ELSEVIER

Available online at www.sciencedirect.com

SCIENCE DIRECT®

Health Policy 75 (2006) 280–297

Health policy

www.elsevier.com/locate/healthpol

Principles and indicators of successful consumer involvement in NHS research: Results of a Delphi study and subgroup analysis

Jonathan Boote[a,*], Rosemary Barber[b,c], Cindy Cooper[c]

[a] Sheffield Health and Social Research Consortium, Fulwood House, Old Fulwood Road, Sheffield, S10 3TH, UK
[b] Sheffield Care Trust, UK
[c] School of Health and Related Research, University of Sheffield, UK

Abstract

Consumer involvement in NHS research is Department of Health policy within the UK. Despite the existence of policy directives and guidance, until recently there has been no consensus among consumers and researchers about what it means to involve consumers successfully in NHS research. This paper discusses the value of consensus research in this policy area, and presents the detailed findings of a Delphi study carried out to reach consensus on principles and indicators of successful consumer involvement in NHS research. Study participants, comprising consumers, researchers and consumer–researchers, were identified using a purposive sampling strategy. Consensus was reached on eight clear and valid principles of successful consumer involvement in NHS research, with each principle having at least one clear and valid indicator. Subgroup analysis revealed few significant differences in how consumers, researchers and consumer–researchers rated the principles and indicators. The implications and limitations of the study are discussed. Further research is needed to assess: (1) the usefulness of the principles and indicators for differing models of consumer involvement, health research methodologies, and subject areas within health research; and (2) the impact of 'successful' consumer involvement on health research processes and outcomes.

Keywords: Consumer; Consumer involvement; NHS research; Consensus methods; Delphi; Principles; Indicators

1. Introduction

There is growing recognition internationally of the importance of consumer involvement in health research [1–3], and it is now United Kingdom (UK) Department of Health policy for consumers to be involved in National Health Service (NHS) research [4–6]. Current NHS guidance on research governance states, for example, that consumer involvement should exist at every stage of research where appropriate [4]. In the UK, consumers are defined as, "patients, potential patients, informal (unpaid) carers, people who use health and social services, and organisations that represent the interests of people who use health and social services, and members of the public who may be the potential recipients of health promotion plans" [7].

---

[*] Corresponding author. Tel.: +44 114 271 8804; fax: +44 114 271 6736.

E-mail address: jonathan.boote@sct.nhs.uk (J. Boote).

0168-8510/$ – see front matter © 2005 Elsevier Ireland Ltd. All rights reserved.
doi:10.1016/j.healthpol.2005.03.012

Consumer involvement in research relates to an active partnership between researchers and consumers in the research process, and has been defined as researchers doing research with consumers, rather than for, at or to them [8]. It is argued that consumers' experiential knowledge can add synergy to the traditional disease focus of health research, and can facilitate the generation of more relevant research questions and outcome measures that are grounded in the social realities of those being researched [9–12]. Consumer involvement has the potential therefore to improve both the quality and relevance of health research [13,14]. To encourage greater consumer involvement in the research process, UK government policy initiatives have been published, and guidance has been provided for researchers and consumers from the INVOLVE (formally Consumers in NHS Research) Support Unit [8,15].

A recent literature review set out a research agenda in order to encourage a more rigorous examination of the impact and associated effectiveness of consumers on research processes and outcomes [9]. It was noted in the review that, "there is no agreement on what constitutes 'successful' consumer involvement in research", and that "one avenue of research is to develop consensus on what is meant by 'successful' consumer involvement in [health] research; this would provide a basis on which to systematically assess the influence of associated success factors" [9].

A study was subsequently undertaken in the UK to examine if consensus could be achieved between researchers and consumers on what it means to involve consumers successfully in NHS research. Using two formal consensus methods—an expert workshop employing the nominal group technique, and a two-round postal Delphi process—the aim was to develop consensus-derived *principles* of successful consumer involvement in NHS research, as well as measurable *indicators* of each principle. A principle was defined as an agreed standard or marker by which it is possible to say that consumers are successfully involved in NHS research. An indicator was defined as a precise measure of a principle. This paper builds on work previously published on the developed principles and indicators [16], by presenting a statistical analysis of the findings of the Delphi panel, including a subgroup analysis. The subgroup analysis was carried out to establish whether the three key panel subgroups (consumers, researchers and consumer–researchers) differed significantly in their ratings of the principles and indicators.

1.1. Why reach a consensus?

We are assuming of course that consensus in this health policy area should be reached. Some people, especially those who see the involvement of consumers in research as a political issue that challenges the traditional dominance in research of academic and clinical professionals, may argue that it is wrong to reach a consensus, as this may dilute the power gains that consumers have been trying to achieve in the research process. Moreover, it may be that consumers and researchers have different or even conflicting ideas about what 'successful' consumer involvement in research means to them, and that consensus cannot be reached.

It is important at the outset therefore that the authors state their position in this debate. We believe that reaching consensus on what constitutes successful consumer involvement in health research should be seen as a positive step. Consensus research in this policy area provides an opportunity to gain an understanding of the degree of common ground between consumers and researchers on what constitutes good practice, and would detail the components of 'successful consumer involvement in research'. Assuming a consensus was reached, this could provide a number of benefits. Firstly, it would further assist researchers on issues of best practice relating to consumer involvement. Secondly, it would provide consumers with criteria by which to assess their 'successful' involvement in research. Thirdly, it would provide funding bodies with guidance on consumer involvement that can be incorporated into applications for funding. Finally, it would provide policy analysts with a tool to monitor the extent of 'successful' consumer involvement in research.

2. Method

Two formal consensus methods were employed: (1) an expert workshop, employing the nominal group technique to structure discussion, was held in January 2002 [17,18]; and (2) a two-round postal Delphi process was conducted between April and July 2002 [19]. The combined use of these two methods has precedents in the consumer involvement literature. For example,