Social Science & Medicine 135 (2015) 84–91

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Power relations and contrasting conceptions of evidence in patient-involvement processes used to inform health funding decisions in Australia

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ARTICLE INFO

Article history:
Available online 23 April 2015

Keywords:
Participation
Power relations
Patient organisations
Health policy
Health Technology Assessment
Patient and public involvement
Health funding
Australia

ABSTRACT

We collected and analysed views of key stakeholders on the processes used to involve patient organisations in health care funding decision making in Australia. We conducted 12 semi-structured interviews with patient organisation representatives and members of Advisory Committees that provide advice to the Australian Department of Health and employ Health Technology Assessment (HTA) as an evaluation framework. Using two theoretical frameworks, we analysed structural and contextual elements pertaining to the involvement processes. The findings reported in this article relate to interviewees' perspectives on contextual elements, analysed using a Foucauldian lens. These elements include: the perspectives of marginalised voices; the diversity of views on what ought to be considered valid evidence in a HTA setting; and the relationships between stakeholders, along with how these relationships impact on involvement processes and the outcomes of those processes. The findings demonstrate that the involvement processes currently used are deemed inadequate by both patient organisation representatives and Advisory Committee members, but for different reasons connected to how different stakeholders conceptualise evidence. Advisory Committee members viewed evidence as encompassing clinical outcomes and patient preferences, whereas patient organisation representatives tended to view evidence as encompassing aspects not directly related to a disease entity, such as the social and emotional aspects of patients' experiences in living with illness. Patient organisation representatives reported interacting with other stakeholders (especially industry) to increase the influence of their conception of evidence on decision making. The use of this strategy by interviewees illustrates how power struggles occur in government decision-making processes which involve both medical expertise and patients' accounts. Such struggles, and the power differentials they reflect, need to be considered by those responsible for designing and implementing meaningful public- and patient-involvement processes.

1. Introduction

Public participation is a long-standing field of study in philosophy, law and other areas (Freeman, 2000; Hindess, 1997; Sanders, 1997). Currently, there are numerous involvement processes being used by Western countries in various areas of public policy, with little consistency in their methods, objectives and patterns of implementation (Baggott, 2005; Stewart, 2013). Some attempts have been made to develop frameworks to categorise and evaluate such processes (Abelson et al., 2003; Barnes, 1999; Jabbar and Abelson, 2011; OECD, 2001; Oliver et al., 2001; Rowe and Frewer, 2000, 2005; Rowe et al., 2004). However, to date, there is still little consensus on optimal methods for involving citizens in government decision making.

In the health sector, increased public and patient involvement in decision making has been promoted since the late 1970s by institutions such as the World Health Organisation (WHO, 1978, 1986). Proponents of public and patient involvement argue that patients can provide important information about values, attitudes and expectations related to the use of medicines, procedures and technologies to be introduced into a health system (Barham, 2011; Facey et al., 2010; Milewa et al., 2002). However, engaging patients

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http://dx.doi.org/10.1016/j.socscimed.2015.04.021
0277-9536/

in decision-making processes remains controversial, partly because the health sector is seen as one in which professional expertise is essential when considering the complex issues inherent in policy development (Hunter, 1995; Prior, 2003; Salter, 2003). In addition, concerns have been raised, by some researchers and decision makers, about patients' ability to contribute useful evidence to health policy, particularly in areas of resource allocation and priority setting (Royce, 1995; Stronks et al., 1997).

The choice of language in referring to patients (also called ‘consumers’ or ‘service users’) reveals ideological assumptions concerning the role they are expected to play in the health sector (Thompson, 2007). ‘Consumers’ or ‘service users’, in connection with a consumerist approach to health care, are conceptualised as making rational and self-interested choices about their treatments and holding power equal to those working within and managing the health system (Dugay and Salaman, 1992). A different approach considers patients as potentially vulnerable, and possibly less powerful because of a lack of competence (e.g. in technical knowledge), a reduced capacity to engage (being blunted by illness) and because of differences in cultural capital between provider and patient (e.g. the prestige of holding an important job) (Sen, 1992).

Nonetheless, patients can still be regarded as key stakeholders with the right to participate in policy decisions that will affect them, thus commending decision-making processes that are inclusive and democratic (Wait and Nolte, 2006). In this study, we deliberately use the term ‘patient’ to emphasise the potential power differentials between patients and health funding decision makers. However, in our analysis, when interviewees mention the ‘consumer’ or the name of a position including this term, we have retained the original expression.

This article reports findings of a research project that explored the views of patient organisation representatives and members of Advisory Committees providing advice to the Australian Department of Health (DoH) on decisions related to public funding for new health technologies. The two Advisory Committees that we chose to examine act as intermediaries between DoH and a range of other stakeholders, including patients, the public, government officials, pharmaceutical companies, medical associations, and clinicians. They also use Health Technology Assessment (HTA) as an evaluation framework. In HTA, information about health technologies (including pharmaceuticals, medical devices and procedures) is collected and evaluated systematically with regard to the safety, effectiveness and cost-effectiveness of the technology, and sometimes with consideration of broader organisational, ethical, legal and social issues (Facey, 2014; HTAi, 2014). The Advisory Committees that we selected use three main public- and patient-involvement processes: online consultations; consumer representatives sitting on the Committees; and consumer impact assessments. The latter are documents via which patients, carers and patient family members can provide information about a health condition. We examined perceptions related to structural and contextual aspects of these three involvement processes and perceptions as to whether these aspects facilitate or hinder patient participation.

2. Methods

We adopted qualitative research methods (Patton, 2002) guided by two theoretical frameworks: one to provide a set of criteria to analyse the structure of involvement processes and another to analyse contextual factors and include marginalised voices. Framework 1 was derived from Rowe and Frewer's article (2000) and Framework 2 was based on works by Michel Foucault (1972, 1982, 1989, 1997, 2000, 2001) and Foucault and Gordon (1980). We used a maximum variation (heterogeneity) purposive sampling strategy (Patton, 2002) to select key informants. This recruitment strategy permits the capture of perspectives that “cut across a great deal of variation” (Patton, 2002, p. 283). Based on Framework 1, we selected as research participants present or past Advisory Committee chairs and consumer representatives, and some patient organisation representatives, whereas Framework 2 supported the selection of participants who could be considered marginalised voices, particularly advocates from patient organisations not represented in the involvement processes (for the sampling framework, see Table 1). Ethical approval for this research project was obtained from the Human Research Ethics Committee at the University of Adelaide (project nº H-2012-167). The use of two different methodologies to inform the recruitment and analyse the data (Patton, 2002) acted as a form of triangulation (further information can be found in Appendix A. Supplementary data).

2.1. Recruitment and data collection

Advisory Committee members identified health technologies that had received substantial public comment and this information was used to identify patient organisations related to particular conditions or diseases. Organisations were selected using the sampling criteria (Table 1). Interviewees indicated that umbrella patient organisations are important stakeholders in involvement processes conducted by the Advisory Committees. (Umbrella patient organisations do not represent patients with a particular condition or disease but rather patient organisations more broadly.) Two umbrella organisations were thus included in the sampling framework (Table 1). A total of 17 individuals were contacted; 13 accepted the invitation to participate and two declined. Two individuals initially accepted the invitation but were unable to be further contacted or could not schedule a time to be interviewed during the recruitment process. Twelve interviews were conducted (two interviewees from the same patient organisation were interviewed together) by telephone ($n = 10$) and face-to-face ($n = 2$) with an average duration of 51 minutes (range 38–74 minutes). Interviewees were drawn from across Australia (Australian Capital Territory, New South Wales, the Northern Territory, South Australia and Victoria) and all interviews took place in Adelaide, between February and August 2013. The names of organisations, participants and diseases are omitted to preserve interviewees' anonymity. Abbreviations describing interviewees' roles are shown in Table 1.

The interview schedule was developed by two researchers (EL and JS), pilot-tested by EL with a consumer representative, and then tailored to each type of interviewee. The interview schedule included questions based on Rowe and Frewer (2000), namely about the involvement processes' structural elements, such as the accessibility of information and process transparency, and questions based on Foucault (1972, 1982, 1989, 1997, 2000, 2001) and Foucault and Gordon (1980). The latter included questions exploring interviewees' conceptualisation of evidence, understandings of the external factors influencing process outcomes, and perceptions of changes in involvement practices over time. This article reports findings related to Framework 2 (Foucault). Findings related to Framework 1 (Rowe and Frewer) are presented elsewhere (Lopes et al., 2015).

2.2. Coding, themes and data analysis

The interviews were transcribed verbatim by an independent professional and checked for accuracy by one researcher (EL). Two interviews were separately coded using NVivo 10 by two researchers (EL and JS) with codes compared and differences discussed and resolved. Using Framework 2 as a basis, data were iteratively coded with additional relevant themes emerging. For