

# Citizens' juries in planning research priorities: process, engagement and outcome

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## Abstract

**Background** Involving members of the public in setting priorities for health research in becoming increasingly common practice. One method used in public involvement exercises is the citizens' jury.

**Objective** This article examines some challenges and benefits of citizens' juries, including issues relating to process, public engagement and outcome.

**Design** In Bristol, UK, a citizens' jury was held with the aim of identifying local priorities for research into health and social care. This jury is used as an example through which key issues in public involvement and jury processes are explored.

**Setting and Participants** The Bristol Citizens' Jury comprised 20 members of the public ('jurors'), an oversight panel and a steering group. The jurors met at 11 consecutive sessions during 2006 over a period of 16 weeks, which culminated in a written report. All the sessions were audio-recorded, five sessions were observed and video-recorded, and 16 jurors completed written feedback forms at the end of the jury process.

**Findings and conclusion** In this article we discuss degree and timing of public involvement in the process of health research; the role of context; representation of communities; processes of deliberation and knowledge production; and how constraints of time and cost may affect public involvement. It was clear that jurors who took part in the Bristol Citizens' Jury were engaged and committed. This engagement may be related to jurors' belief in their ability to shape future research alongside concern about the relevance of the issues under discussion. Opposing emotions of tension and harmony are a crucial part of the deliberation process.

## Introduction

Public involvement has rapidly become the norm within health research. One method of involving the public that has recently undergone a resurgence in popularity is the citizens' jury process.

Citizens' juries have been widely applied in health and other arenas, but remain uncommon in agenda setting for research. Based on the principle of 'deliberative democracy', citizens' juries aim at entailing decision-making based on processes of 'careful consideration', debate and

respect for different viewpoints.<sup>1,2</sup> In brief, citizens' juries bring together members of the public (jurors), and provide structured fora for discussion of relevant information provided by 'expert witnesses'. Citizens' juries represent an attempt to bridge the gap between 'top down' consultations that entail little involvement, and 'bottom up' community participation based entirely on lay knowledge and interests. Citizens' juries share similar aims with community-based participatory research.<sup>3</sup> Facilitators or moderators are present to guide the process and witnesses provide 'expert evidence.' The end result is a written report authored by the jurors.

In the UK the increased popularity of citizens' juries is partly at the behest of central government which has identified dialogue between the public and policy makers and local government as an important part of policy decision-making.<sup>4,5</sup> This has been coming from the very top: when Gordon Brown became prime minister of the UK in 2007. He identified citizens' juries as a key means of involving the public in decisions about key issues ranging from 'anti-social behaviour' to housing. The government plans to use citizens' juries across the UK, including to address health issues. Within the UK's health services there is an increasingly established tradition of public involvement; this is represented by organized patient groups and recognition of the importance of patient and public involvement in decisions about health care and research planning and priorities. Funders for health research, such as the National Institute for Health Research, now expect public involvement in research bids, and a national advisory group (INVOLVE) offers guidance to researchers as to how this can be achieved as well as guidance to the public about the meaning of involvement in research. Mechanisms also exist for involving public and patients in decisions about health service provision, these mainly centre on patient and public involvement forums which will be replaced by Local Involvement Networks (LINKs) in 2008. Within these mechanisms, patients and the public are involved in a variety of ways – as members of steering groups, as advisors, as

assessors and as lay representatives. Internationally, increased involvement of the public in all stages of research parallels increased awareness of the need for public involvement in health-care rationing<sup>6</sup> as well as acceptance that consent in research entails dialogue, although achieving a single model of consent that suits all styles of research may not be possible.<sup>7</sup>

There has been substantial debate about public involvement and the role of citizens' juries in priority setting, literature on these topics addresses several key issues. These include deliberation about the extent of involvement in a variety of 'public involvement' formats,<sup>4,8,9</sup> and discussion of the need for early involvement of the public in setting research questions.<sup>10</sup> The context in which public involvement takes place has been highlighted as an important consideration, and questions have been asked about the extent to which individual views and opinions expressed in consultation exercises represent those of the wider public or of individuals.<sup>11</sup> In addressing models of involvement that entail deliberative democracy, deliberation itself has come under question,<sup>11,12</sup> and although public involvement is being promoted and it is acknowledged that 'citizens' are well able to address complex scientific issues,<sup>13</sup> it has been pointed out that members of the public themselves are aware of limits to their knowledge.<sup>14</sup> Existing literature does discuss the resources required for public involvement initiatives,<sup>15</sup> but this is only infrequently flagged as a problem, even though time and finance are usually sought competitively and often limited.<sup>2</sup> Finally, assessment of whether public involvement exercises are successful rests on establishing criteria for success and evaluating projects on this basis<sup>16</sup> and this includes the need to ensure that the results of public involvement exercises translate into policy or practice.<sup>17</sup> However, questions remain about the extent to which this can be achieved, not least given the long-term nature of any shifts in policy that might follow from public involvement exercises. We reflect on these issues by drawing on the experience of planning and facilitating a citizens' jury in Bristol.

### The Bristol Citizens' Jury

The Bristol Citizens' Jury aimed to bring members of the public into the earliest stages of research by addressing the question: *What are the priorities of the citizens of Bristol for research into the provision of primary health and social care?* The jury process involved 20 jurors drawn from the Bristol City Council's Citizens' panel, a planning team, two facilitators, expert witnesses who presented 'evidence' to the jury, and an oversight panel whose role was to assist in ensuring fairness and in the identification of witnesses. The Jury held 11 consecutive meetings (sessions) during 2006 over a period of 16 weeks. Sessions comprised a full day introductory session, six witness sessions and four deliberation sessions. The process ended with the launch event for the jury's final report, and following this a steering group of jurors and professionals was formed in order to disseminate the report still further. All the sessions were audio-recorded and 16 jurors completed written feedback forms at the end of the process. Five sessions and the launch event were observed and video-recorded by a researcher (J.H.), who also attended planning and oversight panel meetings. Another researcher (R.G.H.) attended the planning and steering group meetings.

The topics identified by jurors at the full day 'introductory' session were used to identify witnesses for subsequent sessions. Key issues identified in the first session included research and health and social care, primary care, mental health, social issues, older people, children and family. A total of 12 witnesses presented to the jurors in the witness sessions; facilitators and the oversight panel identified potential witnesses. The six witness sessions covered: approaches to research in health and social care; older people; public health needs in Bristol; social care and mental health; general practice; and patient complaints.

The final report of the Bristol jury identified the jurors' priority questions for research and presented them according to the degree of consensus. Questions were grouped into categories according to the level of agreement about their inclusion: questions on which the jury was

unanimous, those which a majority chose, those on which the jury was equally divided and those questions which a minority wished to include. Full details of the jury and its findings may be found in the jury's reports.<sup>18,19</sup>

### Involving the public early in the research process

Awareness of the difference between the views of members of the public and those of researchers and professionals<sup>20</sup> implies a pressing need to include the public in setting research agendas at early stages in the research process. It is at these early stages that members of the public have been involved explicitly since the early 1990s in tandem with increasing consultation of the public regarding health-care priorities.<sup>21,22</sup> This shift towards public involvement reflected debate about the politics of representation that took place in the 1980s.<sup>23,24</sup> Involving members of the public at this stage may be key to real empowerment as it is at these stages of research development that there is opportunity to exert influence.<sup>15</sup> In their review of public involvement in setting research agendas, Oliver *et al.* describe how this has been attempted through a variety of methods, ranging from written consultations to face-to-face exercises including workshops and consensus conferences.<sup>10</sup> The authors identify the importance of engaging people 'directly and repeatedly in facilitated debate' but did not identify any examples of the use of citizens' juries to define research agendas, although citizens' juries do have similarities with the consensus conference method.

The broad question about priorities for primary and social care research was designed not only to elicit concerns grounded in the jurors' experiences of local community life,<sup>25</sup> but also to address questions that fell within the remit of the local Primary Care Trust (PCT). At first, jurors found the breadth of the question difficult, and found it hard to separate research from service provision. However, as jury sessions progressed, the relationship between research and eventual service provision became clearer and formed a basis for the final

conclusions of the jury. To engage with the jurors' concerns about their ability to address the question, at the introductory session the facilitators first encouraged discussion about service provision followed by a discussion of the kind of knowledge needed to improve services. This enabled jurors to identify what information they would need and therefore what expertise they would like the witnesses to bring.

During the introductory jury session, the jurors also tried to make the task more manageable by breaking down the question, by asking for further clarification about the characteristics of health research and by requesting information on the scope of health research. Jurors asked for information about the sort of questions that health research addresses, how research is conducted and who carries it out. Facilitators suggested that it would be useful to gain more insight into research methodology by using the first witness session to discuss the nature of health research. The topics of the other witness sessions were chosen solely at the behest of the jurors. The first session focused on research and witnesses were a professor in public health and a member of the NHS patient involvement organization 'INVOLVE'. These witnesses discussed the characteristics and breadth of health research as well as how members of the public can influence and be involved in research. Thereafter, jurors commented that they felt more comfortable with the task, and debated whether their final report should contain broad research areas of interest rather than specific research questions.

In subsequent sessions the jury went on to break down the question still further, for instance by discussing the remit of primary health care and the meaning of social care when a director of public health and a director of social services were invited as witnesses. However, achieving clarity still took some time:

Not being much of an academic it took me a while to catch on, I am not saying that the explanation should have been more simplistic it's just that I was not up to speed at first, spending time on it made the need for the citizens' panel [jury] more apparent. (Juror 14)

As the jurors' understanding of the nature of research developed over the course of the sessions, the relationship between research and eventual service provision became clearer and formed a basis for the final conclusions of the jury. The journey taken to achieve clarity is perhaps an important part of the jury process, as the jurors' own work at achieving clarity themselves serves to avoid the imposition of top-down definitions.

### **Degree of involvement**

There are several frameworks for analysing the involvement of members of the public in health research. For instance, the degree of involvement can be conceptualized using Arnstein's classic 'ladder of participation'. At the lowest end of the ladder is non-participation, and moving upwards are consultation, partnership, delegated power and finally citizen control.<sup>8</sup> The latter entail higher levels of public involvement and citizens' juries can be conceptualized as sitting at the upper end of the ladder. The ideas underlying Arnstein's ladder have been developed in other ways. For instance, Rowe and Frewer suggest that engagement is best understood according to the flow of information between 'participants and sponsors'.<sup>9</sup> They argue that public communication entails a flow of information from the sponsor to the public, that consultation entails a flow from the public to the sponsor, but that within 'public participation' there is dialogue between the two parties.

An alternative way of framing involvement is to focus on the relationship between science (in this case health research) and citizenship. Irwin outlines two existing models through which this relationship may be understood: the social research model and the deliberative democracy model.<sup>4</sup> In the former, researchers are involved in collecting and distilling public views for consumption by policy makers. In the deliberative democracy model, members of the public are more active in the consultation process. Irwin adds a third model to these existing approaches: the 'qualitative and localized' model, which sees

public views as dynamic and discursive. Irwin suggests that this third model provides space for uncertainty, changes in views and lack of consensus. It has been suggested elsewhere this fluidity can be a feature of public views on scientific issues.<sup>14</sup>

Citizens' juries would therefore seem well placed to fulfil the imperative to involve the public in health research in ways that include high levels of involvement and dialogue. For instance, decisions made in citizens' juries are based on consensus, but do not have to be those of the majority; and the presence of facilitators and planning teams is designed to smooth the process. Hence, although citizens' juries are usually framed as entailing a high degree of involvement and as adhering to the principles of deliberative democracy, there is space for their findings to contain representations of disagreement and therefore uncertainty. However, citizens' juries are less able to incorporate changes in views as the production of a report for dissemination to policy makers and other appropriate audiences implies that the findings are 'final' and not amenable to change beyond the date of the report's production.

Although citizens' juries contain deliberation and jurors have a degree of control over the content of the jury sessions, the structure of the jury process is usually pre-defined and stipulated by the planning team. In Bristol, the citizens' jury planning team sought advice from others with experience of running juries, and the number of meetings was determined by the planning team rather than by members of the public. The pre-definition of the jury structure made it easier to plan, budget for and coordinate the jury. It also meant that jurors knew what to expect of the process, for instance that there would be a total of 11 sessions and that there would be facilitated discussion and witness presentations. However, as jurors had no control over the structure that the process took, it could be argued that citizens' juries do not entirely delegate power or control to the public. While this may make it easier to run juries, it is important to remember that control by the jurors may only be partial.

Furthermore, advice on running juries is varied, and some advocates suggest that the jurors may define their own topic or question.<sup>26</sup> In practice this is less common, and many juries work with pre-defined questions or topic areas. This is usually because funders or sponsors are interested in commissioning juries to address specific issues that match their own remits. In Bristol, because the jury took place under the auspices of the PCT, the jury was essentially commissioned to address health service-related research issues. In this way it is normally the case that members of the public do not control the overarching topic that a jury will address and is important that this is clearly reflected in any representations of citizens' juries.

### **The importance of context and structure**

Evaluation of public involvement has highlighted the importance of the context in which it takes place.<sup>11</sup> Context not only defines the agenda that a jury might play to, but also affects the impact that a jury's findings might have. The Bristol Citizen's Jury project was initiated by facilitators of an NHS Research and Development programme entitled 'Improving the Patient Experience' which was part of a PCT initiative. As the programme facilitators began to explore ways to involve community members in defining research priorities, the citizens' jury method emerged as a means of involving members of the community who were not necessarily already engaged with existing patient or special interest groups. Funding was secured primarily from the Medical Research Council's Health Service Research Collaboration with support from Bristol PCT, and the former became the base for the project and its planning team.

Early on in the Bristol Citizens' Jury it appeared that there would be the potential for the PCT to fund research into some of the priority areas identified by the jury. However, during the lifespan of the jury, research funding began to operate on a regional, rather than local, basis. This was made known mid-way through the jury process, presenting some difficulties and tension. Jurors were concerned about

this and the extent to which their findings would influence policy:

I was a bit confused because at first I understood the PCT had money to spend and then later it transpired that it had to apply to various bodies to get the money. If by doing this it has helped in the bidding process then that's good but I wonder if our questions will be good enough for research applications. (Juror 9)

From the outset, the Bristol planning team were aware that it was important to work out how the jury's recommendations might be taken forward into practice. Establishing structures to ensure dissemination and continued involvement of jurors proved to be an important part in the organization of a citizens' jury and in Bristol a steering group was formed following the launch of the report. Although the Bristol jury was a one-off means of involving members of the public, linking it to other longer-term public involvement initiatives helps to ensure continuity.

### **Do juries engage communities or individuals?**

Most citizens' juries attempt to involve people from diverse sections of the community. Although some advocate the use of principles in order to achieve representative sampling,<sup>27</sup> this can run the risk of excluding underrepresented voices. Other juries advocate direct mailing using the electoral roll alongside the targeting of community groups.<sup>26</sup> However, it is recognized that this approach is imperfect, not least as not all members of the community are registered to vote or respond to cold calling approaches. In Bristol, the Bristol City Council's Citizens' Panel provided a streamlined approach to sampling that promised to identify a variety of jurors. Through the Bristol City Council's Citizens' Panel disproportionate stratified sampling was used, and out of 20 jurors who initially took part, 16 jurors regularly attended the sessions. Although it might be reasonable to assume that members of the citizens' panel are those with a particular interest in community issues, to ensure that the jury's composition was not biased in favour of those with a particular

interest in health or social care, the Bristol jurors were not told about the topic of the jury until they came to the first jury session.

It was not intended that the Bristol jury would be a representative sample of citizens, although jurors were recruited with a view to maximum diversity. However, participation of jurors required considerable commitment, and despite the provision of travel costs and an accessible location it is possible that costs such as time, accessibility, availability of childcare and similar issues present barriers to participation, at least in the first instance.

### **Is deliberation ever possible?**

Although citizens' juries provide a structured way of involving the public in research, questions remain about the extent to which the process is truly democratic. Citizens' juries are based on the principle of deliberative democracy, an idea that emphasizes reasoned, informed discussion. In their analysis of NICE citizens' council meetings, Davies *et al.* questioned the role of deliberation, arguing that true deliberation was rare and that emotional engagement fostered rather than hindered participation.<sup>11</sup> Others have highlighted the power relations that can take place within participatory projects, identifying symbolic power as self-perpetuating. Such agencies or individuals who have power at the early stages of a project are likely to still hold that power as the project progresses.<sup>28</sup> Both of these issues resonate with the experience of the Bristol jury.

Emotional engagement stemmed in part from jurors' abilities to share experiences, and their belief that the process might benefit others. Reflecting on their reasons for taking part in the jury, jurors described their desire to contribute, for instance, citing their desire to 'do something to help my fellow citizens' (Juror 1), to 'improve the city' (Juror 12) and 'duty' (Juror 8). However, this was not the only root of emotional engagement as it was also clear that when witnesses' evidence was seen as locally relevant, shocking or compelling, it provoked a greater degree of engagement and thereby bolstered the

case for research in the area of their particular expertise. For instance, in the third witness session, a public health specialist provided data showing health disparities according to area of residence in the local area and prefaced her talk with mention of the importance of this information to her as a local resident. The material that she presented resonated with the jurors who were visibly shocked by the disparities in their home city, to which they could relate in their everyday lives.

Complicating this is the fact that although citizens' juries attempt to provide the space for jurors and witnesses to recount personal experience, power imbalances were evident in the discursive process, and jurors expressed some frustration when the personal presentation style of certain jurors did not match with their own expectations of appropriateness, for instance if a juror took some time to reach a point. It was also evident that some jurors were particularly able to express their views cogently, and these views may have been accorded more weight. For instance on the feedback form one juror wrote: 'Posh articulate got more attention' (Juror 11). Furthermore, it is likely that the content and impact of personal accounts is influenced by the environment in which they are recounted. In the Bristol jury, personal narratives, both from jurors and witnesses, were taken seriously. However, striking the balance between the provision of space for personal narratives and translating them into broader priorities for research was not straightforward and the ability of the final report to represent minority voices was important.

### Confidence and knowledge production

The principle of deliberative democracy relies on the idea that jurors gain sufficient knowledge and expertise to reach informed conclusions. A jury's ability to do this rests on confidence in their ability to do so which in part relates to the question that the jury is posed in the first instance. In a jury working towards priority setting for health care, Lenaghan *et al.* show how broader, open ended questions can present particular challenges for jurors.<sup>29</sup> In the Bristol

jury, in response to the feedback questionnaire, several jurors highlighted difficulty with the breadth of the question:

The question seemed too broad – it also took some thought to be clear about what the question actually was! (Juror 10)

Jurors' difficulty with the question parallels difficulties reported elsewhere when members of the public are encouraged to deliberate and express views on complex issues. It is of course well acknowledged that members of the public are perfectly able to grasp and pass judgement on complex scientific issues, but the public are equally able to acknowledge the limits of their knowledge and their uncertainty.<sup>14</sup>

In addition, early decisions about the topics to be addressed appeared to influence the ultimate outcome in the Bristol jury. The topics identified in the introductory session and therefore addressed in subsequent sessions mapped onto the final priorities outlined in the report. Unlike in other studies about health-care priority setting which show clear shifts in priorities as deliberation progressed,<sup>30</sup> the process of deliberation over many weeks in the Bristol jury did not lead to any changes in the basic areas of interest once topics and witnesses had been identified. In part this could be that such a broad ranging initial question meant that jurors felt compelled to identify key areas in order to make the process manageable, but it could also reflect the efficiency of deliberation in the first all-day jury session. We did not collect information about jurors' priorities prior to attending the jury sessions, and so it is hard to reflect on changes that took place as a result of deliberation in the first session. In their recommendations, the jurors emphasized a public health research agenda and specifically the need to address questions on prevention and inequalities.<sup>31</sup> It is difficult to judge how far this reflected the persuasiveness of the witness presentations in these topic areas or the receptiveness of the jurors due to their existing knowledge, values and experiences.

The Bristol Citizens' Jury identified a number of key areas for research, but those areas that

were not raised in the initial sessions did not feature. Although in itself not a problem, should the report form the basis of research funding, then research commissioners and funders run the risk of excluding areas of research because the jury did not identify them as priorities. The presentation of research areas according to level of agreement (unanimous, majority, equally divided, minority) in the final report has the potential to help funders and commissioners evaluate the jury's findings and weight the questions identified by the jury. This method of presentation also means that minority views *within* the jury are included in the final outcome, although there remains the danger that these views might be neglected by users of the report.

### Constraints of time and costs

Any public involvement process entails financial and time costs. Although members of the public should be compensated for their involvement, the commitment required may present barriers to individual participation, or mean that only those people who are able to overcome any barriers can take part. Furthermore, early stages of research are often devoid of funding,<sup>15</sup> and finding the resources to involve members of the public at pre-commissioning stages can be difficult. Striking a balance between appropriate duration of commitment and having enough time to produce recommendations can be a challenge.

In Bristol it was clear that the dedication, time and energy required of jurors to run a successful jury process was considerable. The financial cost of running the Bristol Citizen's Jury was not greatly dissimilar from those cited elsewhere,<sup>2,32</sup> but it is worth noting that later follow-up stages of dissemination and continuation may also suffer if funding is inadequate, uncertain or time-limited.

### Achieving 'success'?

The success of a jury's work might be assessed in terms of its ability to produce recommendations for research and in terms of the nature of the decision-making process which led to these final

recommendations. Rowe and Frewer describe nine criteria for assessing the success of a participation exercise: representativeness, independence, early involvement, influence, transparency, resource accessibility, task definition, structured decision-making and cost-effectiveness.<sup>9,16</sup> Eight of the nine criteria relate to the processes of the exercise, and only 'influence' relates to the impact that the exercise has on policy. For the Bristol jurors, this element was overwhelmingly important to them, as they expressed their concerns that their input would have some impact on research commissioning.

The potential that a jury's recommendations are not acted upon is a risk taken by many juries, but the damage wrought by failure to progress a jury's findings can be significant. As Pickard has pointed out, failure to act upon a jury's findings renders the process 'deeply disempowering'.<sup>17</sup> In the context of agenda setting it is important to ask what impact user involvement has had on the commissioning process.

Although it remains to be seen to what extent the Bristol jury's findings influence research commissioning on a broad scale, individually, many jurors felt encouraged to continue their participation in agenda setting, which a number did. For example, one juror went on to become a member of the Southwest regional funding committee for the NHS 'Research for Patient Benefit' Programme. The jurors' knowledge about the research process as well as their personal experiences as members of the community means that the jurors have the potential to act as a pool of expertise for future research and research planning.

### Conclusions

Citizens' juries have become a key means of involving the public in policy making. However, until now juries have not featured in the drive to involve members of the public in setting research agendas. There are considerable challenges to the process, and juries are imperfect means of ensuring democracy, representation and influence. However, the structure that the jury process provides acts as a useful framework, which



has meaning to jurors and which can produce recommendations that can be disseminated in a form that is accessible to researchers and research commissioners.

The citizens' jury process enables members of the public to develop a deep engagement with the topic in question. In Bristol, this engagement manifested itself in commitment to the process and continued interest in research. It seems possible that jurors' engagement is not solely a result of calm deliberation and negotiation, but is also connected with their belief in the ability of the jury to shape future research and concern about the relevance of the issues under discussion. The future of research may only become important if emotional and moral issues are at stake. The dogma surrounding consumer involvement stresses the value of continued, repeated engagement, and this may certainly be easiest within a structured process such as the citizen's jury. However, this process can engender tensions as well as harmony, and we would suggest that these two opposing emotions are a crucial part of deliberation and are perhaps a more realistic way of characterizing true deliberative democracy than a model based on the notion of rational, calculating consumers.

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