willing to make between different processes of care and processes and outcomes.

- ii. There is a need to evaluate less traditional methodologies such as patient forums, consensus groups and the internet. An HTA review of consensus methods identified the need to determine the best composition of consensus groups and there is scope for bringing those two methodological research needs together in one project.

Secondary methodological research

- ii. It is recommended that specific attention be given to the methods used in North America for eliciting users' views on the processes of care. It is likely that methodologies currently used in North America, might be effectively transferred or adapted for use in the UK. As stated above however, this work would need to be undertaken as a study in its own right utilizing a similar methodology to this report. It would therefore probably include both a review of the literature on the methods and interviews with the key experts who have used and developed them.

Other recommendations

- iii. There is a need to consider the development of guidelines on good practice in both qualitative research and quantitative research. It is anticipated that such guidelines would need to be flexible rather than prescriptive because they must be relevant to a variety of

methodologies in a variety of contexts. At present a significant proportion of both qualitative and quantitative research is poorly conducted. Ensuring that the quality of research in the area of eliciting users' views improves would be an important role of the NCCSDO.

iv. Further research should build on, and not duplicate, research currently being undertaken, in particular qualitative research at the University of Aberdeen showing that validated instruments for measuring patients' involvement in decision-making about their individual care may be problematic, and the Eurowill Project which has tested six methodological issues about willingness to pay. It would be beneficial to hold further expert seminars and establish a register of research in this general area. Following from that, further research should be commissioned in the light of recommendations of this scoping exercise and the two HTA Systematic Reviews i.e. the HTA systematic review on eliciting public preferences for health care (Ryan, in press) and the HTA systematic review on measuring patient satisfaction (Crowe, in progress).

iv. Quantitative instruments should be developed based on primary qualitative research, with more emphasis placed on the language used in measurement tools and the cultural context of the people who will complete the instrument.

v. Research involving the integration of users' views from the outset, should be funded adequately to allow researchers to undertake qualitative research to develop and use the most valid instrument, and involve users in the process.

- vi. Research should be undertaken on how elicited views are used in practice. This may require action research to identify the barriers to using users' views, identifying solutions to these barriers, and putting those solutions in place. This should occur at local levels (i.e. with the researchers and the agencies they work for) and at a broader level (i.e. in the context of academic organisations to ensure dissemination of information through conferences and journal publications) and at a national or even international level (i.e. in relation to funding of this research).
- vii. Traditional methodologies, such as patient satisfaction surveys, need to be re-evaluated in a range of contexts to take account of socio-economic, cultural and demographic issues (such as age and gender). To date these methods, have failed to elicit the views of hard to reach or marginalized groups.
- viii. It is also important when considering the effectiveness of the outcome of patient satisfaction surveys to draw a clear distinction between the use, for example, of 'ethnicity' or 'age' as variables, and paying attention to the experience and views of marginalized or minority groups in their own right through using either qualitative methods or structured interviews conducted under conditions which pay specific attention to the needs and experiences of the marginalized group.
- ix. There is a need to evaluate users doing the research, paying attention to the tension between maintaining quality standards and participation in the research process.
- x. There is a need to address the skills deficit of researchers in the health service who are involved in eliciting users' views.

- xi. Primary research should be commissioned to help us to understand the effect on outcomes of the processes of care.
- xvi. The views of marginalized groups such as the elderly, need to be incorporated into the mainstream (using methods specified above) rather than being treated as special interest groups.

CHAPTER ONE

Scoping Users' views on processes of health care

Introduction

The NHS Service Delivery and Organisation (SDO) programme of research and development was established to consolidate and build up the evidence base on the organisation, management and delivery of health care services. The aims of this programme are to inform and make accessible good and effective research-based evidence to those who carry out research for and about the health service and health care. This group includes academics, research and development managers, service users and other stakeholders.

Rationale and background to a focus on users' views

Successive UK Governments have been concerned that the National Health Service be more responsive to the needs and views of the public and service users (NHS Management Inquiry 1984; Working for Patients 1989; The Patients' Charter, 1991; NHS Management Executive's Guidance Local Voices NHSME 1992). More recently, Government policy initiatives such as the White Paper 'The New NHS: Modern Dependable (NHS E, 1997) have placed increasing emphasis on the importance of the quality of patient experience and responding to patients' views of services. It has therefore committed the government to conducting annual national surveys of patients' views and experiences in England to enable managers and health professionals to take direct account of users' views in improving services. The results of the first two surveys have since been released (Department of Health, 1999).

In addition there is recent guidance and expectation from the Department of Health for health service researchers to involve service users in their research (Standing advisory Group on Consumer Involvement in the NHS R&D Programme 1998; Department of Health 1999). Health Authorities, Trusts, researchers and consumer organisations have been working along these lines for some time (Wilson & McHarg 1995; Consumers in NHS Research, NHS Executive, 2000).

Health Authorities, Trusts, researchers and consumer organisation have been attempting to emphasise the patient's perspective and demonstrate that their services are responding to patients needs. A variety of methods have been employed to elicit user views of health care. These include health forums, rapid appraisal exercises, action research of initiatives in the community, public opinion surveys, patient satisfaction surveys, one to one interviews, telephone hotlines, focus groups and enhanced complaints procedures (Dixon & Carr-Hill 1989; Milewa, Valentine & Calnan 1997; Poulton 1998; Williams, Coyle & Healy 1998; Fulop & Allen 2000).

Quantitative methods such as the structured questionnaire survey approach have been most common (e.g. McIver & Meredith 1999). However, qualitative approaches are increasingly used to gain greater insight into user perceptions and experiences (Fulop & Allen 2000). Despite the growth of this research, a number of authors have raised concerns about the value of some of the methods employed to date (Williams, Coyle & Healy 1998; McIver & Meredith 1998). The methodologies, which have emerged, tend to have been developed on an ad hoc basis or for specific patient populations (Department of Health, 1998). Furthermore, to date, there are, no existing off-the shelf questionnaires which can satisfy the requirement to elicit user views in all areas (McIver 1998).

The Scoping exercise

At the start of the project, there was a clear need to define terms. However it was of no surprise to the team to find that as work progressed it became clear that this was not to be a simple task. Thus below, we attempt to show the scope of the problem. We offer definitions of users' views followed by brief operational definitions of how the team defined the other key concepts that frame the work that follows.

Definition of users' views¹

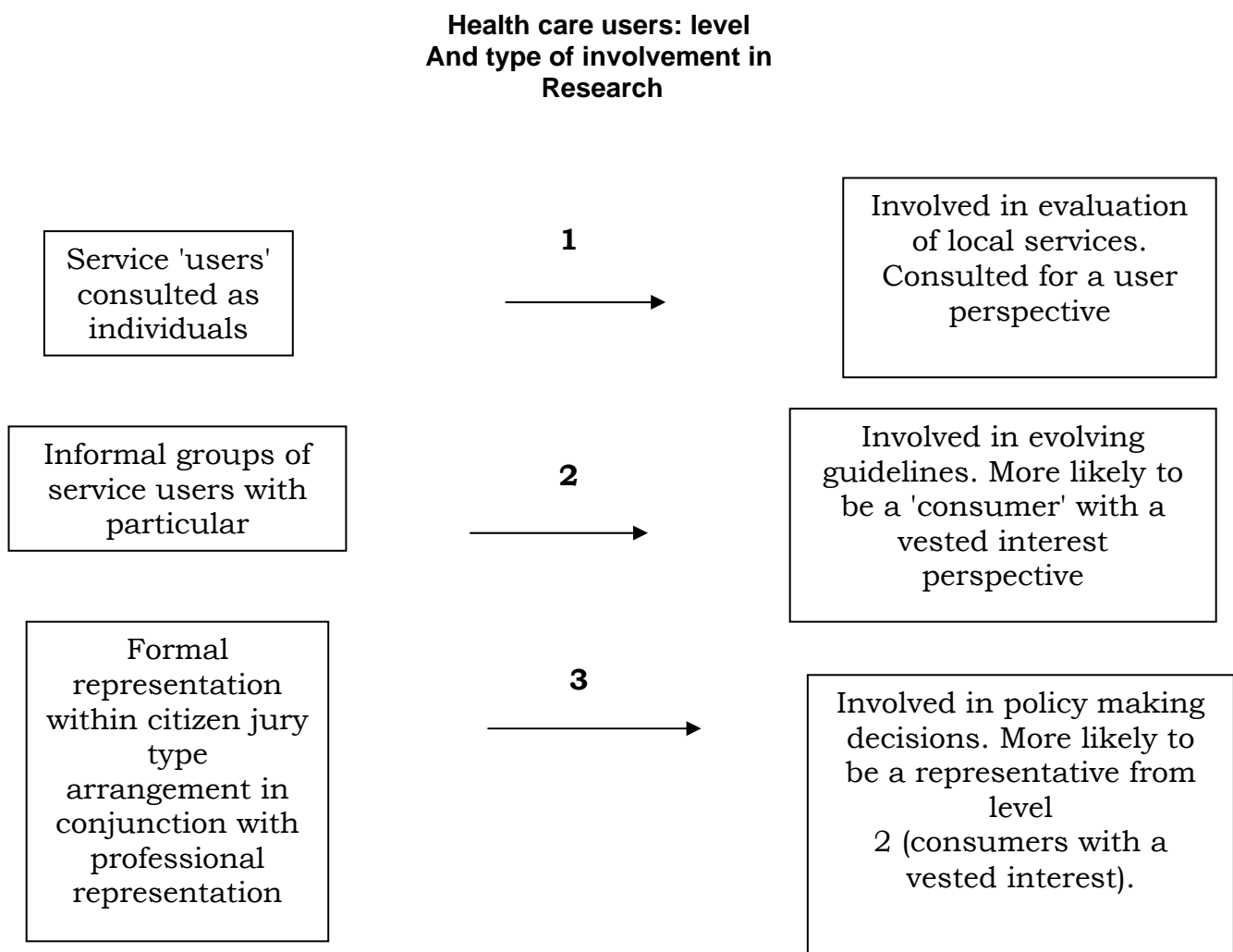
A 'user' in the context of health research is a non-professional, either a non-clinician or a non-academic. However, in practice, authors employ a large number of different terms: as Charles and DeMaio (1993) put it, "the concept of 'lay', 'public' or 'community' participation in health care...while seemingly straightforward is, in fact, fraught with difficulty". Bastian (1994) concurs: "There is no universal agreement about the words meant to specify the people who use, or are meant to be served by, health care...the debate is fuelled by the fact that this is not just an argument about words, but about ways of seeing and portraying people and their relationships with the health care system".

Various writers have considered the various *types* of user. Wright (1996) considers four types on a continuum of increasing numbers: individuals, groups sharing a service, communities of interest, and the general public; while Williamson (1998) differentiates between consumers, consumer groups and consumer advocates. Figure 1 below represents the three levels at which

views of individual and groups of consumers may possibly be incorporated.

The diagram suggests a possible hierarchy in which informal and formal groups have more influence than individuals but in which such groups are more likely to have a vested interest.

Figure One: Definition of users views



¹ We would particularly like to acknowledge the work of Jonathan Boote, Rosemary Telford and Cindy Cooper of SchARR for their work on definitions of 'users'.

Taylor and Lupton (1995)² differentiate between a 'naïve user perspective' and an 'informed consumer' which is presented in the above diagram as the difference between level 1 and 2. However, these terms, whilst useful, have not been used in the above diagram as such, as the term 'naïve' can be misleading.

Current users are people in clinical relationships with doctors or other healthcare professionals. User groups or user support groups consist mainly of patients and former patients. According to The College of Health's database on consumer groups, there are approximately 3000 national self-help and voluntary organisations in the UK (Meredith, 2000). User advocates are people with a general knowledge of the views and interests of consumers and consumer groups. Advocates are often known as activists or 'healthcare consumerists'. Kelson (1995) notes that consumer involvement can be classified in terms of various dichotomies, such as individual versus collective involvement, and voluntary versus involuntary users (e.g. users of mental health services).

Consumers in NHS Research (1999) defined the term 'consumer' to include "patients, carers, long-term users of services, organisations representing consumers' interests, members of the public who are the potential recipients of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services". All these examples are necessarily included in our definition of health service users. The general public are included, not only as potential users of services but also as citizens, who may be low or not users of services.

² Taylor,P. and Lupton,C. (1995) Consumer involvement in health care commissioning (Report No30) Social Services Research Information Unit, University of Portsmouth.

The Diagram of NHS Users (**Figure Two see page 29**) attempts to illustrate a comprehensive range of users. Users are grouped as patients, established organisations or groups where groups are either population groups, staff groups or groups of people specifically convened to discuss health matters such as health forums. Specific groups of people, such as user support groups may fall into two categories, being both patients and organisations. Outside these groups are individual members of the public in various capacities. In certain specific situations it may be appropriate for health care staff to speak on behalf of their patients and are included in the diagram but in this study healthcare staff have been *excluded* from the definition of 'users'.

Furthermore, there can be considered to be 3 areas in which users views may be sought:

- individual patient involvement in clinical decisions related to their own care
- the views on services of individuals, groups or specific communities with experience or expectations of those services
- public opinion: the views of individuals or groups as citizens on issues such as ethical debates, preferences and priorities for spending.

This scoping study attempts to cover this whole range of user views.

Scoping the processes of care

Operationalisation of processes of care are as follows:

- health care needs assessment
- the nature of the intervention
- access
- availability
- timing / waiting times

- location of service delivery
- professionals' attitude
- professionals' competence
- communication
- information
- choice
- involvement in decision making
- convenience
- respect for dignity, privacy, beliefs etc
- expectations and experience of clinical outcomes
- guidelines on delivery and standards of care considered to relate to processes of care.

Perceptions of health status and quality of life and perceptions of health needs other than health care needs, are not included within the scope of this review as these are not

Boundaries for the project

In addition to clarifying the terms for the scoping exercise, it was important at the outset to identify the inclusion and exclusion criteria for defining the processes of care. Decisions relating to this were as follows:

Patient satisfaction

There is an enormous literature on patient satisfaction. SDO informed the team of the HTA systematic review of patient satisfaction. Therefore we have not delved into the 'nitty gritty' of this area. Nor however, could it be ignored because it is one of key ways in which users' views are elicited. It was therefore decided to take a 'broad

brush' approach to the subject, and clarify the boundaries between this project and the HTA report.

Involvement in decision-making

An important process issue for users, is feeling involved in the decision-making process of one's own care. However, like patient satisfaction, it has its own literature and validated instruments. Rather than attempt to critically assess these instruments, once again a 'broad brush' approach was taken to this area.

Outcomes

Processes, rather than outcomes, are the focus of this exercise. At first it seems obvious that processes are different from outcomes. However, it is not as simple as that. Dignity may be a process, in that it is offered alongside a treatment, which will result in a better outcome for the user. However, dignity may be an outcome for a user of palliative care. Thus dignity may be a subscale in a 'quality of life' outcome measurement instrument. We have not studied quality of life instruments in this exercise. An HTA systematic review of eliciting public preferences for health care has included views on outcomes as well as processes of health care (Ryan, in press).

Community development

Community views are included in this scoping exercise. However, community development, which may help communities to give their views, has not been included.

Instruments

We have stayed at the level of a methodology and have not studied the strengths and weaknesses of different research instruments and the ways of measuring views e.g.

ranking, rating and different types of scales. An HTA systematic review of eliciting public preferences for health care has assessed these issues (Ryan, in press)

Health care

We have focussed almost exclusively on healthcare, with some forays into social care. We have not looked at other areas, such as transport and business, which might use methodologies helpful to health care. An HTA systematic review of eliciting public preferences for health care has identified techniques used outside health care which may be useful to explore within health care (Ryan, in press).

Observation

There are methodologies which can help understanding of the processes of care for users, but which do not involve eliciting users' views. A prime example is observational research. We have excluded these methodologies from this exercise.

US Literature

A decision was made early in the project to use only U.K. literature except when very little local literature was available. The decision was dictated by the time-scale of the project. Much of the U.S. literature identified by the search, which was not included, related to issues specific to the U.S. healthcare system, such as health plans and health insurance and did not provide additional information about the methods included in this review. However, it is recognised that this field is much more developed in the U.S. than the U.K. and there may be additional methods which are relatively well established in the U.S. which are not reflected in the U.K. literature. There would be value in specifically reviewing the U.S. literature on methodologies, which have only recently been employed in the U.K. and those which may not yet have arrived over here.

Elicit and assess

The brief from SDO included the request to study how to elicit and assess users' views of the processes of care. By 'elicit' we mean simply to obtain views and by 'assess' we mean to measure or weigh up these views. This brings up issues such as who should weigh users' views and what should they be assessed against - the views of health professionals, cost, health gain?

Why elicit and assess users' views of processes of care?

Four groups of people are potentially interested in eliciting and assessing users' views of the processes of care:

- Commissioners of services e.g. health authorities, primary care groups
- Providers of services e.g. trusts, general practice
- Consumers groups/representatives e.g. community health councils
- Academic researchers

They have different reasons for wanting to elicit and assess users' views of the processes of care and these include:

- i) improving the quality of health care both at an individual level e.g. involvement in clinical decision-making and at a service level e.g. service design or delivery.
- ii) To make resource allocation more sensitive to the electorate
- iii) To improve the quality of research
- iv) To involve users in the development of services
- v) To elicit views so that decision-makers can take these views into consideration.
- vi) To involve users in the decision-making process

The strengths and weaknesses of methods discussed in this report may depend on the researchers' *reasons* for wanting to elicit views.

Methods Reviewed

The following is a brief set of descriptions about the main methodologies reviewed in the report which are discussed in detail under the appropriate headings in the text of the relevant sections in the subsequent chapters.

Citizen's Jury: A citizens' jury brings together a group of between 12-16 randomly chosen citizens, to deliberate on a question or set of questions over a number of days.

Community Participation: is a tool for changing communities in some way with the long term aim of improving health status, attitudes or health related behaviour.

Community participation is not simply a method a method of eliciting user views.

However it can be considered as being at one end of a continuum of involvement of users' in approaches to eliciting their views.

Conjoint analysis is a technique developed in health economics to take account of factors beyond health outcomes, making it a very important methodology when considering users' views of the processes of care. It is used to measure strength of preferences and the trade-offs that people are willing to make between different processes, and between processes and outcomes. The 'discrete choice' method presents pair-wise comparisons of services with different process attributes through a postal questionnaire or interview.

Consensus methods are a formal, rather than an informal approach to gaining agreement on health care issues with decision-making occurring within the consensus group. Sometimes users and health professionals are part of the same groups and sometimes a group can consist only of users, patients, or the general public - a key example of this is citizens' juries. The main methods considered are the Delphi method where individuals are contacted using mailed questionnaires and do not interact directly; the Nominal Group Technique where there is structured face-to-face interaction within a group of experts; and the consensus development

conference where a selected group of about ten people is brought together to reach consensus on an issue in an open meeting.

Deliberative Polling/Referendum/Ballot: can be considered as a type of survey. In a referendum or ballot, people are asked to vote on an option or number of options. In a deliberative poll, a representative sample is asked to vote, after which they learn more about the issue through being given more information through workshops and an opportunity to ask questions of relevant 'experts', and are then asked to vote again.

Focus groups: Tools, which potentially facilitate research on users' views as there is the opportunity to 'empower' participants. They typically involve between 8 to 12 individuals who discuss a chosen topic under the direction of a moderator, leader or facilitator. They provide rich and diverse data, which is mostly qualitative, although it is possible to collect some quantitative data in this context as well.

Health panels, Citizens' panels: A random sample of people drawn from the general public who agree to respond to questionnaires on health related issues on a regular basis. The people involved are intended to be a representative sample of a larger population group drawn from the local area and that their views on various issues are sought repeatedly over a period of time.

In-depth interviews: These are among the most common approaches to collecting qualitative data. They are usually semi-structured, i.e. there is an interview guide covering specific topics. However there are occasions when unstructured interviews might be used and a respondent is asked to talk freely about a particular topic or experience.

Open Surgery: Open surgeries are at a time when members of the public can 'drop in' to meet with a representative of the health authority or local authority to discuss

concerns. The representative needs to be someone at a senior enough level to have sufficient overview to be able to deal with a range of queries.

Questionnaire Based Surveys: a set of questions, on a form with a choice of answers for the respondent to select (closed questions) and/or space for respondents to respond freely. The questionnaire can be distributed by mail or directly by hand.

Rapid appraisal is a methodology used to help plan health services and ensure that the distribution of resources reflects local needs. It involves a community in diagnosing needs and formulating action plans to meet those needs i.e. a community is part of the decision-making process. A variety of methods and techniques are employed: written records, observation, focus groups, structured questionnaires, interviews with key informants within a community. Results are fed back to the community for prioritisation and to determine solutions to the problems identified.

Willingness to pay: is a technique based on the premise that the maximum amount of money an individual is willing to pay for a commodity is an indicator of the value placed on that commodity. It combines, in one measure, people's valuations of outcomes and processes of care. It is an important technique to consider in this study because it has been used to measure the strength, as well as direction, of people's preferences for process attributes in the provision of care. It involves the production of a questionnaire, that can be administered by post or by an interviewer, to determine how much people would pay for a service configured in a particular way.

The structure of the report

The project reported here, which examines and evaluates the *methodologies* used to elicit users' views of the *processes of health care* is a scoping exercise with the ultimate aim of advising the SDO programme and the Methodology R & D Group³ on the effectiveness and value of the methodologies currently available for this purpose. The report will thus inform the SDO on approaches to take when commissioning further research in this area.

Following submission of the report and to further this end, there will be a conference/seminar at which the project team will present and discuss this work with both SDO and relevant stakeholders.

In what follows the methods and findings of the three-month scoping exercise are presented. The report begins in this chapter with a rationale for the study, operational definitions and a brief biographical background to the current situation relating to the way users' views are elicited.

Chapter two describes the methodology used for this project and discusses in some detail the literature search strategy and the methods for conducting the in-depth interviews. Chapters 3, 4 and 5 present the findings from the literature review, which are presented in both a descriptive and then critical way. The literature reviewed demonstrates a wide range of methods for eliciting users' views of the processes of health care. The scope extends from the tried and tested such as the survey, in-depth interview and focus group to conjoint analysis, a variety of consensus methodologies and perhaps most recently the use of the internet.

³ It was the Methodology Group who specifically identified this topic as a priority in 1999.

Chapter Six outlines the findings from the in-depth interviews carried out with key informants selected because they have been involved in research, at some level, in this area. The informants include academic and NHS researchers, members of health care organisations concerned with health care delivery and representatives of patient groups. The themes emerging from the interviews overlap and reinforce many of the findings from the literature reviews.

Chapter Seven, fills in some of the gaps perceived to be important by the research team in the context of this project, but nevertheless these methods and their application to certain groups of users are not well documented in the literature. These include marginalized groups and novel research methods. Once again the interview data underpins the literature in the process of identifying the marginality of certain categories of user and some research methods.

In our final Chapter Eight, we draw together the findings from both arms of this study and make recommendations for future areas of investigation in this field. In the process of carrying out this review a number of parallel studies, currently in progress or recently completed, have been identified which promise to provide valuable information in the field of eliciting user views when they enter the public domain.

These include:

1. A review and synthesis of effective community participation models and methods, by the Health Development Agency: to be undertaken.
2. HTA commissioned systematic review on measurement of patient satisfaction: currently being completed.
3. Eurowill Project to investigate feasibility of use of Willingness to Pay to set Healthcare Priorities: currently being written up

4. HTA review of eliciting public preferences: in press.

Finally, there is a toolbox of diverse methods available for eliciting users' views but in the words of one of the experts interviewed in this scoping study:

'Ultimately the key question is what is the particular purpose [for which] you are trying to access peoples' views - and what sort of people are you trying to access - because my broad conclusion is that different sorts of methods are necessary to achieve different purposes with different groups'.

Users Views Cindy's Diagram

CHAPTER TWO

Methodology

Introduction

This chapter provides an overview of the methods used in this project to scope the range of methodologies employed to elicit and assess users' views on processes of health care and their strengths and weaknesses. The methods utilised comprise a) a review of existing literature on the methodologies used to obtain user' views and b) the synthesis of 'expert' views identified through semi-structured interviews.

This chapter outlines the methods used to review existing literature and to collect and review the interview data.

Aims and Methodology

The aims of this scoping exercised were:

1. To identify the range of methods used to elicit and assess users' views of the processes of health care and their strengths and weaknesses across the range of their different purposes;
2. To identify existing gaps in knowledge.

This was achieved by:

1. Undertaking a review of the available literature on methods used to obtain and assess users' views
2. Soliciting the opinions of expert witnesses through semi-structured interviews about their perceptions of the strengths and weaknesses of different

methodologies, the gaps in the current knowledge of effective and appropriate methodologies and future research needs.

In order to achieve these aims, members of the team divided into two main groups: the literature sub-group, with the overall responsibility for defining the search terms and reviewing the literature; and the interview sub-group who had overall responsibility for contacting potential interviewees and conducting the interviews. There were however occasions for overlap when an individual team member had a specific interest in a methodology and therefore interviewed and reviewed the relevant material⁴. Similarly the development of the interview tool was done in consultation with the literature sub-group.

The full team met on 6 occasions and the sub-groups met frequently as and when various issues and gaps from the search and interviews emerged. Although there had also been an interim meeting planned with the funders, in the end this became a telephone conference due to long-term and on-going train and road transport problems between Sheffield and London.

The time scale for this scoping exercise was 3 months from the beginning of September to the end of November 2000 which clearly produced some constraints. In what follows the methodologies , procedure and constraints for both the literature review and interviews are presented.

⁴ For more information see the review of the team members' responsibilities.

1. The Literature Review

The methods for the literature review are described in two parts: firstly, the initial proposed aims and objectives as stated in the original proposal; and secondly, the development of the methodologies for the review, including defining the search terms and the process of coding and analysing themes, will also be outlined.

The literature review utilised a two-pronged strategy already demonstrated to be feasible in an unrelated methodological review conducted by ScHARR for the Health Technology Assessment Programme (Chilcott et.al. 1999).

Search strategy

The search strategy employed multiple methods in an attempt to overcome the problem of poorly indexed methodology papers on electronic databases. This involved searching traditional electronic databases, more specialised databases and Internet sources covering grey literature, as well as citation searching and following up citations from reference lists.

Electronic databases

Sensitive search strategies using a combination of thesaurus and free-text searching were used in the major electronic health and related databases. The following databases were searched:

- *MEDLINE* 1966-present
- *HealthSTAR* 1975-present
- *Science Citation Index Expanded* 1981-present
- *Social Science Citation Index* 1981-present
- *CINAHL* 1982-present
- *PsycLIT* 1967-present

- *British Nursing Index*

Grey literature

A variety of techniques were used to try to identify unpublished and other grey literature. The *HMIC* (Health Management Information Consortium) database was searched, which provides access to the King's Fund (*King's Fund Database*), Nuffield Institute for Health (*HELMIS*) and Department of Health (*DH-DATA*) collections. The collections of the Health Services Management Centre at the University of Birmingham (<http://spp3.bham.ac.uk/hsmc/homepage.htm>), the *BELINDA* database, produced by Buckinghamshire Heath Authority (<http://strauss.his.ox.ac.uk/belinda.html>), and the University of Sheffield School of Health and Related Research (ScHARR) library catalogue, were also accessed.

Current research

The *National Research Register* (NRR) and *Current Research in Britain* (CRiB) were searched in an attempt to identify ongoing and recently completed research.

Citation searching

Key authors and citations were followed up using *Science Citation Index Expanded* and *Social Science Citation Index*. Reference lists of relevant articles were reviewed in an attempt to identify further references. Finally, additional and more locally conducted studies were identified via the interviews with key organisations, agencies and experts in the field.

Criteria for Retrieval, Validation and Synthesis

A two-stage filtering process based on abstracts and the full-text of articles was undertaken. Studies were divided into methodological and case studies dating back 10 years.

Development of Search Terms and Conceptual Issues

Two different search approaches were adopted as a result of discussions with the project team. Firstly, a search was conducted on 'users' views' in conjunction with specific named methods (e.g. focus groups, interviews, rapid appraisals, etc.).

However, the first difficulty experienced by the literature review team was that of definition. Health care 'users' are described differently within studies and therefore, the search was required to reflect the possible range of terminology used. Therefore, the first search included the terms: 'patient', 'consumer', 'client' and 'user'. The use of the term health care 'user' is also broad and incorporated patient advocates and informal carers although professional carers were not included as they are 'providers' of care rather than users. Furthermore, the terminology used to describe 'views' is also not easily encapsulated and therefore, the search incorporated terms including; 'perceptions' and 'experiences'.

A further concern that emerged as the team considered and refined the search terms was that health care users' views may be elicited at a multitude of levels. Levels broadly defined included: firstly, the personal views of patients for evaluating local services and in clinical decision making. Secondly, a further level incorporated 'user groups', more formalised groups with experience of services and with distinct views on those services. Thirdly and finally, users views could also be expressed in terms of 'public opinion' including views on the need for services and public health

concerns. A simpler distinction is that users' views could be differentiated between *actual* users and *potential* users. The levels and types of user are conceptually represented in **(Figure Two see page 29)**.

Details of the *MEDLINE* search terms and strategy are provided. **(see Figure Three pages 45 and 46)** The emergent abstracts were then divided between team members to assess for suitability for inclusion in the review.

However, and perhaps surprisingly, this series of searches provided particularly limited findings which did not reflect anything like the amount of literature which the team was aware existed. Therefore, a second and more general search on specific methodologies was initiated. The methodologies included: public meetings, focus groups, interviews, citizens' jury, rapid appraisal, community participation, health panels, citizens' panels, piloting changes, open surgery, lay people, service users and carers as committee members, questionnaires and surveys, polling referendum/ballot, willingness to pay and conjoint analysis.

This was further supplemented by searches on methods of consumer participation (e.g. exp consumer participation / [methods] in Ovid *MEDLINE*) and searches on dignity, self-confidence, coping, etc. in relation to users' views. More generic searching on users' views was conducted in the smaller databases. Searches were restricted to English language papers on the grounds that including foreign language papers would greatly increase the cost and time involved and was outside the remit of this three-month scoping exercise. In some cases where the number of references retrieved was unmanageable (e.g. for surveys), the search was further restricted from 1980 onwards and to reviews only.

The results of the second search were divided amongst the team according to particular methodological expertise and interest.

Setting the limits of the Exercise

A second challenge for the team emerged during the search - that of 'boundaries'. To a certain degree boundaries were drawn by time constraints, that the team had only three months for completion and by the recognition that this was a *scoping* exercise and not a systematic review. Nevertheless, the team had to explore issues about what should be included under methods that actually 'elicit' users' views and those that 'assess'. It was agreed that these were two separate components which incorporated 'eliciting' as the processes of gaining access to users' views and 'assessing' which was a distinct component in calculating the weight which these views have, in other words, how representative they are.

It was decided that 'quality of life' measurements, although they do elicit user views, are essentially outcome measurements and therefore, were to be excluded.

Furthermore, the concept of satisfaction remained problematic for the team. The use of satisfaction measurements is an extensive area and under systematic review within the HTA's *Measurement of patient satisfaction*. It was also felt to be the case that tools for measuring patient satisfaction were largely outcome measurements and were therefore, to be excluded. However, the use of the term satisfaction is also, at times, broad and creeps into more generic methods for eliciting user views. One example of where satisfaction emerges is in the method of eliciting users' views through complaints and compliments, which, it could be argued, is also eliciting patient satisfaction.

In addition the concept of *processes* of healthcare required clarification by the team. *Processes* of, or in, health care are evidently broad and may be conceptualised to operate at a macro and micro level. Macro processes could include the development of guidelines and the decisions about the need for and appropriateness of types of care and who should deliver that care. On a more micro level processes could include views on communication, dignity and privacy. However, it was felt that some areas relating to health care could not be defined as *processes*. One specific area was that of health beliefs. Whilst it can be argued that health beliefs impact upon the processes of health care they are not in themselves *processes* of health care.

A further issue that emerged for the literature sub-group was that, with the search being open to include all English speaking literature, the studies, which emerged, were conducted throughout a huge geographical location, including the UK and other areas of Europe and the US. However, it was agreed within the team, again because of time constraints and because of the nature of the exercise, that the initial reviewing of the literature should only include that which originated from the UK. A further issue in analysing literature from outside the UK was that it commonly reflected users' views in different *processes* from those inherent within the UK NHS. For example, literature from the US which elicited users' views commonly did so on methods of payment which clearly does not have relevance in the UK. However, it was felt that where studies from outside the UK provided examples of methods or involved particularly interesting groups of users' that were not reflected in the UK literature that it would be useful to refer to these studies as a case study.

Analysis and Coding the Common Themes

The results of both literature searches were analysed using a technique referred to as meta-ethnography (Noblit & Hare 1998) whereby common themes from across the literature have been mapped. This technique is particularly appropriate where a scoping approach is required as identified themes can be used as a starting point for future commissioning. Furthermore, following the identification of themes sub-themes are identified leading to further complexity resulting in a form of hierarchical tree formation which is represented in **(Figure 4 see pages 47 and 48)**. Meta-ethnography, with its qualitative theoretical base, is also particularly suitable for analysis of themes that are less responsive to a quantitative approach such as acceptability, support, dignity and self-confidence.

The coding of common themes has evolved over the duration of the literature search and is presented in **(Figure 4.1 see page 48)**. The coding presents a broad overview of what is largely covered by the literature incorporating users' views in terms of the methodologies that are used, the 'special groups' involved and the areas in which studies have been conducted. However, a coding of the common strengths and weaknesses shared between the application of distinct methodologies did not emerge at this point, possibly as the use of each methodology presented a distinct range of strengths of weaknesses which appeared to be related to individual use. Therefore, sub-themes only became apparent towards the end of this exercise and are more clearly identified in the discussion of findings relating to distinct methodologies presented in Chapter 3.

Consequently, the evolving coding system presents a map of what is in existence and together with an in-depth analysis of selective case studies in the preceding chapters,

will serve to identify areas for future research. The mapping or coding of the methodological literature together with the analysis of selective case studies from the literature have provided two specific routes towards the identification of further research.

The result is not a comprehensive coverage of the literature, as this was not feasible in the three month time span allocated for this project and was, furthermore, outside the requirements for a *scoping* exercise. The result is a broad sample which illustrates a wide variety of applications of distinct methodologies and which also provides a clear indication of the gaps and limitations in this body of knowledge. It was a source of frustration, for both the literature sub-group and the interview sub-group, that in many respects the findings did not reflect the degree of work that is being undertaken. The literature sub-group were still aware of literature which failed to be identified by the searches but could not continue to develop the search terms because of the time constraints. Similarly, the interview sub-group were provided with more and more contacts but again, did not follow these up because of the time constraints.

The Interviews

The focal points for the interviews with key individuals were to establish the range of methods used to elicit users' views, discuss (where appropriate) their strengths and weaknesses across the range of different purposes and to identify existing gaps in knowledge.

Findings from Twenty-three interviews were undertaken with informants from key organisations, agencies and with acknowledged expertise around methodologies to eliciting users' views of health care.

Participants

From existing knowledge of the research team and from cross comparisons of the relevant literature, key individuals, agencies and organisations known for their work and expertise in the field of methodologies to elicit user views were purposively selected as potential participants to interview (n=13). This group represented researchers, key organisations which conduct research and evaluation studies of health care processes, consumer representative groups and health service professionals. Contacts were also made through asking the initial group of participants to suggest further organisations or individuals who they considered to be pivotal in the area of user views. This resulted in a further (n=33) potential sources being identified (**Figure 5 see page 49**). Some of these 'snowball' contacts (n=10) were followed up and subsequently interviewed. However, due to the short time scale of the study it was not feasible to follow up all contacts. The decision to follow up contacts was made on the basis of whether the contact was adequately represented within the original list of key researchers or organisations. For example, if a participant suggested an individual with expertise in consumer involvement methods and this was well represented within the original list then this contact was not followed up. However where an individual or organisation was not represented and was suggested as a useful contact, for example, a health service professional then this was subsequently followed up. In addition during the course of the study the team also identified further groups and individuals that would have been appropriate to interview, for example, a Community Health Council representative. All snowball contacts were recorded as being important for any future work in the area. It is also important to recognise that the group of participants interviewed were not all inclusive and representative of all groups. Rather they were selected in order

that we were able to further understand and identify some of the key issues in this field thus informing the literature and key recommendations of this study.

In October 2000, letters were sent to all identified key researchers and organisations **(Figure 6 see page 50)** inviting them to participate in the study. This letter outlined the purpose and main aims of the study and asked if the participant, or another suitable substitute, would be willing to be interviewed about their experiences and perceptions of using various methodologies to elicit user views of health care. A follow up telephone call was made one week later to establish willingness to participate and provide more detailed information about the study. The original plan had been to interview all participants face to face. However through discussions within the research team and from searching the relevant literature it became apparent that there were many individuals who it was felt had made important contributions to the area of user views. Therefore the original sampling frame was expanded. The implications of this being that the majority of interviews were carried out by telephone rather than face to face to accommodate the larger number of participants in the tight timescale. The benefits of this decision became apparent very soon after the interviews had started as all of the original participants identified further key individuals or organisations to follow up.

If the participant agreed to be interviewed over the telephone a convenient time and date for the interview to take place was arranged.

A copy of the interview guide was forwarded either by post or e-mail to participants thereafter in order to give them the opportunity to consider the questions prior to the interview taking place. **(see figure 7 page 51)**

All participants contacted agreed to be interviewed (n=13) and many suggested other key contacts. Participants represented a number of groups. These included

academic organisations (n=13), service user/voluntary sector (n= 4), health service professionals (n= 2), NHS Executive (n=2) and carers (n=2).

The Interviews

The aims of these semi-structured telephone interviews were to gain a broad range of participant perceptions and experiences of using methodologies to elicit user views of health care and to explore possible gaps in current research . The interview schedule consisted of eight topic areas which covered:

- Participants' past or present role in eliciting and assessing users' views
- methodologies they have used or have been involved in
- strengths and weaknesses of these methodologies
- particular groups and/or purposes for which these methodologies had worked better than others
- methodologies which we needed to know more about
- perceived gaps in current research that merited further methodological research

Finally the participants were asked if there was any key individual or organisation that would be useful to talk to in relation to this project.

The interviews took place from mid October 2000 to mid November 2000. They were exclusively carried out by two members of the research team. The first interview was discussed with the members of the team in order to ensure the appropriateness of the question and interview style. All participants were assured that the interview data would be treated as confidential and 'raw' data would only be accessible to the research team and that the names of individuals and organisations would not be identified throughout the report or within any quotations used to illustrate emergent themes. All participants agreed to the interview being recorded and the fact that the

data might be used for a subsequent publication and conference poster on the same basis.

Each interview began with a brief description of the study, its aims and objectives and gave the participant the opportunity to ask questions. The interview schedule was used flexibly in order to allow for unanticipated or interesting views to emerge. It also was amended according to the particular individual or organisation interviewed. For example, the focus of the interview for carers was on the methodologies that they had been involved in and what they liked or disliked about the method and which methods they felt to be the most appropriate way to elicit their views of health care.

When all topics had been covered within the interview each participant was asked if there was any individual or organisation that the team should be talking to in relation to this study. Additional contacts were suggested by all participants. The interview ended with contact details being exchanged in order that participants could contact the team if they wished to discuss further the interview or any other aspect relating to the study. They were also informed about the plans for feedback and presentation of findings resulting from this exercise. The interviews tended to vary in length. They ranged from between thirty minutes and an hour and a half.

Data Analysis

While the interviews were conducted in an appropriate and well acknowledged manner with a view to analysis for a research publication, it was only an overview and illustration of the scope of the data that was relevant for this report.

Summary notes of each interview were made immediately following each interview. The interviews were tape recorded and transcribed verbatim, to ensure accurate collection of the interview data. Data were analysed thematically in order to identify

emerging themes across all interviews. This was independently undertaken by two researchers. As well as playing each tape back several times, each transcript was read a number of times. This identified anything interesting or significant about what the participant had said as well as identifying important themes within and across transcripts. Emerging themes, some of which were governed by the questions on the interview schedule, were then compared with other transcripts. These were then modified and became part of the main theme. Verbatim extracts were then incorporated into the report to support the themes identified.

Conclusions

This chapter has provided a comprehensive overview of the methods adopted to conduct a methodological scoping exercise on eliciting and assessing users's views on the processes of health care. It also provides an insight into the difficulties that emerged for the team in terms of defining terms and setting boundaries. However, it should also be pointed out that defining terms and setting boundaries is an implicit component of any methodological enterprise. Moreover, the discussion on defining terms and setting boundaries which has taken place over the process of compiling this report has, if anything, provided a stronger report.

Two approaches have been used for this scoping exercise, including: firstly, a review of available literature on methods to obtain and assess users' views and: secondly that of soliciting the views and opinions of expert witnesses through semi-structured telephone interviews about the strengths and weaknesses of different methodologies in eliciting users' views. This two pronged approach has provided a broad overview of the strengths, weaknesses and gaps in methodology.

The process of meta-ethnography has been described in this chapter in which themes and sub-themes have been identified and mapped. However, a limitation of this

approach when conducted by a multi-disciplinary team where individuals have their areas of expertise is bringing together the results coherently. Nevertheless, the final outcome of this scoping exercise is presented in the form of a multi-layered, conceptual map which represents the centres in which the work that has been done in eliciting and assessing users' views. **(Figure 8 see pages 52 and 53)** The layers represent the gaps in work done in eliciting and assessing users' views, and recommendations for the way forward for future research. In addition, suggestions have been produced for addressing the limitations in the use of existing methods for eliciting and assessing users' views.

Figure 3 :Medline (Ovid) Search Strategy

Users

1. user\$.tw.
2. consumer\$.tw.
3. carer\$.tw.
4. caregivers/
5. public\$.tw.
6. patient\$.tw.
7. client\$.tw.
8. lay.tw
9. or/1-8

Views

1. view\$.tw.
2. perception\$.tw.
3. opinion\$.tw.
4. perspective\$.tw.
5. attitude\$.tw.
6. preference\$.tw.
7. satisfaction\$.tw.
8. or/9-15

Methodology

1. exp health services research/

2. exp methods/
3. methodolog\$.tw
4. or/1-3

Specific methodologies

1. focus groups/
2. (focus adj2 group\$).tw
3. or/1-2
4. interviews/
5. (structure\$ adj2 interview\$).tw
6. or/4-5
7. (citizen adj5 jur\$).tw
8. exp questionnaires/
9. questionnaire\$.tw
10. survey\$.tw
11. or/8-11
12. exp consumer participation/
13. willingness to pay.tw
14. complaint\$.tw
15. consensus development.tw
16. exp consensus development conferences/
17. or/15-16
18. meeting\$
19. ((rapid or participat\$) adj2 apprais\$).tw
20. (health adj2 panel\$).tw
21. (citizen\$ adj2 panel\$).tw
22. (pilot\$ and chang\$).tw
23. (open adj5 (surgery or surgeries)).tw
24. committee\$.tw
25. (poll or polling or polls or referendum or referenda or ballot\$).tw
26. quality-adjusted life years/
27. qaly\$.tw
28. or/26-27
29. (conjoint adj2 analy\$).tw
30. 3 or 6 or 7 or 11 or 12 or 13 or 14 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 28 or 29

Systematic reviews

(Developed by the Centre for Reviews and Dissemination at the University of York)

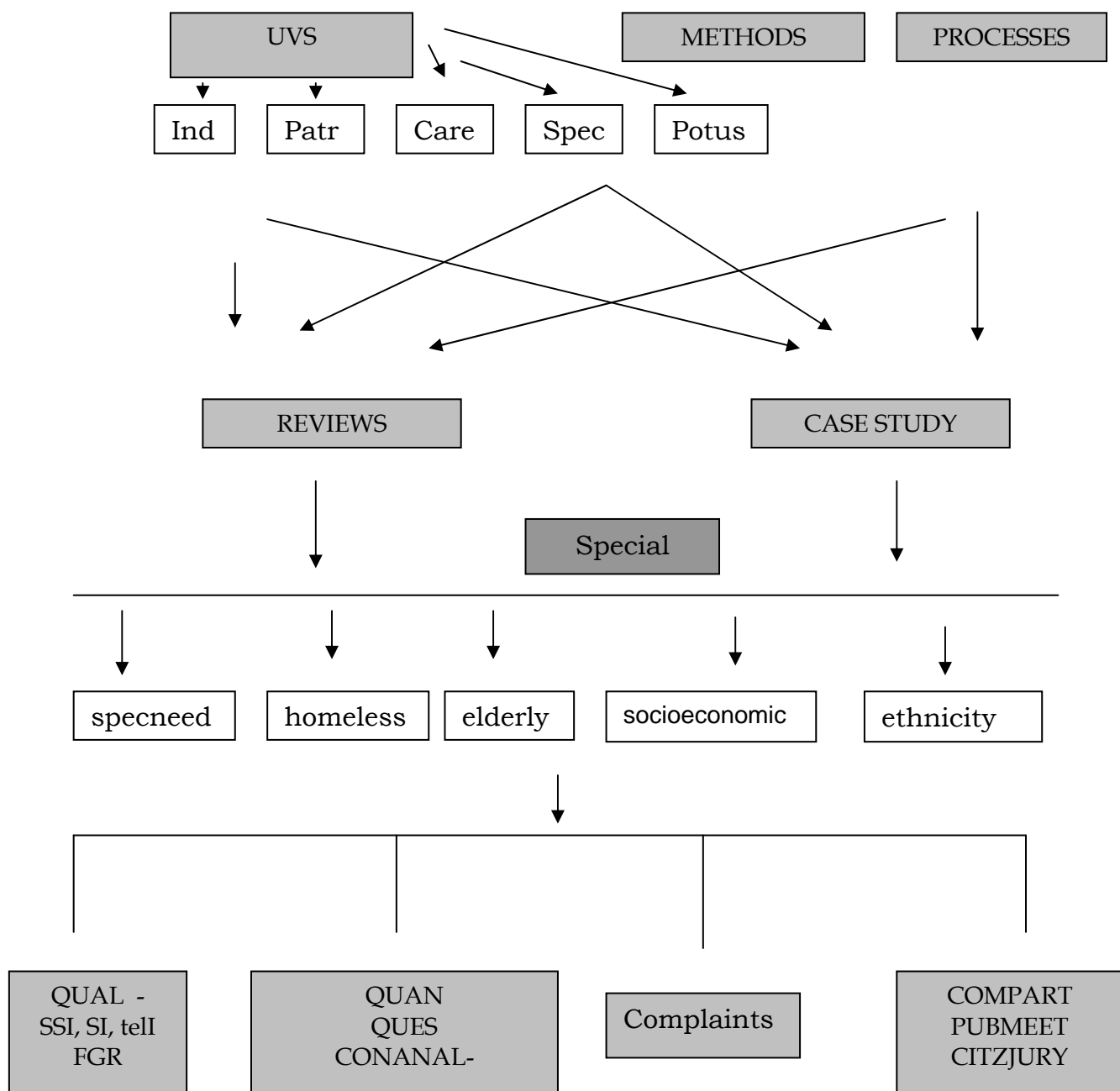
1. meta-analysis/
2. exp review literature/
3. (meta-analy\$ or meta analy\$ or metaanaly\$).tw
4. meta analysis.pt
5. review academic.pt
6. review literature.pt

7. letter.pt
8. review of reported cases.pt
9. historical article.pt
10. review multicas.pt
11. or/1-6
12. or/7-10
13. 11 not 12

Reviews (general)

1. review\$.pt

Figure 4: LITERATURE THEMES



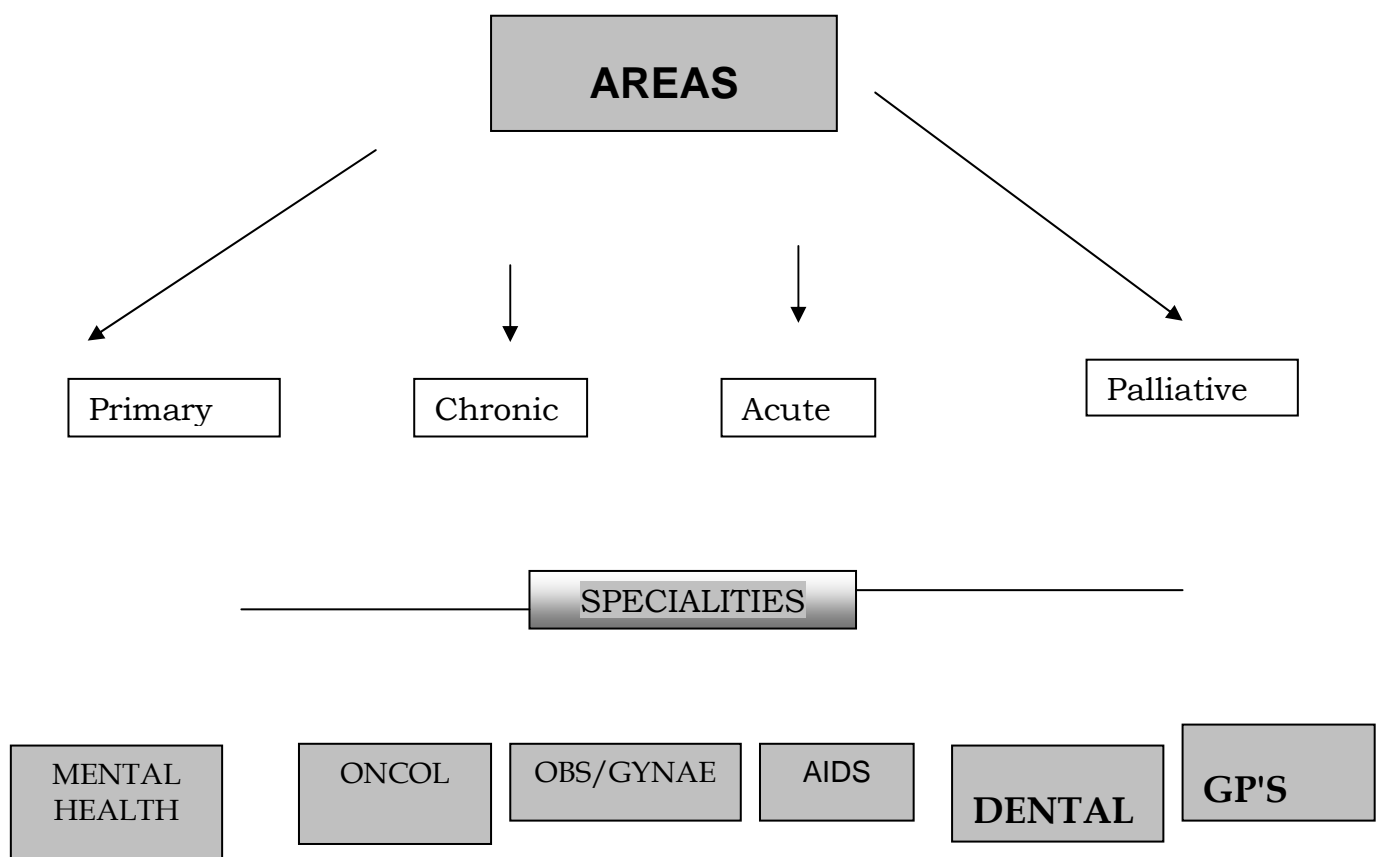


FIGURE 4.1 -CODE DEFINITIONS

UVS: USER VIEWS

INDI: INDIVIDUAL USERS

PATREP: PATIENT REPRESENTATIVES

FGR: FOCUS GROUP

SPEC: SPECIAL GROUPS

POTUSERS: POTENTIAL USERS

CITZJURY: CITIZENS JURY

QUAN: QUANTITATIVE
QUES: QUESTIONNAIRE
CONANAL: CONJOINT ANALYSIS
QUAL : QUALITATIVE
CONANAL: CONJOINT ANALYSIS
COMPART: COMMUNITY PARTICIPATION
SSI: SEMI STRUCTURED INTERVIEWS
SI: STRUCTURED INTERVIEW
TELI: TELEPHONE INTERVIEW
PUBMEET: PUBLIC MEETING
MHEALTH: MENTAL HEALTH

Snowballing Figure

Insert CHEPAS Headed letter

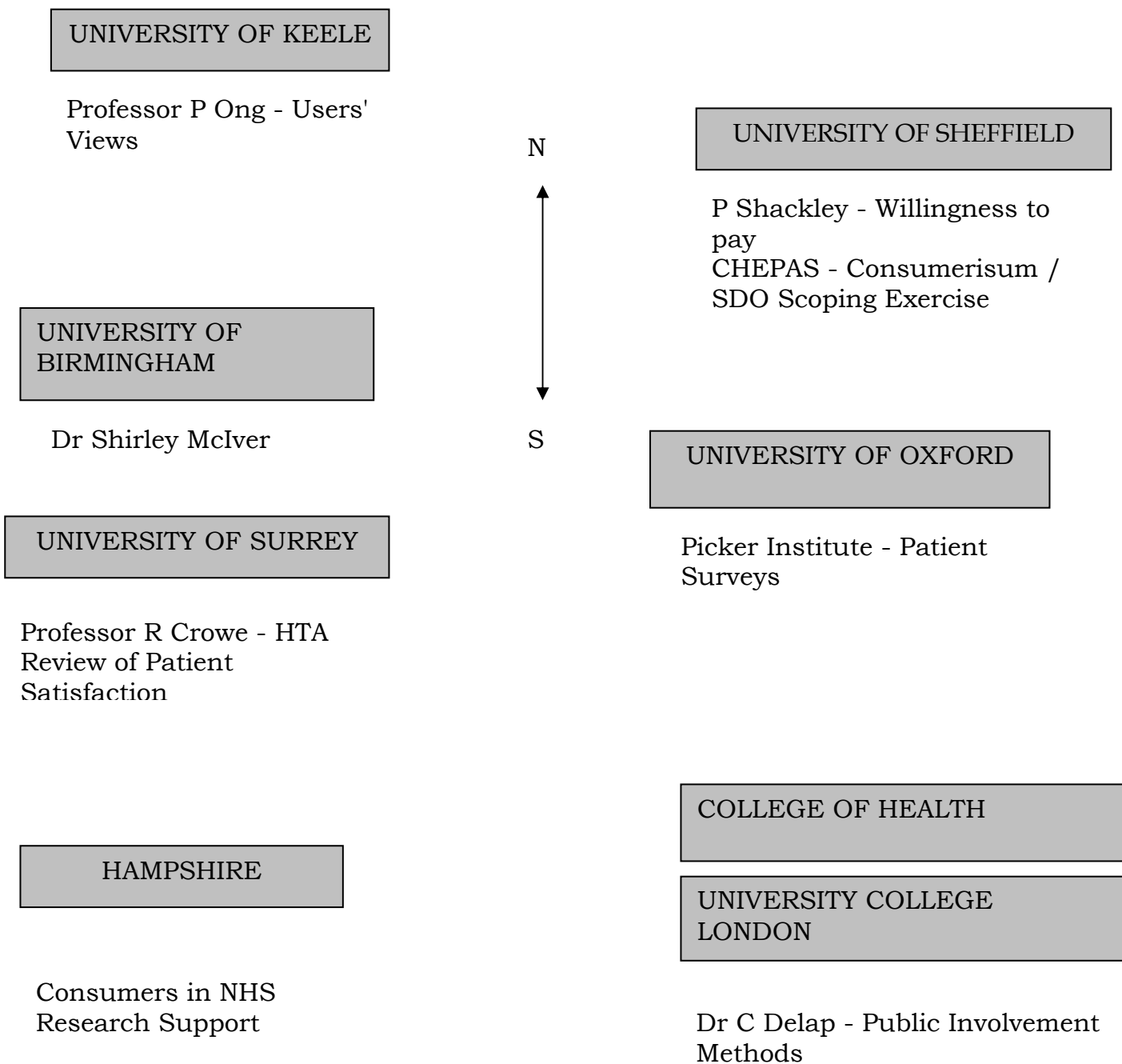
Figure 6: Interview schedule for key informants

1. What role have you taken in eliciting and assessing users' views on the processes of health care? That is, how have you been involved?
2. What methodologies have you used or been involved in?
3. What are the strengths and weaknesses of these methodologies?
4. Are there particular groups and/or purposes for which these methodologies work better than others?
5. Which aspects of the methodologies do we need to know more about? That is, what are the gaps in the research?
6. Are there any methodologies that you have not used or been involved in that merit further methodological research?
7. Is there anything else we should be asking you and other about methodologies used to assess users' views on the processes of care?
8. Is there anyone else we really need to talk to?

Geographic Representation of Centres

conducting Influential work in Eliciting

Users' Views



INSERT JENNIFER'S MAP HERE

CHAPTER THREE

Findings from the Literature Review 1: Qualitative Methods

This chapter describes the results of the literature review of methods for eliciting users' views on health care processes.

As outlined in Chapter Two above, the search strategy detected specific methodologies, for example, 'interview' and 'focus group'. Appropriateness for inclusion in this section was assessed according to whether the methods were eliciting 'users' views', (as opposed to providers views) and whether the methods were used to explore 'processes' of health care, rather than for example, health beliefs.

A further limitation on appropriateness for inclusion was that the research should be conducted within the UK unless there was very limited literature identified.

However, the literature search was not intended to be fully exhaustive. The literature reviewed here, provides a representative and thorough 'scoping' of the use of research methods in eliciting users' views.

The methods reviewed here are:

Qualitative methods including interviews, including semi-structured and in-depth, individual interviews and group or focus group interviews.

The following frame-work is used for describing each of these methods in each of the literature review chapters. The framework is used flexibly as appropriate to each of the methods and the literature available.

- Method description
- Contextual use
- Strengths and Weaknesses
- Examples of use : case study or studies

- Any conceptual issues emerging.
- Methodological research gaps

Qualitative Methods

The aim of this section is to provide an overview of the use of qualitative methods for eliciting users' views in the processes of health care and to highlight the strengths and weaknesses of these methods in application to eliciting users' views. Examples of good and bad use of qualitative methods and the reporting of findings will be provided. Gaps in knowledge about the use of qualitative research for eliciting user views are identified and recommendations are also provided for future work in this area.

A brief definition of qualitative methods is provided and their strengths and weaknesses indicated. Given the extensive use of qualitative methods it is evident that these methodologies are particularly popular for eliciting users' views. It is possible that the popularity of qualitative methods is that they purport to reflect the 'voice' of the health care user and therefore, are increasingly recognised as methods for gaining insight into user's experiences and perceptions of processes in health care.

However, what is evident from this review is that the use of qualitative methods and reporting of qualitative findings is, in many instances, poorly understood and of a poor quality. Whilst there is a comprehensive range of texts which provide clear guidance on qualitative methods (for example Bryman & Burgess 1994) there is an evident lack of analytical rigour in the use of these methods in health care research and nursing research in particular.

What is Qualitative Research?

Qualitative research has different objectives, asks different questions and provides different answers to those of other types of research. Qualitative methods are not concerned with issues of how many people in a given area experience a type of illness or use a type of health service provision. Rather the use of qualitative research can help in understanding what it feels like to suffer from an illness or what individuals think about a particular service.

Sykes et.al (1992) summarise the use of qualitative research methodologies as:

- They provide 'direct access' to the experiences and perceptions of health care users'. Qualitative research has the potential to provide a more in-depth understanding of the behaviour of individuals.
- Qualitative research also has the potential to help people feel 'actively involved' in the provision of health care services rather than the passive providers of information. Qualitative research has the capacity to make people feel more important and that their views are valued.
- Qualitative research can give a 'voice' to people who are traditionally marginalised, including ethnic minorities and people with disabilities.
- Qualitative research is particularly useful in providing information on sensitive issues including the intimate aspects of being cared for and which individuals may find difficult to outline in other research methods.

Qualitative research methods have strengths and weaknesses and are not suitable for all types of research. Qualitative methods are time consuming especially in comparison to more quantitative methods. The limitations of qualitative methods are that they are not generalisable to a wider community in the way that large scale surveys may be seen to be.

The most common methods used in qualitative research are interviews, including semi-structured and in-depth, individual interviews and group or focus group interviews. Participant observation is also considered a qualitative method although its use is not including here, as it does not provide access to user's views but provides access to the *observed practices* of selected social or health care activities. The literature review revealed that the qualitative methods utilised in eliciting user views included individual interviews and/or focus groups.

Individual Interviews

Interviews can be structured to varying degrees of formality and tend to be described as semi-structured. The notion of an 'unstructured' interview is misleading as no interview is devoid of some form of structure (Britten 1995). Semi-structured interviews consist of a loose structure of open-ended questions that guide the respondent through the area under exploration. The interviewee may diverge from the loose structure in order to pursue some aspect of the respondent's comment in more detail. The interviewer requires considerable skill in order to successfully explore the interviewee's frame of reference and not impose their own assumptions.

The Focus Group

Focus groups are recognised as a tool for 'alternative research' due to their potential to 'empower' their participants (Kitzinger 1994)

One simple definition of a focus group is that it:

involves 8 to 12 individuals who discuss a particular topic under the direction of a moderator who promotes interaction and assures that the discussion remains on the topic (Stewart and Shamdasani 1990 p.10).

The focus group can work in conjunction with other methods, or it can stand alone as a self-contained method in its own right (Morgan 1988). The goal in using focus groups is essentially that of learning about participants' experiences and perspectives (Morgan 1988).

The use of focus groups provides rich and diverse data, validated distinctively through social rather than personal processes (Albrecht *et al* 1993). It is the collective identity provided in the focus group, which is likely to result in data reflecting the experiences of the community as a whole, which makes focus groups an ideal research method for exploring the views that different groups of health care user may have.

The collective nature of the focus group allows responses to be placed in their proper context rather than forcing responses into an individualistic and isolated framework which the researcher may consider appropriate (Merton 1956). In this sense the focus group is more likely to encourage 'emic' categories of knowledge, that is knowledge grounded in everyday life through locally relevant terms (Stewart and Shamdasani 1990).

Findings

The use of qualitative research methods for eliciting users' views about the processes of health care are particularly well utilised in the area of mental health. Table 1

provides an overview of the five studies that fitted the inclusion criteria of utilising qualitative methods to elicit user views specifically within mental health.

Table 1: Overview: Qualitative Research Eliciting Users' Views in the Context of Mental Health Care Provision. (see pages 66 and 67)

Table 2: Overview: Qualitative Research in areas other than Mental Health. (see pages 67 and 68)

Table 2 provides a brief overview of the main components of the research studies which have been conducted in other areas to mental health. The studies outlined in Table 2 cover a range of areas as follows: Powell *et.al.* (1994) utilised qualitative methods to explore the elderly's experiences of the provision of care on an elderly unit. Pearson (1991) explored issues around Health Visiting. Two studies explored issues in oncology: Grimes (2000) focussed upon needs in relation to brain tumours and Rees *et.al.* (1998) investigated the information needs of spouses of women suffering breast cancer. Peterson and Britten (2000) explored experiences of asthma care; Dolan *et.al.* (1999) investigated priority setting; Sixsmith and Sixsmith (2000) evaluated the trial use of a home monitoring system. Finally, two studies, Mason (1999) and Somerset *et.al.* (1999).explored issues for patients visiting out-patients:

Use of Interviews

It is evident that interviews are a popular method for eliciting user views. The authors who have utilised this method however, refer to different types of interview format. Semi-structured interviews are the mainstay of the interview format referred to in most studies (Simpson 1999; Powell 1994; Pearson 1991; Paterson 2000; Mason 1992; Somerset 1999). However, Sixsmith refers simply to 'interviews' without clarification (2000) and Grimes refers to 'unstructured interviews' (2000). A 'detailed interview' is referred to by Kendrick (2000) and an 'Open interview format' by McGonagle (1996).

The semi-structured interview format is clearly defined in qualitative research methodology. However, it is not always clear what type of interview these studies are using. For example, it is not clear what constitutes an 'open interview' (McGonagle 1996) and whether the authors are utilising open ended questions, which would be anticipated in an interview anyway, or whether the authors are referring to a more unstructured interviewing format. Similarly, reference to 'a detailed interview' is unclear. A further concern is evident in how Grimes describes the interview format used in this study as 'unstructured' (2000). The notion of unstructured interviewing is essentially non-existent in practice as all interviews have some structure and interviewers require some indication of the topic and areas that they wish to cover in their interviews.

Therefore, in some of these studies the use of the qualitative method is unclear.

Use of Focus groups.

Focus groups are also popular and the mechanics and strengths and weaknesses of focus groups are well-documented (Stewart & Shamdasani 1990). Focus groups are

the single method in the studies by Jackson (2000), Hostick (1998) and Rees (1998) and are used in combination with individual interviews in the studies reported by Simpson (1999) and in combination with questionnaires in Dolan's study (1999).

Jackson (2000) demonstrates a clear understanding of the use of focus groups in order to 'promote a sense of collective remembering between group participants'. In addition, Jackson describes how a component of this collective nature would be that focus group members could 'challenge each other's views, so adding to the range of the data collected' (p. 379). Rees identifies the importance of the focus group in enabling the participants to set their own agenda' (1251; 1998).

Simpson (1999) also justifies the use of focus groups by quoting McIver (1991) in highlighting how a group interview may present a more relaxed forum for people who lack confidence. Furthermore, Simpson describes how the focus group may help individuals contextualise their experience within the shared discussion of the group with the result that they are better able to express their own views. However, what Simpson fails to acknowledge, and what needs to be acknowledged more broadly, is that the focus group can also be potentially very intimidating for many individuals and there are real issues about confidentiality and ethics which are not given any consideration in the papers reviewed.

However, whilst these authors appear to understand the use of the focus group in eliciting views the reporting of data from these studies does not reflect the diversity of opinion that would inevitably arise. The presentation of focus group data is invariably used to indicate a shared understanding which would often be misrepresentative of focus group discussion.

Hostick (1998) utilised focus groups as a forum for discussion to develop a format for an 'ideal' mental health service. The facilitator used the focus group to develop themes and recorded key points on a flip chart. These focus groups were not recorded and transcribed although interesting, the author does provide what would appear to be verbatim quotes.

Dolan uses focus groups 'to facilitate discussion between respondents' (p. 318; 1999). However, these focus groups were highly structured with respondents being asked to rank hypothetical patient cases in terms of priorities and make separate sets of comparisons between patients. The authors also state that all group discussion were tape recorded and transcribed although there was no reporting of focus group data in their paper. Distinct and comparable data would appear to be the required outcome of focus groups in this study rather than rich and diverse data

Hostick and Dolan's use of the focus group is distinct from the other reported uses of focus groups to such a degree that it is questionable that these authors are actually using focus groups. Rather the processes are more akin to the Nominal Group Technique (NGT, see below) in that the authors are reporting agreement in group discussion and are attempting to reach a consensus of views. However, in the focus group the fact that some members of the group may or may not voice an opinion may be a reflection of the pattern of interaction at the time. Counting the occurrence of a particular viewpoint therefore, is potentially misleading. Furthermore, given a different pattern of interaction and different groups, the force of individual's viewpoints may change (Sim 1998).

Using the voice of the respondent

Given that the strength of qualitative research is providing a voice for respondents very little attention is given in these studies to actually using the voice of their respective respondents. The importance of providing examples of data is to illustrate analytical procedures. Furthermore the use of quotations provides the opportunity for the reader to appraise the fit between the data and the authors understanding and use of that data (Elliot 1999)

An example of poor reporting of data is provided in Simpson's study (1999). Following conducting focus groups and semi-structured interviews with 52 service users' Simpson simply describes and interprets what respondents have reportedly stated. For example Simpson states:

'Most users' wanted CMHNS [community mental health nurses] to talk to their carers and to provide them with more information subject to the user's consent. However, there were exceptions and users' saw it as important that CMHNS have the skills and confidence to discuss the matter with clients and to respect the view of the user' (p. 351; 1999).

In contrast, Paterson and Britten (2000) provide a good example of the reporting of data. In a study using semi-structured interviews the authors explored the views of people with asthma about the organisation of asthma care in general practice. They quote the mother of a six-year old girl with asthma who is commenting on 'expert knowledge and therapeutic relationships:

'If she was fine I don't have a problem with seeing the asthma nurse. I mean, I don't if she was fine, but if she was really poorly, then I would rather prefer to see the doctor...I mean, I know the asthma nurse could do that as well, but, I don't know, there's something about a doctor [laugh], there's something about a doctor that gives you the confidence to, you know deal with the situation'. (p. 302; 2000).

Out of these qualitative studies Kendrick *et.al.* (2000), Simpson (1999), Powell (1994) Grimes (2000), Dolan (1999) Sixsmith (2000) and Mason (1992) do not report their findings with reference to the direct quotes by the respondents.

Out of those authors who do report to use the voice of the respondent there are differences in how these quotations are contextualised. For example, some of these authors report quotations with no demographic or personal details attached. In other words, the quotation is left floating. A particularly poor example of floating quotations is provided in the work of McGonagle and Gentle (1996). In this study the authors are attempting to discover the reasons for non-attendance at a mental health day hospital. In elaborating upon how their respondents had described a lack of an individual approach to their care the authors state that 'The general feeling was that they [clients] were offered a set programme regardless of their expressed problems' (p. 63) The authors then quote respondents or a respondent thus:

'It was as though I was a number, a nobody, and one was just put here and there
They treat us all as one
They suggested social groups, but I know they don't help' (p. 63 1996).

As stated it is not clear whether these are multiple responses or from the same person. In addition there is no indication as to who this person is, whether they are male or female, or their age. Such information is important in grounding the findings of qualitative research. Researchers should describe their participants and life circumstances to help the reader judge the range of persons and the situations in which the findings might be relevant (Elliot 1999)

By way of a contrast, and a good example of grounding respondent's quotations, Rees provides the reader with a first name in reporting the findings from focus groups. In reporting how respondents described how information should be made available to them about breast cancer the authors state that respondents had suggested that an explicit offer of information should be made to women and their spouses:

'Michael: Only if it comes in the form of your doctor or the breast care nurse sitting down and saying 'well, you know, after the operation, your wife's not gonna be able to iron your shirts for a week'

Paul: yeah, that's right.

David: Even if it's that...

Michael: That would be a start, a token, a token breaking of the ice really' (1998).

It is clear from this excerpt that there are multiple respondents involved in this discourse and that they are all men. Even though there is no distinct demographic detail this would not necessarily enhance the use of the quotations in this example. However, these quotations are still well grounded. Similarly, Paterson and Britten (2000) identify their respondents in exploring the views of asthma sufferers about the organisation of asthma care in general practice by providing an age and gender.

Analysing Qualitative Data.

The process of analysing qualitative data is fraught with difficulties and ambiguity. Typically, qualitative researchers have not always made their analytical tools accessible. The implicit difficulties in analysing qualitative data are handled in very different ways across these studies. The use of 'Grounded Theory' techniques emerges commonly in these studies as descriptions of both method and analysis. It is acknowledged that the original Grounded Theory technique as outlined by Glaser and Strauss (1967) is particularly complex. It can be a matter for dispute as to how far authors who make claims to be conducting 'grounded theory' actually are. There is no reference in these studies of the formation of hypotheses and the researcher returning to the field in order to clarify, confirm, contradict or expand upon these hypotheses which are all key components in developing original grounded theory.

The use of grounded theory or grounded theory techniques are referred to by Jackson and Stevenson (2000) who also refer to a process of 'constant comparison in coding'. Simpson (1999) also claims to be using grounded theory in a study based upon focus groups and semi-structured interviews. However, focus groups and interviews are not recorded and transcribed so on the basis of a lack of data one could question how far the strategies for developing grounded theory could be properly initiated. Pearson (1991) also described grounded theory as the approach to this study and that 'constant comparison' was utilised as the process of analysis. Rees *et.al.* (1998) referred to 'theme analysis' and that a process of 'cut and paste' was employed reflecting the constant comparative method of the grounded theory approach.

There is evident confusion about what constitutes the grounded theory approach. However, it is clear that few, if any of these studies are utilising grounded theory but rather using a process of identifying and generating themes and subthemes which are coded.

Other authors analyse qualitative data with reference to coding (Sommerset 1999; Jackson 2000). Grimes (2000) only report negative and positive comments. The number of people who agreed or disagreed is used by Dolan *et.al.* (1999) in reporting their findings. Content analysis is described as the process of analysis in McGonagle's study (1996) and findings are reported as the most frequently stated responses. Paterson describes the development of an 'inductive coding frame' for the analysis of this study (2000).

However, there is little analytical rigour given to the process of coding overall and no consideration given to this key component of qualitative research in the studies of Simpson (1999), Sixsmith (2000) and Mason (1992). It has been argued that the counting of data has a place in qualitative research. Whilst frequency is a commonly accepted method of analysis it is somewhat limited and does not do justice to the rich data which may be elicited through qualitative methods. For example: McGonagle (1996) report that 'Forty-two per cent (n=6) experienced attending the day hospital as traumatic because they felt they were not listened to' (p.63). This type of information could have been elicited from questionnaire or survey type methods rather than utilising qualitative methods.

A further concern in the use of qualitative methods in these studies is the lack of critical consideration given to the role of the researcher. Little attention is given to

who is conducting the field-work and the impact they may have upon the findings.

Whilst Powell *et.al.* (1994) state that the process of analysis entailed 'both self reflexivity' (p. 200) there is no discussion as to how this was achieved.

The exception to this overall lack of analytic rigor is found in the study conducted by Paterson and Britten (2000) who acknowledged that the researcher analysing the findings from their exploration of the provision of asthma care in general practice was a general practitioner in the practice. The authors did take steps to overcome this acknowledged limitation including involving a social scientist experienced in qualitative research to discuss analysis as it proceeded.

The concern over the lack of methodological rigor has been echoed elsewhere. In a review of 29 papers, which reported to use qualitative methods in researching issues in general practice, Hoddinott and Pill (1997) concluded that these papers often lacked explicit methodological detail about the relationship between the interviewer and the respondent.

Reliability and Validity

It is the case that the terms *reliability* and *validity* have long since been discredited in relation to qualitative methods which are by their very nature explorative. However, there remains confusion over the value of these terms which appear frequently in the studies reviewed here. For example, Simpson (1999) argues that 'during the collection, collation and analysis of data careful consideration was given to ensure validity and reliability' (p. 350). In an attempt to generate validity and reliability the authors described how summaries of headings, categories and quotes were sent to participants who were asked to comment.

Somerset *et.al.* (1999) also uses the language of *validity*. They state that 'In order to enhance validity of the process of analysis, the researchers discussed their readings and codings and exchanged transcripts' (p. 215). Pearson (1991) describes how 'To check for reliability, some transcripts from each stage were checked for emergent categories by a non-health visitor' (p.523). Reliability is also a concern for McGonagle (1996) who also describes swapping transcripts to check the same themes emerged.

However, a more appropriate use of terminology is evident in Jackson and Stevenson's study (2000). In acknowledging that qualitative methods are criticised for a perceived lack of rigour and for producing non-representative data Jackson and Stevenson described the importance of *credibility*. They state that 'credibility occurs when qualitative study provides a recognisable interpretation of what the participants have said' (p. 380). The authors described how participants were asked to comment on how study results created *resonance* with them.

Paterson and Britten (2000) also utilised techniques to increase quality and rigour in their methods including:

- using an independent researcher to select the sample and carry out the interviews;
- analysing the transcripts without identification of the individuals;
- involving a social scientist to code interviews and discuss analysis;
- relating the findings to wider social theory relevant to chronic disease.

Conclusions

There is often little attention given to methodological context in the qualitative studies reported here. As outlined in Tables 1 and 2 the aims of research was not always explicit (Grimes 2000; Sixsmith and Sixsmith 2000). A further concern is that some studies gave no consideration to methodology (Sixsmith and Sixsmith 2000) yet this study still appeared in a peer-reviewed journal.

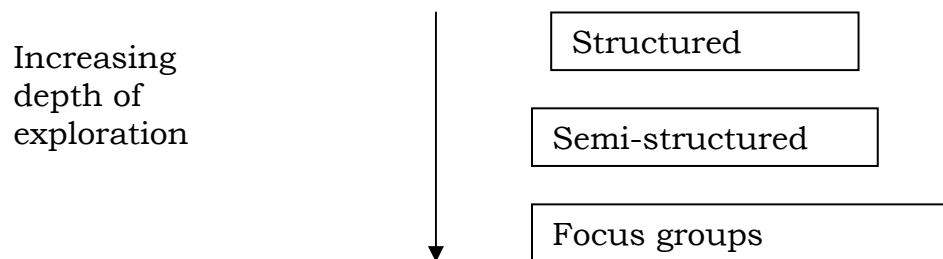
Furthermore, given that the strengths of qualitative methods are that they provide a 'voice', greater attention should be focussed on reporting that voice through selected and appropriate quotations. In addition, when quotes are used they are not always provided with a context, including demographic details, in order to provide the reader with an indication of the scope and applicability of the findings.

The process of analysis of findings is not made explicit and many authors report to use grounded theory when they are referring to a process of identifying themes, sub-themes and coding.

There are clear descriptions provided in research text concerning how and when to use qualitative methods. However, the reporting of what methodology is used is often unclear, for example what type of interview format is used. Focus groups are also popular although there is little understanding of their potential and the reporting of findings do not do justice to the strengths of focus groups in eliciting diverse data.

The depth of exploration provided by interviews and focus groups can be represented as they are in Figure 1, in the form of a hierarchy with structured interviews at the top and focus groups at the bottom with the potential to provide the most in-depth views:

Figure 10: Representation of a hierarchy of qualitative methods that can elicit in-depth data



However, the frequent use of the focus group is at the top of this hierarchy, as a tool for eliciting numerical representations of respondent's consensus views (see for example Hostick 1998).

Focus groups are often inappropriately used to elicit a consensus of views or used when a different group technique would be more appropriate. The use of the focus group is to provide an in-depth exploration of issues which may stand alone or form a framework for an interview format in areas where the issues are ill defined.

Health researchers have utilised theories from social science disciplines particularly the use of grounded theory and have made little attempt to develop independent theories. Unfortunately the use of grounded theory techniques are often misunderstood and misapplied. There is a need for a coherent qualitative methodology which would be adaptable across different settings and contribute to a coherent body of knowledge.

The use of qualitative research is popular in eliciting users' views about the processes of health care. However, there is clearly a requirement to recognise the differences between rigorous and well-designed qualitative research and what Safaer terms as

‘well intentioned but poorly implemented attempts to supplement quantification with more open-ended interviews’ (p. 1103; 1999). It has in fact been argued that a particular advantage of qualitative methods is that ‘they do not require the degree of technical skill needed to produce and interpret statistical data’ (May 1995). There is the need to challenge the assumption that qualitative research can be conducted by anyone, regardless of their training and that conducting and interpreting qualitative data does not require skill.

Recommendations and research gaps

There is a need for more understanding of the research process and the need for analytical rigour in conducting and reporting qualitative research.

Particular attention is needed with respect to:

- Making explicit aims and objectives and research questions for exploration;
- Providing a clear and comprehensive outline of the methods used;
- Providing a clear outline of whom is conducting the research and the relationship between the interviewed and the interviewee.
- The process of analysis should be explicit.
- The use of ‘grounded theory’ has become a short cut for a process of identifying themes and coding. The references to the use of grounded theory are therefore, often misleading and clearly many health researchers do not understand the process. The use of other forms of analysis should be adopted. The use of Ritchie and Spencer’s ‘Framework’ (1994) provides a clear and analytically rigorous approach to the analysis of qualitative data that is also clearly

documented. It also provides the scope for the inductive and interpretative thinking that makes qualitative methods challenging.

- The voice of the respondent is the strength of qualitative research. Researchers should utilise this voice in reporting their findings but ensure that their use of quotations is provided with some form of context rather than left 'floating'.
- The use of qualitative methods has provided an insight into a range of issues for people with chronic diseases: cancer, mental illness and asthma. Also these studies have explored issues in outpatients and for patients who have contact with health professionals such as health visitors. There is a distinct lack however, of the use of qualitative methods in exploring the micro issues of humaneness in the processes of health care. This would include how users' would experience warmth, respect, and kindness and be assured their dignity. These areas are still the bedrock of effective care, often the most difficult to implement for busy staff and yet remain the most over looked by qualitative researchers.

Table 1: Overview: Qualitative Research
eliciting users' views in the context of Mental
Health Care Provision.

| Authors | Year | Journal | Method | Aim | Number | Analysis | Use of data |
|---|------|--|--|---|------------------------------|---|---|
| Kendrick, T., Burns, T, Garland, C., Greenwood, N., Smith, P. | 2000 | Br. J of General Practice. | 'Detailed interview'. No mention of who the interviewer is. | To identify patient and practice factors associated with continuing contact and loss of contact with specialist mental health services. | 102 | Statistical demographic details, symptoms and number in contact with care. | |
| McGonagle, I., Gentle, J. | 1996 | J of Psych and Mental Health Nursing. | 'Open interview format by person 'unknown' to respondent | To discover the reasons for non- attendance at a mental health day hospital | 14 | Content analysis. Interviews transcribed | Reported by most frequent response. Uses quotes but with no personal or identifying reference to who has made the quote. |
| Jackson, S., Stevenson, C. | 2000 | J of Advanced Nursing | 'Grounded Theory' / focus groups. | To explore the perceptions of mental health professionals, service users, ex- service users and carers concerning the needs of people in psychiatric systems and their perception of what psychiatric nursing activity would meet those needs. | 92 | Interviews transcribed . 'Constant comparison in coding. QSR. NUD.IST | Core category. Uses data with identification |
| Hostick, T. | 1998 | J of Psych and Mental Health Nursing | Focus groups: facilitated by psychologist- observed by researcher (Mental health nurse) and member of MIND | Not explicitly stated: to explore participants' views of an 'ideal' mental health service. | 25 | Key points recorded on flip chart. Observers kept field notes | Uses quotes identified from focus groups. (Earlier 1995 publication with no use of quotes) |
| Simpson, A. | 1999 | J of Psych and Mental | Semi- structured interviews and focus | Not explicitly stated: to explore the views of service users and | 52 service users 24 | Not recorded but 'detailed | Does not use respondent's quotes. |

| | | | | | | | |
|--|--|----------------|-------------------------|---|--------|---|--|
| | | Health Nursing | groups: Grounded theory | carers concerning the education and training of Community Mental Health Nurses. | carers | notes were taken and field notes added' | |
|--|--|----------------|-------------------------|---|--------|---|--|

Table 2: Overview: Qualitative Research in areas other than Mental Health.

| Author | Year | Journal | Method | Aims | N= | Analysis | Use of data |
|---|------|---------------------------|---|--|----|--|---|
| Powell, J., Lowelock, R., Bray, J., Philp, I. | 1994 | Quality in Health Care | Semi-structure d interview: questions derived from interviews with staff. Conducte d by 'research nurse' | To examine patient's perceptions of care in the elderly care unit | 83 | Recorded and transcribe d. 'Content analysis' | Does not use data to report findings. |
| Pearson, P. | 1991 | J of Advanced Nursing | Semi-structure d interviews and diaries. Further semi structure d interviews plus 6 case studies. Grounded theory approach. Unclear who researche r is. | Main aims: To explore the process by which members of a client group identify and interpret their health needs: to examine the process by which members of a client group develop perceptions of health visiting | 60 | Recorded and transcribe d. Constant compariso n | Reports data but only from case studies |
| Grimes, K. | 2000 | J of Clinical Excellenc e | Unstructu red interviews . Does not indicate who interviews . | Unclear: 'developing an overview of the service from a patient's perspective' with reference to patients with brain tumours. | 30 | Recorded and transcribe d. Positive and negative comments where copied onto a 'process | No reference to data. |

| | | | | | | | |
|---|------|---------------------------------|--|--|-----------|---|-----------------------------------|
| | | | | | | map' which document ed the patients journey through the system. | |
| Rees, C., Bath, P., Lloyd-Williams, M. | 1998 | J of Advanced Nursing | Unstructu red focus groups. Does not indicate who the moderator was. | To explore the key information concerns of spouses of women with breast cancer from the patients' perspective. To explore the key information concerns of spouses of women with breast cancer from the spouses' perspective. | 309 | Recorded and transcribe d. 'Theme analysis' employed. 'Cut and paste method'; constant comparati ve method. | Uses data which is well grounded. |
| Paterson, C., Britten, N. | 2000 | Br J of Gen Practice | Semi-structure d interviews . Interviewe d by research assistant. | To explore the views of people with asthma about the organisation of asthma care in general practice. | 21 | Recorded and transcribe d. Developm ent of an 'inductive coding frame'. | Uses data which is well grounded. |
| Dolan, P. Cookson, R., Ferguson, B. | 1999 | BMJ | Focus groups and questionn aires. | To investigate the extent to which people change their views about priority setting in health care as a result of discussion and deliberation. | 60 | Reported as how many people agreed or disagreed. | Does not report focus group data. |
| Sixsmith, A., Sixsmith, J. | 2000 | J of Tele-medicine and Telecare | Interviews . | Not explicit: An evaluation of a field trial of a home monitoring system. | Not given | Not discussed . | Does not report data. |
| Mason, C. | 1992 | J. of Advanced Nursing | Semi-structure d interviews and 'observati on | To explore possible reasons for non-attendance at out-patients. | 25 | Not discussed | Does not report data |
| Somerset, M., Faulkner, A., Shaw, A., Dunn, | 1999 | Social Science and Medicine | Semi-structure d interviews . No | To explore the complexities of the outpatient experience for providers and | 9 | Analysed for key themes and sub-themes. | Uses data but not grounded. |

| | | | | | | | |
|------------------|--|--|---|-----------------------|--|----------------------------|--|
| L., Sharp, D. | | | mention of who interviewe r was. | recipients of care | | Topics were 'coded'. | |
|------------------|--|--|---|-----------------------|--|----------------------------|--|

CHAPTER FOUR

Findings from the literature review 2:

This describes the results of the literature review of methods in telephone interviews, rapid appraisal, community participation, open surgery's, use of deliberative policy and health economics approaches.

Telephone Interviews

Use of telephone interviews did not emerge from this literature search, possibly because the standard use of telephone interviews as a method is to supplement a primary research method. Furthermore, the use of qualitative telephone interviews is less common than the use of the telephone to elicit more quantitative data.

The telephone interview is economic and has the potential for providing superficial qualitative data. However, they are less likely to provide the opportunity for a more in-depth exploration of personal issues, which are more likely to be, elicited by face to face contact. With reference to Figure 1 the use of qualitative telephone interviews would be placed at the top of the hierarchy in providing in depth data, above the use of structured interviews.

Rapid Appraisal

Why use Rapid Appraisal

Rapid appraisal (RA), or rapid participatory appraisal, can be used to help plan health services and ensure that the distribution of resources reflects local needs. It involves a community in diagnosing needs and formulating action plans to meet those needs. That is, a community is part of the decision-making process.

Brief description

The approach originated in developing countries for assessing the needs of urban communities. A group of 'resource holders' for the selected community can run the RA or be convened by the researchers commissioned to undertake the RA. A variety of methods and techniques are employed to understand the health and social needs of the community: written records, observation, focus groups, structured questionnaires, interviews with key informants within a community. Three layers of information are obtained – about the composition of the community, the socio-ecological factors influencing health, and services available to the community. Results are fed back to the community for prioritisation and to determine solutions to the problems identified.

Which issues has it been used to address for which groups of users'?

It is used for communities rather than user groups. Examples of use include: identifying the needs of a socially deprived community for a health authority; planning primary care which is sensitive to the health and social needs of people living on a council estate in Edinburgh; developing out-of-hours primary care in a socially deprived multiethnic community in London; identifying the need for reproductive health care in a community affected by civil war; and identifying the unmet pharmaceutical needs of a general practice population.

Case study

Listening to local voices: adapting rapid appraisal to assess health and social needs in general practice (*Murray, Tapson, Turnball, McCallum, Little 1994*)

A GP, a health visitor, an education worker, and two social workers undertook a rapid appraisal of the health and social needs of people living on a council estate in a general practice population in Edinburgh. The team undertook semi-structured interviews with key informants in the community, for example community leaders of self-help groups and residents of the estate. The results from written documents, interviews and observations were fed back to informants in a meeting. Two focus groups of informants discussed priorities and potential solutions. The local newspaper reported on the process. Problems highlighted included poor physical environment, financial hardship, and a long wait to get an appointment at the general practice. Solutions included arranging for a bus to come into the estate and improving local general practice services. The transport office introduced a bus service for the community. The practice made changes such as introducing more toys in the waiting room and addressing older patients more formally.

Strengths

1. The priorities of communities have been shown to be different from the priorities of professionals. This methodology allows the views of the community to be heard.

2. It is a relatively quick way of involving a whole community compared with community development.
3. It places health issues within the context of other issues such as education, security, environment etc. Thus it takes a holistic view of people's experiences.
4. It is a flexible method, which can be adapted for each community.
5. It can identify the strength of feeling about problems rather than just the problems themselves.
6. The community identifies the solutions as well as the problems and thus can influence, and sometimes be directly involved in, the decision-making process.
7. It can be used with relatively deprived communities.
8. It can help to establish an on-going relationship between those commissioning services, providing services and the community.
9. Triangulation of data from different sources contributes to scientific rigour.
10. Non-researchers can successfully use this technique. In fact, it may be a stronger technique if the research team are local workers and therefore have ownership and take action.
11. A multi-agency team can aid collaboration between agencies.
12. The process itself can generate change more quickly than other methods of identifying health needs such as postal surveys and analysis of routine data.

Weaknesses

1. It can only be undertaken in relatively small communities - 10,000 people at the most. Even within this size of community, three or four sub-communities will operate. However, it has been undertaken on a community of 700,000.
2. It takes a broad approach and cannot answer specific questions. For example it can identify what the problems are, but cannot answer the question of how

many people suffer from a problem. So the community perspective may have to be used alongside other methodologies. Indeed, different methodologies give different insights into a communities needs and may complement each other.

3. It is difficult to generalise the findings, although rapid appraisal exercises in different communities tend to find similar issues.
4. It is intensive and can be time consuming for health professionals to undertake.
5. It is open to unrepresentative sampling of key informants.
6. It may not be fully 'participatory' due to lack of time. That is, the community may not be involved in planning the RA, interpreting the results, and may not receive feedback about changes which have occurred as a result of the exercise.
7. The organisations which commission RAs may not be open to change, making RA a theoretical exercise without a real opportunity to influence planning of services.

Methodological research gaps

We found few methodological papers about RA in the field of health. The strengths and weaknesses listed above were based mainly on researchers' experiences of RA. A leading expert in rapid appraisal felt that although methodological work is important, it is time to stop refining methodologies and concentrate on making organisations more open to change. Efforts need to be focussed on developing organisations which listen, reflect on the findings of research such as rapid appraisal, and take action on it. Without commitment to change, rapid appraisal becomes a theoretical exercise and can do more harm than good, by raising the community's

expectations. Thus the main area for further investigation is how to ensure that organisations are able to take action based on the results of RA.

Key references

Ong et al (1991), Murray et al (1994), Naish (1994), Murray and Graham (1995), Dale et al (1996), Palmer (1999), Murray (1999), Williams et al (2000).

Community Participation

Community participation was identified in our original proposal as a methodology for eliciting user views. Both 'communities' and 'participation' can be considered at a range of different levels.

It could be argued that the first level of user participation is patient participation in clinical decision-making related to their own care. This is considered below. The second level relates to the involvement of service users' as individuals or groups or group representatives to influence processes of health care.

The third level is the involvement of communities. These communities could be geographical communities such as housing estates residents, or communities of specific populations such as ethnic minority communities, people with specific medical conditions or disabilities. Where the communities are defined as users' of particular services then there may be overlap with the second level.

An accepted view of community participation is as a tool for changing communities in some way with the long term aim of improving health status, attitudes or health related behaviour. Community participation is seen as 'people's empowerment to overturn current inequalities and increase control over their health' or 'a strategy for solution of public health problems' (Guldan, 1996). This goes beyond the role of

'eliciting user views'. Community participation may have as one of its objectives an aim to facilitate participants to express their views, but this would be only one aspect. Community participation can not therefore be classified simply as a method of eliciting user views.

User involvement can be used to enable users to influence the development of services and has been used, particularly in social services and community care, to allow users' to express their voice, to influence services and to make services more sensitive to users' needs (Wistow and Barnes, 1993). In fact, in reporting on innovations to support carers, Leat, (1992) states that "consultation and involvement should underpin all schemes designed to support carers"

Involving users' in the design and administration of patient satisfaction measures has been reported to improve the validity of the measures (Windle and Paschall, 1981). There is also growing interest in involving users' in the development of guidelines to improve services (Duff, Kelson et al. 1996). However, Duff identifies that the methods for doing this have not been evaluated. Barnes and Wistow (1993) argue that to open up services to influence by their users', the process must be a continuing one. However, they also recognise that frustration can result when continued involvement is not seen to lead to a change in service provision.

Forbes and Sashidharan (1997) goes so far as to argue that (particularly in relation to mental health service users') abandonment of the idea of empowerment will only facilitate the continuation of the current position of the user.

There is therefore a continuum of involvement of users', in approaches to eliciting their views. This ranges from no involvement beyond their immediate response to a degree of involvement which increases their capacity to have more control and influence over services as well as their health and possibly other arenas of their lives.

This end of the continuum may be considered to constitute empowerment and therefore to parallel community participation.

It is not the method used to elicit user views which influences the level of potential for allowing user involvement but the way in which the method is employed. To illustrate, a postal questionnaire may be considered to require minimum involvement from users' but if users' are invited to frame to questions, design the questionnaire and interpret the findings then their involvement and influence could be substantial. There are many voices calling for the active involvement of users' in the process of seeking their views. This has been raised repeatedly by the interviewees of this study and to quote just one advocate of public participation in the consultation procedure "We should be wary of replacing 'the medical gods' with, the 'consultation gods'" (Wolf, 1999).

Summary and recommendation for further research

In summary, community participation is much more than a method for eliciting user views. However, for some groups of people who are less motivated to participate or less able to because of their social and economic circumstances it may be that their views will not be heard unless resources are invested in empowering them to do so. Community participatory methods may therefore be appropriate but the expression of their views should be only be one, arguably relatively minor, objective of such an approach. User involvement is increasingly being seen as a more valuable approach to improving services in response to users' views.

The effectiveness of the established methodologies themselves should not be the focus of future research but rather:

- evaluation of whether, how and in what specific contexts community participation / user involvement facilitates expression of the views of marginalised and excluded groups
- the cost and resource implications of community participation / user involvement;
- review of use of the community participation / user involvement in healthcare with examples of good models of practice

The gap in research in this area appears to have been already identified by the Health Development Agency (HAD). The HAD is intending to undertake reviews and syntheses of effective community participation models and methods, and guidelines on best practice (Health Development Agency, 2000). This is a welcome development and its progress should be followed.

Open Surgery

Brief description

Open surgeries are a time when members of the public can 'drop in' to meet with a representative of the health authority or local authority to discuss concerns. The representative needs to be someone at a senior enough level to have sufficient overview to be able to deal with a range of queries.

Use of Open Surgeries

Surgeries can be run in the community with similar activities organised by other agencies such as social services. They can be used as an opportunity to provide direct feedback to health care managers. However, it is necessary to be clear what the objectives of the surgery are and to make this clear to the public.

Strengths

1. Use of Open surgeries can build alliances between organisations.
2. Continuous dialogue can be established.
3. Helps accountability and gives a channel for people to challenge and question.
4. The initiative can be linked with GP surgeries, Council for Voluntary Services etc

Weaknesses

This method:

1. may be perceived to be for complaints only;
 2. may get the same people attending all the time or very few attending;
 3. takes the time of one or more senior people;
- and
4. there may be a lack of clarity about what the purpose of the surgery and how the information will be used.

(Leicestershire Health, 2000 adapted from Barker et al, 1997)

Research Gaps

There is very little published literature on open surgeries and it is difficult to know how much this approach is being used. It would be interesting to know the extent to which this approach is being used by health organisations and what the costs and benefits are.

Questionnaire Based Surveys

The terms 'survey' and 'questionnaire' are often used interchangeably. To be precise, surveys can be undertaken using a range of data collection techniques including, but not limited to, questionnaires. For example, a survey may comprise routinely collected statistics only. For the purposes of eliciting views, the survey tool would be a questionnaire.

Brief description

A questionnaire based survey is a set of questions, on a form with a choice of answers for the respondent to select (closed questions) and / or space for respondents to respond freely. The questionnaire can be distributed by mail or directly by hand.

Use of questionnaire based surveys

A questionnaire based survey can be used to obtain information from a large number of people on a set of predetermined questions. The data can be analysed statistically providing quantitative information.

The questionnaire is a tool frequently used by healthcare professionals attempting to obtain feedback from service users' about the quality of the service. Critique of the use of questionnaires in this context falls within the remit of the HTA commissioned systematic review on *Measurement of patient satisfaction*. Personal communication with a member of the research team undertaking this exercise verified that methods relating to eliciting user views of the processes of care will be addressed in their report. However, clarity is provided here in relation to the overlap between the HTA review of patient satisfaction and this scoping exercise as not all views related to processes of care can be defined as 'patient satisfaction.'

This scoping exercise focuses on methods for eliciting users' views on health care processes. Views include expectations and reports of experiences and processes are relatively widely defined (see chapter one). Three specific areas are included in this exercise:

- individual patient involvement in clinical decisions related to their own care
- the views on services of individuals, groups or specific communities with experience or expectations of those services
- public opinion e.g. ethical considerations, preferences, priorities for spending.

The first level, patient participation in clinical decision making, is considered later.

The third level, public opinion related to ethical issues, preferences and priorities for spending is addressed within various sections in this chapter including Polling, Health Economic approaches and Consensus methods and Priority setting in Health care.

The use of questionnaires to elicit user views in the second area has been assumed to equate to the use of questionnaires to identify patient satisfaction and is considered to fall within the scope of the the HTA commissioned systematic review on measurement of patient satisfaction.

As this area is already covered elsewhere, literature on the use of questionnaires for eliciting views on the processes of care has not been extensively reviewed here and no attempt has been made to identify gaps in the research. However, the strengths and weaknesses of the use of questionnaires based surveys have been well reviewed (Bless et al, 1979; C.A. Moser & G. Kalton, 1979; Cartwright, 1988; Leicestershire Health, 2000; Barker et al. 1999; Siemiatycki, 1979) and are listed below.

Strengths

1. Questionnaire based surveys can be considered to be a relatively cheap way of obtaining the views of a large number of people. However, if response rates are low the cost per respondent can be quite large. When used with telephone and home interviews to obtain responses from persistent non-responders it can be a cost-effective and high response method.

2. Particularly valuable where the population of interest is widely and thinly spread
e.g. parents of children with a very rare medical condition.
3. Information on a range of variables for a large number of people can be obtained.
If well done, information can be drawn from a representative sample.
4. The data can be quantitatively analysed:
 - questionnaires can be used to describe the characteristics of a population related to their beliefs and attitudes or attributes, ('attributes' refers to characteristics such as age, occupation, ethnicity, social class etc);
 - questionnaires can also be legitimately used to identify relationships between the data collected. These relationships may be purely descriptive (e.g. identifying variations in views between men and women);
 - it may even be possible to draw causal inferences from the data (e.g. use of services by specific population groups dependant on their perceptions of staff attitudes). Extreme caution must be exercised in attempting to use questionnaires in this way without supporting evidence from other sources;
5. The questionnaire designer defines the questions to be included and therefore can dictate the issues to be addressed.
6. They are easily repeatable and can be used to collect the same data at different time-points to monitor changes over time.
7. They can be distributed by post or administered face to face
8. The data collected are mainly quantitative but allows for some qualitative data to be collected.
9. Avoids issues associated with use of interviewers – errors related to interviewer effect and interviewer training

10. Respondent can feel more anonymous than when other methods such as focus groups or interviews are used which may be a benefit when issues are potentially delicate or embarrassing. This method has been shown to yield a higher proportion of valid responses compared with interviews when the responses are of a sensitive (e.g. socially undesirable) nature.
11. Avoids the problem of non-contacts i.e. respondents not being at home when the interviewer calls.

Weaknesses

1. The response rate may be very low and therefore affect the validity of the results.
2. There may be a response bias as certain population groups are less likely to respond to questionnaires.
3. There are specific population groups for which questionnaires are particularly inappropriate e.g. people from ethnic minority communities, people with poor levels of literacy, people with sight problems.
4. The rate of inadequate and incomplete responses may be quite high.
5. The method is only appropriate where the questions are sufficiently simple and straightforward to be understood with the help of written definitions and explanations.
6. It is not appropriate for complex issues where the respondents may require further, individually tailored information in order to respond.
7. The responses have to be accepted as final with no opportunity to explore further areas arising of particular interest or responses with potential for

misinterpretation (unless questionnaires are used in conjunction with other methods).

8. There is no certainty about who has completed the questionnaire.
9. The respondent can see all the questions in the questionnaire. The investigator has no control over the order in which the questions are read and answered.
Some questions may influence responses to others.
10. The investigator has little opportunity to support the respondent if the questions create distress or confusion.
11. Requires substantial administration.

Contextual Issues

The validity of a questionnaire depends on many factors including the sampling frame, response rate, being appropriate for the purposes required and the validity of the questions included. Appropriateness of use relates to its use in relation to the strengths and weaknesses described above. Validity of the questions relate to their reliability, validity and ability to discriminate as defined here (de Vaas,1990):

- Ability to discriminate: often a question to which most people provide the same answer is of little use. If everyone provides the same answer there are no variations to explain, this could be due to loaded questions or having too few response alternatives;
- Validity: a valid measure is one which measures what it is intended to measure;
- Reliability: a reliable measure is one where we obtain the same results on repeated occasions.

Surveys have been repeatedly criticised by researchers for failing to uncover honest views from service users' (Barnes, 1992; Wilson, 1993). Temple et al. (1996) also identify that whose interpretation of the findings is accepted is an issue.

The major issues in the use of questionnaires is not therefore related to the value of questionnaires per se but whether they are employed appropriately for the required purpose and the skill of the person responsible for design, analysis and interpretation of the results.

Key references

Barker et al.,1999; Bless et al, 1979; Cartwright, 1988; de Vaas,1990; Leicestershire Health,2000; Moser & Kalton,1979; Siemiatycki, 1979.

Deliberative Polling/ Referendum / Ballot

Deliberative polling, referendum and ballot can be considered as a type of survey.

Brief description

In a referendum or ballot, people are asked to vote on an option or number of options. In a deliberative poll, a representative sample is asked to vote, after which they learn more about the issue through being given more information through workshops and an opportunity to ask questions of relevant 'experts', and are then asked to vote again.

Use of Deliberative Polling/ Referendum / Ballot

These are, as yet, seldom used within health services. These are methods for getting statistics about people's preferences for or against an option or series of options. The responses obtained will be 'yes' or 'no'. It is not appropriate to use if the purpose is to obtain an understanding of why people have made a decision. People will have high expectations that action will be taken in response to the outcome of the poll, ballot or referendum.

Strengths

1. Provides clear results in statistical form.
2. It is fairly easy for people to participate, especially with postal voting mechanisms.
3. Depending on response rate and participants can be representative of the wider population.

Weaknesses

1. Results may be influenced by media reports rather than based on personal informed view.
2. There may be a poor response rate.
3. The use is limited to where responses are of 'yes/no' or simple checklist format.

(Leicestershire Health, 2000 adapted from Cabinet Office, 1998)

Case study

Manpower Studies for the United States: Demand for Eye care, A Public opinion Poll based upon a Gallup Poll Survey *Reinecke and Steinberg (1981)*

A survey of the general public in the United States was undertaken about their utilization of ophthalmology services and their opinion of the adequacy of the services. Since the consumer's choice or behaviour depends on being informed about the differences between ophthalmologists and optometrists such knowledge was assessed and the responses further evaluated after explanatory statements were made to the responders.

A total of 3,067 personal interviews were conducted on a national sample of adults. The sampling procedure was designed to produce an approximation of the adult civilian population. Two of the questions included were "Does the public believe that a national health care program should cover routine eye examinations and glasses" and "If both an ophthalmologist and an optometrist were available and if you had your choice, would you prefer that your eye care be provided by an ophthalmologist or an optometrist?"

75% of respondents thought that if there is a national health care program it should cover routine eye examinations and glasses.

Of those that knew the difference between an ophthalmologist and an optometrist 78% preferred to have eye care by an ophthalmologist. Of the remaining after being informed about the difference between the two, the majority chose an ophthalmologist.

The use of this type of approach seems limited in the UK as health care is such a political issue and the outcome is sensitive to influence by media coverage of the issues. It's use is limited to simple responses and therefore the approach must be

used with caution as research has shown that the format of the questions and responses can influence the response significantly. Adell et al. (1993) demonstrated that using general questions with only two or three options overestimated the proportions of respondents who either favoured a ban on all abortion or who would allow abortion in all circumstances. Questions that pose circumstances result in movement of respondents out of extreme categories and into more moderate ones. However, it may be an appropriate method where the following circumstances apply: the public have ready access to the relevant information; the issue is of public interest; where public debate is taking place already and where the response options are simply yes /no or for or against.

A further point is that the value of this methodology appears to depend on the scope for informed deliberation. If the feedback to respondents were to be done through 'citizen's jury' type workshops this methodology could be valuable in obtaining informed decisions from the public. However, no UK literature was identifying reporting the use of the method in this way.

Research gaps

There appears to be very little literature available relating to the use of this approach in the UK. On the basis of the literature search which identified U.S literature further research in the use of this methodology was not considered by the authors to be a priority because of the limitations discussed above. However, experience of the use of this method identified through personal communication highlighted the potential value of this method in circumstances where there is substantial scope for informed

deliberation by respondents. In the light of this, further research of the use of his method in the U.K. is recommended.

Health panels, Citizens' panels,

Brief description

The term Health Panel is used to refer to different methodologies. One definition is that of a group drawn from members of the general public or from users' or carers to meet with health service managers to discuss health care issues (Leicestershire Health, 2000).

The term is also used to describe a random sample of people drawn from the general public who agree to respond to questionnaires on health related issues on a regular basis (Wilson and McHarg, 1995). Health panels drawn from specific population groups such as ethnic minority communities (Kirklees FHSA, 1994) have also been described. The unifying elements of these descriptions are that the group of people involved are intended to be a representative sample of a larger population group drawn from the local area and that their views on various issues are sought repeatedly over a period of time. The actual methods of eliciting views may be focus group, questionnaire, face to face or telephone interview (Barker et. al.,1999; Kirklees FHSA, 1994; Leicestershire Health, 2000; Wilson and McHarg, 1995).

Contextual use

Health panels are a popular method of consulting with 'the general public' and have been used extensively by health authorities and local councils. Councils, health authorities and more recently, primary care groups, often collaborate to establish

health panels to meet their statutory obligations to consult with the public (Dowsell et al. 1995; Cooper & Bond, 2000). They are used to enable ongoing, rather than, one off discussion or investigation.

Case Study

Rationing : Use of representative health panel shows changes in public attitudes to rationing. *Worth (1999)*.

Talkback consists of 2000 local residents in the Calderdale and Kirklees Health Authority area (total population 580,000). The panel was jointly established between the health authority and the two local authorities. Its' membership is reportedly representative of the age, sex and ethnicity of the local population. The panel is surveyed 3 to 4 times a year on a range of broad issues. The panel has been used to explore the issue of who should be involved in rationing of health care and what should be rationed. The results of that survey showed that the public thought rationing should be led by local clinicians and that three quarters of the panel supported the health authority's approach to priority setting. The health authority considered the panel to be a helpful mechanism for monitoring changes in public attitude in ways that can contribute to decision making on the rationing of care.

Strengths and Weaknesses

Although their use is widespread there is little evidence of evaluation of this method of consultation (Dowsell et al.1995; Rotherham et al., 2000). This is partly explained by the fact that although the term 'health panel' is relatively new the methods employed i.e. postal questionnaires, focus groups or interviews are established methods. The strengths and weaknesses are therefore dependent on which particular

method is employed (see relevant sections of this chapter). However, Dowswell (1995) identifies the predominate problem with health panels as the issue of representation. No matter how carefully populations are sampled selective participation may make responses less representative. Response rates to the original recruitment questionnaire can be as low as 10% (Rotherham et al. 2000). Further more, attrition of panel members over time may not be random, with the result that the sample will become progressively less representative. Thus she concludes that panels may not only be more expensive than one-off surveys they may also be less valid.

Apart from the strengths and weaknesses associated with the particular methodology employed, listed below are some specific issues related to the use of health panels generally.

Strengths

1. A panel can be made up of a large number of people.
2. The panel is recruited to be representative of the general population or a specific population.
3. Panel members give agreement to participate and therefore are more likely to respond
4. It can be used to gain understanding of public views and perceptions on general issues e.g. their understanding of the role of health authorities and primary care groups
5. It can be used to gain understanding of public feelings on controversial issues e.g. attitudes to priority setting, charging for certain services.
6. Panel members can become more informed over time if information from previous rounds is fed back to members (this can be a potential weakness).

7. There is potential for a more sophisticated or complicated level of questioning as ideas can be explored further over time.
8. There is potential for more complicated level of questioning as respondents may be more committed to respond and more prepared to read additional information provided than in one-off initiatives.
9. Panel members can provide input as citizens and not only as service users'.
10. If the panel is set up to respond to questionnaires, it can be used as a sampling frame for members for focus groups for more qualitative work.
11. It can be used as a sounding board for new developments and ideas.
12. Feedback is relatively quick once the panel has been established.
13. It can be used to track changes over time
14. Costs can be shared between organisations

Weaknesses

1. The sampling frames used by health authorities and local authorities (such as electoral registers) can systematically exclude certain groups of people such as young people and council tenants from the panel.
2. As panels members are making a significant commitment to contribute over an extended period the response rate to the initial recruitment questionnaire can be much lower than to typical postal questionnaires.
3. The two points above may result in the sample not being representative at the outset and it may become increasingly less representative over time with attrition.
4. Specific groups such as ethnic minorities, are unlikely to be represented unless specific measures are taken to address this.

5. Even where specific subgroups are represented in proportion to their numbers in the population the method may not appropriate for exploring their views because of the small numbers actually recruited.
6. Composition of the panel must be continuously reviewed and refreshed.
7. The establishment and maintenance of a panel can be relatively expensive and time consuming
8. The fact that a panel has been established may mean it is used in some circumstances when other methods may be more appropriate.
9. Panel members may become more informed and therefore less representative over time. This can be addressed by refreshing membership regularly.
10. It may be difficult to regularly address issues which are of interest to the majority of the panel members and the investigators
11. Where questionnaires are used, because of the requirements to consult with the panel on a regular basis, resources may not be committed to ensuring the validity of the questions.
12. The questions should be simple, obvious and unlikely to be open to misinterpretation. This restricts the issues, which can be explored with this method.

Research Gaps

As the methodologies employed with health panels are fairly well established e.g postal questionnaires, focus groups etc the methodologies themselves do not need to be researched further. However, there are many limitations (listed above) associated with the use of health panels, in particular, problems of obtaining a representative sample and the views of smaller population groups. There has been little independent evaluation of the use of health and citizens panels by statutory

organisations although they are extensively used and costly to establish and maintain. It is recommended therefore that there is further research into the cost, benefit and validity of the use of health and citizens panels with illustration of examples of models of good practice to inform guidelines for good practice.

Health Economics techniques

When researchers are undertaking economic evaluations of health services, they tend to focus on health outcomes, for example they undertake cost-effectiveness analysis or a Quality Adjusted Life Year (QALY) approach. However, as well as considering clinical outcomes, they may want to consider non-clinical outcomes such as being better informed, and process attributes such as location of care. The concept of 'process utility' was introduced into the health economics literature by Mooney in the early 1990s and its complexities have been discussed in a key paper by Donaldson and Shackley in 1997. They highlight the difficulties of defining 'process' as different from 'outcome', giving the examples of reassurance, dignity and information which we may think of as process utilities but which may reflect a person's mental health state and be interpreted as outcomes.

Two economic techniques are available for measuring preferences for process attributes of services - **conjoint analysis** and **willingness to pay**. They can be used to assess the importance of different processes and outcomes for one service, and for measuring the preferences for alternative models of care with different process attributes, from the user's viewpoint. Conjoint analysis is particularly suitable for identifying the **trade-offs** that individuals make between different attributes of health care processes, and between health outcomes, non-health outcomes and process type attributes of care.

Both techniques require specialist skills and, in the case of conjoint analysis, special software.

Conjoint analysis

Why use it?

Conjoint analysis (CA) also known as discrete choice experiment, has been developed in health economics to take account of factors beyond health outcomes. This makes it a very important methodology when considering users' views of the processes of care. It is used to measure strength of preferences and the trade-offs that people are willing to make between different processes, and between processes and outcomes. The technique can be used with users' and the general public. For example, a commissioning body such as a health authority or primary care group may want to know whether they should introduce local clinics at the expense of increased waiting time. Conjoint analysis can help them to look at the trade-offs that individuals are willing to make between the location of a clinic and waiting time. It can be used to study optimal service provision, estimate willingness to pay, within the context of randomised controlled trials, study patient preferences in the doctor-patient relationship, and prioritise across service developments.

Brief description

The following steps are undertaken:

1. *Defining the attributes of a service.* These can be pre-defined by the policy question or identified directly from users'. For example, two attributes might be distance to travel and waiting time.

2. *Assigning levels to attributes* which are plausible, actionable and capable of being traded-off. For example, waiting times might have three levels: one month, three months, one year.
3. *Creating hypothetical scenarios* with different combinations of attributes and choosing a small subset to present to individuals. Three options exist for choosing this subset: fractional factorial designs, removal of dominant and dominated options, and block design. Tables and computer packages have been devised to help with fractional factorial designs.
4. *Establishing preferences* for scenarios by using a postal questionnaire or interviews and applying one of three methods: ranking exercises, rating exercises, and discrete choices. The discrete choice approach most commonly incorporates pair-wise comparisons and is more difficult to design than ranking and rating exercises. However, it is firmly rooted in economic theory, reflects the types of decisions people make every day, and thus is the most commonly used approach.
5. *Analysing responses* by estimating total and marginal utilities using statistical techniques relevant to the methodology applied for establishing preferences. Regression techniques are commonly used and willing to pay can be estimated if cost is included as an attribute.

Who has it been used with?

It has mainly been used to assess the preferences of users' of services e.g. patients who have undergone a life-saving treatment, users' of an assisted reproductive unit to determine the value of assisted reproductive techniques, patient preferences for

surgical versus medical treatment of miscarriage within a randomised controlled trial, patient preferences for blood transfusion support, and patient preferences in the doctor-patient relationship.

It has also been used to assess the preferences of potential users' e.g. the general public for place of elective surgery on the Isle of Wight, undergraduate students for avoiding surgery versus continuing knee pain, the general public on their preferences in public health research, university employees and their preferences for the allocation of donor liver grafts for transplantation, and the trade-offs people are willing to make between location of clinic and waiting time in the provision of orthodontic services.

Case studies

Eliciting patient's preferences for different models of out of hours care (*Scott, Watson, Ross, Torrance 1998*)

Over 6000 questionnaires were posted to parents of children under 13 years old to determine their preferences for out of hours care. The attributes were chosen from existing literature and through piloting the questionnaire. The response rate was 68%. The most important attribute of out of hours care was whether the doctor seemed to listen. People were willing to trade this attribute for shorter waiting time for consultation and desired location of consultation. The study identified the importance of communication skills for GPs.

Patients' preferences regarding the process and outcomes of life-saving technology

(Ratcliffe and Buxton 1999)

Conjoint analysis was undertaken to assess the relative importance of health outcomes and process attributes, such as waiting time and continuity of contact with medical staff, for liver transplantation services. The attributes were defined using existing literature and 12 interviews with patients. A postal discrete-choice questionnaire was piloted and then sent to 213 patients who had received, rather than were waiting for, transplantation. Fifteen percent of respondents were not prepared to trade outcomes for process attributes. However, the majority of respondents were willing to trade a reduction in health outcome for an improvement in process characteristics. This shows the importance of processes of care as well as outcomes to people, even with life-saving services. Respondents were willing to exchange an increase in waiting time to achieve a high level of continuity of care. The authors note that the results may have been different had the survey been sent to patients awaiting treatment.

Strengths

1. Measures *strength* of preference rather than simply preference.
2. Identifies the trade-offs individuals are willing to make; this is more akin to the real world and real policy decisions.
3. Identifies the trade-offs between processes and outcomes as well as between different aspects of processes.
4. Measures preferences for services which may not exist, as well as existing services.
5. Can provide 'willingness to pay' if cost is included as an attribute. It does not meet the resistance met by direct willingness to pay approaches, where respondents register protest views, and it may even provide more accurate measures of willingness to pay because it eliminates incentives to understate preferences. However, there are methodological concerns when using CA to measure willingness to pay.
6. Methodological research has been undertaken to show that it has internal validity, internal consistency, and is not sensitive to ordering effects.
7. Results of CA studies have been found to be consistent with economic theory.
8. It is acceptable to users' in that it *can* achieve relatively high response rates and can be quick and easy to answer.

Weaknesses

1. The researcher must identify the attributes important to users', otherwise misleading results can be obtained.

2. Attributes are pre-specified and thus restrict the aspects that respondents include in their deliberations.
3. It needs specialist skills and analysis packages.
4. Experts in CA may not be experts in survey research. There were many examples in the literature of the lack of use of reminders in postal surveys, resulting in response bias.
5. The scenarios selected for use in the questionnaire are selected at random from hundreds of options. A different selection may give different results.

Methodological research gaps

Although conjoint analysis is a relatively new technique in health care, a considerable amount of methodological work has been undertaken to date. The HTA review of eliciting public preferences addresses this methodology in detail (Ryan, in press). Here, the strengths and weaknesses of the technique have been determined from existing methodological literature as well as from expert opinion. There are important research gaps:

1. Qualitative research needs to be undertaken alongside CA to ensure we know what goes through people's heads when they are making decisions during CA. We need to know how this can best be undertaken - people can be asked to express their views on the questionnaire, they can be interviewed after the process, or focus groups can be used to assess the results of the CA. Additionally, we need to understand if there is added benefit in undertaking qualitative research, over and above piloting of a questionnaire, when determining the attributes.

2. More research is needed on estimating willingness to pay using CA. Qualitative research may help us to understand how people consider a cost attribute – they may consider cost of treatment, rather than value of treatment in their deliberations.
3. Some people do not have preferences, for example 70% of people did not want to trade cost of travel with waiting time in one study. Non-traders are excluded from the analysis in CA. This may not be a problem for some policy questions but for others, this indifference may need to be measured and incorporated into the analysis.
4. Some health economists feel that we do not have a good enough understanding of theoretical issues for CA and would like to see a literature review of the use of CA in transport, where the theoretical issues have been studied, and lessons for health care.
5. What is the external validity of CA i.e. can it predict real behaviour in the health care field?
6. Would two different selections of scenarios give the same results?
7. Computer software is used to reduce the number of scenarios to 16 say, and then 8 pairwise comparisons are undertaken. We need empirical research comparing this approach with showing all relevant combinations of the 16 scenarios.
8. What are the costs and benefits of collecting data by postal questionnaire, interview or computer software.
9. Even though some research has been undertaken in this area, we need to know more about the effect of ordering of comparator scenarios, ordering of attributes within scenarios, the choice of comparator, and the number of levels on preferences.

Key references

Ryan, Scott, Farrar, Shackley, Vick, McIntosh (1996), Scott, Watson, Ross, Torrance (1998), Ryan, McIntosh, Shackley (1998), Bryan, Buxton, Sheldon, Grant (1998), Farrar and Ryan (1998), Ratcliffe and Buxton (1999), Ryan (1999), Jan, Mooney, Ryan, Bruggermann, Alexander (1999), Ratcliffe (1999), Ratcliffe (2000), Ryan, McIntosh, Dean, Old (2000), Ryan, Farrar (2000).

Willingness to pay

Why use it?

Willingness to pay (WTP) is based on the premise that the maximum amount of money an individual is willing to pay for a commodity is an indicator of the utility or satisfaction of that commodity. It combines, in one measure, people's valuations of outcomes and processes of care. It is an important technique to consider in this study because it has been used to measure the strength, as well as direction, of people's preferences for process attributes in the provision of care. For example, if a health authority wanted to know the value placed on a service provided in a particular way they would undertake a WTP exercise (also known as a contingent valuation study). It has been used with users' of services and the general public. It has been used in the context of randomised controlled trials.

Brief description

WTP involves the production of a questionnaire that can be administered by post or by an interviewer. Four main techniques are used:

1. *open-ended*, where respondents are asked directly what the maximum amount of money is that they would be prepared to pay for a service.
2. *bidding card*, where the individual is asked if they would be willing to pay a specific amount of money. The interviewer increases the bid until the individual says they are not willing to pay and then lowers the bid until the maximum amount is found.
3. *payment scale*, where respondents are presented with a range of bids and asked to circle the maximum they would be willing to pay.
4. *close-ended*, where individuals are asked whether they would pay a specified amount for a commodity and are able to give a yes/no response. Different bid amounts are given to different respondents and everyone is asked whether their maximum WTP is above or below the bid given. There are two variants of this approach – with and without follow-up.

These four (five) techniques have been compared in empirical studies. They have advantages and disadvantages which we are unable to summarise without taking a more systematic approach to the literature. For example, the bidding method needs an interviewer, the payment card/ scale is easier to answer than the open-ended question but only provides an interval estimate of WTP, the close-ended approach reflects the decisions people make every day but WTP is more difficult to estimate

and requires a large sample size to ensure accurate estimation. A consistent issue is that the open-ended approach is not favoured. However, there are mixed opinions on which technique is superior.

Who has it been used with?

WTP has been used with people on a waiting list for cataract surgery to see whether they were willing to pay for a shorter wait, users' of a screening service to see how much they would pay for a scan, women receiving antenatal care and their WTP for different models of care, patients on a waiting list for surgical treatment were asked about how much they would pay for laparoscopic surgery over and above payment for traditional treatment, outpatients were asked how much they would pay for tape recordings of doctors' explanations and recommendations.

It has been used to elicit public preferences for water fluoridation.

Case studies

Using WTP to value alternative models of antenatal care (*Ryan, Ratcliffe and Tucker 1997*)

Women may have preferences for systems of care that provide more (or less) choice and continuity of care, as well as more (or less) involvement by midwives and general practitioners. The WTP technique was used to compare the benefits from shared care, where the obstetrician is the lead provider, versus GP/midwife-led care. The process attributes studied were involvement of different staff, location of antenatal appointments, choice in delivery of care; the non-clinical outcomes were provision of information and reassurance. A questionnaire was posted to over 900 women applying the close-ended technique to these attributes. A response rate of 69% was obtained for the WTP questions, illustrating that this was acceptable to the women. Women were willing to pay approximately £2,500 for antenatal care, with no difference between shared care and midwifery-led care. The authors question whether willingness to pay was right technique to use to compare two services.

Willingness to pay: a method of measuring preferences for maternity care? *(Donaldson, Hundley, Mapp 1998)*

The willingness-to-pay technique was applied to valuing the benefits of different locations of intrapartum care by measuring women's strengths of preference for maternity care and delivery in a midwives' unit relative to care and delivery in a consultant-led labour ward. One hundred and fifty women at low obstetric risk at their booking visit were sent a postal questionnaire, with a response rate of 75%. One third did not express a preference, half expressed a preference for a midwives unit and the remainder preferred a consultant-led service. Although most women preferred the midwives' unit, the strength of preference of a small group of low risk women for a labour ward was large.

Strengths

1. Provides a single measure of the value of the benefits of health care.
2. Firmly rooted in economic theory.
3. Easily understood and therefore acceptable to the majority of respondents.
4. Behaves in accordance with a priori expectations.
5. Does not predetermine what people think about in their deliberations. They can incorporate anything into their thinking.
6. Can be used within a randomised controlled trial, although there are only about three studies which have done this.

7. There is evidence from the environmental literature supporting the reliability and validity of the WTP approach.
8. Guidelines for use of WTP in environmental studies have been produced (National Oceanic and Atmospheric Administration. Report of the NOAA panel on contingent valuation. Fed Reg 1993;58:4602-14.) Their application in the health field has been disputed.

Weaknesses

1. The political sensitivity of using WTP in the NHS, where commissioners and providers of health care may be concerned that they will be seen as attempting to privatise the NHS. Users' can respond with 'protest bids' because they object to being asked to pay even in theory. They may refuse to complete the question for other reasons too, for example retired people may think WTP is not relevant to them because they do not pay taxation if the question is worded in taxation format. One way around this is to stress that the exercise is theoretical but this does not stop all problems. It may introduce strategic behaviour and overbidding.
2. The most frequently levelled criticism is that WTP depends on ability to pay. It is such a strong finding that it is used to test the validity of findings. This means that the preferences of those on higher incomes are given more weight, and thus resources are allocated based on ability to pay. There is also evidence that people who leave fulltime education earlier find WTP less acceptable, adding to this bias.

3. External validity has been tested in the environmental literature but we do not know whether these results are transferable to health care.
4. A potentially important weakness is scope sensitivity – does WTP increase as benefit increases? NOAA, the expert panel in the environmental field, says that it should be expected. But there is evidence that it may not be true and that people may just be WTP for a “good cause”.
5. There are other potential weaknesses such as starting point bias and range bias. The results of WTP are sensitive to the starting point in the bidding technique, or the bid design or range bias in the selection of values presented to respondents in payment methods, and the allocation of individuals to each bid level in the close-ended technique.
6. Problems with using WTP in RCTs are starting to emerge. For example, if people are asked to value the service they received, they value it relative to nothing. If they are asked to value two options they think about which one costs more. WTP experts recommend that researchers take a marginal approach by asking how much more people would be willing to pay for the option they prefer. Experts also suggest that people in the trial are not asked WTP questions because they cannot value the service offered in the other arm of the trial and sometimes researchers do not want people to know what services are being offered in the other arm. They recommend that data are used from the trial to formulate the scenarios and then a WTP exercise is undertaken with people not involved in the trial.

Methodological research gaps

Health economists have undertaken a large amount of methodological work on willingness to pay in the field of health care and understand the relevance of methodological work undertaken in environmental and transport economics. There are two reviews of the literature. The HTA review of eliciting public preferences addresses this methodology in detail (Ryan, in press). The Eurowill Project, funded by the European Community, was established to investigate the feasibility of WTP to set health care priorities. Six surveys were undertaken in six countries to explore research gaps in WTP such as scope sensitivity, closed-ended questions versus payment method, ordering, and framing the question from a community or an individual perspective. Currently the results of these surveys are being written up. A researcher in the Eurowill study has helped us to identify research gaps in the light of the results emerging from Europe. Here, the strengths and weaknesses of the technique have been determined from existing methodological literature as well as from expert opinion. There are important research gaps:

1. Researchers using this methodology have called for primary qualitative research on the thought processes of individuals when they complete WTP exercises, to understand the reasons why people have their preferences and to understand what goes through their heads as they complete WTP exercises. Verbal protocol analysis, where people talk through their thought processes as they complete a WTP exercise, is a technique used in environmental WTP and should be tested in the health care field. Qualitative research could also be used to explore reasons

behind protest votes and ways of reducing them, and the issue of scope sensitivity.

2. We need to test the external validity of WTP i.e. whether respondents behave in the way they say on the questionnaire. This would need empirical research in private health care say, recognising the ethical constraints of undertaking this kind of research.
3. Of the four approaches available, it appears that the open-ended approach should not be used. The NOAA panel recommends the close-ended approach, but health economists are far from convinced. A large amount of empirical work has been undertaken comparing the different methods. However, more empirical work is needed to help to decide on the best approach to use in the health field.
4. A possible solution to WTP being related to ability to pay is to weight responses by income band. This should be explored.
5. Researchers in environmental research recommend that WTP exercises are undertaken by face-to-face interview rather than by post. We need to look at the cost-effectiveness of different ways of administering questionnaires, particularly if qualitative research becomes an essential part of WTP.

Key references

Nathan, Bont, Minz (1994), Donaldson and Shackley (1997), Ryan, Ratcliffe and Tucker (1997), Donaldson, Thomas, Torgerson (1997), Diener, O'Brien, Gafni (1998), Donaldson, Hundley, Mapp (1998), Klose (1999), Smith (2000), Slothuus, Larsen, Junker (2000), Shackley and Dixon (2000), Bishai and Lang (2000), Thomas, Donaldson, Torgerson (2000)

CHAPTER FIVE

Findings from the literature review 3

In this chapter, Consensus methods, involvement in clinical decision-making, priority setting and the use of the internet are discussed.

Consensus methods

Why use consensus methods?

The definition of consensus is 'general agreement'. Consensus methods are a formal, rather than an informal approach, to gaining agreement on health care issues. The decision-making process occurs within the consensus group. An HTA systematic review of consensus methods for clinical guideline development has been undertaken (Murphy 1998). Involvement of users' in the development of clinical guidelines is important and sometimes lay people and patients have been included in these consensus methods as experts. However, sometimes a group can consist only of users', patients, or the general public. A key example of this is citizens juries, a type of consensus development conference. Citizens juries are dealt with later.

Brief descriptions

Three main consensus methods have been used to develop clinical guidelines in the health field: the Delphi method, the nominal group technique and the consensus development conference.

1. **Delphi method** Expert individuals are contacted using mailed questionnaires.

They do not meet face-to-face or interact directly. They are asked to give their views on items suggested by themselves and other participants. Individuals make decisions

privately. The findings are summarised and fed back formally to individuals who can revise their judgements in the light of this feedback. This process can be repeated a number of times. There is explicit aggregation of views using statistical techniques, sometimes weighting views by expertise. Strengths are that it gives numerical estimates of participants' views and allows the exchange of information at low cost. A weakness is that there is no face-to-face interaction to help determine reasons for disagreements, although sometimes participants are allowed to meet once.

2. Nominal Group Technique (NGT) The aim of the NGT is to structure interaction within a group of experts. There is face-to-face contact, where each person contributes an idea in turn until all ideas are listed. A facilitator runs the group, records the ideas and ensures that idea is discussed by the group. Individuals privately record their judgements or vote for options. Further discussion and voting may take place. Judgements are aggregated statistically to derive the group judgement. Strengths are that it allows all members to express their ideas, allows articulation and discussion of all ideas, and reduces the dominance of some members. It has been likened to focus groups but is undertaken with a single goal in mind rather than to generate a range of ideas.

3. Consensus development conference A selected group of about ten people is brought together to reach consensus on an issue. The meeting is open, operating as a public forum for discussion. Experts or interest groups, who are not members of the decision-making group, present evidence. Implicit aggregation of views takes place by the group retiring to make a decision.

Which issues have they been used to address for which groups of users'?

The Delphi technique has been used to identify research priorities for nursing and primary care priorities for physically disabled people. The NGT has been used to determine appropriate indicators for health care interventions, identify changes in the US health system to help improve care for patients, guide medical education for doctors working with people near the end of their lives, and to generate items for quality of life measures. The techniques have been used mainly with health professionals rather than users'.

Case study

Indicators of the quality of general practice care of patients with chronic illness: a step towards the real involvement of patients in the assessment of quality of care.

Wensing, Grol, van Montfort, Smits (1996)

A panel of GPs and a panel of patients with chronic illness such as asthma, diabetes, and migraine were established. Focus groups were set up to explore the aspects of general practice felt to be of importance for the care of people with chronic illness, four with GPs and five with patients. These generated a list of ideas, which were clustered into five areas by researchers. A postal survey was undertaken to allow participants to rank the importance of the issues identified. A second survey was undertaken to explore controversial issues from the first survey. The study identified agreement between patients and GPs on issues important to patients e.g. doctor-patient relationship, and areas of disagreement concerning whether some issues were suitable for patient evaluation e.g. technical aspects of care.

Strengths and weaknesses

Focus groups, interviews and questionnaires can help to elicit users' views.

However, interpretation of these views is then left to researchers and service providers. Consensus methods can formally involve users' in the decision-making process, for example choosing items to include in a patient satisfaction instrument, writing guidelines for processes of care.

The HTA methodological review has identified some weaknesses of consensus methods for the development of clinical guidelines e.g. the way in which information is presented to the group affects the decisions made. The review could not draw conclusions about which particular technique was superior. An HTA review of eliciting public preferences for health care (Ryan, in press) has included these techniques and gathered and assessed studies which involve users'. The techniques seem to have been applied to professional groups rather than patient groups or the public. We know that the views of patients differ from those of health professionals e.g. patients who had suffered a stroke generated different items for communication issues for quality of life measures than a group of clinicians. However, there are unanswered issues around the best composition of groups. An example was a study of consensus views on medical education about end of life care in intensive care. The group included three specialists in critical care, six in palliative care, seven in medical ethics, three in medical education, one in communication and one consumer advocate. This power imbalance between different experts, in particular health professionals and patients, needs to be addressed.

Methodological research gaps

There is value in exploring these techniques further because they formalise users' involvement in decision-making. A research gap identified by the HTA review of consensus methods is relevant here. The HTA review concludes that the composition of groups is important in determining the decision reached. We need to understand more about the effect of including users' on consensus groups, and the optimum composition of such groups.

Key references

Jones (1995), Wensing (1996), Murphy (1998), Danis (1999), Ryan (in press)

Citizens Jury

Brief description

A citizens' jury brings together a group of between 12 - 16 randomly chosen citizens, to deliberate on a question or set of questions. They are enabled to make an informed decision through provision of written information and through hearing from expert witnesses. Over a number of days, typically 2-4, participants are exposed to information about the issue and hear a wide range of views from witnesses, who are selected on the basis of their expertise or on the grounds that they represent affected interests. With the help of trained moderators the jurors can cross examine the witnesses and call for more information. Following deliberation the jurors produce a decision or provide a report of citizens' recommendations (Smith and Wales, 2000; Leicestershire Health, 2000).

Use of citizen's juries

Citizen's juries can be used to obtain a detailed, considered and well informed view from a broadly representative sample of the general public. The Institute for Public Research and The King's Fund have sponsored pilot projects in a number of local authorities and health authorities (McIver, 1997). They have generally been used in two ways. In one approach, the 'decision making model' jurors address a decision on a contentious live issue where there are a clear set of options. In the other approach, the 'deliberate model', jurors are asked to respond to fairly broad, open ended policy questions such as how decisions relating to priority setting in the NHS should be made (Lenaghan et al., 1996).

Strengths

1. People participate as citizens not patients or carers and so should provide an objective view.
2. Can be a way of achieving organized public participation.
3. Participants can be chosen to broadly reflect the characteristics of the wider population.
4. Are considered to play a part in democratising decision making processes and enabling a more active form of citizenship
5. Can enable people to become more competent in decisions and develop a habit of participation

6. Their greatest strength is the opportunity for informed deliberation – jurors can call in other people: professional, patients etc. to give evidence so they are able to get a rounded understanding.
7. They can be used as a method for priority setting where the subject is emotive and controversial and depends on value or moral judgements.
8. The process is not rushed, so jurors can think carefully and discuss things over with fellow jurors

Weaknesses

1. As a relatively small group, the jurors views may not represent the views of the wider population.
2. Jurors may be introverted and unable to make their views known.
3. There may be a range of issues requiring decisions and it can be difficult to narrow them down so that they can realistically be handled by the jury in the time given.
4. The value of the jury can depend on the precise phrasing of the question.
5. Organisation of a jury can be costly and take months.
6. A consensus may not be reached.
7. Little work done to address public acceptability of this method
8. Not suitable for all issues

(Barker et al., 1999; Coote and Mattinson, Smith and Wales, 2000; Leicestershire Health, 2000 adapted from Barker et al, 1997; Lenaghan et al., 1996).

Case Study

Setting Priorities: is there a role for citizens' juries? *Lenaghan J., New, B. and Mitchell E. (1996)*

The Institute for Public Policy Research and Cambridge and Huntingdon Health Authority have recently piloted the first jury in the United Kingdom. Sixteen jurors sat for four days, hearing evidence from a number of expert witnesses. The jurors were asked to consider how priorities for health care should be set, according to what criteria and to what extent the public should be involved in this process. This pilot was also an attempt to assess the process itself, and our initial evaluation indicates that, given enough time and information, the public is willing and able to contribute to the debate about priority setting in health care.

Contextual Issues

The process rather than the principle is where citizens jurors can fail. Just one of many components, the role of the moderator, is crucial. The moderator needs to be skilled in ensuring that all members of the jury have opportunity to express their views as well as keeping the discussion on the chosen topic. To successfully undertake a citizens' jury requires considerable expertise.

A less costly and time consuming alternative to citizens juries is community workshops which may involve 12-20 people representative of a section of a community. They meet for one day to discuss a specific question. Aided by a moderator people work in small and large groups and produce recommendations.

Citizens' juries are being advocated to address major questions such as the introduction of a breast screening programme. There are high expectations of the citizens juries as they are being expected to take account of all the costs, both human and financial to all those affected, both participating and organizing, as well as the benefits (Thornton and Baum, 1999). It is therefore important that good evidence is made available on the scope and limitations of this method in eliciting views on health care processes.

Three of the experts in methods for eliciting user views interviewed in this scoping exercise expressed opinions about citizens juries.

One advocated adaptation of the citizens' jury approach for patients:

'There's is no reason why you shouldn't run an adapted form of citizens' jury with patients. ..it allows it to involve patients in decision making, that's its focus to get a consensus view from a group of people ... you could adapt it for patients, to get a consensus view from a group of people with a series of recommendations about a question to address an issue.'
(academic researcher)

'...it is an intense period of time for people who are strangers, ordinary people to the NHS to come and give four and a half days of their time on this question so they were paid 250 pounds, that makes it expensive....patients are usually concerned because they've got an illness and they have been through the service ..they are often committed to trying to improve things for other people and are very interested and very knowledgeable about services, especially if they have got chronic conditions and I think that they probably wouldn't need paying'(academic researcher)

One interviewee identified advantages and disadvantages from experience:

'Definite positives about them they do enable people to get access to information in order to assess that information and make more informed judgements. The people take part generally enjoy experience welcome opportunity to be seen as experts and to draw on their experience as well as new knowledge to contribute to decision making. There are problems around the time scale. On the one hand people are saying there is not enough time to engage with often quite complex information and make sense of it and come to a decision on the other hand people also recognise that its very demanding activity that hard to take time out from work or family care so time problem. Because the imperative in a citizens jury is to, at the end of 4 day or whatever, to actually come up with some sort of agreed report and a series of recommendations there is a tendency to emphasise agreement rather than explore disagreement'

I wouldn't for instance use citizens' juries when what I was looking for is the views of a particular group of people who have experience of using services or in relation to a particular service for example... it seems to me what you want to access is expert experiential knowledge of those who have had direct contact with the service'

And another from experience of evaluating citizens' juries

'I'm critical of them [citizens' juries] as result of my evaluation because of the nature of the method. It is by its very nature exclusive for example we're talking of people meeting over a period of four days for intensive tiring work, you are not going to get very frail older people involved in that sort of activity. Another citizens jury I looked at involved young people and I don't think that worked.' (academic researcher)

Conclusions and research gaps

This relatively new method has been evaluated in a number of pilot studies.

Although costly, the findings indicate that the citizens juries can be an effective method of involving the public in decisions on policy issues. However, expectations of this method are high and it is being advocated for use in a much wider context than it is intended for including its use with patients rather than citizens. Further research is required to explore the range and type of issues for which the method is suitable, its benefits and limitations and to develop guidance on the detailed practicalities of using this approach.

Key references

Barker et al., 1999; Coote and Mattinson, Smith and Wales, 2000; Lenaghan et al., 1996; Leicestershire Health, 2000 adapted from Barker et al, 1997; McIver, 1997; Thompson, 1997.

Assessing users' involvement in clinical decision making about their individual care

Why do it?

Prior to the 1980s both doctors and patients expected the doctor to take a dominant role in treatment decision-making. With the rise of consumer sovereignty and the increase in situations where there is no best treatment, but rather tradeoffs between risks and benefits of different treatments, there is a general consensus that patients should be involved in making decisions about their own care. Although patients vary in their desire for involvement in decision-making, depending on the

presenting problem, age, social class and other factors, a large proportion of them want to participate to some extent.

There are many reasons for wanting to measure people's views of how involved they felt in the decision-making process. First, we may want to evaluate decision-aids designed to promote informed or shared decision-making. Second, we may want to look at how different patterns of participation affect outcomes. Third, we may want to develop indicators to judge the performance of clinicians.

Brief description

Various methods have been used for measuring patients' preferences for, and actual participation in, decision-making. Examples are showing video vignettes and asking for patients' preferences, undertaking qualitative and quantitative assessment of audiotapes and videotapes of medical encounters, interviewing patients, and quantitative instruments for completion by patients. This latter method is attractive when the views of large numbers of patients are required. The most popular instruments in use have been developed in North America: the Decisional Conflict Scale, the Satisfaction with Decision Scale, and the Control Preference Scale.

Strengths and weaknesses

Focussing on the strengths and weaknesses of quantitative instruments, the scales available have undergone psychometric testing and have been shown to perform well. However, work about to be published on the Control Preference Scale shows that people give the same rationale for choosing two very different options of passive

and active participation. Further work is being undertaken to assess the performance of the Satisfaction with Decision Scale and the Control Preference Scale in five clinical areas using qualitative techniques of interview and observation. This Health in Partnership project, funded by the Department of Health, is unpacking what it means for people to participate in decisions about their individual healthcare in order to inform which measures should be used.

Methodological research gaps

Quantitative instruments exist to measure patient involvement in decision-making. However, further qualitative research is needed on the validity of these instruments for different decisions. They have good psychometric properties but what interpretation do people make when they are answering them? The aim of such research should not be to dismiss the instruments but to be critical of them and understand the contexts in which they do and do not work. Experts in this field have plans to undertake research looking at what participation means in contexts where there are no clear treatment options to choose. Further research should be commissioned in the light of ongoing work at the University of Aberdeen.

Key references

Roter (1992), O'Connor (1995), Ruckdeschel (1996), Holmes-Rovner (1996), Degner (1997), Edgren (1998), Sims (1999), Charles (1999), McKinstry (2000)

Priority setting in Health Care

Why do it?

Commissioners of health services may want to seek public views on health care priorities to ensure that allocation of resources is influenced by the population they serve.

Brief description

People are asked to rank services or treatments in order of importance or priority for funding. The most well known UK study involved interviews with over 400 inner London residents asked to rank 16 health services or interventions.

Strengths and weaknesses

Research has shown that people's answers in surveys are influenced by the phrasing of questions, and that discussion and deliberation within focus groups affects people's answers. The conclusions to draw from this are that a much more sophisticated approach is needed to eliciting public views on priorities in health care than simplistic questionnaires. The deliberation and discussion which takes place in focus groups, consensus groups and citizens' juries seem to be an essential ingredient in any exercise. The issue of lack of representativeness affects all methods.

Key references

Jacobson (1995), Dolan (1999)

Use of the Internet to elicit user views

Recent developments in the Internet and the World Wide Web (WWW) clearly offer much potential in eliciting user views of health care and health services (Murray 1995; Houston, 1998; Gillespie, 1999). Two facts need to be highlighted when considering the contribution to be made by such technological developments. First that use of the Internet remains in the category of *potential*, there being few studies looking at the application of the Internet to this specific context. Second, that although the Internet addresses the perplexing problems of access its use is still constrained by many of the threats to validity apparent in more established methods, for example, sampling bias (Coomber, 1997) or selection bias (Fischbacher et al, 2000).

Description

Most proposed applications of the Internet merely seek to reproduce established methodologies in a way that is facilitated, but not extended, by the technology. So, for example,

- The questionnaire is translated into the online questionnaire, distributed via email or as an email attachment (Selwyn & Robson, 1998; Cooper, 2000).
- The interview can be conducted asynchronously via email (Thach, 1995; Selwyn & Robson, 1998; Cooper, 2000) or synchronously via real-time audio or video links.
- The focus group can be enabled asynchronously via a mailing list discussion group or a newsgroup or synchronously using a chat room or virtual meeting room (Lakeman, 1997).

- A Delphi process can be achieved through successive rounds of staged email messages.

Contextual use

The main concern with the validity of Internet-enabled approaches relates to the fact that contact can only be made with those who can and do use the Internet. The published demographics (Nielsen & CommerceNet, 1995; Kehoe & Pitkow, 1996) show clear inequalities with regard to age (Lakeman, 1997), gender (male rather than female), education (degree-level rather than non-degree educated), ethnicity (European rather than Asian or African) and resources (affluent rather than those of limited financial resources) (Coomber, 1997). The relative exclusivity of Internet use is likely to become less of an issue as the technology becomes more widespread and data collection is thereby extended to a population more closely representing that reached by established techniques (Houston & Fiore, 1998). For specific subgroups the Internet may actually prove a more effective means of gathering data precisely because of the over-representation of particular members of the population. For example, recreational drug users' (Nicholson et al, 1998) and bisexuals (Kaufman et al, 1997) may be particularly elusive for questionnaire or interview but may be amenable to email approaches. Consideration needs to be given to the exact population that the research is aiming to reach and also to the complementarity of other approaches.

The Internet has also been suggested as a mechanism for the wider sharing of data collection instruments such as questionnaires (Wilcox, 1999). It can be used to make

contact with potential study participants who may then be interviewed using established methods (Fischbacher et al, 2000).

Fischbacher and colleagues (2000) suggest a number of ways of making electronic surveys more useful. Kittelson (1997) suggests that the same recommendations for postal surveys apply to email questionnaires - keep the surveys short, to the point and easy to complete. The same study has even assessed the appropriate numbers of follow-ups needed to obtain the maximum return rate.

Strengths and Weaknesses

An excellent summary of the strengths and weaknesses of Internet-enabled surveys, dealing variously with emails, the World Wide Web, newsgroups and electronic bulletin boards has recently been published by Fischbacher et al (2000). Lakeman (1997) discusses the difficulties and advantages that a wider range of Internet methods might hold for data collection.

Jones and Pitt (1999) looked at differential responses and costs for e-mail alone, email plus a World Wide Web form and a postal questionnaire within a workplace setting. The postal survey obtained the best response rate (72%) compared with 34% for email alone and 19% for email plus WWW. Mavis & Brocato (1998) similarly found that postal surveys have a higher response rate than electronic mail-based methods.

However postal survey was also the most expensive at 92p per reply compared with 35p for email and 41p for the WWW (Jones & Pitt, 1999). Most of the electronic responses were made within five days. They conclude that email and WWW surveys,

being easy, quick and inexpensive to administer may be useful for pilot studies, notwithstanding their low response rates. Hypertext markup language (HTML) can be used to create interactive forms with an intuitive interface while collection of responses using common gateway interface (cgi) scripts can assist in compiling data and subsequently exporting it to software packages (Houston & Fiore, 1998).

Email interviewing, either one-to-one or via an electronic focus group, reduces the problem of interviewer effect. It can also reduce problems caused by dominant or shy participants (Selwyn & Robson, 1998). Nevertheless the richness of data is not comparable to that of face-to-face interviewing in a number of ways. It requires a different set of interaction skills and the content and style of an email message has been said to lie somewhere between a telephone call and a memo. A great deal of tacit information is lost in terms of non-verbal data - this is hardly compensated for by emoticons or parenthetical remarks.

Use of the Internet for data collection has certain inherent characteristics such as the problems posed by multiple email addresses, the difficulty in identifying respondents and verifying their identities (Stephenson, 1998), and the ease with which data can be submitted. As an example of the last of these, the results of an online survey with instant cumulative feedback, such as the readership surveys for the BMJ, can easily be distorted by repetitive use of the "submit" and "back" buttons on a Web browser. Multiple responses with numerous checked options can thus be submitted in a fraction of the time required to complete even a single paper-based questionnaire. Fisher et al (1996) have suggested a combination of "political and technical strategies" to improve the representativeness of samples when surveying the Internet including the use of screening techniques to improve feedback about

where responses originated. Other approaches might include purposive sampling and stratification of both issue-committed and issue-neutral groups.

Suggestions to limit selection bias include (Chappel et al, 1999):

- Using clearly defined eligibility criteria;
- Estimating the number of eligible subjects from multiple sources;
- Validating email addresses;
- Using reminders to obtain a high-response rate.

Examples of use

Although Fischbacher and colleagues (2000) identified 43 reports describing use of the internet for health surveys the majority of these cover use of computing and the internet, the patient experience of particular conditions, research methods and health professionals' perceptions of use of health services. No reports have been found of Internet-enabled surveys eliciting the views of general users' of health services or canvassing the opinions of those within a defined geographical location or community. In fact, the general availability of the Internet across national and regional boundaries poses a number of additional considerations not encountered by local-based approaches to data collection (Stone, 1998)

Conceptual issues

A major contribution of the Internet could lie in establishing longitudinal approaches to data collection. For example a new generation of set-top boxes and 24-hour cable television links to the Internet (Bieler & Stevenson, 1999) looks likely to extend its use

to communities for whom keyboard and telephone based access has previously proved an obstacle (through factors such as lack of skills, disability or cost). The prospect of the elderly or housebound completing brief responses to a small number of questions, and indeed being able to return to an online questionnaire, survey or video-facilitated interview whenever they want is afforded by touch screen technologies and password or PIN-number access to specific facilities. Such methods have previously been used for computer assisted panel research where respondents receive a microcomputer and modem and fill in an electronic questionnaire about once a week (de Leeuw and Nicholls W, 1996).

An important issue here would be the extent to which such means of data collection are integrated with other daily activities e.g. online shopping, contacts with primary health care or social services, recreational activities such as online bingo, or other forms of interactive cable entertainment. Similarly, these passive means of data collection, though convenient for the researcher, are unlikely to prove acceptable to such communities if they are not seen to lead to involvement in decision-making or to contribute towards making changes or improvements. In the United States Internet health care surveys are already in place for some users' of Health Care Financing Administration-funded nursing homes (Bonifazi, 1999).

If creativity and imagination are needed to optimise use of established methodologies then this is equally true for Internet-enabled approaches. The seductiveness of the new technology should not tempt researchers and commissioners of research to circumvent the same issues of rigour, acceptability and empowerment so essential for optimal use of established methodologies.

Methodological research gaps

Concerns shared with established methods include, for example, the characteristics of responders and non-responders and the reasons for non-response. However, analysis of such issues is made more complicated by the fact that they may be related to the technology itself and not simply to considerations around the topic being investigated or the limitations of the chosen approach. More research is required on public attitudes to research conducted via the Internet.

In the absence of other direct research one might hypothesise, extrapolated from the evidence from online pharmacies, that people may prefer to have human interaction to supplement their interface with the technology. On the other hand there is some research to suggest that there may be systematic differences between the way that respondents to computer-administered answer questions from those who respond to paper surveys (Kiesler & Sproull, 1986; Rosenfeld et al, 1991).

Experience with Web-based administration of a personality questionnaire (Davis, 1999) suggests that, at least for certain topics, a patient may be more willing to share information with an anonymous technology than to disclose it to a fellow human being. Similarly a randomized controlled trial with a 2 by 2 factorial design of Web versus pen and paper and anonymity versus nonanonymity found participants using the Web anonymously showed lowest levels of social desirability whereas those answering with pen and paper non-anonymously scored highest on the same

measure (Joinson, 1999). These issues require further investigation within the specific context of eliciting users' views.

Conclusion

In conclusion, the Internet in general shares many of the characteristics of one of its important constituents, namely email, in that it "offers the researcher many advantages, temporally, spatially and in terms of easy access to otherwise unreachable samples. Nevertheless, its use should always be offset against the wider considerations of population access to the medium and the limitations of the (admittedly plentiful) data that are generated" (Selwyn & Robson, 1998).

References

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CHAPTER SIX

Findings from the Interviews

The main themes emerging from the interviews are presented below in two sections which are not mutually exclusive. The first section focuses upon *general themes* about methods for eliciting users' views and the second section, presents those which emerged specifically relating to perceived *gaps in current research and methodologies* that respondents believed warranted further research.

General Themes

Eight themes were identified from the interview data in the manner outlined in Chapter Two.

These were:

- the need for multiple methods
- issues about publication
- feedback to users
- implementing research findings
- skills development
- the value of user involvement in research
- representativeness
- long term funding

The need for multiple methods

Some preference for using either quantitative or qualitative methods to elicit users' views was expressed, particularly in relation to survey methods. The value of the

survey in this context seemed to bring to bring out great enthusiasm or serious criticism from the respondents. Some respondents were more forthright than others in their support or condemnation of a particular methodology.

'The well designed survey can be infinitely more powerful when it comes to actually persuading people to change than the focus groups and that's been demonstrated time and time again.' (academic researcher)

'I don't like them [surveys]. My view of questionnaires is that they are useful as a means of accessing factual information from a large number of people. I think they are very poor instrument in terms of assessing views and experiences.' (academic researcher)

'With surveys you get good generalisable results, but the depths to which the information gives you is superficial, you can only get...they are best at collecting facts and not opinions which are much too complex really to be gathered in a questionnaire survey.' (researcher in the health service)

However the main message overall was that both types of methods are needed, with different methods being appropriate for different purposes and with different groups. Thus *'There is no all singing all dancing method.'* This view was expressed strongly across the groups represented.

'... patient stories are good if it's an individual experience whereas if you want to learn more from a group of people a focus group is better.' (researcher in the health service)

'Surveys can provide you with a much broader perspective from those who would never turn up to a group, you know the non participator and their views are just as important, but they

tend to get left out in all these methods that require active involvement.' (academic researcher)

'qualitative methods are good and stronger when you are trying to identify the dimensions and parameters and sort of initial scoping of patients' views' (academic researcher).

Different methods were regarded in most cases as being complementary and serving different purposes and the majority of respondents had a sophisticated and unbiased grasp of this.

'clearly what you need is plurality of methods. Actually when you are talking about giving people a clear picture of the generality of patient experience of course focus groups can never be representative... they are not designed to be, they never can be so you get an interesting and a very rich picture of the views of a small group of people, but that on its own is useless and you have to have also the quantitative data, you have to have both. (academic researcher)

Issues about publication

There was a view expressed that while innovative and creative practice was being undertaken by some researchers it wasn't being written up, published or disseminated in an effective way. There seemed to be several reasons for this which varied across the organisations consulted. For example those working for charities, NHS Trusts and others outside universities had limited time to write research papers. This was also true for some university research staff who had to move from project to project and thus time for reflection and dissemination which was

frequently limited to the end of grant report itself and perhaps one or two conference papers.

There was a feeling among the respondents that outputs of research need to be made more visible with more examples of the ways in which different methodologies had been applied to different groups and in what situations. Thus the literature on users' views of the processes of health care is limited for these reasons.

'It is difficult as there are not enough methodology papers, people aren't writing them up, the qualitative, it's getting better because people are valuing them now, so other people can try it and voices can be heard and learning from it.' (researcher in the health service)

'There is no time to write stuff up ...and good research never getting in public domain with bits that never saw the light of day and never got written up because it got marginalised [within the research].' (academic researcher)

The importance of feedback to users

The importance of feedback to users who had participated in the research process was raised by a number of participants. There was an apparent tendency to neglect this aspect of the research process even though some respondents clearly considered it to be a responsibility of all such research projects. The message that was coming across strongly in the interviews was that feedback to users needs to become integral to all projects that aim to elicit user views.

'I think that research should be accountable to the participants ... Because people take part because they want something to change and they need feedback and I think we owe it to them as well.' (academic researcher)

A number of participants referred to users' feeling 'swamped' and 'fatigued' by the different methodologies used to elicit their views and it was deemed essential to provide this feedback to demonstrate how user views affected change. It was felt that this would increase users' likelihood of participating in future studies.

'.. user fatigue' particularly in things like mental health. People get really fed up about being asked the same questions in different ways over and over again and never seeing any difference to the way care is provided.' (voluntary sector representative)

'I mean I must say I get two questionnaires a week from somebody or other you know university researchers researching say the voluntary sector or ...and I mean they all assure me that somehow in some vague way I or my organisation will benefit fantastically from my filling in their questionnaire and sending it back to them but I have to say I'm rarely convinced and I rarely do it.' (voluntary sector representative)

Implementing research findings

This is very much related to the previous theme. Here issues were raised around the difficulties of implementing the findings of research. There was a view that users get 'fed up' if they do not see changes occurring as a direct result of their participation, but that services find it difficult to make changes based on the findings of some types of research. Although this issue was raised occasionally by participants working in academia, it was an issue most strongly expressed by those working in the health service.

'I was very distressed when the NHS brought in these big national patient surveys'

(researcher in the health service)

'What happened when we tried to implement the findings was when it came down to a particular ward they would say well we're not sure whether this is applicable to us, if 72% of patients said verbal communication with doctors was poor then that's not the case on our ward.' (researcher in the health service)

It is not just users who will have a concern here. The researchers themselves, particularly those working outside the University sector, demonstrated a clear sense of frustration.

Skills development

More guidance from research experts, funding bodies, NHS research and development staff and journal editors was felt to be necessary to promote good practice in research and prevent inappropriate methods being used. This need is especially acute for those working outside the traditional research environment without enough recognition and peer support. There was a perception that there was a skills gap and a need to develop awareness about specific methods as well as develop skills to enable effective working with particular groups of users. This applied primarily to health service professionals undertaking research about the health service.

'people do shoddy shoddy work which hurts patients and is unethical, now it's done under the quality management, clinical audit banner so someone will say I'm doing an audit, there's no explanation of how it was going to be used, what it's for, or how they get their name and address' (researcher in the health service)

'I get calls all the time from people in trusts saying they want to do focus group with say cancer patients and haven't done one before and because its flavour of the month they think they can with a couple of hours talking to people on the phone they can walk into a group and run one. So you need to think careful about who runs them and having others there to help run it, again that has cost implications.'(researcher in the health service)

'more work needs to be done explaining to people what's involved as there's a huge amount of poor quality data.'(academic researcher)

The need for more sharing of skills was also raised by a number of participants.

'I mean there is experience out there, the question is about access and learning from that experience and sharing the skills.'(academic researcher)

'This is about the need for skills development and need to get away from this awful competitive bidding culture'(academic researcher)

The value of user involvement in research

The value and importance of user involvement in research was expressed by most participants. They felt that it was essential that users be partners in the research process.

'A lot of research is about consumers. It isn't with consumers and that's quite difficult to get across to some people.'(voluntary sector representative)

There was a feeling that involving users in research increased the quality of the research by making research findings more relevant and pragmatic.

'Consumers ask piercing questions that often cut through academic jargon that experts use in research panels' (voluntary sector representative)

'for me the closer the methodology brings the patient and provider of the health care together the more likely you are to get change simply because you're actually talking about...it's two experts talking to each other, it's the lay expert and the clinical expert.' (researcher in the health service)

Examples were often provided, including users' contributing to book chapters, users interviewing users, involvement in grant application process, user led workshops and users being paid members of research teams.

'I think there would be things said to the fellow service user that would never ever be said to either a professional or sort of straight forward researcher.' (voluntary sector representative)

'I haven't done it but would like to support user-led user consultation. I find it inspiring, users interviewing user. I have seen other work and it seems to be very self led and the outcomes are very different than if it had been researchers interviewing or health professionals'. (academic researcher)

'we worked with a group of service users who themselves were involved in both designing the interview schedule and carrying out the interviews. The material we gained was very rich.' (academic researcher)

The importance of the user having adequate social skills to be able to express a view or opinion was also expressed. In addition that more than one user on a group, panel or committee was necessary in order to ensure views were adequately represented and that the process didn't become disempowering to the lone user.

'There is a tendency for professionals to stamp on users and say that's just anecdotal and it's a question of what kind of evidence you're going to consider. You shouldn't undermine what people say, and that happens a lot. You also need to choose lay representatives carefully. They need to have personal and social skills to be able to participate effectively. You also need at least two users as they are often working against entrenched clinicians or professionals who are often steeped in grades of evidence.'(academic researcher)

'The worst approach is well people aren't paid in the way professionals are so there's an assumption that you can just stick a couple of consumers on a committee that somehow they're on a par with professionals on that committee well that just isn't true, so essentially they're disadvantaged even before you start.'(voluntary sector representative)

Representativeness

Representativeness was considered to be an issue for all methodologies and it is clearly an intractable problem particularly in qualitative approaches where it is depth rather than generalisability that is being sought.

However much of the focus here was upon involving consumers/users in research per se rather than eliciting users' views as a research method.

'If you only take two or three views you might get opinion in extreme one direction or another whereas if you have a wide panel you capture all. Because that's where I think mistakes a lot of people make is that they have a token one or two consumers and then you get people who have got a particular axe to grind.'(voluntary sector representative)

'I suppose I am uncertain is where there is a relatively small number of people who are either selected by the researcher or self selected on the basis of being volunteers who can come to a committee meeting and hold their heads up.'(voluntary sector representative)

Need for adequate funding to elicit user views

Future work on user views was felt to require a long-term commitment to ensure that the views of users became an integral part of the research process rather than being a 'bolt on' approach. Thus future work needed to be adequately funded and better resourced.

'They could think more about properly resourcing it. That if you're going to do things properly it does cost money you can't just do it on a shoe string,'(researcher in the health service)

'you've got to ensure there's the resource and capacity to support people because the time it takes people just needs so much time not only needing regular correspondence and feedback and communication. I mean I can spend hours, not hours but at the beginning a lot of my time was taken up with calls and things and its got added to my job so it's really difficult, so it's not a full time job but it could easily be.'(researcher/voluntary sector)

Gaps in research/more research needed

Six themes were identified from the interview data. These relate to and complement the issues described above.

These were:

- (i) building on existing methodologies
- (ii) evaluating new methodologies
- (iii) implementation of research findings
- (iv) user involvement initiatives
- (v) difficult groups to access
- (vi) need for more qualitative approaches

Building on existing research methodologies

Some participants felt that research on existing methodologies to elicit user views were already well documented. Rather than 're-inventing the wheel' future research should focus on using existing long established methods in a more innovative way:

'So it's just thinking beyond the normal barriers of just using standard focus groups or the standard survey so you can twiddle with the techniques that fits the client group really.' (academic researcher)

The current gap in research was perceived as being *the lack of evidence* that establishes the appropriateness of methodologies for which group, in what situation and for what purpose. Further work establishing what works and what doesn't in practice needs establishing .

'.. you have to be pragmatic about what's going to work with your particular group not with what's been written up in social science and medicine really.' (academic researcher)

'We have got a little about good practice but there is still a huge agenda of research about what are the best ways, how can we adapt some of methods, cost effectiveness of methods, ground rules or standards of quality for these methods.' (academic researcher)

'I don't think its about finding new methodologies I think its about finding which methods work in which situations. Its about lets evaluate clearly what's being done and what works and what doesn't and then stop doing what doesn't work.' (academic researcher)

Evaluating new methodologies

Participants felt it would be useful to know more about the development and implementation of 'newer' methodologies such as citizens' juries, health panels, patient forums and patient stories/diaries. However there were also some suspicions about their possible effectiveness, validity and value.

'other methods have not been well tested citizens juries, health panels and having people as members on committees, using advocates' (academic researcher)

'these new patient forums that we're going to be asked to set up they would be interesting research project on looking at the representativeness of those patient forum. The culture changes needed to truly empower them to inform on how the trust runs. And what kind of changes are needed to make something like the patient forum just as important as some of the other committees, say the clinical risk management committee. How does that have as much weight? How patient forums are configured, where the membership is drawn from. It would be interesting to investigate on a case study basis say three or four trusts and watch how they actually do it and see good and bad bits and what blocks were and what things that allowed it to move ahead. ' (researcher in the health service)

Three of the participants felt that there was a need for greater understanding about the relative potential of The Internet. It was felt that it was currently unclear as to the extent to which users might perceive and respond to the internet and whether or not in the future the internet would be a good method of collecting user views.

'I'm a huge believer in internet and people rightly say at the moment well the internet really doesn't reach disadvantaged groups and I totally accept that but there are two things, the internet reaches more people than people think and the fastest growing group now are over 55s and within next few years when internet available on television there's 99% television penetration in UK household, so through TVs rather than computers is going to be very widely accessible and will be interesting to see if the commercial world starts to develop television internet which capable of getting at very large populations of people.' (voluntary sector representative)

'Electronically I think there is a huge potential about almost developing conversation or a chat room about particular issues what I don't know in research terms is how you ever control for all the variables...but I do think its worth exploring.' (researcher in the health service)

Implementation of research findings

Participants, particularly those working in the health service, expressed the need for more sustained evaluation of the impact of research on policy making and implementation. What changes actually occurred as a result of eliciting user views, what were the incentives for change and what actually persuaded individuals or organisations to change as a direct result of research findings that had elicited user views.

'Inside the NHS we're just doing it, the government keeps throwing things at us and we're just doing it. Because we're having to put into place all the patient partnership requirements, the NHS plan, the public involvement document, from the modernisation agenda to the professional service framework it's all just kind of happening you know and the sort of research activities you're describing would really help support that by understanding its going on and understanding the issues around policy implementation instead of looking at the issues again' (researcher in the health service)

'I'd like to see how consumer views are being used effectively to change practice with examples of that useful... the good stuff is where stuff has shown the difference about how things have changed as a result of having consulted with consumers and they're usually really powerful things that are very minor for example often things around outcomes.'
(academic researcher in voluntary sector)

'My experience with surveys is if you share the results very quickly and then do an action plan and implement changes it can be seen as being worthwhile what they don't like is surveys done for surveys sake and they never get the outcomes. Rather that it has been a data collecting exercise with nothing ever happening.' (researcher in the NHS)

The need for more user involvement initiatives

Many of the participants commented on the need for more examples of evidence based user involvement. How and in what situation users had been successfully, or not, involved in the health care process. There is a need to demonstrate the benefits of involving users in research to convince people that involving users is worthwhile.

'There is actually very little research that you can use to prove that user involvement is worth doing and I think that's the biggest gap in research. Certainly for us if you're trying to

convince people who think evidence base is the important thing to look at and you don't have an evidence base it's bloody difficult actually. Something that you could wave under peoples noses, doctors particularly, to say look here's the evidence that it's worth spending time on because we know its time consuming, it's costly, it's not easy, and you could say to people we know those things but we can see it does definitely make services better or more appropriate or whatever it does. That for me is the big gap in research.'(academic researcher)

'Personally I would want to see the development of the commissioning of research that was being undertaken by service users themselves because I certainly think that is an area that needs development. '(academic researcher)

'thinking more about getting users themselves perhaps to do some of the research because people are much more open if talking to their peers than if they are talking to somebody who they think is part of NHS, and more resources for user led research.'(researcher in the health science)

There was also an expressed need to get users involved in both the decision-making and research making process. What change had resulted as a result of the users being involved was also felt to be important by a number of participants.

'Also involvement in planning and decision making,, you know different ways of involving users in decision making, that area needs a lot more work.'(academic researcher)

'The other area of involvement in decision making and that's deliberative techniques and techniques which help people take part in decisions we are at base one with that ground level research.' (academic researcher)

Difficult groups to access

Participants felt that there are particular groups of users that are difficult to access. More work was felt to be necessary to establish the most appropriate and effective means of involving and eliciting the views of marginalised groups. There was a range of groups that were identified by participants however there was no consensus or pattern that established one group as more difficult to reach than another. Groups such as the elderly frail, mental health users, non English speaking views, the young, those with poor literacy, disabilities, and users and carers living in rural settings were all mentioned as being groups that were difficult to access in terms of eliciting their views about health care.

'We've struggled with issues around involvement of marginalised groups not just black communities but learning disabilities or dementia. I would want you to be addressing those. Thinking about marginalised groups more broadly than just black ethnic minority groups that are marginalised.' (academic researcher)

'The weakness of nearly all the methodologies is that it's quite difficult to reach the inarticulate or disempowered consumer' (voluntary sector representative)

Need for more qualitative approaches

'the Chinese talk about ying and yng, the indians talk about hot and cold and we talk about different categories and unless you capture that within your measurement tools about illness experience and care experience, you miss out a very important aspect.' (academic researcher)

Some participants felt that there was a need to undertake detailed qualitative research when constructing quantitative research instruments, to ensure that these instruments were grounded in the views of users by identifying what was important to users and the language they used.

Conclusions

While it is clear that there are a variety of perspectives held by these key informants - researchers, members of patient groups and health care organisations - there are also some important areas of agreement, which the interviews have highlighted.

There is an emerging perspective displayed by many participant's here, that mixed methods and fitting the method to the research problem are essential if users' views of the processes of health care are to be reported in a valid, reliable and robust manner which could impact upon future health care practice.

It is likely that these views are more commonly held now than might have been the case ten years earlier. Patient and NHS user satisfaction surveys had traditionally been viewed as quick and easy to administer and a means of gaining. They also represented a means of data collection that caused the least disruption within the research procedures.

As qualitative research has become increasingly and rapidly more visible, as well as innovative, a tension has developed between researchers who saw themselves as the advocate and practitioner of one or the other. As the respondents here identified, however, qualitative researchers have improved their skills and became more rigorous in implementing them. Thus there has been a burgeoning of qualitative approaches to eliciting users' views - especially through focus groups and in-depth interviews.

Respondents provided examples of the range of methods used, discussed some of their strengths and weaknesses and outlined their perceptions of where the gaps in knowledge and information currently lie. There is a useful correspondence here between the literature review and the interviews.

CHAPTER SEVEN

Additional Issues: Special Groups, Outcomes and Novel Methods

Introduction

The aims of this report, in scoping the methods used for eliciting and assessing users' views, are broad. They include identifying the range of methods used to elicit user views, and their strengths and weaknesses across the range of different purposes and secondly, to identify existing gaps in knowledge. The methods reviewed so far have included the broad use of qualitative and quantitative methods which have been adopted to elicit and assess users' views at different levels of care. However, it is evident that there are some minority research methods that are not commonly used but have an important role in eliciting and assessing users' views. Furthermore, there are particular groups of the population who have been traditionally marginalised from more mainstream research concerns and continue to present distinct challenges to researchers.

This chapter, therefore, will present the findings relating to the review of studies relating to specific areas in six important areas:

1. social and cultural differences in users' views with specific reference to ethnicity, age, gender, socio-economic status and other hard to reach groups.
2. the possible impact of type of condition, for example, chronic and acute, on users views.
3. the impact of outcomes (positive and negative) on users' views.

4. the trade offs that people are willing to make, for example, the trade off between convenience of access and quality of care.
5. users' views on participating in research as part of the health care process.
6. novel methods for eliciting users' views which have not been discussed elsewhere in this report.

1:1 Eliciting the views of minority ethnic communities

Nazroo (Nazroo et al, 1997) reporting on the results of a nationally representative survey of the main minority ethnic groups in Britain state that their data indicate strongly that a key factor in explaining the health status of different ethnic minority groups is socioeconomic status. However, he states that the quality of health care received by patients is related to their ethnic background. It is therefore important to understand the issues which affect that quality.

McIver reported in 1994 (McIver, 1994) that there was already a substantial body of research undertaken on the views of people from black and minority ethnic communities on the quality of health services and that the same issues arose repeatedly. These were issues of communication, information provision, diet, religious and cultural needs. Later research reports indicate that the issues of concern to minority ethnic communities remain unchanged. Other issues identified as important are staff attitude, racism, stereotyping, low cultural awareness of staff, for example in relation to spiritual needs, and a fear of victimisation (Cabinet Office, 1995; Kirklees FHSA, 1994; Sheffield Health 1995; King's Fund, 1995).

There is a growing body of evidence and advice on appropriate methods for eliciting the views of users from ethnic minority communities. McIver (1994) identifies in particular that surveys of the general population using postal self-completion questionnaires usually fail to collect the views of black people. The reasons are clearly stated.

- That black people and people from ethnic minorities form a very small proportion of the population in many areas of the country
- They may lack the motivation to complete the questionnaires seeing no benefit to themselves
- Many may be unable to read the questionnaire because English is not their first language

Questionnaire based surveys have however been effectively used with minority ethnic groups when delivered through a structured interview carried out by lay interviewers matched for ethnicity and language (Kirklees FHSA, 1994; Nazroo, 1997). In both of these examples considerable efforts were made to identify the population to be sampled through door to door enquiry and quota sampling. The method therefore requires many more resources than a postal survey. Response rates were good but there were still certain groups such as younger people who were more likely not to have been interviewed. Nazroo reports that the proportion of women agreeing to be interviewed varied with ethnic origin. Caribbean and Indian men were less likely to be interviewed whilst for the Bangladeshi community, women were more likely not to be interviewed (Nazroo, 1997).

It has been argued from a critical social research perspective that the survey is likely to elicit views within a structured framework that is portrayed as 'neutral' in terms of age, gender and ethnicity (Bell & Roberts 1984). This claim to neutrality presents very real concerns particularly in that specific issues for women, the older population and ethnic minority groups may be unrecognised even within the questions themselves. Therefore, the questions in surveys may have little direct relevance to the lives of marginalised groups.

Similarly, in terms of ethnic minority groups, and as qualitative research has illustrated, the findings from interviews conducted in the language of respondent may illicit different findings from interviews conducted in English (Nazroo 1997). English language and British cultural concepts do not always translate into other languages and visa versa. Therefore, consideration must be given to the provision of surveys in a range of language and representing the context of the lives of the people they claim to ultimately represent.

It is also important to draw a clear distinction between the *use of 'ethnicity' as a variable*, which would be the case in a survey, and paying attention to *the experience and views of ethnic minority groups in their own right* which would probably only be the case using qualitative methods or a structured interview under the conditions discussed immediately above. As a variable in a general population survey, 'ethnicity' may provide data that distinguishes the behaviour or choices of a specific minority group, or minorities in general, from the behaviour or choices of white majority or other minorities (provided of course that there is an adequate response from minority groups to make the exercise statistically valid which may be unlikely as argued above).

However, the *quality and relevance* of the survey data to the minority groups' *self-identified needs* is, by definition, not going to emerge through a general population survey. The assumption is made that the survey (if well-constructed) has scientific validity. There is evidence that this is only the case if the instrument is developed and validated in relation to a specific population. In order to do this, more information is required about the population and its characteristics. The survey method used across a heterogeneous population frequently fails to do justice to the views of distinct and hard to reach groups.

The use of more qualitative methodologies, including interviews, focus groups and consultation with community groups, has been reviewed by McIver (1994). This approach can be effective (Kai and Hedges, 1999; Share, King's Fund, 1995) but success using either quantitative or qualitative methods may also depend on attention to the following factors:

- identify the whole of the population and understand the diversity of the population in terms of language, culture and socio-economic demography
- avoid stereotyping
- establish legitimacy within the community through raising awareness of the initiative; exploit local channels of communication e.g. media, community leaders, networks
- build relationships with the community and develop a good understanding of relevant cultural issues
- consider cultural implications related to methodology e.g. separate focus groups for men and women, appropriate genders of interviewers
- consider most appropriate way of translating material
- consideration of the method of classification of ethnic origin*

- collaboration between members of the minority community and the research team to increase the validity and relevance of the findings
- ensure availability of sufficient time and resources to address the above

(McIver, 1994; Leicester, 2000; Napholz, 1998; Marin & Marin, 1991; Hanley et al. 2000).

The issue of ethnic classification is not straight-forward. Nazoo (1995) provides a helpful discussion and comparison of the value of using self-classification and classification based on country of family origin.

Recommendations for improving health service delivery in response to these issues and for tackling the issue of staff racism have been documented (McIver, 1994; Share, King's Fund, 1995). Furthermore, Sheffield Health Authority in conjunction with the Commission for Racial Equality have developed a tool kit to promote racial equality in delivery of healthcare (Codner, 2000).

Summary & Research Gaps

In summary, the resources and skills required to elicit the views of people from the black and ethnic minority communities can be quite substantial but the issues to pay attention to in such an undertaking are well documented and valid findings can be obtained if these are addressed. There would be value in carrying out a systematic review of the appropriate ways to elicit the views of people from the black and ethnic minority communities to update the review carried out by McIver in 1994.

However, the research tends to elicit the same findings and people from ethnic minority communities are frustrated with the fact that the findings are slow to influence service delivery (Boote et al. in preparation). In addition there is already guidance available for healthcare organisations on making services more culturally sensitive. It is recommended therefore that further research in this area should focus on evaluation of user perspectives of initiatives to implement this guidance to improve quality of service delivery to people from ethnic minority communities.

Eliciting the views of older people

The literature on eliciting the views of older people in relation to health care processes is very sparse. Apart from individual case studies, the literature on older people mainly relates to their use of social services and community care services. As the methodologies and findings are very relevant to health care processes that literature has been used here.

There are clearly specific problems related to eliciting the views of older people that are documented here in this section of the report. Once again, as with other hard to reach groups, the survey is a useful instrument for identifying *age as a variable* and thus potential *differences* between age groups in their perspectives of the processes of care. However there is very limited information about the experiences and self-identified special needs and views of older people in relation to health care. A qualitative approach is far more likely to identify the range of experiences among the older population particularly in the context of *subjective experience of ageing and being older*.

Part of the explanation for the paucity of literature may be due to problems in defining older people and the fact that people do not necessarily identify themselves

as 'old'. There are examples of attempts to obtain the views of people using services for older people (Waldman et al. 1996; Kazi M, unpublished) and examples of seeking older people's views in needs assessment in general practice (Ormond, 1994; Pringle, 99). In both these arenas the population of elderly patients is pre-defined. There is little evidence of attempts to obtain the views of older people who are not yet recipients of services for older people. Waldman (Waldman et al. 1996) terms this group of people 'pre-users'. Waldman provides a brief overview of the literature in a report of an attempt to gain the views of this group in relation to Community Care Services (Waldman et al. 1996). She describes the term 'older person' as little more than a generic term for overlapping cohorts of people. She also identifies that in relation to health and social care services the term carries with it the connotations of problem and potential need for services associated with deterioration in health and independence. "So for the young old the issue may be about not yet being in a state of oldness". Further more "the image of ageing associated with declining health and capabilities is less accepted than it used to be".

Lupton (Lupton et al., 1998) reviewing the health care literature related to vulnerable older people states that there are differences between people's private attitudes and the statements that they are prepared to make in public. They identify the role played by low expectations and limited sense of entitlement as important. They state that direct questions are likely to elicit a public statement whilst indirect questioning may reveal more private opinions and highlights the tendency of many older people to give researchers the answers they think they want.

Despite the paucity of the literature, review of case studies has identified some useful findings. Waldman (Waldman et al. 1996) found that the number of activities for older people in the community may give a false impression of the proportion of older people actually participating. Her research found that the majority of

respondents had no contact with voluntary organisations in their communities. Thus a reliance on established fora within the community is unlikely to give a representative view of older people. Furthermore the identification of older people as a 'hard to reach group' (Leicester,2000) is justified.

Pringle (1999) included the views of older general practice patients in a needs assessment study. Data were collected using rapid appraisal methods and the main theme identified was the problem of social isolation amongst elderly people.

Case Study

Ormond (1994) similarly attempted to involve older people in assessment of their needs.

Ormond (1994) attempted to involve older people in assessment of their needs employing a method referred to as 'mutual enquiry'. This involves qualitative in depth interviewing which relies for success on 3 preconditions

- A power shift from assessor to older person
- Sufficient time for assessment
- Finely-tuned listening skills which rely on the power shift having taken place

One of the principles behind this approach is that the assessor is constantly conscious of taking a backseat role throughout the assessment. No single prescribed manner, tone or set of words can be appropriate to all individuals and situations. It is up to the interviewer to adapt the style presented. In practice going into the interview equipped with a topic schedule may be inappropriate in some situations.

Although a broad range of health needs are likely to be elicited by this approach, the results of the pilot revealed needs for health that can be broadly categorised as a need for opportunities to exercise autonomy.

The assessor came to perceive the older person in a new light, thus reducing ageist attitudes.

Services derived from the reality of need will be of higher standard.

Case study

Lankshear and Giarchi (1995) sought the views of users and potential users of community care services, including older people and their carers on their preferences for consultation. The methods employed to do this were focus groups, discussion groups and questionnaires. They found that the majority of people were extremely cynical about public consultation in general and public meetings in particular. One group of disabled people commented that the statutory organisations on receiving the report of the study would “put it in the bin”. People did not like public meetings as they did not think that they got a fair hearing and felt at a disadvantage.

Interestingly respondents did not consider the researchers visit to their group to be linked with ‘consultation’. Self-completion questionnaires were not popular either. The idea of forums, where members of particular groups could attend together, were more popular. Members of groups such as age concern were keen to establish better links with social services. Others were keen on people coming out to them, where they were based.

Interestingly three-quarters of elderly non-users of community care replied (to the questionnaire) that they would not be prepared to actively participate in consultation. The quarter that said they would be prepared to participate said they would do so with reluctance. Reasons Lankshear and Giarchi (1995) cite for this lack of interest include “I’m not old enough for that yet (from a 70 year old)” and “I don’t take interest in elderly people (from a 79 year old)”. The authors concluded that “if real consultation was to be possible the mountain must go to Mohammed”.

Summary and research gaps

Older people should be considered a ‘hard to reach’ group and specific consideration should be given to appropriate methods of eliciting their views and methods of

reaching a representative sample. There is very little literature directly related to the views of elderly people on health care processes. This may be due to the difficulty of defining the population and the reluctance of people to be defined as elderly. There is a moderate but very useful body of literature related to eliciting the views of elderly people in general practice and in relation to community care and social services. This literature demonstrates some effective methods as well as the views of older people about how they would like to be consulted.

It would be valuable to distil the evidence from the literature on older people and other related areas, such as other vulnerable or hard to reach groups, to produce guidance on eliciting the views of older people.

Further research should be undertaken on the views of older people on healthcare processes.

Gender related issues

There appears to be very little literature on user views related to gender issues. The literature that exists is generally about services used specifically by women or conditions specific to women. For example there is a body of literature related to the involvement of maternity service users in service developments and case studies of women's views of antenatal care (Langer et al. 1998) and continence services (Clayton et al.,1998) . The national Child Birth Trust involves its members in service quality and development through a range of consultation methods based on its

newsletter and network of branches and local representatives (But Will it Work, Doctor? Conference Report, 1993).

Case study

Quantitative and Qualitative methods were used to assess women's perceptions of the quality of antenatal care, as part of a large randomised trial in four developing countries Langer et al. (1998). Focus group discussions and in-depth interviews contributed useful insights into the cultural milieu in which care is provided, users expectations and their concept of quality. Based on these findings the investigators developed a standardised questionnaire which was administered to a representative sample of pregnant women (n=1600). The paper reports on the findings of focus group discussions and in-depth interviews with women in one country. Women expressed their point of view concerning a reduced number of visits, type of provider, information they get and interpersonal relations with health professionals.

The case study is interesting in that it identifies that the concerns of women reflect those of other specific subgroups, as well as users generally e.g. communication with health professional, the attitude of the professional to them, information, the quality and nature of the services available and access to those services.

It also illustrates how women as a group are very diverse in their composition in terms of social and cultural values, socio-economic status, capacity to participate actively in their pregnancy and the gap between the genders that they experience. These issues may all influence differences in expectations of services and the way individuals are able to express them.

Other important aspects of the methodology are that:

- multiple qualitative methods were used,
- both focus groups and interviews were carried out by social scientists with expertise in the application of these methodologies,
- special attention was given to the composition of the groups with respect to participants age, parity and conditions
- meetings took place in a non-clinical environment and it was made clear to participants that information would be kept confidential and would not influence the care received at the health facility
- the quantitative measures developed were informed by the findings from the qualitative research.

Summary and research gaps

Research into the views of women should recognise that this population group is very diverse in terms of their expectations, language, socio-economic and cultural factors, the gender gap that they experience and their capacity to express their views. These factors are not static but vary at different points in their lives. Qualitative methodologies, used well in conjunction with quantitative methodologies can be effective tools for eliciting the range of views of this diverse group.

However, the research relating to eliciting women's views on the processes of health care does not reflect the issues that clearly exist for women. Women use services more than men, and are more likely to visit services on behalf of other members of the family (Graham 1984). In addition, women live longer and are more likely to suffer chronic mental and physical illness than are men (Foster 1995). However, very

little research reflects this. The quantity of research conducted into women's health and childbirth belies the fact that women are also consumers and participants in the whole range of health care services other than those that are concerned with their reproductive capacity.

A further concern expressed in feminist literature is that health care research has traditionally presented a neutral voice which is typically also male (Roberts 1981; Harding 1991). There remains a need for researchers to make explicit the voice and views of women rather than attempting to present a gender neutral voice which remains particularly evident in more quantitative methods used for eliciting users' views.

Socio-economic status

The literature on the consideration of socio-economic status and user views appears to centre on community participation, community development and the empowerment of communities. As discussed in chapter three, community participation was originally included by this research team in the list of methods of eliciting user views. However, as discussed earlier, community participation is much more than a method for eliciting user views associated as it is with changing communities with the aim of improving health status and reducing inequalities.

Nevertheless, attempts to elicit the views of people on low incomes, people who feel marginalised and people who feel powerless may fail unless resources are invested in empowering them to do so. It may be that full community participatory approaches would be appropriate. On a less ambitious scale the literature

(Leicestershire Health, 2000) identifies specific issues to address when dealing with people on low income, particularly that:

- people in poverty may have different agendas where health and health care takes a low priority
- success may depend on addressing areas of concern to them which may include issues such as their living conditions and environment
- people's circumstances may mean a heightened wariness and fear of officialdom that limits their willingness to become involved. It may be prudent to gain access through existing voluntary projects, health workers, social services and other agencies.
- there may be a need to deal with people's feelings of powerlessness to change things. Poverty can make people feel that their feelings do not count or will not be used.

Summary and Research gaps

The gap in research in this area appears to have been already identified by the Health Development Agency (HDA). The HDA is intending to undertake reviews and syntheses of effective community participation models and methods, and guidelines on best practice (Health Development Agency, 2000). As described above, which should address the research gaps in this area.

Special and hard to reach groups

Qualitative research methods such as focus groups are generally more appropriate for reaching special and harder to reach groups including those discussed above and others such as younger people and vulnerable people (Hildebrandt, 1999). However, quantitative methods such as surveys can be used effectively if efforts are made to

address the specific requirements and issues related to the target population as illustrated by Nazroo (1997). Methods using multiple approaches are also more likely to reach the target population and obtain reliable results. Furthermore, obtaining the genuine views of people less motivated to participate or disempowered, disenfranchised groups of people may depend on building relations and trust over time and building the capacity of such groups to be able to participate. These points are illustrated by Cambridge Youth Participation Scheme, winner of the Guardian's Institute for Public Policy Research Public Involvement Award (Guardian, November 2000).

Case study

A three stage exercise was launched that eventually involved more than 1,150 young people being invited to "shoot your mouth off".

Stage one involved a survey of 700 young people through street interviews and a survey at secondary schools. They were asked to identify key issues. Stage two, a grand jury of 40 young people thrashed out these ideas at two half-day seminars. Key priorities were drugs, alcohol and crime. Issues and solutions were identified.

Stage three was a longer process in which a jury of 15 young people were taken on fact finding missions followed by four half day jury sessions. Written and oral reports were presented to the council. The participation programme remains ongoing. One jury member who was involved when they were 14 commented " I was apprehensive at first but once the 15 member jury went away for a weekend together, real trust was established. It has given me much more confidence. I was even able to address 500 people from the city platform. The council has listened and is moving with our agenda."

Summary and gaps in research

The success or otherwise of attempts to elicit the views of hard to reach groups is likely to rest not on the methodology, e.g. focus group versus survey, but in clearly identifying the target population and dealing with the issues, discussed above, relevant to that group.

A review of examples of good and bad practice of employing a variety of established and newer approaches (such as Citizens Juries) to eliciting the views of hard to reach groups of people would therefore be valuable with specific emphasis on the detail of implementation.

Possible impact of acute or chronic illness

A large quantity of the research conducted to elicit users' views on the processes of health care relate to patients with chronic diseases and disorders. It is the case that, as a group, patients who are chronic sufferers are also easier to initiate and maintain contact with. Moreover, chronic sufferers are more likely to possess expertise and knowledge about health care services and are more likely to be motivated to become involved in research. In contrast, health care users who experience an acute condition are more likely to receive services over a relatively short period of time and may be less inclined to be involved in research.

Research on sufferers of chronic disease may illicit views on a range of issues including overall impressions of the services they experience. The study reported in case study below reports on psychosocial needs:

Case Study

Buckley et.al. (1990), in a study conducted in the US, surveyed patients with rheumatoid arthritis (RA) about the importance of 8 psychosocial and 8 educational issues and asked patients from what source they preferred to get help with these issues and which sources of information they would not use. The authors also considered individual variables, including sex, age and disease duration and severity to see if they effected patients choices. The issues rated most important by patients included communicating with the doctor, understanding medication, dealing with pain, and the effects of arthritis on energy level, the future and work. Most patients preferred to seek help from their doctors although up to 75% were willing to attend groups and 68% were willing to see individual counsellors for some issues. There were few significant correlations between these variables and disease duration and severity.

There are areas of chronic illness that remain popular for eliciting users' views including cancer and some mental illnesses. There is a need for a systematic review to identify the areas that are well represented and the gaps where further research is required. This scoping exercise revealed a need for research, which elicited users' views on issues of humanity to the process of health care including, for example, ensuring dignity and maintaining privacy.

The impact of outcomes on users' views of the processes of care

The commissioners of this scoping exercise wanted us to address the impact of outcomes on users' views of the processes of care. This is a complex issue which we have not addressed in detail because of the difficulty we had in identifying relevant literature.

Our starting point was patient satisfaction, where a number of studies have shown an association between poorer health status and dissatisfaction with care (Fitzpatrick 1993). This association is confirmed within the HTA systematic review of patient satisfaction, where the conclusion drawn is that satisfaction scores should be interpreted in the light of the health status of the group of patients from whom the scores are taken.

Fitzpatrick (1998) found it impossible to disentangle different possible explanations for this association and put forward three possible explanations. First, that patients with poor health outcomes blame this on the quality of their care. Secondly, that poor quality of care might lead to poor outcomes. Third, that depressed patients may make negative judgements about their care. This last point was referenced to Sensky and Catalan (1992) who argue that patients' answers should not always be taken at face value because symptoms of depression and anxiety occur in up to 60% of people with serious physical illness, and this can be associated with distorted patterns of thinking. Sensky and Catalan focus on perceived health status rather than processes of care and therefore we need to draw implications about processes of care from this.

Our next approach was to identify citations of the Sensky and Catalan paper. This proved fruitless. Our final approach was to search on the 'halo effect', a commonly

used expression in maternity research, where a healthy baby can temporarily blot out memories of poor processes. However, this focused on the timing of eliciting views. The HTA systematic review on patient satisfaction concludes that we do not know enough about the effect of outcomes on views of processes. We support this conclusion.

Have the trade-offs between different aspects of care been taken into account?

It is common to elicit views on the processes of care, but not to look at the strength of preferences which people have for different aspects of care. This is particularly the case for patient satisfaction surveys, which usually fail to offer providers of services guidance on *priorities* for changing aspects of care.

Health economists have been undertaking most (if not all) of the research measuring strength of preferences and the trade-offs that users are willing to make between different aspects of care. The common approach they take to studying trade-offs has been conjoint analysis, also known as discrete choice experiments (see section on conjoint analysis). Studies have shown that people are willing to trade outcomes for better processes, and trade some processes for other process improvements. They have also shown that some people are totally unwilling to trade.

Commissioners and providers of services have finite resources and understanding the trade-offs which users are willing to make might enable them to take action on users' views. There is scope for making more use of methods which address trade-offs. However, we need to understand more about what people are really thinking when they take part in such exercises before we promote their further use.

Users views on participating in research as part of the health care process

There is now clear guidance and expectation from the UK Department of Health for health services researchers to involve consumers more actively in research (Standing Advisory Group on Consumer Involvement in the NHS R&D Programme, 1998; Department of Health, 1999). Advice and information has been prepared for both consumers (Consumers in NHS Research, 1999) and also researchers (Hanley *et al.*, 2000) to inform all participants in the research process of effective ways of achieving successful involvement of consumers. There is also a clear expectation of Trusts holding NHS R&D Support Funding that they demonstrate evidence of involving consumers in their research activity (Department of Health, 1999).

Population groups which have become involved particularly in NHS research include maternity service users (Oliver 1995) and cancer service users. This is due in part to the organisational structures which exist for these groups of patients. There is, for example, a well established network of breast cancer support groups. The National Childbirth Trust (NCT) comprises a network of branches with good communication links. This has made it relatively easy to have an informed discussion of current and potential research throughout the network with identification of members priorities for future health care research (But will it work, Doctor? Conference Report, 1993).

Cancer patients have typically been involved in research as the subjects of clinical trials. A systematic review of the literature on the ethics of clinical trials was undertaken in 1997. The study (Ashcroft *et al.*, 1997), revealed that relatively little work has been done on the qualitative analysis of patients and communities attitudes to trials and in the work that has been done has been, the emphasis has been on issues of access to trials and on comprehension and capacity to understand. Edwards

(Edwards et. al , 1998) reporting on the same review states that self interest rather than altruism was more commonly given by patients as a reason for participating in trials. The authors describe the studies reviewed as being of poor quality and called for further research into what well informed members of the public really think about trials and why they expect to benefit, if indeed they do. However, patients with cancer are increasing demonstrating that they are willing and capable of participating more actively in research at the stage of setting the research agenda and influencing the research design (Speed, 2000) and have stated that they wish to promote the attitude to research based on the belief that patients and the profession alike have a responsibility to further the progress of research (Thornton, 1998). The National Childbirth Trust is working with health professionals and researchers in planning clinical trials, setting priorities for research, systematically reviewing research reports and getting research findings into practice (Oliver, 1995). Despite the strong encouragement from the NHS Executive for researchers to involve users in research the amount of research project successfully doing so appears to be minimal (Telford et. al., in preparation). An expectation is that an important source of users to participate in research will be user groups. However, although some are involved or express an interest to be involved in research, patient support groups emphasise that their primary role is to support patients and or carers (McCoy, Walker, 2000). There is a significant body of literature on the value of involving users and the methods for doing so (Entwistle et.al 1998; Chenoworth & Kilstoff; 1998; Oliver, 1997; Brienza et al. 1995; Thornton,1998; Bradburn et al. 1995; Hanley et al. 2000; Temple et al. 1996) but very little reporting the perspective of the user on whether they are interested in being involved in research.

Summary and Research Gaps

There appears to be very little research on the users perspective of the value of involving users in research, the ways in which they would prefer to be involved and the resources they need to participate. This is as true for public attitudes to participation in clinical trials as it is for users or user group involvement in other types of research. Considering the political imperative to involve users in research it would be informative to explore the user perspective.

Other ways of eliciting users views

Numerous ways exist of capturing the perspectives and perceptions of users of health services. While a number of these, such as direct observation, videorecording etcetera, may be excluded from this study because they merely *record* users' experiences rather than *actively eliciting* them this still leaves a large number of additional techniques that have not received consideration. Narrative forms such as **patient diaries** or **patient stories** can be a rich source of qualitative data. **Video diaries** with or without spoken commentaries can provide a unique insight into what the user is encountering at a given point in their pathway of care. **Video playback** can also be used to act as a catalyst for a discussion of what the patient was experiencing, for example during the consultation (Cromarty, 1996). **Critical incident techniques** can be used to obtain both patient and staff views of particular episodes of care (Norman et al, 1992). **Video booths/soapboxes**, increasingly being used as a means of providing health information, may equally be employed to gather data, either from a general population (in libraries, supermarkets and walk-in centres) or from users of health services (in GP clinics, health promotion centres or outpatient settings). **Answerphones** or **chat lines** can be provided to elicit views in an

anonymous and non-threatening environment and provide a contemporary alternative to the more established **suggestion box**.

Poetry written by health service users about their feelings and experiences can have a powerful effect on staff, carers and managers. Art forms, most particularly **painting and drawing**, can be very effective, particularly for obtaining views from user groups such as children, those with problems with verbal or written communication or those with mental impairment (Liddon, 1996). Similarly **drama** techniques could be used to recreate particular situations or scenarios with a view to identifying problems with health care systems or to improve a patient focus.

Photovoice

Photovoice is described as a participatory Action Research strategy. This novel method was described in a US paper (Wang 1999). It is described as a process by which people can identify, represent and enhance their community through a specific technique. It has three main goals:

1. To record and reflect community strengths and concerns
2. To promote critical dialogue and knowledge and personal and community issues through discussion about the photographs
3. To reach policymakers.

Wang reports the use of Photovoice as applied to women and argues it has the potential to demonstrate women's diverse experience of education, childcare, reproduction and access to care. In the US this method has been used to allow marginalised groups, including the homeless and elderly, to present diverse images of their experiences. Wang argues that this technique requires that planners 'bring

policy makers and other influential people to the table to serve as the audience for community people's perspectives' (p. 191: 1999).

Photovoice has potential as both a novel and potentially exciting research method in eliciting users' views.

Complaints

The use of complaints in providing access to users' views did not emerge from this literature search as a method in the UK. However, in considering a study from the US the analysis of complaint, and indeed compliment, data has the potential to provide some useful information, albeit limited (Burstein & Fleisher 1991). The complaints and compliments about a paediatric emergency department formed the basis for this study and mostly entailed complaints about waiting times.

Complimentary comments most frequently addressed staff attitude and quality of care. It was suggested that invalid complaints were more likely to arise from less urgent illnesses. These complaints were expressed in letters or telephone calls to the administrator or medical director.

Complaints and compliments provide a limited data from a slice of users, those who are motivated to make a complaint or express a compliment. Given that the study above referred to comments made retrospectively it is also likely that these were well considered comments. An interesting dimension to the study of complaints would be an analysis of comments made from individuals who are actually engaged with the service at the time delivered through a suggestion type box.

Summary

All of the above are characterised by the fact that there is little or no evidence available to establish their effectiveness or acceptability to patients. It is possible that a focus group, consensus conference or Delphi approach could be used to identify those techniques that carry most promise and to capture innovative approaches that have not been identified through the published research.

Conclusions

It is evident from the literature reviewed for this chapter that research has been conducted to elicit the views of different groups of the population and that there remains a need to utilise appropriate and culturally sensitive methods to illicit views on processes of health care. There is also a need for a systematic review of the literature that has been conducted in these areas and to ensure that research findings are implemented. Furthermore, there is a tendency with the groups identified in this chapter, for researchers to emphasise differences. For example, for research eliciting the views of ethnic minority health to emphasise cultural difference; for research eliciting the views of women to emphasise biological difference; with older people there is the tendency to emphasise age. However, many studies reveal consistency across findings. Typically users' views are expressing the need for greater information, that staff treat them with dignity and also respect individual needs. There also remain gaps in how far users' views are effected by type of condition, outcome and trade offs. Furthermore there has been little done in the area of eliciting users' views on participating in research. However, what is evident is that alongside a wide range of research methods that have already been explored within this report is that there are also new method which actively seek the explicit views of health care

users. There is a growing emphasis on the importance of empowering the health care user in the research process which emerges from the areas reviewed for this chapter. Nevertheless, there is a more urgent need to analyse what the term empowerment means in practice and how far it is actually possible when there exists a distinct gap between those who conduct research and those that have research conducted upon them.

CHAPTER EIGHT

Recommendations and Conclusions

1. The effectiveness and value of the methodologies currently available and gaps in existing knowledge

This report features our recommendations to the NCCSDO for future research on the methodologies used to elicit users' views of the processes of health care. It is based upon a three-month scoping exercise carried out between August and November 2000 at the University of Sheffield. This comprised a review of the literature and in-depth interviews with key informants whose work has had a significant impact in this field. In addition the advice derived from a specially invited seminar of relevant experts, held at the NCCSDO in February 2001 has been incorporated into the report and its recommendations.

The report describes the conduct and findings of the scoping exercise – both the interviews and the literature search.

Our conclusions were as follows:

- *there is no 'best' methodology*

The end results of both the interviews and the literature review reveal the same issues. Many of the methods, such as *surveys, interviews and focus groups*, are well established and have been comprehensively evaluated with clear documentation of guidelines for good practice. This does not prevent them from being repeatedly used inappropriately and with poor attention to methodological rigour.

For example, postal surveys are not an effective way of eliciting the views of minority ethnic users; a more effective method would be structured interviews undertaken by lay minority ethnic interviewers.

- *There is only limited data (and research experience) available on what works and what does not*

At present there is not enough published about which methodologies work or fail to work with different groups, in different situations and for particular purposes. There are a number of newer methodologies emerging for eliciting and assessing users' views, e.g. health panels, citizens' juries, consensus groups, committee membership, patient stories and the internet.

- *More information is needed about the costs, benefits, and validity of these newer methodologies*

Other less well established methods such as deliberative polling/ referendum and surveys to help set priorities appear to be too simplistic to address these complex issues.

- *For all of these methods and particularly for those such as Rapid appraisal, which have a high level of user or community involvement and generate expectations for change, future research should focus on identifying how eliciting users' views can be effectively translated into changes in health-care practice.*
- *All methods suffer from a lack of representativeness.*

Rather than be paralysed by this, a better understanding is required of which groups respond and which do not respond to different methodologies.

- *The use of multiple methods is likely to be the only way of taking this issue forward .*

- *Some methodologies involve users in the decision-making process. These latter methodologies, e.g. conjoint analysis, willingness to pay, consensus methods, committee membership, should be the focus of further investigation.*

2. Incorporating users' views on the processes of care in research

There were further important issues relating to the methodologies that questioned the way users' views were incorporated as part of the ongoing research process.

These are as follows:

Benefits need to be identified

Many experts felt that it was important to involve users in research and service development but felt that not everyone was convinced about the benefits of involving users. Evidence was needed of the benefits derived from involving users.

- *Users' perspectives need to be taken seriously*

There is little evidence in the literature about users' perspectives on being involved in research.

- *The costs of incorporating users' views into research need to be assessed*

There is a cost to involving users in both research and service development. Users may need training to attain the skills needed.

- *Extra research funding needs to be available to make this practice an integral and effective part of research*
- *No particular method can make superior claims in relation to eliciting users' views*

There was some frustration from experts that this scoping exercise might result in recommendations to 'tweak' methodologies when organisations were struggling to know what to do with findings elicited by any methodology. Thus there appears to be a need to evaluate the impact of eliciting users' views on research and service development. That is, identify the incentives that persuade individuals or organisations to change as a result of eliciting users' views, identify the barriers to using research findings, and establish what is needed to make research findings more usable.

There was evidence of disillusionment with eliciting users' views because changes did not occur to services. Experts felt that it is essential to give feedback to users who have participated in these exercises, explaining what changes have been made or why no changes have occurred.

3. Recommendations

Primary methodological research

- Primary qualitative research should be undertaken to understand users' thought processes when completing quantitative techniques currently in use, in particular conjoint analysis, willingness to pay, and instruments to measure involvement in decision-making and patient satisfaction. As part of this qualitative research, researchers should assess how their findings can be incorporated into guidelines for undertaking these techniques, in particular

would in depth qualitative research be essential for every situation in which the technique is employed, or would cognitive testing or extensive piloting be more appropriate. This is most important for conjoint analysis because this technique is so useful for determining trade-offs people are willing to make between different processes of care and processes and outcomes.

Secondary methodological research

- ii. It is recommended that specific attention be given to the methods used in the USA for eliciting users' views on the processes of care. It is likely that methodologies currently used in the USA might be effectively transferred or adapted for use in the UK. As stated above however, this work would need to be undertaken as a study in its own right but utilizing a similar methodology to this report. It would therefore probably include both a review of the literature on the methods and interviews with the key experts who have used and developed them.

Other recommendations

- iii. There is a need to consider the development of guidelines on good practice in qualitative research as qualitative methods could potentially make a major contribution to knowledge in this area. It is anticipated that such guidelines would need to be flexible rather than prescriptive because by definition, qualitative research has a different agenda from more traditional, quantitative methods. However at present a significant proportion of both qualitative and quantitative research is poorly conducted. Ensuring that the quality of research in the area of eliciting users' views improves would be an important role of the NCCSDO.

- iv. Further research should build on, and not duplicate, research currently being undertaken, in particular qualitative research at the University of Aberdeen showing that validated instruments for measuring patients' involvement in decision-making about their individual care may be problematic, and the Eurowill Project which has tested six methodological issues about willingness to pay. Further expert seminars and a register of research in this general area would benefit all.
- v. Following from that further research should be commissioned in the light of recommendations of this scoping exercise and the two HTA Systematic Reviews i.e. the HTA systematic review on eliciting public preferences for health care (Ryan, in press) and the HTA systematic review on measuring patient satisfaction (Crowe, in progress).
- vi. Quantitative instruments should be developed based on primary qualitative research, with more emphasis placed on the language used in measurement tools and the cultural context of the people who will complete the instrument.
- vii. Research involving the integration of users' views from the outset, should be funded adequately to allow researchers to undertake qualitative research to develop and use the most valid instrument, and involve users in the process.
- viii. Primary research should be undertaken on how elicited views are used in practice, particularly the role of trade-offs. This may require action research to identify the barriers to using users' views, identifying solutions to these barriers, and putting those solutions in place. This should occur at local levels (i.e. with the researchers and the agencies they work for) and at a broader level (i.e. in the context of academic organisations to ensure dissemination of

information through conferences and journal publications) and at a national or even international level (i.e. in relation to funding of this research).

- ix. Traditional methodologies, such as patient satisfaction surveys, need to be re-evaluated in a range of contexts to take account of socio-economic, cultural and demographic issues (such as age and gender). To date these methods, have failed to elicit the views of hard to reach or marginalized groups.
- x. It is also important when considering the effectiveness of the outcome of patient satisfaction surveys to draw a clear distinction between the use, for example, of 'ethnicity' or 'age' as variables, and paying attention to the experience and views of marginalized or minority groups in their own right through using either qualitative methods or structured interviews conducted under conditions which pay specific attention to the needs and experiences of the marginalized group.
- xi. There is a need to evaluate less traditional methodologies such as patient forums, consensus groups and recent methods such as the those which use the internet.
- xii. There is a need to evaluate users doing the research, paying attention to quality standards, maintaining them without being too rigorous.
- xiii. Gaps in the skills of those conducting and evaluating research in the health care
- xiv. Primary research on the effect of outcomes on views of processes of care needs to be conducted.
- xv. It would be useful and possible to develop a systematic, accessible (and flexible) checklist of the issues (practical and theoretical) for researchers to consider when planning research in the area of users' views.

- xvi. The views of marginalized groups such as the elderly, need to be incorporated into the mainstream (using methods specified above) rather than being treated as special interest groups.

Conclusions

Health service workers are being asked to elicit users' views and involve users without necessarily having the skills needed to do this, and without knowing what to do with the results.

This can lead to frustration in the workforce and disillusionment in users. It costs time and money to involve users and at present there is not enough knowledge about the best and most effective methods.

Eliciting users' views is unlikely to be integrated into practice until the benefits of doing it are shown, and organisations are helped to take action based on those views. Research is needed to identify facilitators and barriers to using users' views to develop services.

Academic researchers need to reassess instruments and techniques currently in use and develop new instruments with more emphasis on the validity for the user and context in which the instrument is used. Asking researchers to include users in the process of research will result in an unsatisfactory 'bolt on' process unless some research projects are resourced to involve users in different ways, to identify users' desire to be involved, in what ways, what skills and support are needed, and to identify the best way to produce benefits for both researchers and users.

The ultimate aim of this project has been to advise the SDO programme and the Methodology R & D Group⁵ on the effectiveness and value of the methodologies currently available and the gaps in the research literature and thus (possibly) the research practice.

The project reported here examined and evaluated the *methodologies* used to elicit users' views of the *processes of health care*. It is a scoping exercise; that is it outlines existing research and traces important links between the methods used to elicit users' views of the processes of health care. This has been achieved through a *review of relevant literature* and conducting *in-depth interviews with key informants*.

⁵ It was the Methodology Group who specifically identified this topic as a priority in 1999.

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