King's Fund

Healthy Debate?

An independent evaluation of citizens' juries in health settings

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Executive summary

This is the report of an evaluation of citizens' juries carried out by the Health Services Management Centre for the King's Fund. The evaluation covers six pilots which took place in the National Health Service (NHS) between June 1996 and March 1997. The pilots were sponsored by the Institute for Public Policy Research (IPPR) and the King's Fund.

The evaluation had three aims. The first was to assess the extent to which a citizens' jury was effective in enabling local people to contribute to debates about the health services in their locality and have a positive influence on health policy. The evaluation found that the citizens' jury enabled local people to take part in the debate for several reasons, including the fact that local people were given a specific issue to address; the presentations by witnesses at the jury enabled the jurors to hear about aspects of an issue in an interesting and accessible way; the time allowed for discussion and deliberation enabled local people to exchange views, share ideas and work together as a team; the citizens' jury enabled local people to formulate a number of practical recommendations about what actions the health authority should take to address the issue; and the citizens' jury allowed local people to put these recommendations on the health authority's agenda by presenting them at a board meeting.

The second aim of the evaluation was to assess the benefits and drawbacks of citizens' juries. Those involved in the pilot citizens' juries considered that the benefits of the method were that it enabled local people to understand complex health service issues sufficiently to make practical and useful recommendations to the health authority. The jurors enjoyed working in a team with others and found learning about the NHS and taking part in health authority decision-making a rewarding experience. The drawbacks were considered to be that the method involved a lot of planning and expense and only a small proportion of the local community (16 people) was involved. This meant that a large community of stakeholders and other members of the public had not been involved.

The third aim of the evaluation was to consider citizens' juries in the context of other public involvement methods. Despite its limitations, the citizens' jury had a number of strengths. For example, citizens' juries were clear about the

role that jurors would play and the jurors' task was well defined. Unlike many public involvement initiatives the pilot citizens' juries had built-in mechanisms to ensure that citizens' views would have an influence on services. These mechanisms included: the fact that the findings were reported as recommendations which made clear what was expected of the health authorities concerned; the existence in most cases of a working group which was expected to implement the recommendations; and the fact that the jury recommendations received publicity and so progress could be monitored by local media, interest groups and community health councils. Citizens' juries introduced new elements which strengthened the public involvement process from the point of view of both health authorities and citizens, and these could be used to improve current practice.

Introduction

The public can relate to the NHS as:

- individual users of services;
- family carers who may be regarded as 'co-providers' or 'co-clients';
- a group of users of a particular service, e.g. patients on a psychiatric ward; groups of people experiencing a common health problem or who share an identity as disabled people;
- members of a community served by a particular service, e.g. those living in a locality served by a primary care centre;
- citizens with an interest in ensuring the availability of high quality, publicly accessible health services.

For their part, those working within the NHS may have a range of reasons for wishing to involve the public. These include:

- to plan user-sensitive services;
- to monitor and evaluate the quality of services;
- to increase public knowledge about services available;
- to raise awareness of local health issues;
- to explore community views on local health needs;
- to involve the public in decisions about local services.

The research reported here aimed to examine one small area of this complex map, that dealing with the involvement of the public as citizens in decisions about local health services.

There has been an expectation by the Government that the NHS should involve users and the public to a greater extent in decisions about service planning and review. Many different types of initiatives have been taken in response to this expectation but there has been little comparative analysis and few evaluations. The studies that exist have received limited publicity or review and can be difficult to find. Most research has been carried out in the area of user involvement in community care (see, for example, Lindow *et al.*,[1,2,3] and McIver[4]). Mildred Blaxter confirms this apparent paucity of research in her review of consumer issues within the NHS for the Research and Development Directorate:

> *there is little information as to whether consumer consultations or exercises in priority-setting have, anywhere, had any effect, or whether needs assessments have influenced purchasing plans in any way ... Surveys of all the consequences of attempts to promote consumer participation are badly needed, whether case studies in depth of outcomes of particular exercises, or secondary research over a range of initiatives to show what sort of issue or what manner of consultation actually produces change.*[5]

Evaluations of public and user involvement initiatives can help those working in the NHS in many ways. For example, they can describe how methods work and what seems to be best practice based upon experience. They may also look at the strengths and weaknesses of different methods and show where their use is appropriate. Evaluations can help too in clarifying when and how user and public involvement should take place by examining the impact of the particular initiative concerned on those taking part.

This report provides an evaluation of citizens' juries based upon six pilots which took place in the National Health Service (NHS) between June 1996 and March 1997. The pilots were sponsored by two organisations: the Institute for Public Policy Research (IPPR) and the King's Fund.

IPPR sponsored three citizens' juries, of which two were with Kensington, Chelsea and Westminster Health Authority and one with Walsall Health Authority. The King's Fund sponsored three, one each respectively with Sunderland Health Authority, East Sussex, Brighton and Hove Health Authority, and Buckinghamshire Health Authority. A project officer was employed by the King's Fund to help the health authority pilot sites to organise the citizens' juries. The King's Fund also employed two jury facilitators. It commissioned the Health Services Management Centre (HSMC) at the University of Birmingham to evaluate these and the three IPPR juries. A table showing brief details of the case studies included in the evaluation can be found at the end of the Introduction.

In seeking to evaluate citizens' juries, the King's Fund had three aims:

- to assess the extent to which a citizens' jury is effective in enabling local people to contribute to debates about the health services in their locality and have a positive influence on health policy;
- to assess the benefits and drawbacks of citizens' juries from the perspectives of health authorities, jurors and local interest groups;

- to contribute to a wider debate on citizen participation by examining citizens' juries in the context of other ways of involving the public in health care decisions.

In carrying out the evaluation, HSMC and the King's Fund were keen to address a number of research questions arising from the aims. These were related to structure, process and outcome, and broadly aimed to investigate:

- why the health authority wanted to organise a citizens' jury, what it was hoping to get out of the exercise, how the citizens' jury fitted into its history of public participation, what the background to the question set for the jury was, and what the views of local stakeholders were;
- the way in which the health authority set the timetable and planned the witness presentations, whether the type of question affected the jurors, the way in which the jurors were recruited, how the evidence was presented, how the jury was moderated, and how this affected the jurors;
- the impact of the citizens' jury on the health authority, jurors, and local people and the way the health authority responded to the jury recommendations.

Several citizens' juries have taken place in the UK which have not been formally included in the evaluation. The data collected relate only to the six juries mentioned. However, information about some of these other juries has now been published.[6,7] Where relevant, this information has been included in the analysis to support or qualify inferences made.

The rest of this report is organised as follows. Chapter 1 explains the background, describing why the NHS is interested in public involvement, what methods have been used, why citizens' juries are important and where they originated. Chapters 2 and 3 describe the pilot citizens' juries, covering: why the health authorities concerned decided to use this method and how they decided on the question which was put to the jury; how they prepared for the jury; how the jurors were recruited; the jury process; the jurors' report and recommendations and the impact this had on the health authorities. This section provides a summary of what took place drawn from the detailed case studies of each pilot site.

Chapters 4 and 5 provide an analysis and discussion of the issues emerging from the pilot citizens' juries. There are two kinds of issues: Chapter 4 examines those related to the process of running a citizens' jury, such as what

kinds of questions can be addressed with this method, how jurors should be recruited and what types of facilitation seem to be necessary; Chapter 5 discusses the place citizens' juries might take in the range of methods available for public and user involvement, examining when it might be advantageous to use this method rather than another. Chapter 6 reports on the conclusion of the evaluation.

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BOX 1 BRIEF DETAILS OF THE CASE STUDIES INCLUDED IN THE EVALUATION

Case Study	*Sponsor*	*Sponsors' Project Officer*	*Health Authority Involved*	*Health Authority Project Officer*	*Date of Jury*	*Question Addressed*
One	Institute for Public Policy Research	Jo Lenaghan	Kensington, Chelsea and Westminster Health Authority	Geoff Shepherd	June 1996	People with mental illness live in the community: What can be done to improve the quality of life for mental health service users, carers and their neighbours?
Two					July 1996	
Three			Walsall Health Authority	Kimara Sharpe	August 1996	What are the priorities for improving palliative care in Walsall?
Four	King's Fund	Bec Hanley	Sunderland Health Authority	Maureen Dale	January 1997	A number of services are currently available from GPs: Would local people accept some of these services from any of the following: a nurse practitioner, a pharmacist, another doctor?
Five			East Sussex, Brighton and Hove	Zoe Nicholson	Feb 1997	Where should women with gynaecological cancer who live in Brighton, Hove and East Sussex be offered treatment?
Six			Buckinghamshire Health Authority	Gill Needham	March 1997	Should Buckinghamshire Health Authority fund treatment for osteopaths and chiropractors for people with back pain?

Chapter 1

Background to the evaluation

When the welfare state was established in the 1940s, it replaced the existing piecemeal provision of state, charitable and self-help services with a comprehensive system of public support. The public were able to influence the provision of services mainly through the medium of the ballot box.

The relationship between the welfare state and those it serves began to change in the 1960s, at a time of growing social unrest in the inner cities, low turn-outs at general elections and research suggesting that the aims of public services were not being realised. A number of reports called for increased public involvement. For example, in 1968, the Seebohm Report on the reorganisation of the local authority personal social services encouraged the new Social Services Departments to involve clients more in decision-making and service delivery. Similarly, the Plowden Report favoured parent and community support for schools. In the NHS, the 1974 reorganisation introduced the post of Health Services Commissioner, or Ombudsman for Health, to investigate patients' complaints about health services. At the same time, Community Health Councils were established to provide a way of enhancing the voice of the public and patients.

From initial concerns that public services were not achieving their aims, government interest in increasing public participation in welfare services became linked to doubts about the efficiency and quality of public services. Patient and public participation was encouraged in government documents as a way of tailoring services more closely to users' needs. Within the NHS, the 1983 Management Inquiry, led by Sir Roy Griffiths, was one of the influences that lay behind the concern to make services more responsive to users. The Griffiths Report's comments included:

> *Businessmen have a keen sense of how well they are looking after their customers. Whether the NHS is meeting the needs of the patient, and the community, and can prove that it is doing so, is open to question.*[1]

One of the recommendations of the Griffiths Report was that health service managers should carry out market research to find out the needs of service users. This led to an increase in surveys of patients and in some cases to the appointment of various personnel with responsibilities for overseeing developments in this area, such as quality assurance managers and consumer relations officers.[2]

An additional influence on the development of interest in public participation has been the steady growth in community and voluntary organisations of various kinds. Many of these have developed around users of particular services, focusing either on gaps in state provision or on the inadequacies of existing services. Some, such as the Consumers' Association, have developed to represent consumers generally. In the health field, a number of voluntary groups have emerged, including those working on behalf of patients as a whole, such as the College of Health and the Patients Association; and those representing the interests of particular groups of users, for example, the Association for Improvements in Maternity Services (AIMS).

Alongside voluntary organisations, during the 1970s there developed a community health movement emphasising community participation. Although this had its roots outside the NHS, it attracted some support from those working within the health sector. Among the earliest initiatives were six community health action projects set up in 1977 by the Foundation for Alternatives. Others developed either around communities of place, such as the Stockwell Health Project, or on communities of interest, for example, the Lambeth Women and Children's Health Project.

The establishment of the London Community Health Resource in 1981, and the Community Health Initiatives Resource Unit in 1983, consolidated these initiatives. By the mid-1980s there were thousands of local health groups across the UK, having a variety of relationships with health care workers. The community health approach has been supported in public sector initiatives such as the 'Healthy City' and 'Health for All' initiatives[3] and the basic principles were made explicit in the World Health Organization's 'Health for All 2000' report.[4] Box 2 provides a chronology of the key health policy developments influencing public and user involvement.

BOX 2 KEY HEALTH POLICY DEVELOPMENTS

1974 Establishment of CHCs to represent the interests of the public

1983 The NHS Management Inquiry Report (Griffiths Report) encourages market research

1990 NHS and Community Care Act requires local authorities to consult over community care plans

1992 Publication of *Local Voices* by the NHS Management Executive encourages health authorities to seek community views on health needs and priorities

1992 The Patient's Charter is introduced, making clear patient's rights and the standards of service they can expect to receive

1994 Patient's Charter League Tables are published for the first time to enable comparison of performance

1996 Launch of *Patient Partnership: Building a collaborative strategy,* to support the DoH medium-term priority of giving a greater voice to users in their own care and in the development of policies and standards

1997 Establishment of Centre for Health Information Quality to improve the quality of patient information

1997 Government announces new national survey of patients' views, and a national telephone advice line for patients

The importance of involving service users in order to make health services more sensitive to their needs was emphasised in government guidance associated with the 1991 reorganisation of the NHS. The 1990 NHS and Community Care Act separated purchasers from providers of health and social care and in so doing introduced an internal market. The Act included a requirement that health and local authorities should consult users over community care plans. Furthermore, the Patient's Charter, launched in 1991 along with over 40 other national public service charters as part of the Citizen's Charter initiative, made patient's rights explicit for the first time. In parallel, the NHS Executive produced guidance which encouraged greater consultation with users and the public.

Most of this guidance concerned patients and users rather than the public. For example, *Patient Partnership: Building a collaborative strategy*, which was

published in 1996,[5] supports one of the Department of Health's medium-term priorities for the NHS, which is to:

> *give greater voice and influence to users of NHS services and their carers in their own care, the development and definition of standards set for NHS services locally and the development of NHS policy both locally and nationally.*[6]

There has been one main exception to this focus on users. In 1992, *Local Voices: The views of local people in purchasing health* made it clear that the Government expected health authorities to take into account the needs and preferences of local people when purchasing services.[7] It introduced the notion that health authorities should be 'champions of the people' in that

> *their decisions should reflect, so far as practical, what people want, their preferences, concerns and values.*[8]

The 'champions of the people' role can be seen as consumerism extended to the local community. Although *Local Voices* encouraged the involvement of people in roles beyond that of the direct service user, it did not use the term 'citizen' or refer to accountability to the public.[9] Nevertheless the document encouraged a closer relationship between health authorities and the public and advocated greater public influence over purchasing decisions:

> *The aim should be to give local people the opportunity to influence the debate at crucial stages of the [purchasing] cycle.*[10]

In practice, health authorities have interpreted *Local Voices* in different ways and there have been wide variations in the methods used and the extent to which the public has been involved.[11] For example, some health authorities have seen their role as primarily one of needs assessment and have carried this out using quantitative methods such as surveys, or qualitative methods like focus group discussions. Others have used community development and modified community development approaches such as rapid appraisal. Yet other health authorities have interpreted their role as that of championing the people's health and have sought to collaborate with local agencies, such as the chamber of commerce, city council and voluntary organisations to pursue this aim. Elsewhere, attempts have been made to engage the public in priority setting, using approaches such as surveys, workshops, health panels, discussion groups and citizens' juries.[12,13,14]

Variations in the way that health authorities have responded to *Local Voices* may be due in part to a speech given by the then Minister of Health, Brian Mawhinney, which was sent to health authorities in 1994. This included four reasons for public and patient involvement in the NHS:[15]

- health authorities need to know about local people's preferences, perceptions and experiences of services;
- health authorities need to establish legitimacy for their priorities and purchasing intentions with local people;
- public consultation can help to win the 'hearts and minds' of the public and prevent opposition to change;
- health authorities need to have communications strategies aimed at informing the public about health and health services.

As the Minister's speech made clear, public involvement serves various purposes and it is therefore not surprising that many different methods have been used in practice.

The need to enhance public involvement in the NHS also has to be seen in the context of a wider debate about the nature of democracy in contemporary society. Some writers have argued that although the UK has a system of representative democracy, this does not mean that the role of citizens should be limited to voting in elections. In restricting citizen participation in this way, it is argued:

> *It is as if the citizen is treated as not being capable of any involvement beyond deciding between conflicting parties on who should constitute the government.*[16]

From this perspective, citizens should take a more active role in the process of governing. As a consequence they should have more opportunity to take part in decision-making which results in changes to public services. In relation to the NHS specifically, it has been argued that the NHS is not sufficiently locally accountable to the public,[17] and that the changes introduced as a result of the 1990 NHS and Community Care Act have further reduced local accountability.[18] It follows that action needs to be taken to involve the public in ways that go beyond lay involvement in the work of NHS boards and community health councils.

In this context an analytical distinction can be made between citizens and consumers. Citizens can have an interest in public services even though they do not currently use them. As Beresford has argued:

> *It is not enough for service users to be conceived of as data sources or for our rights as citizens to be reduced to consumer rights. What is at issue is the responsibility of a democratic state to uphold the rights of its citizens.*[19]

Whether or not this argument is accepted, it is clear that a person's views may change, depending on whether they are speaking as a service user or a citizen. This means that the aims of consumerism and those of participative democracy may not always be the same. Rudolf Klein sums this up nicely with regard to the NHS:

> *In short, we have to be clear whether we are concerned about strengthening the responsiveness and accountability of the NHS to a wider body of citizens, or of strengthening consumers as an interest group within the NHS. Both may be legitimate aims of policy, but they are not the same or necessarily congruent.*[20]

What these comments indicate is that although there have been no major statutory changes to the relationship between the NHS and the public since the introduction of Community Health Councils in 1974, there has been an expectation by the Government that those working in the NHS will involve the public, particularly service users, to a greater extent. The main reason for this is in order to make services more sensitive to users' needs. More recently, a need to increase the legitimacy of health service decisions has been perceived. This has meant that health professionals and managers have been under pressure to find ways of involving lay people in service planning and review. A wide range of approaches has been tried. These include research methods such as surveys, focus groups and interviews; community development techniques; patient advocates, representatives and link workers; and various types of groups, such as health forums, patient's councils and patient participation groups.[21,22]

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Chapter 2

The pilot citizens' juries: context and process

Until recently, there have been few examples of methods which enable informed views to be heard. Several publications have introduced a number of possible methods, including deliberative opinion polls, consensus conferences, citizens' panels and citizens' juries.[1,2,3]

It has been argued that these methods do more than provide a means whereby the informed views of the public can be gathered. They also introduce the public discussion of issues, or deliberation, into the democratic process:

> *Deliberation is the process by which views are tested and arguments are put forward and countered in discussion. It involves discourse about an issue and reflection on what is said. Through deliberation new possibilities can be opened up and differences reconciled. If one seeks to persuade, one has to take account of others' views.*[4]

The citizens' jury is one of the new methods which have been suggested. It has been developed and used in several other countries, primarily the USA and Germany, over a period of about 20 years. In the USA, the Jefferson Center has developed and piloted citizens' juries. The Jefferson Center is an independent organisation which was founded by Ned Crosby in Minneapolis in 1974 to improve democracy. The juries have been funded by a range of different sponsors, sometimes more than one. For example, in one project carried out in the mid-1980s, eleven organisations including four state agencies, two major farm groups and two environmental groups, sponsored five regional citizens' juries in Minnesota, to study the impact of agriculture on water quality. Representatives from each of the five juries were then assembled to come up with a set of recommendations for the state as a whole.[5]

The German model operates in a slightly different way. Professor Peter Dienel of the University of Wuppertal has developed a similar process over the last 20 years, which he has called the 'planning cell'. This has been adopted by government at a local and federal level as a way of involving the public.

Approximately 26 cities or communities have used planning cells as a method of local planning. At a national level there have been several projects, including one in which the Federal Ministry of Postal Services and Telecommunication sponsored a planning cell process with 22 panels. The goal was to debate and evaluate the 'future telephone'. The citizen report produced included 66 substantial recommendations, and the German ministry adopted several of these recommendations.[6]

Both citizens' juries and planning cells follow a similar procedure:

- a group or several groups of citizens are recruited to be representative of the community. Each jury or planning cell comprises about 10–20 people;
- the group(s) meets over a period of several days and is presented with verbal and written information about an issue that has been formulated into a question which they are required to answer;
- discussion and deliberation over the issue is facilitated by a moderator who helps the citizens to work out their response to the question;
- a report is produced which describes the deliberations and recommendations of the citizens.

The running of a citizens' jury is a complex procedure and involves a range of individuals and organisations (see Box 3).

BOX 3 PEOPLE INVOLVED IN A CITIZENS' JURY

- Sponsors
- Organisers
- Project managers
- Steering group
- Jury recruiters
- Facilitators
- Jurors
- Witnesses
- Expert adviser
- Observers
- Evaluators

The citizens' jury was introduced into the UK in 1994 by a collaborative team from the Institute of Local Government Studies at the University of Birmingham and the Institute for Public Policy Research (IPPR) in London.[7] IPPR has sponsored a number of pilot citizens' juries which have been facilitated by Opinion Leader Research. In 1995, the Local Government Management Board sponsored a series of pilot projects in local authorities, making a contribution to the costs involved. These pilots were evaluated by the Institute of Local Government Studies at the University of Birmingham. The evaluation of pilot citizens' juries in local authorities showed that they were valuable in three main ways.

Firstly, the pilots demonstrated that the potential of citizens in taking part in local government decision-making was often unrealised. All those involved in the juries were impressed by the ability shown by the juries, their competence in handling the process and the degree of understanding reached. Secondly, the citizens' juries had a deep impact on the participants and they valued involvement in the process of government. Thirdly, their place in the work of the local authority was seen as one of informing the decision-making process, not determining it. The citizens' juries gave the councillors access to the informed view of ordinary citizens.[8]

User and public involvement activity

Five pilot sites were involved in the evaluation of health authority citizens' juries commissioned by the King's Fund: Kensington, Chelsea and Westminster (KCW) which organised two citizens' juries, Walsall, Sunderland, East Sussex, Brighton and Hove (ESBH), and Buckinghamshire, which each organised one jury.

Each of the pilot sites had carried out consultations with service users before considering the use of citizens' juries. In some cases those interviewed considered these to be fairly extensive.

For example, KCW had two members of staff dedicated to consultation with users and had mechanisms in place to listen to users of mental health services. Walsall had consulted with users about mental health services, and had been involved in an interagency Health Localities Project which included community participation. Sunderland had developed a user involvement structure for the planning and review of mental health services which was being used as a model in other areas, such as HIV services.

Public involvement work had been on a project basis in most of the sites. For example, in 1994, Sunderland gained project money from Northern Regional Health Authority to run public focus group discussions, in liaison with the Community Health Council, on what local people understood by health, as part of developing a 'Strategy for Health'. Similarly, ESBH had carried out several large surveys of the local population and service users. The health authority regularly consulted with user groups and voluntary organisations, and had established two geographically based user panels.

Buckinghamshire had taken a strategic approach to public and user involvement and had incorporated it within a wider communications strategy. This was influenced by membership of a regional public involvement network which had developed performance indicators for successful public involvement. The largest and most recent public consultation undertaken was over the strategy for cancer services. This involved 13 group discussions with stakeholders and a conference. In addition, the NHS Executive funded Buckinghamshire to carry out a survey of the local population and a market research company was commissioned to carry out interviews with 1000 local residents on issues which came out of the group discussions.

Reasons for running a citizens' jury

Although each of the pilot sites had different reasons for wanting to run a citizens' jury, all were interested in experimenting with methods of public involvement and wanted to improve their activities in this area. KCW, for example, was anxious to hear what members of the public were saying about mental health issues to compare the public's views with those of professionals. The health authority particularly wanted to hear public opinions about current policy:

> *'There is an opportunity, even though the question is not asked directly, there is an opportunity to say, 'I do not agree with this community care lark'.*

Citizens' juries interested KCW because they had the potential to gain an informed view from the public:

> *You can take your standard opinion poll but that's a reactive opinion, uninformed, and it hard to say whether that is truly representative of what people think or whether they are just reacting to a question. Whereas this is a chance to get them beyond the knee-jerk reactions.*

Not only this but also the time involved in a citizens' jury was seen to offer benefits:

> *standard focus groups are for two hours, or at the most you might have it for a day, and you are starting to get there. With four days you can get there even more so.*

In Walsall the health authority was keen to allocate some of the funds released from a hospital closure to the improvement of palliative care services in the town. It had found consultation over palliative care services confrontational because there was a pressure group which was fighting for a hospice. The chief executive saw the citizens' jury as a way of 'getting a sensible view from the public not a blast of prejudice'. He was keen to hear what people with 'no particular axe to grind' who could listen to all aspects of the argument would decide was the best way forward in terms of the provision of palliative care in the area.

Sunderland's chief executive set the citizens' jury within a priority-setting context. Resources were finite and so priorities had to be determined. This had generated public concern:

> *I don't think the service is failing but we need more public awareness ... we need to treat the public as grown-ups. We have to do this ourselves because politicians will duck it.*

The development of primary care posed a problem because Sunderland had low levels of primary care services relative to the level of deprivation. The health authority was hoping the jury would give it an indication of what the public would find acceptable in family doctor services.

ESBH saw the citizens' jury as one stage in a wider consultation process on the issue of the development of cancer services. It wanted to involve both users and the public in this process. The lead manager involved in planning the jury hoped

> *that the jury begin to appreciate the complexity and can come up with some thoughts and recommendations about how to go forward.*

Buckinghamshire had a number of issues which might have been suitable for a citizens' jury. As the authority was already involved in the production of

evidence-based protocols, and information for patients, a subject which involved talking to the public about evidence of effectiveness was particularly attractive. The purchasing of services for back pain, a subject which involved the complex issue of whether alternative therapies such as osteopathy and chiropractic should be purchased, was thought to be an appropriate choice. The chairman of the health authority commented:

> *we are looking for a more effective way of consulting the public than previous methods ... We hope the public will provide an appraisal of complementary medicine and give us their views on its effectiveness.*

Those involved at the sites also mentioned two other main objectives they hoped to achieve in running a citizens' jury. These were the opportunity to engage other stakeholders in an issue, and as a learning experience for those working in the organisation.

Planning the citizens' jury

Once a decision has been taken to hold a citizens' jury about a particular issue, a question has to be formulated (sometimes called a 'charge' in the USA) which can be addressed in the time allocated. This is an important part of the process because it sets the task for the jurors. All of the pilot sites developed the question over a period of time. In addition, the King's Fund pilot sites tested the question with lay people.

All of the juries had a steering group (described in more detail below) which was responsible for coming to agreement about the question. In all cases, the question was altered by the lay people consulted. For example, at ESBH the question was changed from one asking about purchasing services for gynaecological cancer, to one asking where women should be offered treatment. This was because the lay people consulted thought the use of the word 'purchasing' placed too much emphasis on the financial side of the issue.

The questions addressed in the pilot juries varied from the specific to the general. Some of those interviewed at the sites had particular views on what was appropriate for the jury. For example, the project officer at Buckinghamshire said the question had been deliberately focused quite narrowly to enable jurors to understand it, back pain being too big an issue to tackle without a specific question. She commented:

We thought that if we gave them a narrow question they could always broaden it out if they chose to, but if we'd given them a broad question it would have been difficult for them to focus in.

Each of the sites had a steering group. Although there were variations in their membership and the way they worked, there appeared to be general agreement on the purpose of the group. The following main objectives of the group were identified by the pilot site and King's Fund project workers (see Box 4).

Box 4 Objectives of steering group

- To involve stakeholders and make sure that they are committed to the process and will take the recommendations seriously
- To help in the implementation of the recommendations
- To shape the question
- To construct the agenda
- To identify witnesses
- To prepare information for the jurors
- To make sure that the question, agenda and information are fair and well balanced
- Over all to provide legitimacy to the process by making sure that a wide range of interests other than the health authority are involved in the process

The composition of the steering groups varied due to the different subject matter and local factors. They included stakeholders such as representatives from local trusts, clinical representatives such as GPs or members of the LMC, the local authority, relevant user or voluntary organisations, and community health council representatives. Those interviewed were in agreement that the steering group should be chaired by a senior person, preferably an executive such as the director of communications, or public health, because this would show the organisation's commitment to the project. In this way, the person concerned would bring the necessary authority to the role.

Most members of the steering group took an advisory role with a small core carrying out the practical work. To co-ordinate these activities, a project

worker was seen as essential and she or he needed administrative back-up. The project worker was occupied with the citizens' jury work virtually full time during the planning period which took approximately five or six months. Experts in the area emerged as particularly important in helping to identify possible witnesses and constructing background information for the jurors. In Buckinghamshire, for example, a GP prepared most of the background information, including a glossary of technical terms likely to occur during the jury.

In the pilot juries, the jurors received on their introductory evening an information pack containing a few pages of background information about the health authority and about the issue. This information had been tested on the groups of local people who also looked at the question. They were able to improve the clarity of the written material and suggest other information which might be useful.

Later pilots were able to learn from the earlier pilots in the preparation of witnesses. In the earlier juries there was a tendency for witnesses to over-run their allocated time and to present too much information. For the final jury, witnesses were asked to supply a resumé of their presentation on a single sheet of paper, restrict their presentation to fewer than six transparencies if they were using the overhead projector, and stay within their allocated time of 10–15 minutes. The main concern of witnesses was the type of questions they might receive because the time allocated for questions was usually about 30–45 minutes. Most of the witnesses were given no remuneration for their appearance, although some received travelling expenses. A summary format of the health service citizens' juries is provided in Box 5.

BOX 5 FORMAT OF HEALTH SERVICE CITIZENS' JURIES

- Health authority steering group sets question and agenda
- Independent agency recruits 16 jurors
- Citizens' jury takes place over four and a half days
- Witnesses present information
- Independent facilitators conduct the process
- A report and recommendations are produced
- Jurors are paid £200 plus expenses

Providing the right amount of information, both in presentations and in written handouts, proved to be a difficult task because individual jurors needed different amounts. This dilemma was handled in a novel way in Buckinghamshire by the construction of several copies of a file of additional useful information which some jurors had requested. This was made available to be taken home by those who wanted to do so.

Many people wanted to observe the pilot citizens' juries and this could have disrupted the jury process. All but one of the juries handled this by limiting the number of observers to about a dozen, and making sure that they were placed discreetly behind the jurors at the back of the room.

The exception was Sunderland which had an observers' room linked to the jury room by closed circuit television. The observers' room became very crowded at times. It also verged on becoming a second citizens' jury with the observers debating the way the evidence was presented, and discussing issues. The argument and discussion was in danger of overspilling into the jury room and room management became necessary. This ended up as an additional responsibility for the project workers who were already fully occupied.

The last main element of jury preparation was choice of venue. Some of the pilot juries took place in health authority premises and others in outside venues. On the whole, all appeared to work well. From the comments of those organising the jury, it seemed that in terms of comfort, ease and organisation of space for all concerned, the outside venues (including those which were authority-owned but empty during the jury) worked best. Reasons for this are summarised in Box 6.

BOX 6 ADVANTAGES OF OUTSIDE VENUES

The outside venues, hotels and conference centres (including the empty health authority building in the case of ESBH) had enough room to make it easy to separate jurors and observers at breaks and meal times. This was felt to be important to prevent discussion of the question between jurors and observers who might provide selective evidence or otherwise influence some of the jurors' views. It was possible to achieve this in health authority premises but usually some discreet 'policing' by facilitators was necessary. Space was more likely to be a problem in occupied health authority premises because it was necessary to keep the jury session away from the other activities which went on in the building. This was difficult given the amount and type of space needed, which included small discussion rooms, rooms for observers and jurors to congregate at breaks, desk space for handouts and written information, somewhere for witnesses to be received, as well as the main large jury room and access to catering, and toilets.

The outside venues provided the catering (in the case of ESBH, an outside caterer was employed) and this was a far greater task than the health authority staff had imagined it would be. The jurors needed a constant supply of water and fruit juice, tea and coffee, and biscuits, apart from their lunch, and there was a correspondingly large pile of cups and saucers which needed washing up. This burden fell on the administrative staff and project officers who usually had more pressing jobs to do.

No matter how hard it tried, it is unlikely that a health authority could provide the same level of comfort and catering as a hotel. The facilitators also found that the hotel surroundings enabled them to feel less stress because they were able to relax more easily between sessions and after the day had finished, for example by going to their room or using the hotel facilities.

In addition, one of the pilot site project workers said that she had deliberately arranged for the citizens' jury to take place in a non-health authority venue, in order to appear impartial.

Recruitment of jurors

All of the pilot sites used market research or similar organisations to recruit jurors. These organisations charged approximately £4,000–£6,000 for doing this, a fee which usually included two group discussions with members of the public. Sixteen jurors were recruited for the juries to make sure that if some dropped out, the total available would not fall below twelve. Few jurors dropped out in practice and most of the pilots ran with sixteen jurors. The jurors were paid £200 plus travel expenses for their involvement.

The organisations who selected the jurors were given a recruitment brief which specified selection criteria along age, gender and employment status lines. Geographical area was added following a problem with one of the early (IPPR) pilots where it was found that most of the jurors had been recruited from one housing estate. Despite this brief, there were still problems with the later (King's Fund) pilots.

In Sunderland, the first King's Fund pilot, the shortness of preparation time was largely responsible. The company used was not a local one and so did not know the likely socio-economic composition of the different areas. It succeeded in achieving a good geographical spread of people but according to the project manager, the demographic mix was not as balanced as it might have been. Had more preparation time been available, the health authority would have been able to ask the recruiters to go back to particular areas to achieve a better mix.

Having more time, ESBH was able to correct a mistake which their recruiters had made. The company showed the selected jurors to the project manager a week before the jury. When she noticed they had missed out a complete geographical area, the market research company was able to go back and recruit two jurors from this area.

In Buckinghamshire the recruiters appeared to have cut corners because some of the jurors arrived in the same car together and seemed to know one another. The project manager had not specified that jurors should be unacquainted and so when some of the jurors dropped out at the last minute, the company asked them to recommend friends who might be interested. Several observers, including one of the community health council representatives, thought that the jury was not representative of the local population because there appeared to be too many professional people and there was no minority ethnic juror. However, the health authority and the recruitment company said that the juror profiles showed a reasonable mix bearing in mind that minority ethnic communities comprised only 1 per cent of the population in Buckinghamshire. Given the difficulty of achieving a balanced mix of jurors, the project managers felt it necessary for recruiters to work to a detailed and strict brief encompassing selection criteria based on age, gender, geographical area, employment status combined with housing tenure as an indicator of socio-economic group, ethnic group where appropriate, and lack of knowledge of one another. In the words of one of the project managers:

I would be a lot more 'hands on' with the recruitment company next time, getting weekly reports and making sure they did not cut corners.

Facilitation

Once the agenda has been constructed, the background information produced, and the witnesses prepared, it is largely the responsibility of the facilitators (also known as 'moderators') to make sure that the citizens' jury achieves its objectives. During the pilot juries there were variations in the style of facilitation. This was largely due to the fact that two organisations supplied the facilitators. The IPPR juries (at KCW, and Walsall) used facilitators employed by Opinion Leader Research (OLR). The King's Fund juries (Sunderland, ESBH, and Buckinghamshire) used facilitators employed by the King's Fund. The facilitators had different backgrounds and so worked to slightly different models of facilitation, although there was a considerable amount of overlap in the two models.

The OLR facilitators and the King's Fund facilitators both carried out the following main tasks (see Box 7).

BOX 7 MAIN TASKS OF FACILITATORS

- Helping the jurors to plan the time available so they could answer the question they had been set and make their recommendations
- Getting the jurors to discuss their own experiences in relation to the question so that they were able to make connections with the issue
- Getting the jurors to identify the underlying principles which were important to them in relation to the issue, and which would guide their recommendations
- Providing the jurors with reassurance on their ability to do the job and giving them regular supportive feedback on their achievements
- Making sure that the witnesses kept to their time and that jurors were able to ask the questions they wanted
- Finding out whether they understood the information and evidence they were given, whether they needed more information, whether they wanted extra witnesses called or witnesses called back for further questioning, and whether they wanted an expert of some kind to help them make decisions
- Making sure that everyone behaved properly during discussions; that is, people did not interrupt or cut across one another, chat with their neighbour at the same time, become abusive, stray too far from the point, etc.
- Enabling everyone to get their views across by having small group discussions which reported back, as well as discussions in the large group
- Helping them to deliberate by engaging them in prioritisation exercises and similar tasks
- Helping them to encapsulate their views in a series of statements that would be understood by the health authority as recommendations

The OLR facilitators used a modified focus group discussion style of working. They spent a relatively short amount of time with the jurors dealing with reflections on the process, and were consequently quite task-oriented. Therefore facilitation concentrated on the large group, hearing the individual views of jurors, or enabling them to discuss issues among themselves, with the outcome of such discussions being recorded and summarised. They did not appear to be particularly concerned about achieving a consensus view and made use of techniques which recorded individual views, such as voting forms. The OLR facilitators were not experts on the subject and so did not offer suggestions about how the information might be analysed or summarised into categories or headings.

The two King's Fund facilitators had different backgrounds. One was experienced in citizen advocacy and the other in community arts and drama, training and development. They drew on these backgrounds to create an approach which empowered the jurors to work as a team. The King's Fund facilitators spent much more time on process, agreeing with the jurors their roles as facilitators, and the ground rules which would operate, the hopes, fears and expectations of the jurors, and the stages of the task and how they would accomplish them.

Although there were two facilitators in both models, the roles of the OLR facilitators were more interchangeable than those of the King's Fund facilitators. In the King's Fund pilots, one facilitator acted as a jurors' friend, or process facilitator, doing most of her work in the small group discussions, in private sessions and during breaks. She saw her role as:

> *concerned with jurors' empowering themselves as citizens ... about reflecting back, listening, supporting and believing in an individual's abilities to work through complex issues when they are lacking in self-confidence or feeling out of their depth.*

The other King's Fund facilitator carried out most of the large group facilitation and saw his role as one which enabled the jurors to complete the task. This included time-keeping and pacing, recording appropriate items on flipcharts, and boundary maintenance. The King's Fund facilitators held private sessions 'in camera' (without observers) with the jurors every day, during which they discussed different aspects of the process. They also used these sessions to explore the experiences of the jurors.

As a result of this greater concentration on process there seemed to the observers to be much more of a collective spirit operating, with the jurors appearing to be consciously working together to get the job done. This was reflected to an extent in the post-jury evaluation questionnaires where comments were made about working as a team in the King's Fund juries which did not appear in the OLR juries. For example, when asked what they thought the best things were about the citizens' jury, comments included:

We all worked as a team. (Sunderland)

The whole debate and being able to work in a team and as individuals. (Sunderland)

The interactivity: working as a team. (ESBH)

How well the people worked together who had never met before. (ESBH)

Working together as a team. (Buckinghamshire)

The way everyone worked in the group and how well everyone got on. (Buckinghamshire)

The jury report

In the pilot juries, the jurors' report was written by a project officer who drew together the recommendations. The project officer was either employed by the Institute for Public Policy Research (IPPR) or the King's Fund, depending on who was responsible for the pilot. There were some differences in the way the reports were written by the two project officers concerned but they covered the same general topics. The content of each report is listed in Box 8.

Box 8 Content of jury report

- Background information about citizens' juries and the jury in question
- Method used to recruit jurors
- A summary of what happened on each day of the jury
- Jurors' recommendations
- The results of an evaluation questionnaire given to jurors before and after the jury
- Comments about the role of the facilitators

Differences between the IPPR and King's Fund reports were in the amount of space devoted to the different topics. The reports from the two KCW juries contained much more detail of the jurors' discussions, including some quotations. This made the reports long: 24 pages for the first KCW jury, and 28 pages for the second. The report of the Walsall jury contained no quotes and ran to 18 pages. Most of this space was devoted to the summary of what happened during the jury and the recommendations, with three pages of background information including the role of the facilitators, one page on the juror recruitment specifications, and two pages on the jurors' evaluation questionnaires.

The reports from the three King's Fund pilots were shorter – about eight pages each, including background information, with an additional page for the juror recruitment details, two pages for a facilitator's report and approximately ten pages for a separate analysis of the jurors' evaluation questionnaires carried out by HSMC. The King's Fund project officer said she had taken her lead from the director of performance management at Sunderland who said that a summary of about seven sides would be the right length for the board of the health authority to consider. Nevertheless, she felt unsure whether this was right as she was unclear who the audience should be:

> *I wrote the report for the jurors and the health authority and for someone who was interested in citizens' juries and wanted an overview of it, but I'm not sure who the report should be written for.*

The health authority project managers also showed some confusion about the way the jury should be reported. The project manager for Sunderland, for example, thought the report was fine but also wanted more detail of the jury:

> *The report was what we required. It was perfect for the health authority meeting because the members don't want anything too long and involved. Everyone got a copy and it is concise. But it doesn't do justice to the amount of work the jurors put in. That's why I want a transcript of the jury so I can use more of it. The way the jurors reached their recommendations is interesting and useful.*

The project manager for ESBH said she expected a longer report which they could have summarised themselves for the health authority meeting:

> *Complete summaries of each day would be useful rather than the very short ones we have here. The ones produced at the time were good. In ours there was a*

moment when a juror turned the question around and that's not reflected here in the report. I envisaged a thick report and then a thin one we wrote from it, or Bec did, but based on a thick one.

The proceedings of the King's Fund juries were taped and there seemed to be general agreement among the project workers at the pilot sites that a copy of the transcribed tapes was useful if it could be prepared at a reasonable price. A transcription could also provide further information about the way jurors reached their decisions and this would be helpful to the health authority in progressing the jurors' recommendations, either as a source of further detail on jurors' views, or should anyone challenge the accuracy of the recommendations, as back-up evidence about how the recommendations were arrived at.

There was agreement among the King's Fund pilot site project officers that the report should comprise a summary of the jury proceedings and recommendations. Any confusion was over how long this should be, and what else it should include, such as whether details of the jurors' recruitment methods were necessary, or the results of the jurors' questionnaire and the facilitators' report.

Each report was checked with the jurors to confirm their agreement over its accuracy. This was done in two different ways. In the IPPR juries, there was a meeting of the jurors at which the report was discussed, whereas in the King's Fund juries, the report was sent to the jurors individually for comment, together with a stamped addressed envelope. The King's Fund project officer adopted the second method because a jurors' meeting provided the jurors who attended with the opportunity to further discuss the issues and possibly try to change the recommendations or the emphasis given to different elements of them. Some of the jurors had written or phoned with comments but the project officer only made changes or added their suggestions to the report if these were confirmed by her notes and were due to an oversight. She did not add any new suggestions because they would not reflect the recommendations of all the jurors.

The jurors' recommendations

An examination of what happened to the reports showed that they were not just used to inform the boards of the health authorities about the jury recommendations. In most cases they received much wider circulation, with

the explicit aim in some cases of taking the question and suggested recommendations out to wider consultation.

One of the most important questions which can be asked about the jurors' recommendations is whether or not they are practical. Evidence from the pilots indicates that jurors do not make recommendations which are solely 'wish lists' which pay no attention to funding constraints. Some of the recommendations deal with the reorganisation of existing services, such as the Walsall jurors' recommendation that there should be a review of the management of palliative care to ensure that people do not continue to die in unsuitable surroundings. Another example was Buckinghamshire jurors' recommendation that the health authority set up meetings with GP representatives to discuss and agree guidelines for an early diagnosis and referral system for back pain sufferers.

It was clear to observers that jurors wanted the best for their area and were not prepared to settle for anything less, being wary of 'doctors on the cheap' (nurse practitioners, Sunderland), or 'a second rate hospice' (nursing home option, Walsall). These high expectations were expressed in the recommendations, with mention of a local 'centre of excellence' (ESBH), local specialist palliative care unit (Walsall) and local back pain clinic (Buckinghamshire). Despite this, the jurors recognised that money would not be immediately available to fund these ambitions and in most cases their recommendations were staged, into either short and long term (Bucks, ESBH), short, medium and long (Walsall), or for different levels of action (Sunderland).

Despite fears that jurors would want to re-establish long-stay institutions for mentally ill people, for example, at KCW their recommendations were in harmony with government community care policies, although they placed more emphasis on primary care services in this area than is currently supported by the Government. Similarly, the ESBH jury recommendations were consonant with the Calman/Hine report on cancer services, and the Sunderland jury supported policies developing primary care services.

Although accepting that funding may not be immediately available, jurors did not necessarily accept the budget said to be available to them by the health authority. In most cases they challenged the limits of the sum allocated, but made suggestions about where further money could be sought. This included investigating alternative sources of funding from industry, the NHS R&D budget, and the social security budget to finance back pain clinics in the long

term, at Buckinghamshire; and to make industrial development incentives available to primary care for buildings, new technology and so on, to attract GPs to Sunderland.

Conclusion

The five pilot sites had all consulted with service users and had set up mechanisms to involve some types of users on a regular basis. Public involvement work had also been carried out but had been less extensive than user involvement and had been on a project basis. Each of the sites had different reasons for wanting to run a citizens' jury, although all were interested in experimenting with alternative methods in order to improve their public involvement activities and thought it would be a good learning experience for those working in the organisation. The reasons given by the pilot sites included: comparing public views with the views of professionals; hearing from people with 'no axe to grind'; and finding out how the public would set service priorities and what they would be prepared to accept if given certain options.

The wording of the questions addressed in the pilot citizens' juries was tested out on groups of lay people and was refined by a steering group. Together with a project worker, the steering group carried out the planning of the citizens' jury which included developing the agenda, finding witnesses, and choosing the venue. The pilot sites commissioned outside organisations to recruit the jurors, although it proved to be difficult in practice to obtain a balanced mix of people to serve on juries. During the pilot citizens' juries, there were some variations in the way the juries were facilitated, although a core set of tasks performed by the facilitators could be determined. There were also variations in the extent to which the jurors were encouraged to work as a team.

The jury report was written by a project officer employed by the jury sponsors rather than the health authority. There were differences in the content of the reports but a core set of topics could be found in all of them. Jurors' recommendations were practical in that they did not go against government policy and were not 'wish lists', although they wanted the best for their area and made this clear in their recommendations. Jurors staged their recommendations and suggested other sources of funding to enable their recommendations to be addressed.

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Chapter 3

The pilot citizens' juries: impact and outcome

Those involved with the citizens' juries at the pilot sites found the period before the citizens' juries to be busy with the complex planning and preparation necessary for the four and a half days of intensive activity. What happened afterwards? This section describes the impact of the juries, including the way the health authorities responded to the jury recommendations, whether the recommendations influenced decision making, what those involved thought of the method and whether the juries had any impact on the public.

Health authority response to the jury recommendations

All five of the sites officially received the jury recommendations at a health authority meeting shortly after the citizens' jury. The time interval ranged from one month in the case of Walsall, Sunderland and Buckinghamshire, to two months in East Sussex, Brighton and Hove, and three months in Kensington, Chelsea and Westminster. Three of the five sites provided written responses to the recommendations at the time of the meeting. Sunderland and Buckinghamshire were the exceptions. Of these, Sunderland received the recommendations but did not respond immediately. Instead it sent the jury report and recommendations out to consultation with a number of stakeholder organisations, including the community health council, local NHS trusts, the Royal College of Nursing, and the Clients' Council for Older People. Sunderland then presented a written response, which included the results of the consultation, to a health authority meeting two months later. In Buckinghamshire, the chairman presented the health authority's response to the recommendations and this was recorded in the minutes of the meeting.

Each of the sites committed itself to assessing progress in implementing the recommendations at a meeting approximately six months later. Box 9 charts this process.

BOX 9 DATES OF HEALTH AUTHORITY MEETINGS RESPONDING TO JURY

Health Authority	*Date of jury*	*Date of HA meeting*	*Date of response to report*	*Date of 1st progress meeting*	*Date of 2nd progress meeting*
KCW July 1996	June 1996	Oct 1996	Oct 1996	April 1997	Not committed to
Walsall	Aug 1996	Sept 1996	Sept 1996	May 1997	Not committed to
Sunderland	Jan 1997	Feb 1997	May 1997	Nov 1997	March 1998
ESBH	Feb 1997	April 1997	April 1997	Oct 1997	Not committed to
Bucks	March 1997	April 1997	April 1997	Oct 1997	Not committed to

In some cases jury recommendations were received at a special health authority meeting, whereas in others, they were received at a regular meeting where the report was an agenda item. At all sites, the jurors were invited to attend, and the meetings were open to the public.

All of the sites had pre-meetings where the jurors discussed the report. At the three IPPR citizens' juries, the meeting was intended to provide jurors with an opportunity to check that the report accurately represented their views. At the three King's Fund juries, the meeting was to enable the jurors to discuss how they would present the report. Where this pre-meeting took place some time before the health authority meeting, as in KCW and Walsall, few jurors attended the subsequent health authority meetings. Where the pre-meeting took place immediately before the health authority meeting, the jurors' attendance at the health authority meeting tended to be higher. Jurors who did not attend the meeting were sent copies of the health authority response to the jury recommendations.

The health authority written responses to the recommendations at each of the sites, except Buckinghamshire, were similar in format. They included a mixture of statement of acceptance, comment or explanation about the health authority's current position, and a description of what was currently being done or what would be done to implement the recommendations. All addressed each recommendation, except Buckinghamshire which provided a general response which was recorded in the minutes of the meeting. The

following extracts from responses at each of the sites provide a flavour of how the health authorities reacted.

Kensington, Chelsea and Westminster Health Authority

We welcome the recommendations made by the two juries. It is particularly reassuring that most of these areas have been acknowledged by both the Health Authority and the two Local Authorities to be priority areas ...

Inter-agency communication

Both juries strongly recommended the need for constant liaison between all the agencies involved in caring for people with mental health problems ... The Joint Mental Health Strategy is a plan developed between the Health Authority and its two partner Local Authorities for the future pattern of mental health services within the district ... Within the document we are committed to developing Community Mental Health Teams ... There will eventually be up to 13 teams within the district. Two teams are already up and running ...

Actions

1. Plans for development of the teams should be in place by December 1996. We should ensure that discussions with local Trusts take account of the recommendations of the Juries around the need for liaison between services and that this is fully included within team standards. Timescale: March 1997 and ongoing.

2. The Sainsbury Centre is undertaking some work for the Health Authority looking at how the Care Programme Approach works in practice. The Care Programme Approach (CPA) is the documentation which outlines the care which will be provided to a mentally ill person and draws together all the professionals involved in that person's care ... Although the project will last 2 years, some indications of how things are working will be available in mid 1997 and the Health Authority will need to ensure that this is fully discussed with providers. Timescale: July 1997

Walsall Health Authority

The Health Authority appreciates the quality of the report ... The recommendations appear to be broadly acceptable to the Authority, showing a sense of priority and showing a good appreciation of the complex issues that have to be taken into consideration. They will need some further investigation by the Palliative Care Working Group before they can be incorporated into the Palliative

Care Strategy and their implementation will depend upon the availability of resources ...

Nursing support

Recommendation: Increase nursing support, so that there is a 24-hour easily contactable service – this may require more District, Marie Curie or Macmillan nurses.

Walsall Health Authority has agreed to recruit two more Macmillan nurses for the Community and one more for the Manor Hospital, and we are discussing implementation with Cancer Macmillan; this would enable a 24-hour advisory service to start. A 24-hour District nursing service has been initiated this year, with the out-of-hours service co-located with WALDOC at Goscote Hospital, and we will need to assess whether this is helping to strengthen the service for palliative care patients. We will review the future requirements for district nurses and Marie Curie nurses and include proposals in the Palliative Care Strategy.

Sunderland Health Authority

Recommendation: To continue to develop the nurse practitioner pilots only as an enhancement to the primary care team (i.e. the nurse practitioner should not work alone), while continuing to develop primary care nursing in GP practices.

The Jury recommendation is broadly supported. No new nurse practitioner pilots will be established where the practitioner is outside of the Primary Health Care Team. Further developments of nurse practitioner models will be encouraged where practices are willing to participate in the context of the extended primary care team. These will take account of current and future legislation, and accountability through defined protocols.

East Sussex, Brighton and Hove

Recommendation: That the Health Authority centralise gynaecological cancer services within the county.

The Authority gives, in principle, support to the overall recommendations the Jury make on centralisation of services at a Cancer Centre within East Sussex, Brighton and Hove. The Authority notes that the process of implementing the recommendations is very complex, and will involve the following:

Discussion with the Sussex Gynaecological Tumour Group on clinical guidelines, audit mechanisms, and patient pathways, with a view to making changes to the contract 1998/9/2000.

Consultation and discussion widely with Community Health Councils, cancer support groups, and women who have used gynaecological cancer services.
Discussion and consultation with GPs, GP Commissioning Groups and Total Purchasing Groups.

Continuing to work with the Trusts and clinicians to develop audit mechanisms and outcome data on gynaecological cancer treatment. To maximise adherence to clinical guidelines.

To work with colleagues in West Sussex Health Authority to ensure there is continuity of approach on this issue.

Buckinghamshire Health Authority

The Board re-joined the meeting and the Chairman presented the Health Authority response to the recommendations. He said that the funding implications caused the most concern at a time when the Health Authority was trying to eliminate a £4m deficit by the end of the financial year, but that a project team would be set up to look at the proposals in more detail. A member of the Jury was invited to join the project group and the Jury agreed to consider this. The project team would report back to a future Health Authority meeting in the Autumn.

Three out of the five pilot sites – KCW, Walsall and ESBH – had existing project groups which were able to take over the implementation of the jury recommendations. Sunderland had various projects and initiatives connected to the implementation of the White Paper, *Choice and Opportunity*, into which the relevant jury recommendations were fed. Buckinghamshire set up a project advisory group to oversee the implementation of the jury recommendations. Box 10 summarises the implementation mechanisms used at the sites.

All of the sites therefore treated the recommendations seriously.

Box 10 Implementation mechanisms for jury recommendations

KCW	Joint Mental Health Strategy, Primary Care Led Purchasing of Mental Health Services Project
Walsall	Palliative Care Strategy Steering Group
Sunderland	Working group implementing White Paper *Choice and Opportunity,* special projects such as Patient Participation Group project
ESBH	Cancer Services Steering Group, Gynaecological Cancer Tumour Group, job objectives of those implementing Calman/Hine. Corporate contract with regional office
Buckinghamshire	Newly set up Back Pain Project Advisory Group. Corporate contract with regional office

Effect on the decision-making process

There are difficulties in measuring the impact of public views on health service decisions because decision-making is a complex process. However, one way in which a citizens' jury might be judged to have had an impact is if it introduced new material or insights into an issue over and above that obtained during consultation with service users, community health councils, or other stakeholders such as GPs. Those involved with the citizens' juries at the pilot sites were asked whether the jury recommendations had had this effect. The responses to this question were not straightforward. In one case, individuals within the authority gave completely differing views over whether they thought the jury had introduced new elements. In two others, a positive response to the question was given but was qualified, either by the person concerned or by others. This is illustrated by the following quotations from two managers at KCW:

> *Some of the things the jury mentioned in their recommendations we were not doing: crisis intervention, respite care, and education of the public, were not being actively pursued ... Some of this was mentioned during our earlier consultation with service users, but the area which users have not concentrated on, which the jurors did, was that of education.*

> *It didn't tell us anything we didn't know already.*

Similar differences emerged in ESBH:

> *The jury has helped us to interpret the Royal College Guidelines and has provided detail. We now know that local people are prepared to travel for an excellent local service, but they don't want to go to London. We would have probably got to these same conclusions in the end, but it would have taken longer and it wouldn't have had the impact that the citizens' jury had ...The thing we really didn't know was whether people felt that gynaecological cancer should be treated in a cancer centre rather than a gynaecological unit. I knew I would want to be treated at a cancer centre, but would the rest of the population? (HA)*

> *They confirmed what others wanted ... nothing was new. (Trust)*

In the case of Walsall Health Authority, the following comments were made:

> *The recommendations were helpful in the sense that they didn't ask too much ... The 'hospice with a difference' came out as a result of the jury; that was new. Ian Poole, a GP witness, came up with the phrase and it stuck. The jury was a good 'hot house', it forced ideas up. (HA)*

> *The recommendations largely mirrored our own views in this area and so I consider them to be solid and valid. (CHC)*

At both Sunderland and Buckinghamshire, those involved thought the jury had come up with new information. In Sunderland, a number of the recommendations introduced new elements. For example, in relation to the recommendation on raising public awareness of the full potential of the primary care team, the observation was made:

> *I don't think we'd have thought about it in the same way. It has made us more proactive.*

Similarly, the jury's recommendation that patient participation groups should be developed elicited the comment:

> *This is new. We wouldn't have done anything about this otherwise. It's not new as a concept but the public have said it is a good idea and this has made us consider promoting it among GPs.*

On one issue, the jurors signalled a definite change of approach. They recommended that the health authority should continue to develop pilots

using nurse practitioners only as an enhancement to the primary care team, and not ones where they worked alone:

> *This was new in that they have discouraged nurse practitioner pilots in the way we were doing them. We had given the issue attention by encouraging them through locality-based affairs with no GPs present. We were trying to let a thousand flowers bloom but here they are telling us to rein in. This recommendation directs us to only encourage them as part of primary health care teams.*

In Buckinghamshire, those involved commented that the jury had been 'incredibly thorough', but they thought that some of the recommendations would be difficult to implement because they cut across other areas which had higher priority. For example, one recommendation was that the possibility of introducing chiropractors and osteopaths into existing physiotherapy departments within acute trusts should be explored. This cut across the acute services review which was currently a top priority in that this work would need to be taken forward by people currently working on the Acute Review Team. Another recommendation was to look at funding for a pilot project using chiropractors and osteopaths through savings made by the adoption of guidelines (e.g. savings from less frequent use of outpatient clinics or X-rays). It was difficult in practice to link a project to savings made in trusts:

> *There is work in trusts looking at reconfiguration and changes in practice, but any money released would be re-allocated to other priority areas. It would cut across other priority areas to make a direct link in the way they ask for. We are talking here about systems within trusts.*

The extent to which the citizens' jury introduced new material into the decision-making process did not appear to be a major criterion of success for the health authorities concerned. Other ways in which the citizens' jury had influenced the decision-making process were mentioned. To begin with, some considered that the jurors in their recommendations were able to 'add weight' to particular aspects of an issue and so re-order priorities within a service area. Not only this but also the citizens' jury process itself reinforced the views of the public and made it more likely that they would be acted upon. This was because of the high profile of the jury, the fact that it received media attention and the outcomes were being monitored, and the amount of time, money and effort invested in it.

A further point made was that even if the jury process produced nothing new, it was still important to test out the acceptability of policy decisions with the

public. The citizens' jury was a way of finding out whether proposed service developments stood up to public questioning and debate. It was also a means of widening out a public debate which had become polarised or gridlocked.

Holding a citizens' jury was a way, too, of demonstrating to the public that health authorities were concerned about an issue and were giving it serious attention. At two of the sites this proved to be useful some time after the event when the health authorities were contacted by a complainant in one case, and the press in the other, about problems related to the question addressed. The fact that the health authority was able to explain how it was dealing with the problem through addressing the jury recommendations was felt to be of real benefit to those involved.

Citizens' juries compared with other methods

As part of the evaluation, the sites were asked to compare citizens' juries with other methods of public and user involvement. All concerned saw the citizens' jury as a good way of getting informed views from a cross-section of the general public. Some were very definite about the superiority of the citizens' jury compared to other methods:

> *I am clear there is no way other than the citizens' jury that we could have asked the question. We couldn't have done it because they needed the information, and the deliberation, and we needed the demographic representativeness. We could have perhaps asked part of the question in another way, but not the whole. For some questions, I would say this is the only method.*

> *We couldn't have got the same from other methods. Time is one of the reasons. We tested out the question with a couple of focus groups before we ran the jury and we got opinions from them, but many things didn't come up. There was no input and they couldn't go beyond their own thoughts.*

> *It is the Rolls Royce of methods. The rest are Minis. There is a lot of work to prepare for it, but it covers the subject thoroughly.*

> *As a methodology it is a very good way of involving people at the beginning of a piece of work – at the beginning of a strategy rather than as in normal consultation, at the end. We found the level of debate and grasp of issues shown by the jurors was beyond our expectations.*

In terms of the methodology, I am impressed with it. It did get people to look at the evidence and reflect on it. We don't do this ourselves as a health authority and we should do.

As far as the citizens' jury process has made us report back and follow up, it is better than other models. In our other public participation work we are more diffuse. There are too many comments and no rigorous process to handle the outcome. With joint planning forums for example, they are well documented but they are too routinised and so the comments that come out of them tend to be ignored – 'here the comments come again'. They don't have the impact of the citizens' jury recommendations. They get attention because they are one-off and special. Also the planning forums and similar just throw up issues and problems, whereas the jury thinks through the issues and creates recommendations for action.

Notwithstanding these benefits, cost was a major drawback for nearly everyone. This came out specifically when those involved were asked whether they would consider running another citizens' jury:

Would we do a citizens' jury again? Not sure. I like the idea but they cost too much. It felt good as an approach, but it has to be a large issue to justify the resources.

It's a rare event job because of the time and effort involved. It hasn't solved the problem of how to consult with the public because of the cost. We can't afford to do it if the Government want us to cut management costs.

The health authority is keen to hold citizens' juries in future but needs to discuss the resource issues. We could find funds but it is a question of what we didn't do instead.

In discussion, those interviewed acknowledged that other methods could be costly, too, and it emerged that it was a combination of cost and the amount of time and effort it took in relation to the relatively small number of members of the public involved that was of concern. There were also worries about justifying the expenditure to the public and other stakeholders at a time of financial hardship. This led to the view that citizens' juries should only be used occasionally for issues of major importance. Unlike some of the other methods employed, they were not seen as suitable for use on a regular basis.

Organisational learning

Those involved directly in the planning, design and running of the citizens' juries had the potential to learn from the project management experience they gained. This was mentioned by several of the project officers. Some aspects of the experience singled out were: compiling good quality information, handling the press, meeting the public, dealing with tenders for market research, handling other agencies such as the CHC, and learning about group dynamics and facilitation. As one of the project officers said:

> *People get an awful lot of job satisfaction out of being involved.*

A second group of people who were reported as having benefited from the experience were observers of the jury. Non-executives were mentioned specifically under this heading, although all observers, including those working for the sponsors (IPPR and the King's Fund) and the evaluators (HSMC), should be included.

A third group of people were the witnesses who gave evidence at the juries. These were often health authority managers or health professionals, such as doctors and nurses. They were thought by the project workers at the pilot sites to have gained from their experience of being made to translate complex information into a concise and easily accessible form so that it could be presented at the jury, and from being questioned by jurors.

Those interviewed at the pilot sites were asked whether they had altered the way they worked in any way as a result of their experience of running the citizens' jury. In the main this question provoked thought and reflection rather than answers, but several nascent initiatives were mentioned:

> *We have organised some seminars with managers dealing with different areas of work and we will be discussing whether the public should be involved and how. I think those not involved in organising the citizens' jury feel left out and it's a way of getting others involved in projects. We want to learn from the process now with others.*

> *The citizens' jury gave us the idea of talking to a wider range of users than those we would normally consider – the less seriously ill and those not involved in voluntary groups.*

We have put into our corporate contract with the NHSE that we will review the citizens' jury and consider ways of adapting it for local use. One area we've thought of is in briefing members. We learned how to present information in a better way by getting people to give their views on an issue rather than relying only on one person to summarise it.

Holding the citizens' jury has put citizen participation on the health authority's agenda. When I talk about public participation now, they feel they've experienced some. It has stimulated us to be more pro-active and we will be looking at other methods. I regard it as an uphill battle – someone has to push it all the time ... Unless you have someone at the right time and the right level saying you could do this another way, it doesn't happen.

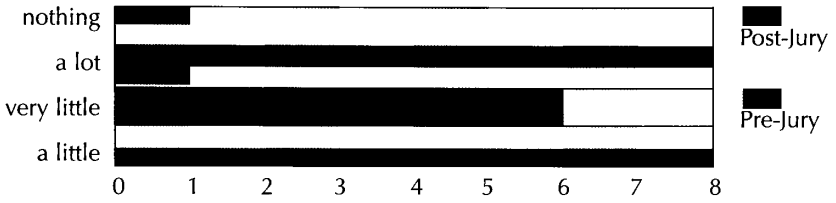
In addition, learning took place between the sites, with the later juries benefiting from the experiences of those held earlier. This was partly due to the co-ordination of the sponsors but also involved direct contact between different organisations. The sites also shared their experiences with others at conferences, and in one case, through a video recording of the event which they produced.

Impact of the citizens' jury on the jurors

In looking at the impact of the citizens' jury on the jurors, both the short-term and long-term effects need to be considered. In the short term, one of the questions would be whether the jurors had changed their views about issues as a result of the jury process. Some indication of whether this had occurred can be gathered from an analysis of the questionnaires which jurors completed before and after the jury. The questionnaires contained questions which asked jurors for their views on aspects of the question being addressed by the citizens' jury, with the same questions being asked before and after the jury. Questions of this nature were asked at four of the juries (the exception being the two organised by KCW) and some changes of view can be observed (see Boxes 11, 12 and 13).

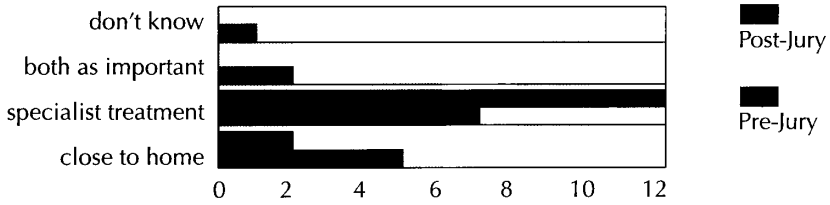
Box 11 Graph from questionnaire responses at Buckinghamshire Health Authority

Q. How much do you know about services provided locally for people with back pain?



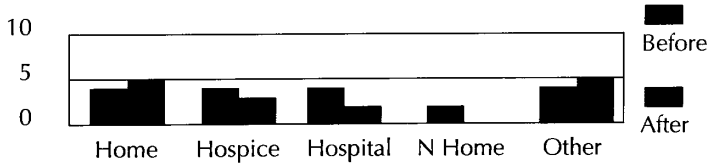
Box 12 Graph from questionnaire responses at East Sussex, Brighton and Hove Health Authority

Q. What is more important for women: being treated close to home or receiving specialist services?



Box 13 Graph from questionnaire responses at Walsall Health Authority (taken from IPPR's jury report)

Q. Which do you think is the most appropriate ... ?



The impact of the citizens' jury on the jurors, once the jury was over and they had returned home to their jobs and families, is difficult to measure without a follow-up survey. This was not included in the evaluation. The only information available is the amount and type of contact that jurors have subsequently had with the health authority pilot sites. This information is not consistent across all sites because they have varied in the amount of encouragement and opportunity for contact that they have provided. There are also differences in the sites' understanding of the role that jurors played.

At KCW, the lead project officer deliberately did not encourage further contact:

> *We didn't build up a relationship with the jurors after the event as others have done. This is deliberate. We think lay people lose their edge because they try to understand too much. We deliberately haven't said 'please keep in touch'. We have our own band of associate non-executives who fill this kind of role, and we advertise for these in the press to make access open ... Is a citizens' jury supposed to be a public service like a jury, a one-off event, or some kind of continuous relationship? We think it should not be continuous, it should not get too cosy, it should be uncomfortable. Familiarity breeds contempt, and there is a risk that in a continuous relationship the health authority will take what the jurors say less seriously ... With a citizens' jury, it is not possible to rubbish what has been said because you don't like the personalities of the people involved, as you can with the CHC and similar groups.*

The contact with the jurors at Walsall has also been limited although not through any deliberate policy. The jurors were sent newspaper cuttings relating to the jury, and material concerning the recommendations. A draft specification for a 'hospice with a difference' was also sent to the jurors for comments. The health authority intends to send jurors information about any major developments connected to the jury recommendations but does not anticipate any further contact. The CHC chief officer in Walsall had spoken to several of the jurors and found that they thought the process was valuable. Three of them wanted to become more involved in health service issues and had asked if they could become members of the CHC.

At Sunderland, some of the jurors have been involved in conference presentations describing the jury. The project officer sent the jurors details of conferences where she had been asked to speak about the jury and a number volunteered to participate in some of the events. Two jurors went with the project officer to a Patient Partnership conference in London, organised by the NHSE, and took part in the presentation. Half of the jurors went with her to a Charter Office Quality Network Group meeting, where they answered questions from the floor about their experiences.

At ESBH, three jurors and three of the service users who acted as witnesses at the jury volunteered to attend the Patient Partnership conference organised by the NHSE. This seemed to increase the jurors' commitment:

Our jurors talked to the Buckinghamshire jurors and came back with the idea that they wanted to be part of the implementation group, so I have written to all of them to ask how they want to do it. They felt empowered to ask us – we didn't want to impose our requirements on them. It's amazing to see how two months later they were still fired up.

At Buckinghamshire, the project officer has written to the jurors several times, sending photographs taken at the jury and various reports connected to it. This was the only jury to hold a celebration for the jurors with cake and tea when the jury finished. Jurors were invited to a staff seminar, and various conferences where the project officer had been asked to speak, including the Patient Partnership conference in London and one run by IPPR. Several have attended these events.

One or two of the jurors have said the jury has had a big impact on their lives. One in particular, a housewife with a child who has been at home for several years. She is thinking about joining the CHC. Some of the female jurors talked about how their confidence increased over the four days of the jury and how they miss the other jurors ... One man said he wouldn't now be able to enjoy doing jury service because he would have to be passive and he liked the active jury better.

Impact of the citizens' jury on the wider public

All of the sites received coverage in the local media, although this was made up of news items about the local jury, rather than opportunities for discussion or debate about the issue addressed. Only one site attempted to involve the wider public in examining the issue set before the citizens' jury. Buckinghamshire ran a computer-accessible citizens' jury which gave information about the jury as it happened, and for some time afterwards. Colin Finney, a research fellow at the Science Museum in London, set up the web site which had pages providing introductory material, background information, and witness evidence, daily summaries and jury recommendations. Those accessing the site were able to vote on the recommendations, contribute to the discussion and make comments.

At the time of writing, a detailed report of the way the site was used was still in preparation, but basic details were available. Between 8 and 29 March 1997, which formed the time frame of the electronic citizens' jury (although the site was accessible for some time afterwards), there were 411 accesses to the home

page. Of these, 235 went on to access the recommendations, and 62 the voting pages. The majority of those voting agreed with the jurors' recommendations.

An analysis of computers connecting to the electronic citizens' jury showed that 36 per cent of the accesses came from Powernet, which provided all the public access site internet connections. The public access sites were located at two surgeries in South Buckinghamshire, libraries at Aylesbury, Milton Keynes and Stoke Mandeville Hospital, and Blackberry Orthopaedic Clinic, Health Information Matters, and Buckinghamshire Health Authority. The public access sites accounted for 66 per cent of the votes cast, but were less dominant in the contributions to the discussion and the comments.

Colin Finney regarded the experiment to use public access sites to extend coverage of the citizens' jury as a 'mixed success'. It was clear that the objective was achieved to some extent but problems occurred at certain sites. The librarian at Stoke Mandeville Hospital library was unsuccessful in attempting to interest health care professionals in the electronic citizens' jury, and restrictions on access may have been caused by the fact that several of the sites had significant problems installing the internet connection and maintaining the equipment in working order.

Conclusion

The sites treated the citizens' jury recommendations seriously in that they set up formal mechanisms to receive, respond to, and implement them. The mechanisms were to some extent public in that the recommendations were received at a public meeting of the health authority and all the jurors were informed of the health authority's response. All but one site provided a detailed written response addressing each recommendation and all had working groups given the specific task of implementing the recommendations. In addition, the sites committed themselves to a progress review at a public meeting of the health authority approximately six months after the recommendations were received.

The majority of those involved at the sites thought that the citizens' jury had influenced the decision-making process within the health authority. Although the jury had only introduced new material at some of the sites, at others the recommendations had 'added weight' to issues which were then given higher priority than they had before. There were a number of reasons why the jury was

able to increase the importance of issues, such as the amount of investment in the process and the fact that the public were now seen to support the issue.

Most of those involved considered the citizens' jury to be superior to other methods of public involvement because it enabled them to get an informed view from a cross-section of the local population, but they considered it a method to be used sparingly because of the high cost involved.

Individuals directly involved in the process of planning and running the citizens' juries felt they had learned from the experience but that learning had only just begun to spread more widely throughout the organisation and seemed to be in quite a fragile form. Only one site had set up a learning mechanism, although a second had agreed to review the method as part of their corporate contract with the regional office of the NHSE. The sites had put a considerable amount of effort into helping other organisations learn from their experience.

There seems to be evidence that some of the jurors had been stimulated by the citizens' jury to become more involved in health service activities. Several had attended conferences and expressed a desire to join the local community health council. One or two of the sites had encouraged this interest by inviting jurors onto project groups responsible for implementing the jury recommendations. There was some disagreement over whether this role was a useful one because it might create 'tame' members of the public or alter the attitude of the health authority towards their views.

All of the pilot sites received fairly widespread coverage about the citizens' jury in the local media, although this was made up of news items rather than opportunities for local people to join in the discussion. One pilot site ran an electronic citizens' jury which had some success in reaching a wider range of people.

Chapter 4

The citizens' jury process

The previous two chapters have been descriptive, providing an account of the experiences of the pilot sites. This chapter analyses these experiences to identify good practice. Factors common to the sites are examined and experience at the sites is compared with the aims of citizens' juries to assess whether these aims have been fulfilled.

What kind of issues are suitable?

Three points can be made about the types of issues that appear appropriate for a citizens' jury.

Firstly, the questions set by the sites came within the broad category of planning the design of particular services: mental health services, palliative care services, primary care services, gynaecological cancer services and services for back pain sufferers. Secondly, the questions were mainly concerned with establishing priorities within these service areas. The three King's Fund pilots narrowed the question down still further, asking whether services would be acceptable from a nurse practitioner, pharmacist or doctor (Sunderland), where women with gynaecological cancer should be offered treatment (ESBH), and whether treatment from osteopaths and chiropractors should be funded for people with back pain (Buckinghamshire). Thirdly, the issues all involved areas of controversy which either had, or could, cause public concern. For example, the provision of care in the community for those suffering from mental distress often arouses a 'not in my backyard' response; the provision of palliative care in Walsall had become locked around an argument over whether a hospice should be provided by the health authority; the reorganisation of services for those suffering from gynaecological cancer was likely to mean some services would be stopped; and the possible funding of osteopathy and chiropractic was an area of controversy with apparent public support for complementary therapies in the face of medical doubt about their effectiveness.

Based on their experience of piloting citizens' juries, IPPR identified four factors which should be taken into account when establishing whether an issue was suitable for a citizens' jury. These were:

- the question should be a 'live' issue not a hypothetical one;
- the issue should be one which the authority is willing and able to act upon;
- the authority should be prepared to hear an answer that it does not anticipate or like;
- the authority should be clear about what it wants from the jury process.[1]

Data gathered at the sites confirm the importance of these factors. For example, the sites chose issues which were difficult to resolve and over which there was public or medical controversy. The recommendations made by the jurors were practical and many were at the specific rather than general level. There was evidence that the jury's priorities were not always identical with those of the health authority and on one or two issues, such as the piloting of nurse practitioners in Sunderland, the jury signalled a change of direction.

Another consideration is that given the relatively high cost of running a citizens' jury, it is likely that the issue will have to be one which involves a large amount of money or one which will have a significant effect on local people to justify the investment.

When should citizens' juries be organised?

Linked to the choice of issue is the need to identify the stage at which an issue should be taken out to public consultation, whether by means of a citizens' jury or other method. Guidance on good practice in public and user involvement (described in Chapter 5) suggests that lay people should be involved as early as possible in the decision-making process. At the very least, there should still be questions which need answers. Having said this, it is clear from experience at the sites that for a citizens' jury to take place, most of the relevant factors need to have been explored so that a coherent and comprehensive agenda can be constructed for the jury. Not only this but also other stakeholders, such as relevant local service providers, need to be part of the citizens' jury planning process and so they probably need to have been consulted earlier.

The pilot sites called a citizens' jury at different stages of decision-making on the issues concerned. This can roughly be plotted as follows:

The stage in the planning process at which a jury took place is reflected in the reason why the health authorities concerned called the jury. For example, care in the community policy, planning and implementation for mental health services was already well developed when KCW called a jury to find out how quality of life could be improved for users, carers and their neighbours. The jury was called during the service implementation stage of decision-making in order to address problems which were occurring. At Buckinghamshire on the other hand, the health authority was at the stage of looking at the medical evidence to inform its decision-making about how to purchase services for back pain. Sunderland had recently received a White Paper about the future of primary care services and was in the initial stages of examining how it related to the local situation. ESBH and Walsall were further along the service planning path in their areas, but major decisions about service provision were still unresolved.

Formulation of the question

Experience at the sites suggests that the question should be one which allows the jurors some room for manoeuvre, or the freedom to choose aspects which they consider important from their point of view. This is because the jurors seemed to want to question the underlying reasons for the task they had been set. Also, if given the opportunity, they wanted some say in the way they addressed it (e.g. in Buckinghamshire where in their recommendations they chose not to directly address the question given).

It is important to add that the main question asked was split into a series of sub-questions at most of the pilot citizens' juries to enable the jurors to work towards answering the main question. The sub-questions were decided by the steering group and often the agenda was built around them. For example, at Walsall, the jurors were asked whether palliative care should be provided following one model of provision rather than another (i.e. home, hospital, hospice, nursing home). In the event, the jurors chose to make recommendations which drew from all the models in order to improve palliative care in Walsall. In KCW where two juries took place on the same question, each used different sub-questions. IPPR considered that the sub-questions used in the second jury were clearer and this enabled the jurors to answer the main question.[2]

The role of the steering group

One of the criticisms that has been made about citizens' juries is that the question and agenda are set by the sponsor, either on their own or more usually in collaboration with the independent organisation which runs the process. This means that the jurors, and citizens generally, do not have an equal chance of putting their concerns on the agenda.[3] In the UK, the King's Fund juries partially addressed this problem by having lay representatives on the steering group which decided the question and planned the agenda. In addition, the question was tested on one or two groups of citizens. Neither the steering group nor the citizen groups were able to change the issue and so this problem was only partially addressed. Nevertheless, the presence of a wider range of people than just members of the convening authority can bring a degree of independent scrutiny into the planning process.

The steering group also performed the function of involving different stakeholders in the process. It was particularly important to involve the local community health council (CHC). In the UK, the most consistent critics of the citizens' jury have been members of CHCs. In 1996, the Association of Community Health Councils for England and Wales issued a briefing paper on the subject which contained a number of concerns which had been raised by their members about pilot citizens' juries.[4] These were:

The views of the CHC had not been sought at the early stage of planning.

They were not convinced that citizens' juries provide good value for money given the lack of investment in public consultation overall.

They were concerned that the health authorities will use citizens' juries as a public relations technique. This high profile exercise may replace other methods of consultation and research.

They felt there is a danger that such exercises can turn into 'managed consumerism' where the questions are set and witnesses chosen by the health authority in order to influence the juries' decision.

They felt that the time needed for the exercise was excessive. Witnesses are not paid, which makes it difficult for CHCs to participate fully.

Experience at the pilot sites suggested that early involvement of the CHC meant a better working relationship and helped to overcome many initial concerns of CHC members. Box 14 provides two contrasting examples of the way in which the sites worked with the CHC.

BOX 14 EXAMPLES OF WORKING RELATIONSHIP BETWEEN COMMUNITY HEALTH COUNCIL AND HEALTH AUTHORITY

At Sunderland difficulties arose in the early stages of planning the citizens' jury because the chief officer of the CHC left, leaving a gap in communication between the health authority and the CHC. During this time the Association of CHCs for England and Wales sent out information to its members which was critical of citizens' juries. This meant that when attempts were eventually made to involve the CHC, members were quite hostile. At a meeting called by the new CHC chief officer, none of the members was in favour of a citizens' jury taking place. Sunderland Health Authority invited four members of the CHC and the chief officer onto the citizens' jury steering group and after they had attended meetings, the members involved changed their views. Initially these members thought that the health authority would manipulate the process to obtain the answer they wanted but they were impressed by the way the planning process was handled. The chief officer thought this was due to the presence of the King's Fund, an authoritative outside agency adding legitimacy to the process.

In contrast Buckinghamshire Health Authority invited a CHC representative onto the steering group as soon as it was set up. The second meeting of the steering group took the form of a training day with an outside facilitator which enabled everyone involved to express their concerns and develop good relationships with one another. As a consequence the local CHCs were not openly hostile to the citizens' jury and were willing to co-operate. The CHC sent observers to watch the jury process and were interested in the method as a way of involving the public.

The extent to which the steering group can involve stakeholders or represent their interests can be questioned, however. It is likely that a very large group would be needed to involve all the different viewpoints and this would make it difficult for the group to meet and plan the jury. A steering group does not take away the need for wider consultation with stakeholders.

The role of the project worker

The health authority project worker was seen as essential by the sites. This person was responsible for co-ordinating the planning of the jury and doing much of the work involved. The project worker's tasks included convening the steering group; making sure that witnesses were recruited, information was prepared and jurors were recruited; that the four and a half days of the jury ran

smoothly; and that the jurors' report was received by the health authority. At four of the five pilot sites, the project worker was someone who had a public involvement or communications remit. At the fifth site, the project worker had responsibilities in the subject area addressed by the jury.

Some of those interviewed thought it was unwise to have someone who was responsible for implementing the recommendations as the project officer. If this person was too closely involved in the complexity of the subject, he or she may find it difficult to stand back and disengage from the outcome. Even if the project worker succeeded in doing so, he or she may be open to accusations of having a vested interest and being in a position to influence the process. Against this view, a senior officer at the pilot site concerned argued that the commitment of the project worker meant that the jury recommendations were likely to be followed up more thoroughly in the longer term.

The jury process

Citizens' juries have been criticised because the jurors do not have the opportunity to choose the facilitator or decide the ground rules which operate during the process.[5] The facilitator is in a powerful position and can have a controlling influence on the jurors and their deliberations. In Germany, this problem is partially addressed because the participants are able to remove the facilitator if they wish:

> *Although the selection of the facilitator is done prior to the first session of the participants, all members of the Planning Cells can reject a facilitator that they regard as biased or demand changes with respect to style and structure of moderation.*[6]

In the King's Fund juries, the jurors were given the opportunity to discuss the roles of the facilitators and mutually agree on ground rules, but they were not able to reject the facilitators if they had wanted to.

In considering the facilitation process in the light of experience at the sites, the following questions arise. First, does it matter whether or not the facilitators are knowledgeable about the subject area? It is likely that someone who has an in-depth knowledge of an area would, given the amount of time the facilitators spend with the jury and the intensity of the experience, convey some of this knowledge to the jurors. They are also likely to have opinions about the issue which it would be difficult to keep from the jurors and there

would be a real danger of them falling into the role of expert. A broad general knowledge of the area would probably not produce the same dangers.

One of the King's Fund facilitators had a broad general knowledge of health issues and although he provided strong guidance on occasions, there were no real examples of him changing the direction of the jurors' deliberations. In their reports, the facilitators gave examples of occasions when the jurors had questioned the facilitators' use of terms and made other suggestions of their own which were adopted. As these examples occurred during the private sessions, they were not observed.

Second, should the jury be working towards consensus? The citizens' jury model seems to have its roots in a notion of democracy which is predicated on the assumption that through participation (and only through participation) a general will can emerge from the plurality of wills. This seems to be behind Ned Crosby's concept of 'the authentic voice of the people'.[7] Certainly if an aggregation of individual views was required there would be other ways of achieving it, such as a deliberative opinion poll or some kind of referendum. Without wishing to accept entirely the notion of 'an authentic voice', the special features of the jury process would suggest that the aim was to achieve an agreed view.

Third, should some jury sessions take place in private without observers? Although it is reasonable to assume that the jurors will feel more relaxed in private, and perhaps more able to describe any painful experiences or discuss sensitive issues, private sessions pose a threat to the legitimacy of the process. Even if it does not happen, the facilitators leave themselves open to the suggestion that they could influence the jurors in particular ways during these sessions. None of the jurors in the pilot juries said that the observers bothered them and so there would seem to be no reason why private sessions should be necessary.

Fourth, how much emphasis on process should there be within the juries? There would seem to be a need for some group attention paid to process if a collective view is to be achieved. Individuals need to have the opportunity to reflect upon how consensus is being achieved, and on how well they are working together. The problem lies in the fact that reflection on process is time- consuming. On the whole the OLR facilitated juries felt less rushed at the end than the King's Fund ones, which were more process-oriented. In all three of the King's Fund juries, the facilitator had to work very hard to pull the

threads together and get the jurors to consolidate their recommendations at the end of the last day.

Fifth, how much free discussion among the jurors should there be? The OLR facilitators tended to allow more unguided discussion among the jurors than the King's Fund facilitators. In fact in one of the early pilots, the first held in KCW, it was a subject of concern to some of the observers. As a consequence, in later juries the facilitators allowed less unguided discussion. In this early jury, the jurors were generally given more responsibility to determine what happened, including being given the job of facilitating their own discussion on the final day. Freer discussion seemed to have the effect of allowing more dispute and dissatisfaction among the jurors.

However, free discussion allows a greater range of ideas to be expressed and can introduce creativity into the process. It was possible to observe this taking place in the OLR-facilitated juries because more open discussion took place in the large group. In the King's Fund juries, free discussion mainly occurred in the small groups and this was not observed. Space for creativity in the large group could be achieved in a managed fashion through the use of brainstorming or similar techniques and this may make it easier to encourage spontaneity in the large group without risking unruliness. Having made this point, a small number of people in each jury said they found it difficult to speak in the large group although they felt comfortable in the small group. This may mean that the small group is the most appropriate place for most of the discussion to take place. If this is the case, there probably needs to be some way for observers to monitor the small group discussions to make sure this is happening.

Legitimacy of the citizens' jury process

The legitimacy of the jury is an important aspect of the method. Coote and Lenaghan have described one of the essential elements of the citizens' jury as *authority* which is:

> *derived from an understanding that the jury is unbiased and the proceedings are fair and appropriate to the task of citizen participation.*[8]

Authority is achieved in a number of ways, including the establishment of a steering group and the use of independent facilitators. Experience at the sites suggested that observers might also help to bring authority. There was a variety

of observers present during the juries, including: CHC members and officers, health authority members, health authority and trust staff, journalists, representatives of the King's Fund and IPPR, and the evaluator. Observers were present for a number of reasons, including the desire to learn about the subject under discussion and to hear the views of the public, but one of the chief roles of observers, particularly those from the CHC, was to monitor the jury process.

Whether or not the citizens' jury method has authority depends to a large extent on whether it is seen as legitimate by policy makers and the public. If the citizens' jury was expected to deliver 'the authentic voice of the people' as intended by Ned Crosby, who designed the American model, the issue of whether local people consider it has authority to make recommendations on their behalf is particularly important. The public might recognise the authority of the jury if they considered it to be representative of their views.

The representativeness of the jurors is a very visible aspect of the jury and one which is likely to generate comment. At least three different meanings of the term have been distinguished:

- it can refer to someone who is elected by means of a democratic process to represent the views or interests of those who elected him/her;
- it can refer to a sample of people who have been statistically selected to contain characteristics of the total population;
- it can mean that someone is typical of others who share similar experiences.[9]

Jurors cannot be said to be representative according to any of these criteria. The jurors have not been elected to represent the views of members of the community. Without delegated authority from local people, legitimacy would lie in whether or not the jury recommendations were likely to be 'typical' of those other similar jurors would suggest. This could only be determined by running several citizens' juries on the same topic and collating the recommendations. The model of citizens' juries or 'planning cells' adopted in Germany follows this procedure.

Some writers consider a serious criticism of citizens' juries to be the question of whether the recommendations of the jurors are in any way typical. As Armour writes:

> *This is perhaps the most significant limitation of the Citizens Jury model. It does not provide for ratification of the normative choices of the Jury.*[10]

Her suggestion is that this could be done by convening public workshops in which jury members explain how they came to the choices they made, answer questions, exchange ideas and obtain feedback:

> *This would allow the Jury to test the consistency of its choices with the general will while at the same time allowing other average citizens an opportunity to learn more about the policy issue and how their peers addressed it.*[11]

The pilot citizens' juries made some attempt to check the acceptability of the jury recommendations with the local population. For example, Sunderland took the jury recommendations out to wider consultation with a small number of stakeholders which included a carers group, and Buckinghamshire had a simultaneous electronic citizens' jury which featured the jury on a Web site and provided a number of local access points. These were, however, the exception, and experience elsewhere suggests that there may well be differences between jurors' views and those of the local population. For example, IPPR sponsored a citizens' jury in Camden which concluded that the local market should be abolished, but several thousand local people signed a petition to maintain it.[12] In this situation the health authority might find that instead of clarifying an issue, a citizens' jury could make the situation more complex.

The jury report would also appear to be a way of confirming the legitimacy of the process. This implies that it needs to contain explicit details of certain aspects of the process, such as the way the jurors were recruited, the independence of the facilitators, the type of evidence jurors received from the witnesses, the way they came to their decisions, and the report of an independent person(s) who observed the jury, such as a member of the community health council or user group.

Did the pilot citizens' juries enable jurors to participate?

Webler has argued that two basic goals of public participation can be identified in the literature.[13] These are fairness and competence. He defines fairness as the extent to which people are provided with equal opportunities to determine the agenda and the rules for discourse, and to speak and raise questions, as well as equal access to knowledge and interpretations. To what extent did the pilot citizens' juries achieve these objectives?

Firstly, did all the jurors have an equal opportunity to participate? The small group work certainly allowed this to happen, although the feedback from the small groups to the large group was usually carried out by any men in the group and men tended to dominate the large group discussions. Also a small number of people, usually four or five, tended to speak most frequently in the large group. The jurors' evaluation questionnaires showed that some of the jurors valued the small groups as their main opportunity to participate. One of the King's Fund facilitators thought that the women jurors were able to get their views across and felt that the jury process enabled this to happen. The facilitator offered the following examples as illustrations:

- in all three (KF) juries, some women expressed their reservations about speaking in the large group to begin with. However, in all three juries the confidence of many of these women developed to such a degree that they were willing and able to present the jury recommendations to the relevant health authority by the end of the process;
- on one jury, two of the women who expressed the most anxiety about their contribution to the process became the media representatives of their jury;
- as both the facilitators were concerned with developing as much juror-led facilitation as possible, on the afternoon of day four, the role of 'chair' was offered to a juror for the presentation to the health authority. In two out of three juries, this role was taken on by a woman, and in the third was taken by the youngest juror;
- in all three juries, female jurors were well represented at health authority board meetings following the juries and several had presented recommendations to the board.

A criticism of the USA model of citizens' juries is that the people who make the final decision do not appear before the jurors.[14] This has not been the case with the IPPR and King's Fund juries where many managers and professionals from the health authorities concerned acted as witnesses, presenting information and taking questions. In all cases, jurors met the chief executive and were able to question him or her, if they wished.

Secondly, in the ideal type model of participation, jurors have the power to put their concerns onto the agenda and influence the issue to be addressed, and to have some say in the moderation style and rule enforcement. The jurors were able to influence the question to some extent in that in most cases they broadened out the question and included in their recommendations areas which they considered to be important, such as health prevention and health

education, and engagement with local schools and industry. In the King's Fund juries the role of the facilitators and ground rules were discussed with the jurors and so they did have the opportunity to agree to what would happen rather than having it imposed upon them.

In Webler's evaluative framework, competence is based on shared social constructions of reality and mutual understanding. He argues that firstly there should be agreement on language, terms, and definitions. A criticism of the USA model of citizens' juries relates to whether all jurors are given equal access to commonly agreed definitions, and to relevant information.[15] In the King's Fund juries this was achieved through the construction of a jurors' information pack, which contained background information and a glossary of terms.

A second requirement is that there should be shared knowledge about scientific data and similar expertise, facts and figures. During the health authority juries, the witnesses presented data, such as the results of clinical trials, and financial data, although in some cases it was difficult to be sure that the facts were correct.

Practical information about implications from different perspectives is also considered necessary to generate shared understanding and during the pilot juries the witnesses helped the jurors to discuss the implications of the evidence, although it is possible that due to the time constraints not all the different interest groups or stakeholders were represented by the witnesses. Mutual understanding also depends on sharing personal experience and this occurred in all the juries.

Finally, participants must be given time to verify their recommendations. The facilitators in all the juries wrote the recommendations up on flipcharts and checked that they were correctly expressing their views. On a number of occasions, the wording was changed by the jurors. In addition, the report was circulated to the jurors for verification.

Did the pilot citizens' juries achieve their intended objectives?

Looking more broadly at the citizens' jury process which took place at the pilot sites, did it fulfil the intended objectives? The citizens' jury process has been summarised in the following way:

> *A small group of people representing the 'general public' meet together to explore a specific policy issue. Witnesses present information and jurors cross examine their statements. Jurors deliberate on the issues among themselves and then make public their conclusions.*[16]

Four main objectives of the citizens' jury process can be identified. These are:

- To allow a representative group of members of the public to become informed.
- To allow the group to discuss the information with one another in order to interrogate the evidence, reflect on it, and explore the different viewpoints which it may engender.
- To provide the group with the opportunity to deliberate on the question, using the information and evidence in a rational way.
- To enable them to make a number of recommendations relating to the question, to agree these, and to record them in a report for the organisation setting the question.

Did the pilot juries meet these objectives?

In relation to the first objective, most people in all of the juries said they had enough information, although a few in each jury said there was too much. Most people in all of the juries said they understood all of the information both written and presented, with nearly all of the remaining saying they found some of it difficult to understand. Only one or two people said they found most of it difficult to understand. This suggests that the amount and type of information provided was acceptable to most of the jurors.

Early on in each jury it was fairly common for observers to be concerned about whether the jurors were asking questions which were searching enough or which picked up on contradictions in evidence. The questions of the jurors tended to become more focused as they became familiar with the process and gained confidence in what they were doing. A marked improvement occurred when the King's Fund facilitators introduced a ten minute small group session after each witness had given evidence, in which the jurors could work out the questions they wanted to ask. This preparation time allowed jurors to reflect on the evidence and work out what else they needed to know to better understand a particular perspective. In other words, the pilot citizens' juries developed a way of allowing the jurors to make sense of the information they received in order to identify what additional information they required.

Secondly, did the juries allow them to discuss this information with one another in order to interrogate the evidence, reflect on it, and explore the different viewpoints which it may engender? Most jurors said they were able to get their views across in both large and small groups, although a minority of people said they did not like speaking in the large group. The King's Fund facilitators used one or two novel approaches which seemed to help make this happen. In the ESBH jury they introduced six service users who sat with small groups of the jurors and helped them to reflect on the evidence they had received. In the Buckinghamshire jury, a director of finance at the health authority and a director of finance at one of the trusts carried out a role-play about the financial implications of the health authority reducing spending on physiotherapy for back pain. This allowed the jurors to see in a concrete way what could happen if their recommendations went in a particular direction.

Thirdly, did the juries provide them with the opportunity to deliberate on the question, using the information and evidence, in a rational way? Much of the evidence was of the same kind as that used by managers in making their decisions. This was most obvious when the jurors heard about examples of good practice in the particular area they were dealing with. In Sunderland, for instance, they heard about a primary care resource centre in Newcastle, a talk which was essentially the same as that observed being given to a group of health service managers and professionals a couple of months earlier. The jurors asked similar questions to the professionals and it seemed to spark their interest in the same way it had that of the professionals.

Having made this point, some of the witnesses produced such a bad impression on the jurors that their evidence was perhaps not taken as seriously as it should have been. For example, in Sunderland a GP putting the case against salaried GPs made a statement which could be interpreted as implying that salaried workers were not as conscientious or caring as those who were self-employed. This aroused the jurors' indignation and they paid little attention to his argument. In ESBH the aloof manner of a gynaecologist alienated the jurors and influenced their view that the Brighton trust should not have a cancer centre. It is difficult to know whether the jurors' recommendations would have been different had these arguments been presented by more sympathetic witnesses, but clearly the personalities involved did make a difference.

Fourthly, did the juries enable jurors to make a number of recommendations relating to the question, to agree on these, and to record them in a report for

the organisation setting the question? This happened in all the juries although this part of the process could have been stronger, particularly in the King's Fund juries. The jurors seemed to have difficulty condensing their knowledge into recommendations. They looked as though they needed more time and this came out in comments on the evaluation questionnaires. When asked what they thought the worst things were about the jury, jurors made comments such as:

More time to discuss in separate small or complete groups. (BHA)

No time left for collecting thoughts. (ESBH)

Always rushing against time. (ESBH)

Trying to get your head round the points in the time given. (SHA)

Rather rushed at times. (SHA)

In this context it is relevant to note that the KF facilitators saw the jury as having five stages which they charted as follows:

- Understanding the challenge (day 1)
- Assessing the evidence (days 2, 3)
- Deliberating the options (day 4)
- Developing the recommendations (day 4)
- Presenting, concluding, closing, leaving (end of day 4)

This is a useful breakdown, but in the light of experience it probably leaves too much to day 4. The facilitators themselves felt they needed five days with such complex questions and that is a possible solution to the problem. Another would be to start deliberating the options on the third day.

Conclusions

There is potentially a wide range of issues over which the public could be consulted. Citizens' juries were used at the pilot sites to inform controversial issues about funding within some service areas which either had, or could, cause public concern.

Jurors were not representative of the local population in an elected or statistical sense. This meant that there could be differences between jurors' views and those of the local population and a health authority might find that instead of clarifying an issue, a citizens' jury made it more complex.
The citizens' jury report was found to be a way of confirming the legitimacy of the process and so needed to contain explicit details of how jurors were recruited, the independence of the facilitators, the type of evidence received from the witnesses, the way the jurors reached their decisions, and the views of an independent person who observed the jury.

The US model of citizens' juries has been criticised for not bringing policy makers in contact with jurors. This was not the case with the UK pilot citizens' juries where jurors met the chief executive and many officers of the health authorities concerned acted as witnesses, presenting information and taking questions.

The jurors considered the process to have been rushed at times and the stage at which jurors develop their deliberations into recommendations may be better started on the third instead of the final day.

The pilot citizens' juries achieved their intended objectives in terms of enabling jurors to become informed; helping them to discuss the issues; deliberate on the question; and make a number of recommendations.

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Chapter 5

Citizens' juries and public involvement methods

This section examines the place citizens' juries might take in relation to other methods of public involvement, the strengths and weaknesses of citizens' juries, and the implications of the findings of the pilot sites for developing public involvement in the NHS.

The public's relationship with the NHS

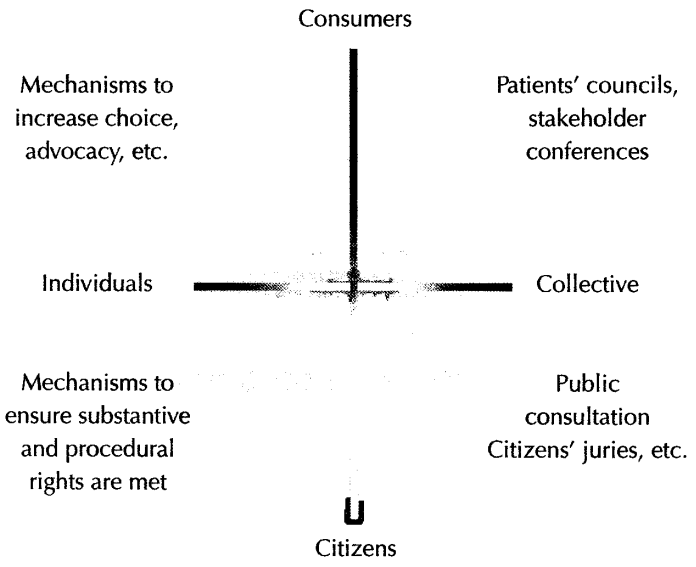
One of the difficulties in comparing citizens' juries to other methods is that there is a very wide range of methods in use. This is partly because the public relate to the NHS in many different ways. These different ways have been summarised by Barnes.[1] People may be involved as:

- individual users of services;
- family carers who may be regarded as 'co-providers' or 'co-clients';
- a group of users of a particular service, e.g. patients on a psychiatric ward; groups of people experiencing a common health problem or who share an identity as disabled people;
- members of a community served by a particular service, e.g. those living in a locality served by a primary care centre;
- citizens with an interest in ensuring the availability of high quality, publicly accessible health services.

People who use public services are both service users and citizens. Their position as service users is more complex than that pertaining in the private sector. Their relationship to the service will differ depending on factors such as whether their illness is chronic or acute, and whether their service use is voluntary or enforced. They can relate to the service as individuals or by participating in groups, such as self-help groups or pressure groups. The existence of a variety of different relationships between the public and the NHS makes it necessary that there be a range of methods for seeking the views of the public.

In addition, those working in the NHS could have different purposes for wishing to involve the public and some methods may be more likely to suit a particular purpose than others. For example, the aim of involvement may be to improve services, to involve users in decisions about their treatment and care, to understand health needs, or to make health services more publicly accountable.

A diagram which helps to map the different types of methods against the various ways that the public can relate to the NHS has been developed by Barnes:[2]



Citizens' juries aim to involve the public as citizens rather than consumers, and to involve them collectively rather than empower them individually. With this in mind, it is useful to compare the method with others having a similar aim rather than methods better suited to a different purpose, such as individual empowerment or the involvement of service users. Having made this point, there are few evaluations of methods which involve the public in their role as citizens. There are more examining cases of user involvement and it is worth briefly looking at some of these before turning to public involvement methods.

Lessons from user involvement

A major user involvement initiative which has been evaluated was the Birmingham Community Care Special Action Project (CCSAP). Between

1987 and 1990, Birmingham City Council and the Birmingham Health Authorities carried out a series of initiatives as part of the project. These included the development of user councils for people with mental health problems, a series of public consultations with people caring for an elderly or disabled relative or friend, and consultations with physically disabled people and those with learning difficulties.

The evaluation made a number of points which are relevant to the pilot citizens' juries:[3]

- it found that reasons for seeking user involvement may be unstated and hence open to different interpretation by those involved. This may be a source of misunderstanding or conflict and so authorities should explain to users the reason why they were seeking their participation and what role they were expected to play;
- the decision made by CCSAP not to focus on potential as opposed to actual users, nor on citizens who were also not users of services, placed constraints on the success of CCSAP. In particular, it meant that the project could address neither the actual nor potential problems caused by opposition to the integration of disabled people within the community (the 'not in my back yard' syndrome); nor could it seek to build a constituency of support for the development of high quality community care services among voters and local charge payers;
- some elements of CCSAP did not develop effective mechanisms for ensuring that user views would have an influence on services and this led to dissatisfaction among the users involved;
- one of the basic lessons learnt from the evaluation was that user involvement could not be a one-off activity if change was to be achieved.

In the light of these points, the citizens' jury method has advantages in that it recruits citizens and so can address the 'NIMBY' syndrome; and the role the jurors will play is clearly explained to them. The pilot citizens' juries had to some extent a built-in mechanism for ensuring citizens' views would have an influence on services. This was: firstly, the findings were reported as a number of recommendations which made it clear what was expected of the health authorities concerned; secondly, in all but one case there was an existing working group which was expected to implement the recommendations; thirdly, the jury recommendations received publicity and so progress could be monitored by local media, interest groups and community health councils.

However, the citizens' jury could be seen as a one-off activity given that it takes place over a clearly defined time period. This did not appear to be the case at the pilot sites because the health authorities concerned had all engaged in previous public consultation, but it will depend on how the term 'one off' is defined. If it is seen as relating to a particular issue, then to date only some of the sites would come within this category. KCW and ESBH had consulted with users on the issue concerned before running the jury; Walsall had engaged in discussions with voluntary organisations about palliative care; Sunderland sent the jury report and recommendations to a range of other organisations, including user groups, for their comments. Of course, the other sites may involve users or the public in discussions during the implementation of the jury recommendations. The implications of the point made by the evaluation is that a citizens' jury should be part of a wider public involvement strategy and not an ad hoc project.

A review of research findings on user involvement in community care[4] also identified the need to develop mechanisms to act on what users said during consultation. In relation to this is noted the fact that organisations often act according to agendas which get in the way of meaningful consultation. Several examples are cited in which the outcome of consultation was driven by pressures which exerted an influence contrary to the wishes of users. In these cases it did not seem sensible to consult on the issue, or if consultation went ahead, the areas around which flexibility existed should be made clear. With reference to the pilot citizens' juries, it can be noted that the issues at the pilot sites allowed some flexibility over decisions and the jurors learned about some of the pressures on the health authority as part of the process. Had the issues generated juror recommendations which were very different from those of the health authority (for example, over the closure of a local hospital), the outcome may have been less satisfactory for health authority and jurors alike.

In addition the review of research findings on user involvement in community care identified a range of practical factors which were necessary for good consultation in community care. These included physical access, transport, information, clear language, and making the experience enjoyable for participants. As far as these aspects are concerned, the pilot sites seem to have addressed them. For example, they ensured that jurors could attend by paying travel expenses (including taxi fares) and they provided information and briefed the witnesses to ensure the minimum of jargon. Feedback from the jurors suggested that they found the experience worthwhile.

Good practice for managers in developing consumer participation in community care has identified a number of issues relevant to public and user involvement.[5] This includes many of the issues identified above, such as the need for clarity about the role of users and the provision of information for users. One other suggestion is relevant here. This is the need to make sure that participation is personal and that time spent with users is built into the workloads of senior managers. The pilot citizens' juries did provide managers and professionals with opportunities to meet the public in their roles as witnesses or observers.

The literature on user involvement describes some projects which have been set up independently of statutory organisations. For example, Fife User Panels Project was run by Age Concern Scotland to ensure that statutory agencies heard the voices of older people themselves as well as those of Age Concern workers.[6] It may be more difficult for these initiatives to influence health policy at the local level. An evaluation of the Fife Project found evidence of substantial differences in the responses of officers in local health and social work agencies to the issues raised with them by panels and this experience combined with that of similar projects led the evaluator to comment:

> *Challenge from users to established practices can be threatening and workers may feel themselves powerless to make change.*[7]

Nevertheless, support for independently run user groups as a consultation mechanism is supported in the user involvement literature. The evaluation of the Birmingham Community Care Special Action Project, for example, noted:

> *As users start to play a part in decision-making, it becomes more important that their input draws strength from groups controlled and led by users themselves. CCSAP was a provider-led initiative, but sowed the seeds of user-controlled groups among carers and people with mental health problems. Support for such groups must be part of a longer term strategy for involvement.*[8]

This is an important point because it could just as easily apply to public and citizen involvement. It confirms again the need for a range of methods for public involvement and also reinforces the fact that independent facilitators in citizens' juries are necessary in order that those taking part can feel they have enough strength to fully engage themselves in the process.

Lessons from citizen involvement

There have been fewer initiatives involving citizens (rather than users) and not many of these have been evaluated. The PART initiative run by Bromley Health is one that has. This initiative involved a tool comprising a set of questions and stimuli cards designed to encourage discussion among groups of the public. The objectives of the tool (the Public Awareness Raising Tool) were: to increase public understanding of Bromley Health's role; to generate an informed debate among the public around the need to prioritise; to explore the capacity of the method as a way of capturing the views and values of local people on specific purchasing dilemmas; and to contribute to organisational development by bringing staff in contact with the public to hear their views.

The evaluation found there was a lack of knowledge about Bromley Health among those who took part and that the initiative was largely successful in raising levels of awareness among those who participated, although not more widely. The debate stimulated was reasonable but showed a bias towards more 'emotive' yet fairly marginal topics, such as gender reassignment and tattoo removal. There were found to be some problems with the method as a way of capturing the views of local people. In particular, the groups were not representative of the local population, the headings used to categorise the views of PART participants in relation to some types of treatment were potentially subjective, and the evaluators had doubts about whether treatments other than the example used (IVF) would excite similar breadth and depth of comment. Finally, as a result of the PART initiative there was a tendency among the staff and members of the public involved to value local participation and support the objectives of PART.[9]

Southampton and SW Hants and Portsmouth and SE Hants Health Commissions and the Office of Public Management developed 'The Climbing Frame' as an action learning resource for management concerned with public involvement in purchasing. As part of the process, in-depth interviews took place with a number of lay people who had been involved in some way in public participation. Comments by the lay people reflected many of the concerns outlined above in relation to service users. For example, they complained about the lack of change in the aftermath of consultation and the lack of feedback from those who initiated it. Honesty and realism about what public participation could achieve were seen as necessary. Some pointed out that health managers were working to their own and not a community agenda and some areas were not open for discussion. Lay people did not want to be

asked to contribute a view if decisions had already been taken and a consultation document was really a final draft. Different groups had very different ideas about how much they felt they ought to be involved. A key conclusion was that there were instances when good information provision was more useful than ambiguous attempts to involve people in decision-making.[10]

A review of a number of initiatives involving the public in service reconfiguration was able to suggest ways in which the initiatives could have been improved.[11] For example, a well-organised campaign of opposition to the closure of St Mary's Hospital, Roehampton, may have been prevented had the health authorities involved:

- engaged CHCs earlier;
- integrated GPs and MPs more fully in the debate;
- used lobbying techniques;
- started an open debate rather than an assessment of possible closures;
- been more open about the dangers of inadequate staffing and clinical standards of safety;
- devoted more time to airing issues with opinion leaders;
- had a tradition of working with other stakeholders;
- made the service benefits clearer.

Some of these recommendations are generalisable to other situations and are reinforced by the experiences of the citizens' jury pilot sites. For example, the importance of the early involvement of CHCs; the need to involve other stakeholders such as GPs, the value of providing the public with relevant information, such as that relating to the benefits and drawbacks of lines of action; and the need to make the debate as open as possible.

Methods for public involvement

Although there have been few evaluations of methods used to involve the public, it is possible to draw lessons from the available literature about the appropriateness of different types of methods. This applies particularly to critical reviews of the practical application of methods, such as those by Gurney,[12] Martin, Smith and Fenner[13] and McIver.[14] For this, it is useful to divide the methods into two groups: research, and consultation.

Research methods include quantitative methods such as surveys and opinion polls and qualitative techniques such as focus group discussions. These have all been used quite widely for obtaining the views of the public, by both independent researchers and health service managers and professionals. For example, Calnan and Williams[15] explored lay views about high technology medicine, while Charny, Lewis and Farrow[16] looked at public values about who should be given priority in decisions about treatment. Bowling used a postal survey, interviews, and group discussions in her research on public views about health care priorities.[17] Judge and Solomon provide a review of public opinion polls about the NHS.[18]

In some circumstances surveys about health issues can be extremely useful and Cartwright offers examples.[19] Where complex issues such as priority setting, service reorganisation and service planning are concerned, however, they have not proved to be very effective. This is for a number of reasons:

- slight changes in question wording can alter responses, as can the order and context of questions;
- people respond differently when asked about their own experiences rather than hypothetical situations;
- there is dispute over how stable across situations a person's values are;
- views may change with increased knowledge;
- it is difficult to obtain a representative sample of the population in postal surveys particularly in inner city areas where there may be sizeable minority ethnic populations.

These problems undermine the validity of the information collected using surveys and limit the usefulness of such information, although some of the problems can be addressed by using interview surveys rather than postal or telephone questionnaires. Also, when using qualitative methods some of the above weaknesses can be overcome because there is more opportunity for information exchange. Focus group discussions provide an opportunity for some information provision and for participants to explain their views in a way which enables complexity to be recorded. Interpreters can be used, as they were in a study by Shah, Harvey and Coyle,[20] so that non-English speakers can give their views. Despite this, research methods, although useful ways of collecting information, are not designed for public consultation and involvement. There is no real opportunity for a two-way exchange of information.

The most commonly used consultation methods in the NHS have been sending plans to the community health council for comment and public meetings. A number of writers have described the inadequacies of these methods.[21,22] Public meetings provide a very limited opportunity for the audience to speak and only the most vocal participants succeed. Community health councils have complained that consultation documents are sent too late to allow distribution to a wide audience, are full of jargon, and when comments are returned, health authorities do not feed back information about how they have used them.

More recently, a number of methods which aim to create the opportunity for more information exchange have been tried. Among these is a variety of group methods. These include consultation with local voluntary and community groups about health plans in Bristol,[23] and health panels in Somerset[24] and Bedfordshire.[25] Also included are conferences which aim to involve a range of stakeholders, including users, citizens, voluntary organisations, health professionals and managers and representatives from local relevant organisations. Within this category are search and stakeholder conferences which have been used to plan mental health services.[26] Stewart[27,28,29] has described a variety of approaches which have been used in other countries, including deliberative opinion polls and the use of new technology in teleconferencing and the internet. He also identifies other ways in which citizens can be involved in public services, such as in the monitoring and appraisal of services.

Most of these are examples of 'top down' initiatives which involve statutory organisations experimenting with ways of involving the public. Is there any evidence of which methods lay people prefer? Lankshear and Giarchi[30] carried out a study of preferences in consumer participation in the planning of community care. The researchers wanted to find out what older people, disabled people and carers thought about their involvement in consultation. They found that individual home interviews were the first choice of these groups of people with group discussions second choice. There was a general dislike of public meetings and postal questionnaires and self-completion questionnaires were viewed with 'dislike and mistrust'.

In the citizens' juries pilots, jurors taking part in the King's Fund pilots were asked to complete a questionnaire both before and after participating in the jury. One of the questions asked jurors to rank methods in order of preference. Panels, interviews, group discussions and postal questionnaires were

consistently selected in the top three positions, as well as citizens' juries. Public meetings and guided discussions at pubs, community centres and so on, were ranked lower. This finding suggests that different people prefer different methods but confirms that public meetings are not liked. The consultation and involvement preferences of citizens are an under researched area, although one of the problems in carrying out research would lie in the fact that the public have not experienced many of the newer methods and so may find it difficult to make choices. Research in this area would therefore have to involve some degree of experimentation with the methods concerned.

Until more of the new methods have been tried and evaluated, it is not really possible to compare them with citizens' juries. However, it is clear from the evaluation of the pilot citizens' juries that this method has some limitations. For example, it is only suitable for certain issues, it is quite costly, and it only involves a small number of citizens. There are also lessons which can be learned from citizens' juries in order to improve methods currently in use or in the development of new approaches.

Strengths and weaknesses of citizens' juries

There were three main perspectives involved in the citizens' juries at the pilot sites. These were: health authority personnel; stakeholders, such as community health councils, members of the steering group, and witnesses; and jurors. What were the benefits and drawbacks of citizens' juries from these different perspectives?

Health authorities were clear on the benefits of citizens' juries. The jury process did what they hoped it would do: it enabled a group of local people to understand complex health services issues sufficiently for them to make practical and useful recommendations. Against this, there were four main drawbacks as far as the HAs were concerned.

Firstly, the amount of planning involved meant a long lead time was necessary. As a senior manager at one pilot site said:

> *The work involved is all front-loaded.*

About 5–6 months of fairly intensive planning, to agree the wording of the question and sub questions, plan the four and a half day agenda, agree and

invite witnesses, prepare and test out background information and plan the venue, are needed. Although some of this could become streamlined as the health authority developed expertise, it was still a major time commitment.

This was linked to a second drawback, namely the cost of running the jury. It was a lot more expensive, in terms of both staff time and cash needed, than the methods usually employed to involve the public, such as holding a public meeting or consulting with the community health council. It was also more expensive than most other methods that those working at the pilot sites had experienced, such as focus groups and stakeholder conferences.

A third drawback was that for all the time and expense involved, the jury did not include other stakeholders in a way which would enable them to feel their views had been taken on board. Work still had to be done in winning acceptance, ownership and commitment from these stakeholders before the recommendations could be implemented. Finally, a great deal of effort was needed to involve 16 local people.

Stakeholders concurred with health authorities on the benefits of citizens' juries and they raised some of the same drawbacks, particularly those related to cost and the representativeness of 16 people. In addition they were worried about four other factors:

- the extent to which the public really understood the issues involved and thus the solidity of the grounding on which their recommendations were based;
- whether the health authority was able to manipulate the evidence so that they would receive recommendations they wanted;
- why the recommendations of the citizens' jury should carry more weight and be treated more seriously than views from other stakeholders, such as trusts, GPs, the community health council, etc. There was a fear that health authorities would use citizens' juries to legitimate and push through recommendations which other stakeholders did not agree with;
- that use of the citizens' jury, because of the cost and time involved, would lead to the neglect of other methods, and established routes of consultation would be wasted.

Jurors who took part in the King's Fund pilot citizens' juries were given a self-completion questionnaire which included questions asking what they thought

were the best and worst things about the citizens' jury. An analysis of their responses showed that the reasons why they appreciated the citizens' jury came into three main categories:

1. The opportunity it gave them to work with other people in a team. This was mentioned 16 times in ways such as:

We all worked as a team.

Complete strangers getting together and working well on difficult problems.

A feeling of collaborating.

The interactivity: working as a team.

How well the people worked together who had never met before.

The way everyone worked so well together and the friendliness of it all.

2. The opportunity it provided to learn and become knowledgeable about the NHS. This was mentioned 12 times, for example:

To obtain in-depth knowledge of health care in Sunderland.

Have learned a lot about primary care, secondary care, etc.

Getting the facts.

Learning new facts.

To have access to such high quality information and to have the ability to question this.

3. The opportunity to take part in health service decision-making. This was mentioned seven times, for example:

Being part of decision-making in Sunderland.

Very good debate and feeling of being involved.

The opportunity to allow the public view to be heard with sufficient backup so as not to be ignored.

The chance to give an outside view of the issue.

Involvement in community decision-making process.

Few comments were made on what jurors considered the worst things to be, but one main category could be identified. This was the speed at which they had to absorb information and there were 13 comments of this kind, for example:

Too much too quick.

Not enough time to (A) question fully witnesses, (B) absorb all information.

Rather rushed at times.

Time constraints.

It was rather hectic.

No time left for collecting thoughts.

Short time to take in a lot of information.

One other category contained three comments and this concerned their consciousness of the responsibility of being a juror:

Thinking you were dealing with people's lives if you got it wrong.

If I was the right person to speak on behalf of others.

Daunting to think of the implications of our recommendations.

These comments indicate that those involved in the pilot citizens' juries considered that the benefits of the method were that it enabled local people to understand complex health service issues sufficiently to make practical and useful recommendations to the health authority. This was done in a way which was acceptable to the jurors who enjoyed working in a team with others and found learning about the NHS and taking part in health authority decision-

making a rewarding experience. The drawbacks were considered to be that the method involved a lot of planning and expense and only sixteen members of the public were involved. This left a large community of stakeholders and other members of the public who had not been involved. Some of these other stakeholders were suspicious that the process was open to manipulation and were not convinced that the public could fully understand the issues in the limited time available. There was some concern about how the recommendations of the jury would be balanced with those of other stakeholders.

Two further limitations to the citizens' jury method have been identified by researchers. The first is that the format of the citizens' jury is an intensive examination of an issue over a short time period. It can only deal with problems which can be addressed by a decision and set of recommendations at a particular point in time. As Hans-Jorg Seiler points out, not all problems are of this kind:

> *Many of the political problems do not fit this mold [sic]. They need a permanent process of revisitation rather than a single decision.*[31]

The second limitation is that the process does not provide much opportunity for jurors to have a dialogue with policy makers. The input of the jurors into the decision-making process is restricted. Jurors provide a report which is taken into consideration along with other inputs, but they are not involved in discussions with decision-makers about the results from the different types of input under consideration. As one writer has pointed out:

> *Providing input to the policy making process is not the same as taking part in it. The Citizens' Jury model, like so many models of public participation, still leaves citizens outside the policy arena, talking among themselves and hoping that their input will somehow be taken into account.*[32]

This did not appear to be completely the case in the UK citizens' jury pilots. There was some evidence that policy makers had made a commitment to considering the jury recommendations and had made this clear to the jurors.

Citizens' juries have been distinguished from other models of citizen participation in that they combine the following elements:

- information;
- time;
- scrutiny;
- deliberation;
- independence;
- authority.[33]

Although other methods may have one or two of these elements, none except the citizens' jury ensures that all are present to a substantial degree.

Three other features would also seem to be particularly important because they were identified by those involved in the citizens' juries at the pilot sites as contributing to the fact that the jury recommendations had some impact. These were:

- the fact that the jury comprised a group of ordinary citizens who could examine the issue without a vested interest and without a prior history of contact with the health authority. This meant their views were given more credence than those collected through established means. It was not as easy to 'rubbish' their views, as one manager put it.
- the fact that the public views were presented in a recommendations format made it easier to action them. The opinions and views of users and the public usually have to be collated and the implications for service planning and provision worked through. The jury did some of this work for them and so the format of the report was immediately useful.
- the fact that the jury and the health authority response to the recommendations were being publicly scrutinised. There was an expectation that they should act on the results of the jury or give their reasons why they were unable to – in fact they had made a commitment to the jurors and the public (through the media) that this is what they would do.

It may be possible to design new methods which include all of these features but are less costly and involve more citizens. For example, one-day citizens' workshops could be developed which involved 10–15 people. A series of these could be organised and so greater numbers of people would be involved. As citizens would only be involved for a day, remuneration (apart from travel expenses) may not be necessary. The above elements could be maintained,

including recruitment of a random sample of citizens, independent facilitation and the publication of a report with recommendations, although this might be compiled drawing together the results of a number of one-day workshops.

A further possibility would be to redesign existing methods, such as public meetings, so that they incorporate as many as possible of the features present in citizens' juries. Stewart describes examples of how public meetings are being improved to make them more acceptable to participants and more useful to authorities.[34] Finally, the elements of citizens' juries can be incorporated into the internal activities of an organisation in order to improve the way in which decisions are made and to allow greater participation by members of staff.

Conclusion

The citizens' jury has some weaknesses, such as the fact that it can only be used for some issues and questions, it does not provide much opportunity for jurors to have a dialogue with policy makers, and it does not involve many citizens. On the other hand it has a number of strengths compared with other methods, such as clear aims and role for jurors, a mechanism for implementing jury recommendations, and the incorporation of features such as information provision, time to question witnesses and deliberate, and a degree of independence and authority. These are important features which could be used to strengthen existing public participation methods such as public meetings, or as a basis for the development of new involvement methods. They could also be used to improve internal decision-making processes and contribute to a more democratic working environment within the NHS.

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Chapter 6

Conclusion

The evaluation had three aims. The *first* was to assess the extent to which a citizens' jury was effective in enabling local people to contribute to debates about the health services in their locality and have a positive influence on health policy. There is potentially a wide range of issues over which the public could be consulted. Citizens' juries were used at the pilot sites to inform controversial issues about funding within service areas which either had, or could, cause public concern.

The citizens' jury enabled local people to take part in the debate for several reasons, including the following:

- local people were given a specific issue to address. The debate was focused around a single question and a small number of sub-questions which enabled local people to get to grips with the issue;
- the presentations by witnesses at the jury enabled the jurors to hear about aspects of an issue in an interesting and accessible way. The opportunity to question the witnesses allowed people to gather information which they considered to be relevant;
- the time allowed for discussion and deliberation enabled local people to exchange views, share ideas and work together as a team. This process was enhanced by the facilitators who made sure that it happened fairly so that everyone had the chance to contribute. The opportunity to work in small groups as well as the large group was also found to enable local people to have a say;
- the citizens' jury enabled local people to formulate a number of practical recommendations about what actions the health authority should take to address the issue;
- the citizens' jury allowed local people to put these recommendations on the health authority's agenda by presenting them at a board meeting.

The citizens' jury also enabled local people to have a positive influence on health policy. There was an indication from the pilots that the jury recommendations had some influence on decisions made by the health authorities in question. This impact was thought to be largely through the jury

recommendations 'adding weight' to issues which were then given higher priority than they had before.

The *second* aim of the evaluation was to assess the benefits and drawbacks of citizens' juries. Those involved in planning the citizens' juries at the pilot sites considered the method to have two main *benefits:*

- the health authority was able to hear the views of a broader cross-section of local people than they were used to. The fact that the jury comprised a group of ordinary citizens who could examine the issue without a vested interest and without a prior history of contact with the health authority was thought to be important by many of those involved;
- the views heard by the health authority were the informed views of citizens rather than uninformed or 'off the cuff' responses. The jury process enabled lay people to understand complex issues and make suggestions about ways forward. As a consequence, their views were more useful. Some of the health authority staff involved thought that for some questions, the citizens' jury was the best method to hear the views of citizens.

Many of those involved at the pilot sites were surprised at the level of ability among ordinary people to understand and deal with complex issues. The citizens' jury seemed to bring out an unexpected level of competence. This finding supports that of the evaluation of the pilot local government citizens' juries.

Further benefits can be derived from the experiences of the pilot sites. For example, the juries enabled a considerable amount of organisational learning to take place. A variety of staff working for the health authority learned about different aspects of public consultation, such as preparing information on complex issues for lay people, meeting the public and listening to their views and experiences, working with other organisations, and about facilitation and group processes.

From the point of view of the members of the public who took part, the citizens' jury gave them the opportunity to work with other people in a team. They were also positive about the opportunity it gave them to become knowledgeable about the NHS and take part in health service decision-making.

The evaluation of the local government citizens' juries concluded that the process had a deep impact on participants. There was some evidence to suggest that the health authority citizens' juries had an impact on a number of the jurors beyond that of increased knowledge about the NHS. A few jurors became involved in presentations at NHS conferences, some joined working groups to implement the jury recommendations, and several had expressed an interest in becoming members of a community health council.

Three main *drawbacks* of citizens' juries were highlighted by the evaluation. The first drawback was the necessity of having a long lead-in time in order to plan the jury. About five months of planning was needed to set up a steering group, agree the wording of the question and sub-questions, plan the agenda, agree and invite witnesses, prepare and test out background information, and plan the venue. This meant that consultation had to be planned well in advance and that this method may not be suitable for consultation over some issues. A related limitation was the fact that the citizens' jury provided an intensive examination of an issue over a short time period, which meant that it could only deal with problems that could be addressed by a set of recommendations at a particular point in time.

The second drawback was the cost of running a citizens' jury. There was a general view among those in health authorities and stakeholder organisations at the pilot sites that £16,000 plus staff time, was a large amount of money to pay for consulting the public. This view must be set within the context of limited finances and a lack of government guidance on what would constitute an appropriate amount of money to allocate to public consultation.

The third drawback was the small number of local people who could be involved in a citizens' jury. It was difficult to see how these people could be representative. They were not elected representatives, nor were they a statistically representative sample. If the recruitment process was rigorous and ensured a typical mix of people, then this was considered by the pilot sites to be a useful indication of what local people might think. However, there was always the possibility that the jury recommendations might not meet the approval of the majority of the local population.

The *third* aim of the evaluation was to consider citizens' juries in the context of other public involvement methods. This was found to be difficult because there had been few evaluations of the different methods used to involve the public. Slightly more evaluations had been carried out on service user

involvement initiatives than public involvement. An examination of the findings of these evaluations showed that the pilot citizens' juries addressed many of the issues highlighted as weak areas in user involvement initiatives.

For example, citizens' juries were clear about the role that jurors would play and the jurors' task was well-defined. Unlike many user involvement initiatives the pilot citizens' juries had built-in mechanisms to ensure that citizens' views would have an influence on services. These mechanisms included: the fact that the findings were reported as recommendations which made clear what was expected of the health authorities concerned; the existence in most cases of a working group which was expected to implement the recommendations; and the fact that the jury recommendations received publicity and so progress could be monitored by local media, interest groups and community health councils.

The evaluation of user involvement initiatives stressed the value of continuous involvement rather than 'one-off' initiatives and there was some question over whether citizens' juries could be regarded as meeting this criterion. It would depend on whether or not a citizens' jury was part of a wider public involvement strategy.

A range of practical factors were identified by the evaluation as being important in good user consultation (e.g. physical access, transport, information, clear language, and making the experience enjoyable for participants). Citizens' juries appeared to have addressed them successfully.

Fewer examples of evaluations of public or citizen involvement were identified. However, the recommendations arising from some of the initiatives were reinforced by the experience of the pilot citizens' juries. These included the importance of the early involvement of CHCs and the need to involve other stakeholders such as general practitioners, the value of providing the public with relevant information such as the benefits and drawbacks of lines of action and the need to make the debate as open as possible.

It was possible to draw inferences from the literature available about the appropriateness of different types of methods for involving the public. Quantitative research methods, such as surveys, although essential for investigating many health issues, had not proved to be very effective where complex issues such as priority setting, service reorganisation, and service planning were concerned.

Qualitative research methods, such as focus group discussions, had been found to be more useful in allowing an exploration of public views about complex issues. However, because research methods had been designed to collect information rather than involve participants in decision-making, they were not particularly appropriate for public consultation and involvement where the opportunity to debate issues and suggest ways forward is essential.

Until recently, the most commonly used public consultation methods in the NHS had been sending plans to community health councils for comment, and public meetings. A number of writers had described the inadequacies of these methods. Alternatives had been suggested, but the citizens' jury could be distinguished from other models of citizen participation because it combined six elements: information, time, scrutiny, deliberation, independence and authority. The evaluation of the pilot citizens' juries confirmed the value of these elements. Three other features were also found to be particularly important because they were identified by those involved in the citizens' juries at the pilot sites as contributing to the fact that the jury recommendations had some impact. These were:

- the fact that the jury comprised a group of ordinary citizens who could examine the issue without a vested interest and without a prior history of contact with the health authority;
- the fact that the public views were presented in a recommendations format which made it easier to action them;
- the fact that the jury and the health authority response to the recommendations were being publicly scrutinised.

It was suggested that it may be possible to design new methods which included these elements but which were less costly than the citizens' jury and involved more citizens. The redesign of existing methods, such as public meetings, was also a possibility. Finally, the elements of citizens' juries could be incorporated into the internal activities of health authorities and trusts in order to improve the way in which decisions were made and contribute to a more democratic working environment within the NHS.

Appendix

Evaluation is a particular kind of research which has the purpose of assessing the effects and effectiveness of an innovation or intervention. There are many different types of evaluation models, including quantitative measurement such as systems analysis, and qualitative approaches, such as illuminative evaluation. The focus of evaluations can also vary, some looking mainly at process and others at outcomes. In evaluating citizens' juries there were potentially a wide range of questions which could be asked.

The context for the evaluation, and resource constraints, meant that there were restrictions on the amount of information which could be collected from the many different stakeholders who might have an interest in the pilot citizens' juries. The fact that the health authorities involved had a large investment in the pilot juries together with the identified need among other NHS organisations for practical help in this area meant that the evaluation had a strong health authority focus, rather than, for example, a focus on the process as a tool for citizen development and empowerment, looking at issues from the point of view of participating jurors.

The data for the evaluation were collected in a number of ways:

- Face-to-face and telephone interviews were carried out with those at the health authority pilot sites who were involved in organising the citizens' jury, and influential people at the sites who were interested in the jury. This always included the project managers and a senior executive, frequently included the chairman, and often included members of the steering group which planned the jury. Interviews were carried out before and after the jury and an interview checklist was used covering topics such as their expectations for the citizens' jury, their views on the process, and their understanding of what was happening in response to the jury's recommendations.
- Observation of the pilot citizens' juries took place. A researcher observed all of the juries apart from the first two days of the first jury at Kensington, Chelsea and Westminster HA. Notes were kept of four main areas: (1) description of the *environment*, including who sat where; (2) an account of the *process*, including the order of events and how long each event took; (3) brief details of the *content*, including summaries of witness

presentations, what facilitators said, the jurors' questions, and the kind of discussion that took place; (4) *researcher impressions* and thoughts, including feelings about the jurors' mood, whether they were asking perceptive questions, whether the deliberation was getting anywhere and jottings about items of interest.

- A semi-structured self-completion questionnaire was filled in by jurors both before and after the jury. This asked for their views on public participation in the NHS, the issue tackled by the jury, and the jury process. A similar questionnaire was used for the three King's Fund pilots. During the IPPR pilots, a different questionnaire issued by IPPR was used.
- There was participant observation at various meetings associated with the running of the pilots, including steering group meetings and debriefing meetings during each jury. Participation involved providing details of the evaluation and sharing observations about the jury process, to help in the learning process which went on during the pilot juries.
- There were discussions with the jury facilitators, and the jury development workers employed by IPPR and the King's Fund.
- Relevant material was collected, such as media coverage of the juries, minutes of meetings, and jury reports.

All of the data were analysed by hand. The qualitative data generated by interviews were analysed by themes linked to the questions asked. For example, what were the respondents' expectations for the jury? What did they think of the recommendations? Would they use the method again?

The data from observation of the juries were analysed by taking a theme, such as the environment the jury took place in, or the way the facilitators conducted the jury, comparing the differences and similarities across the juries, taking into account what those who took part said on this issue (if anything) and drawing out reflections and possible implications.

Comparison between the different juries was difficult for a number of reasons: firstly, the method was new and those taking part learned from each occasion. This meant that the later juries were better organised and run than the earlier ones. Secondly there were differences in content due to the range of questions asked. As a result, comparisons between the juries over the way the jurors handled the evidence, or the way they reached their recommendations, was problematic. Thirdly, as this was a method being piloted for the first time in the UK, it was not clear what would and would not be good practice. In the absence of any existing UK model for citizens' juries which could have acted as

a standard for comparison purposes, the UK pilots have been compared as far as possible with those which have been organised in the USA and Germany. At the time of the pilots, in-depth descriptions of juries which have been run in these countries were unavailable and so comparison was necessarily limited. The results of the evaluation of pilot citizens' juries in local authorities carried out by the Institute for Local Government Studies at the University of Birmingham have also been used as a resource.

Finally, an evaluation framework for public participation has been produced by Thomas Webler, an American researcher.[1] Webler's framework is different to the one used in this evaluation, in that it describes an 'ideal type' of participation based on the goals of fairness and competence. The framework has not been used in any formal way during the evaluation but was found to be useful as an aid to reflection during the analysis and discussion of the data.

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1. Webler T, (1995) 'Right' discourse in citizen participation: an evaluative yardstick. In: O Renn, T Webler, P Wiedemann, *Fairness and Competence in Citizen Participation*, Boston: Kluwer Academic.

Six citizens' juries pilot schemes, sponsored by the Institute for Public Policy Research and the King's Fund, took place in the NHS between June 1996 and March 1997. This book evaluates all aspects of this experiment, from an explanation of the background to the pilots to descriptions of the jury processes and public involvement methods.

The evaluation found that the participating citizens found the whole experience very rewarding. They were able to address specific health issues, hear from witnesses, share ideas and make practical recommendations to the health authority. This report also describes some drawbacks of the pilot schemes, including the amount of planning involved and the limited number of people who participated in any one health authority. However, the overall finding was that citizens' juries introduced new elements which strengthened the public involvement process from the point of view of both health authorities and citizens, and these could be used to improve current practice.

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