

# Rights or rituals? Why juries can do more harm than good

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## Introduction

Citizens' juries have been developed in both Europe and the USA as a means to improving public involvement in policy decision-making, particularly in the area of local government. While citizens' juries are only one of many inputs into the policy-making process, they may, through confidence building, encourage more active citizenship. For some, the great strength of citizens' juries is the opportunity they provide for informed deliberation. However, a closer look at a citizen jury in action in Wales (UK) suggests that this may be overstating the case.

## The Welsh citizens' jury

The Welsh Citizens' Jury, organised by the Welsh Institute for Health and Social Care, was held in Cardiff in November 1997 and addressed the following question:

*'What conditions should be fulfilled before genetic testing for people susceptible to common diseases becomes available on the National Health Service (NHS)?'*

This was an attempt to extend and develop the jury model in a number of ways. First, its members were chosen to represent a much larger population, the Principality of Wales, than had been the case on previous occasions in the UK, when they were selected from the local authority or similar constituencies. Second, the commissioning body was a large transnational pharmaceutical corporation which had given no commitment to act on any recommendations the jury may provide, but which had commercial interests in the area. Instead, a list of detailed recommendations was submitted by the jurors in person to the Advisory Commission on Human Genetics in London. Third, the focus on genetic testing required the jury to be briefed on the medical, scientific and technical background of genetic testing, in addition to the structure of the NHS and the mechanics of jury procedure. However, both the objectivity of this process and how it may have interacted with the resources brought to it by individual jurors, are open to question. The following offer important lessons.

- *The role of 'local' knowledge.* One of the key issues which is said to underpin the democratising credentials of the citizens' jury approach to decision-making is the input from lay members of the public. The proponents of the process in the policy arena see the jurors themselves as providing the lay input when they evaluate the 'evidence' in arriving at their recommendations. But, there is also a growing recognition that the knowledge brought to the process by the jurors themselves cannot be overlooked. Any juror, when faced with expert opinion, does not evaluate the knowledge claims in isolation from his or her experiences and perceptions. Arriving at a set of recommendations may constitute more a process of renegotiation of knowledge claims than a competent or incompetent evaluation of expertise as implied by the concept of 'judging the evidence'. Little or nothing was known, for example, about the resources brought to the Welsh Citizens' Jury by the jurors themselves, except when they chose to share these with each other during the event.
- *Terms of engagement and framing.* There is a danger of ignoring the power of experts to set agendas, define boundaries of discourse and impose assessments of risks and hazards. One important element in the terms of the engagement process centres on the 'gate-keeping' role of the Steering Committee in deciding what preliminary information is made available to jurors. The kind of background information used to provide the lay members with a balanced account of the scientific and technical knowledge needed to discuss the topic is very important. Much of this is written by actors in the public debate and it is normally impractical to include all aspects of an issue. Selection by interested parties is inevitable. This is particularly so with the selection of witnesses by the Steering Committee in Wales, which singularly omitted to provide any witness from an ethnic minority (for example sufferers from thalassaemia<sup>1</sup>), or those opposed to genetic testing.
- *Pseudo-expertise.* The jury was often presented with pseudo-scientific speculation rather than evidence-based

<sup>1</sup> A specific single gene inherited disorder to which some ethnic groups are particularly susceptible.

knowledge so that the 'halo' effect of certain kinds of expertise can be seen to justify a wide range of responses to jurors' questions, many of which lie well outside the witness's areas of specialisation. In the Welsh case, one medical expert often gave opinions (for example about the organisation of the NHS) far removed from his specialisation of paediatric medicine. While legitimately based upon his personal experience of hospital and NHS Trust work, they did not reflect the primary reason for his participation. In the Welsh Citizens' Jury, it was also clear that the scientific and medical witnesses downplayed the role of human agency in the production of knowledge, presenting scientific 'facts' in abstraction from the socio-political context of their creation.

- *The jury and 'rituals of precision'*. The experience in Wales suggests that transposing the jury model from the courts may only serve to highlight the jury's ritual and symbolic nature. 'Rituals of precision' contribute to the legitimisation process. In particular, these concern the emphasis on procedures; the segregation of the jury from witnesses and public, the interrogation of witnesses, the serving of a subpoena on new witnesses, the use of expert evidence, the process of decision-making about a verdict, and delivering the outcome and any subsequent action. These, along with other similarities between legal and citizens' juries, provide the necessary *ritual* elements in establishing the legitimacy of the outcomes, be they legal verdicts or political decisions. In the Citizens' Jury in Wales, most of these procedures inadequately mimicked those found in a court of law. The jury members often lunched with witnesses and were able, when going out for a break between sessions, to interact with observers. Witnesses were asked to make a presentation before answering questions, rather than being closely interrogated about specific issues. The jury did wish to see witnesses who had not been asked to attend by the Steering Committee (particularly a representative of any major religious denomination), but for practical, organisational reasons, were unsuccessful in their attempt. Experts were called but some were accorded greater status than others and one was asked to both introduce and conclude the event. The moderator orchestrated the discussions of the jury to encourage a high degree of consensus about the outcome. The Recommendations were drafted by the organisers, based upon the jury members' discussions and published after their agreement as to wording. The sponsors, while known to all the participants, must be seen to stand aside from the process until the end, when they agree to act on the Recommendations. This at least has the symbolic effect of being 'sentenced'. Unfortunately, in the Welsh case, the sponsors had not entered into any such undertaking prior to the event, and were therefore not bound by the jury's recommendations.
- *Representation and typicality*. A market research organisation was employed to choose the Welsh jury in an attempt to ensure the necessary independence from the sponsors and organisers required to establish the integrity of the process. It developed a multi-stage methodology which could be considered fairly robust in principle. However, it transpired that only one juror had experienced post-18 full-time education, seven had left school at the minimum age, relatively few claimed to be in full-time employment, none wished to be considered as native Welsh speakers, one was a Welsh resident but not a British citizen and none appeared to come from the many, well-established ethnic minority groups. As a result, it was never likely that the Welsh jury would be representative of the Welsh nation, even in some very loose sense of typicality, thereby largely eroding one of its key democratising principles.
- *Representation and difference*. One key aspect of representation which appears to be missing from discussions of the development and application of the jury process is the need to give weight to gender, disability and ethnicity. Women's experiential understandings of the issues are particularly heightened in relation to the new genetics, since many of its applications relate to genetic testing and the reproductive process. Similar comparisons can also be made with disability, whether impairment stems from illness, accident or genetic inheritance, and the two come together in the increasing tendency to terminate pregnancy on the grounds of foetal handicap. Ethnic minorities with specific single gene inherited disorders such as thalassaemia or sickle cell anaemia are also very much more focused on the issues. The Welsh jury, while able to bring some of these resources to their deliberations, only briefly addressed these issues, suggesting that the importance of 'representation' in this case may be more symbolic than real.

Together, these shortcomings may have contributed to reducing the value of the Welsh jury approach to involving the public in the decision-making process. In more general terms, wider issues, such as the role of the jury as an additional constituency in a pluralistic, decision-making process of health policy formulation appears not to have been given sufficient thought.

Key actors may establish juries as part of a sophisticated public relations exercise. User involvement becomes a *technology of legitimation*. It can also become a token in the armoury of more powerful champions (in this case the National Health Service or the multinational pharmaceutical company) translated as 'playing the user card'. This suggests that an important role for juries may be educational and consultative rather than the promotion of active citizenship.

Also, through its symbolic tokenism and rituals of precision, the jury approach appears to sit rather too comfortably within the relations of production that exist between government regulatory authorities, multinational pharmaceutical and biotech companies and the health services, while giving the appearance of developing a critical challenging perspective. The case study of the Welsh citizens' jury raises important questions of social control disguised as democratic emancipation.

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### Further reading

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