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The use of citizens' juries in health policy decision-making: A systematic review



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ABSTRACT

Deliberative inclusive approaches, such as citizen juries, have been used to engage citizens on a range of issues in health care and public health. Researchers engaging with the public to inform policy and practice have adapted the citizen jury method in a variety of ways. The nature and impact of these adaptations has not been evaluated.

We systematically searched Medline (PubMED), CINAHL and Scopus databases to identify deliberative inclusive methods, particularly citizens' juries and their adaptations, deployed in health research. Identified studies were evaluated focussing on principles associated with deliberative democracy: inclusivity, deliberation and active citizenship. We examined overall process, recruitment, evidence presentation, documentation and outputs in empirical studies, and the relationship of these elements to theoretical explications of deliberative inclusive methods.

The search yielded 37 papers describing 66 citizens' juries. The review demonstrated that the citizens' jury model has been extensively adapted. Inclusivity has been operationalised with sampling strategies that aim to recruit representative juries, although these efforts have produced mixed results. Deliberation has been supported through use of steering committees and facilitators to promote fair interaction between jurors. Many juries were shorter duration than originally recommended, limiting opportunity for constructive dialogue. With respect to citizenship, few juries' rulings were considered by decision-making bodies thereby limiting transfer into policy and practice.

Constraints in public policy process may preclude use of the 'ideal' citizens' jury with potential loss of an effective method for informed community engagement. Adapted citizens' jury models provide an alternative: however, this review demonstrates that special attention should be paid to recruitment, independent oversight, jury duration and moderation.

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1. Background

Deliberative inclusive approaches, as a vehicle for citizen engagement, have particular appeal both because of the fiscal importance of health policy and because health matters touch the lives of citizens very personally. Such approaches aim to bring together diverse citizens, supported by a range of resources, to discuss issues of public concern (Davies et al., 2006, p.4). Some deliberative inclusive approaches methods have been well described in the theoretical literature including citizens' juries (Parkinson, 2004; Pickard, 1998; Smith and Wales, 2000),

consensus conferences (Dryzek and Tucker, 2008; Hendriks, 2005), planning cells (Hendriks, 2005) and deliberative polling (Fishkin, 1991). Others, such as World Cafe (Brown, 2001), remain primarily outside academic peer-review and critique. Some deliberative methodologists advocate combining methods in order that "the weaknesses of one would be overcome by the strengths of another" (Carson and Hartz-Karp, 2005, p.121), while others argue that their application, as originally described, is unworkable in real-world settings (Pickard, 1998).

Citizens' juries, in particular, have undergone a process of evolution and adaptation. Developed in the 1970s, the term is a registered trademark of the Jefferson Centre (2004, p10) purportedly to "preserve the integrity of the process". The Centre has described, essential characteristics of a citizens' jury and, within the USA, the term has been tightly regulated. Elsewhere, it has been used much less precisely, as researchers have variously adapted the

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citizens' jury approach. However, the nature and impact of these changes has not been documented.

Citizens' juries offer a useful tool for engaging citizens in health policy decision-making: they are small enough to permit effective deliberation, relatively inexpensive compared to the larger deliberative exercises of planning cells and consensus conferences, yet sufficiently diverse that the citizens engaged are exposed to a broad range of public experience and perspectives. In this paper, we review use of citizens' juries for community engagement in health research, focussing on methodological aspects. We have taken an interpretation of citizens' juries that accepts that the term is now used more loosely and covers a broader array of activities than originally described. We examine ways in which researchers have adapted the citizens' jury model and explore the fit between these methodological adaptations of the historic citizens' jury and principles associated with deliberative democracy: inclusivity, deliberation and active citizenship. In this comparison, we draw on the conceptualisation of these principles described by Smith and Wales (2000).

2. Methodology

2.1. Sources

Published documents identifying studies under the broad heading of deliberative inclusive methods in health-related areas, including health care and services, were sourced for the years 1995–2010. The choice of the year 1995 reflects the onset of health authorities' and researchers' use of deliberative processes for citizen engagement on health issues (Abelson et al., 2003; Parkinson, 2004). Databases, Medline (PubMED), CINAHL and Scopus, were selected for their coverage of health-oriented research, as well as political and social science materials.

2.2. Search strategy development

Searches were carried out by one researcher (SK) based on criteria developed by all authors (Table 1). Search terms were selected to identify deliberative inclusive methods deployed in health research. Terms centred on public participation, as opposed to expert discussion, with the term, citizen, and its synonyms included. Terms related to deliberative processes were included, specifically names given to variations of deliberative methods (Abelson et al., 2003). The final search strategy was revised with the assistance of a research librarian. The full search is provided online (Appendix 1).

2.3. Article screening and criteria

Relevant search results (Fig. 1) were combined in a citations database. Abstracts were scanned by one author (SK) using Table 1

Table 1Criteria used to select material for analysis.

Inclusion criteria:

- English language
- Article describes use of a deliberative forum (e.g. citizen jury, citizen panel, planning cell, consensus conference)which aimed for deliberation, inclusivity and influence in policy or practice
- Forum was applied to topics, activities or projects that impacted on public health, health care and health services
- Participants were lay citizens OR lay citizens were included in the deliberative forum

Exclusion criteria:

- Insufficient detail provided to gauge nature of the forum
- · Forums not explicitly addressing a health issue

as a selection guide. Full-text review of selected articles was performed by two research assistants. A deliberative inclusive method was identified as being a citizens' jury if it contained all or most of the elements of the citizens' jury model (Coote and Lenaghan, 1997; Smith and Wales, 2000; The Jefferson Center, 2004). Specifically, a jury was characterised by: 12–25 participants selected to reflect the community and acting as independent citizens rather than experts or representatives; a charge or research question(s) provided by organisers; deliberation informed by evidence provided by expert witnesses and a verdict delivered by jurors. Studies not meeting this description were excluded. In this paper, we use the term 'jury' to describe any deliberative forum conducted in the style of a citizens' jury.

Articles lacking methods description were excluded since informed comment could not be made on the nature of the jury. This followed cursory inspection of the article, its references and a Google search for relevant grey literature.

2.4. Analysis

Data were managed with a Microsoft Access database using a framework comprising eight domains (Table 2).

The jury research questions were classified into categories (Table 3). Where questions addressed more than one category, the primary category (as assessed by the authors), was selected.

Analysis was informed by the description of citizen juries by Smith and Wales (2000). This framework was chosen for its focus on how key tenets of deliberative democracy, namely inclusivity. deliberation and active citizenship, play out in the implementation of the citizens' jury model. Smith and Wales describe how citizens' juries approximate the inclusivity ideal "by aiming for a broadly representative jury selection" (Smith and Wales, 2000, p.56) where inclusivity describes participation of "all citizens' in public dialogue", with all viewpoints given "equal right to be heard" (Smith and Wales, 2000, p.53). Furthermore, citizens' juries have implemented deliberation by establishing "rules of conduct" between jurors (Smith and Wales, 2000, p.58), with this tenet described as discussion that "encourages mutual recognition and respect and is orientated towards the public negotiation of the common good" (Smith and Wales, 2000, p.53). Citizens' juries have advanced an active value of citizenship by encouraging citizen participation in decision-making processes. Realisation of active citizenship may be bolstered by good facilitation and pre-jury contracts binding commissioning organisations respond to to iurv recommendations (Smith and Wales, 2000, p.60). Attention to fulfilling the tenets of inclusivity and "egalitarian, uncoerced, competent" deliberation "free from delusion, deception, power and strategy" permits the practice of active citizenship where individuals can engage with the diverse "knowledge, experience and capabilities" of others (Smith and Wales, 2000, p.53-54). Such engagement "has the potential to transform the values and preferences of citizens in response to encounters with others" (Smith and Wales, 2000, p.54).

We thus examined overall process, recruitment, evidence presentation, documentation and outputs (e.g. reports), to explore the relationship between deliberative democratic tenets, as described by Smith and Wales, and the practice of citizens' juries in health research.

In particular, we wished to know where and how the citizens' jury model has been adapted to meet the needs or restrictions of a research or policy context and how such methodological changes have impacted on the outcome. The word 'outcome' describes the findings or verdict of the jury, reached by consensus or vote, including any record of dissent and underlying reasons for the

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