Article:

Boote, J., Ward, P.R., Thompson, J. et al. (4 more authors) (2009) Critical perspectives on ‘consumer involvement’ in health research: epistemological dissonance and the know-do gap. Journal of Sociology, 46 (1). pp. 63-82. ISSN 1741-2978

https://doi.org/10.1177/1440783309351771

Journal of Sociology

Critical perspectives on 'consumer involvement' in health research: epistemological dissonance and the know-do gap.

Journal:	*Journal of Sociology*
Manuscript ID:	JOS-2008-077.R2
Manuscript Type:	Original Manuscript
Keyword:	Consumer involvement in research, Consumerism, Qualitative analysis < Data analysis, Epistemologies
Abstract:	Researchers in the area of health and social care (both in Australia and internationally) are encouraged to involve consumers throughout the research process, often on ethical, political and methodological grounds, or simply as 'good practice'. This paper presents findings from a qualitative study in the UK of researchers' experiences and views of consumer involvement in health research. Two main themes are presented in the paper. Firstly, we explore the 'know-do gap' which relates to the tensions between researchers' perceptions of the potential benefits of, and their actual practices in relation to, consumer involvement. Secondly, we focus on one of the reasons for this 'know-do gap', namely epistemological dissonance. Findings are linked to issues around consumerism in research, lay/professional knowledges, the (re)production of professional and consumer identities and the maintenance of boundaries between consumers and researchers.

Critical perspectives on ‘consumer involvement’ in health research: epistemological dissonance and the know-do gap.

Abstract

Researchers in the area of health and social care (both in Australia and internationally) are encouraged to involve consumers throughout the research process, often on ethical, political and methodological grounds, or simply as ‘good practice’. This paper presents findings from a qualitative study in the UK of researchers’ experiences and views of consumer involvement in health research. Two main themes are presented in the paper. Firstly, we explore the ‘know-do gap’ which relates to the tensions between researchers’ perceptions of the potential benefits of, and their actual practices in relation to, consumer involvement. Secondly, we focus on one of the reasons for this ‘know-do gap’, namely epistemological dissonance. Findings are linked to issues around consumerism in research, lay/professional knowledges, the (re)production of professional and consumer identities and the maintenance of boundaries between consumers and researchers.

Introduction

The emergence and rise of consumerism in late modern society is being mirrored by a similar rise in consumerism within research, with the role of the ‘consumer of research’ being defined and refined (Henderson & Peterson, 2002; Hill, 2007). Whilst there are large literatures about the role and impact of consumerism on and for medicine and the role of consumers in healthcare planning, this is not the case with respect to health research. Of critical importance for the present paper is the impact and role of consumerism on and for research, given the current push for public accountability and consumer involvement, which begins to move the consumer to centre stage. Given the empirical and theoretical research on the impact of consumerism in medicine and healthcare, questions emerge with regards to existing and future relationships between researchers and consumers and the benefits of involving consumers for research, as well as for individual consumers, researchers and for society at large. We cannot deal with all of these issues here, so this paper focuses on the current situation of consumer involvement in health research, from the perspective of health and medical researchers.

Numerous reasons for involving consumers in research have been cited in the literature, falling mainly into three categories; moral/ethical, political & methodological. The moral and ethical reasons for involving consumers in research centre on concepts of rights, citizenship and democracy, specifically related to publicly funded research whereby the word ‘consumer’ is seen as a synonym for ‘taxpayer’ (Dyer, 2004; O'Donnell & Entwistle, 2004). The political imperative is centred on current policy directives, funding and governance requirements (Department of Health 2005; NHMRC and Consumers’ Health Forum of Australia 2004). The methodological reasons focus on the potential benefits that consumer involvement may have on the research process, including increasing its relevance, credibility, dissemination and transferability of research findings (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006; Oliver, Clarke-Jones, Rees, Milne, Buchanan, Gabbay et al., 2004). For these reasons, we argue that consumers should be involved in all stages of research, although this paper is focused on the views of other health and medical researchers who may not share our view.

Despite such strong imperatives and policy directives to involve consumers in research (Department of Health 2005; NHMRC and Consumers' Health Forum of Australia 2004), recent studies (Barber, Boote, & Cooper, 2007; Telford, Beverley, Cooper, & Boote, J. 2002) have provided evidence of a gap between policy and practice that we refer to as the ‘know-do gap’ (World Health Organisation, 2005) whereby researchers are involving consumers much less than the policy makers would hope for. Whilst this provides some quantitative evidence on the prevalence of consumer involvement in research, little work has been undertaken to explore researcher perspectives on both the policy and practice of consumer involvement in health research (Telford *et al*, 2002). The present paper reports data from a qualitative study of researchers about their perceptions and experiences of consumer involvement in research. Our data focused on the nature and extent of consumer involvement in health research in the UK, and the implications for the future of the research relationship. However, we begin the paper by exploring the relationship between wider movements of consumerism and commodification within research, definitions of consumers of research and what does/might consumer involvement mean in/for research?

The nature and extent of consumerism in research

There has been a great deal of sociological writing around the rise of consumerism in general, and some specifically related to health and healthcare (Gabe & Calnan, 2000; Hibbert, Bissell, & Ward, 2002; Lupton, 1997; Shaw & Aldridge, 2003). There has been less sociological work on the rise of consumerism specific to research, although the sociological and health-related literature has explored constructions of ‘consumers’ (Cawston & Barbour, 2003 and the shifting relationships with professionals (Lupton, 1997; Scambler & Britten, 2001). Consumerism in health has led to increased calls for equal weight to be given to lay voices *vis a vis* those of health professionals. In relation to research, a similar call for consumer involvement is evident in health policy and the requirements of a number of research funding bodies, Research Ethics Committees (RECs) and research governance frameworks (Department of Health 2005).

Theories of consumption have a long history in the social sciences. Some of the earliest work in this area was Veblen's 'conspicuous consumption' (1899/1970) and Marxist conceptualizations of, and distinctions between, production and consumption. In more contemporary times, consumption has been theorised as both a form of distinction within 'consumer society' (Bourdieu, 1984) and between consumers and professionals (Campbell, 1987; Falk, 1994; Lupton, 1997). There have been arguments made about the 'commodification of the body' (Falk, 1994) and post-modern theories on consumerism (Bauman, 2001; Featherstone, 1991). These theoretical frameworks set up some important issues for researchers involved in 'consumerism in research', such as the changing relationships between the production and consumption of research, and between researchers and consumers, the nature and extent of the commodification of research (indeed, research as a commodity within a marketplace) and the shifting place or importance of research within late modern society. This latter point is particularly pertinent, given that the process and outcomes of consumerism may rest on individuals (re)producing self and identity, meaning, wellbeing and/or psychic security (Lasch, 1980) within the process of reflexive modernisation (Beck, Giddens, & Lash, 1994) – the role that research, as a consumer commodity, can play in this intersubjective process is yet to be understood.

In one sense, consumerism could be viewed as a step towards greater inclusion, empowerment and participation, notions that are believed to be intrinsically positive, emphasizing choice and consumer rights (Shaw & Aldridge, 2003). Using this definition 'consumerism' and 'citizenship' are often seen as closely linked terms. However, as has been pointed out (Aldridge, 2003), citizenship implies much more of a reciprocal relationship based on rights and responsibilities, whereas consumerism is merely concerned with rights, with one commentator (Hobsbawm, 1999) going further to suggest that consumerism constitutes a threat to citizenship. The important point to take from this, are that consumers and citizens are seen to occupy different functional roles within society, which therefore begs the question, what are the responsibilities with respect to consumer involvement in research (on the part of both the consumers and researchers)?

Whilst the role of consumers may have an overarching definition, such as “acquiring and/or using goods or services for their own benefit” (Gabe & Calnan 2000; 255), there seem to be two major ideological strands that have implications for the researcher-consumer relationship, particularly given that “the culture-ideology of consumerism is the fundamental value system that keeps the system intact” (Sklair 1998: 140). Gabe and Calnan (2000), following on from others (Edgell et al., 1996), make the case that New Right and New Left agendas both promote consumerism, although for differing reasons, and with differing implications for the future of the research relationship. The ideology underpinning the New Right push for consumerism rests on the neo-liberal values of the centrality of the market, self-reliance and individual choice. The New Left push for consumerism is based on the rights of individuals and groups to have a voice, with underpinning values of equity and advocacy. Both of these ideologies imply ‘choice’, although the ability to make choices actually demands some knowledge and an understanding of available information (Lupton, 1997). The ‘consumer’ is therefore framed as an active participant who engages with the available information to make rational and educated choices, in line with the notion of the ‘reflexive actor’, a central plank in the reflexive modernisation thesis (Beck et al., 1994).

In terms of consumer involvement in research, it is more difficult to see relevance of the New Right ideology, given that consumers are not really looking (‘shopping around’) for research studies to be involved in (even though researchers may be ‘shopping around’ for consumers to be involved in their research). It seems more likely that consumer involvement in research will be based around the civil and human rights of consumers and the advocacy roles of consumer groups to both shape research and benefit from their findings (Harrison, Dowswell, & Milewa, 2002).

Conceptualising consumer ‘involvement’ in research

Given the issues raised above, the term ‘consumer’ in relation to consumer involvement in research is contested and reflects various political, economic and social assumptions which are culturally and historically contingent (Boote et al., 2002; Hill, 2007). The ‘consumer of research’ is also situationally contingent, since one could argue that other researchers are consumers of research (albeit, often the disseminated end-products of research, such as peer-reviewed publications and reports) in addition to policy makers, journalists and University administrators. Whilst these groups all ‘consume’ research findings, the prime focus of health and social care policy with respect to ‘consumer involvement’ tends to be centered on the lay populace.

There have been some attempts at providing a definition or taxonomy of consumers, with respect to both healthcare and health research (Boote et al. 2002; Williamson 1995). With respect to research, three types of ‘consumer’ have been identified: individuals, local groups, and national or international organisations (Boote et al., 2002). Examples of individual consumers may include service users, carers, patient representatives and members of the public who are potential users of services. In terms of local consumers groups, this may include support groups, self-help groups and pressure groups. National and international consumer organisations may include charitable organisations, non-governmental organisations, statutory bodies and global pressure groups.

In UK health policy and research governance, the term ‘patient and the public involvement’ is used rather than consumer involvement, although the latter terminology is the term preferred by the Cochrane Collaboration and in Australian health policy. The term ‘patient’ has “historically been seen as occupying a subject position, with implications of dependency and unquestioning compliance” (Hibbert et al., 2002; 47). In traditional Parsonian terms the patient refers to a person occupying a sick-role which may not be the case for people (consumers) involved in research. The term ‘public’ may make sense in terms of general policy – after all it could be argued that we all ‘consume health’ (Henderson & Peterson, 2002) and can be seen as having a stake in research on health. However in order to actively involve people in the research process, researchers need to be more discerning in their choice of who to involve.

In terms of providing clear guidance to researchers about the nature and extent of ‘involvement’, some of the most useful definitions make explicit reference to changing power relationships between researchers and consumers, whereby involvement becomes active rather than passive (Williamson, 2001; INVOLVE, 2007), for example “doing research with or by the public rather than to, about or for the public” (Hanley et al 2004) or “where consumers and researchers work in partnership with one another to shape decisions about research priorities, policies and practices” (NHMRC and Consumers' Health Forum of Australia, 2004). Both of these definitions use the term ‘involvement’, but seem to suggest ‘participation’, whereby consumers engage in some level of power sharing or empowerment, rather than solely being ‘involved’. A definition used in UK health and social policy renders the roles of consumers in research even more explicit, stating that “Relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research”

(Department of Health, 2005). This provided both the policy context within which our study was undertaken and the definition we gave to study participants; we asked study participants to reflect on their experiences of involving consumers across all of these domains of research (i.e. from design through to dissemination) and then to talk about the barriers and facilitating factors to enabling such 'consumer involvement in research'.

Whilst these definitions start to allow researchers and consumers to negotiate their respective roles and responsibilities, it is also useful to highlight some potentially useful conceptual models of involvement or participation. Williamson (1995) distinguishes between 'overt' and 'covert' involvement: 'overt consumers' get involved because they are motivated through personal experience or health issue, whereas 'covert consumers' bring particular skills as part of their role (e.g. member of a relevant NGO or patient support charity). An early model was Arnstein's 'ladder of citizen participation' (Arnstein, 1969) which provides eight symbolic rungs of citizen participation, moving from the first rung (non-participation), through rungs relating purely to informing and placating, onto the higher rungs of partnership, delegated power and citizen control. The key aim of current policy is to move 'consumer involvement in research' further up the ladder, away from 'non-participation' in research and towards creating and maintaining partnerships with researchers. There have been attempts at refining the model, combining other conceptual frameworks and developing new conceptual models (Charles & DeMaio, 1993; Oliver et al., 2008), although the important point to take from these is that there are differing levels of consumer involvement, which will be socially, culturally and politically contingent (INVOLVE, 2007; Nilsen et al., 2006).

In addition, consumer involvement as a 'tick box exercise' (on whatever rung of the ladder) is very different to 'real' involvement, as Arnstein argues: "there is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcomes of the process" (1969: 216). This brings up the issue of 'tokenistic' involvement of consumers, which has been highlighted by other studies in relation to involving consumers in healthcare planning (Nilsen et al., 2006), but has not been empirically studied in relation to consumer involvement in health research. In addition, little is known about researcher perceptions or experiences of consumer involvement in health research which is particularly important if we are to both understand current practice and overcome any identified barriers.

Methodology, method and analysis

The research methods most commonly associated with a qualitative methodology were considered to be, not simply most appropriate, but particularly sensitive in their nature and 'fit' with the research aims and objectives. In the present study, we used semi-structured interviews, which allowed for explorations and discussions of relevant experiences and perceptions of consumer involvement in research, in addition to creating an atmosphere conducive to an open and uninhibited flow of conversation. The interviews were regarded as a social encounter in which knowledge was constructed and not simply an occasion for information gathering.

The sample population for the study was University health researchers in England and Wales. Potential university departments were identified from their websites and information about the department staff and their current research interests and projects were reviewed. In total 18 University departments were chosen to reflect diversity in terms of geographical location, academic discipline and type of health research. We received 22 responses from University researchers willing to participate in the study, and of those, fifteen interviews were undertaken. Data collection ceased after fifteen interviews because it was believed that data saturation had occurred.

Table 1 shows details of the 15 study participants, in terms of their gender, research background (and primary research methodology) and academic discipline. We hypothesized that researchers would be likely to view 'consumer involvement in research' differently, and also have differing experiences of involving consumers in their research, so we aimed for a diverse sample. In terms of research background, we had a mix of health services, public health and primary care research (both qualitative and quantitative) through to clinical trials and laboratory research. In terms of academic disciplines, we had social and behavioural sciences, medical and health sciences (public health, nursing and general practice) and biomedical sciences. Therefore, our findings need to be contextualized within the context of these diverse research and academic backgrounds.

TABLE 1 ABOUT HERE

A broad topic guide, derived from a comprehensive review of the literature, was endorsed by the research team and pilot interviews. The topic guide covered issues such as the scope, limitations, key purpose, experiences and arguments in favour or against consumer involvement in research. Throughout the interviews, participants were asked to provide examples of any experiences they had to illustrate their thoughts and opinions.

All interviews were tape recorded and transcribed verbatim. All transcripts were analysed separately by both PW and JT, and the codes and categories discussed and refined over a number of meetings. The transcripts were analysed using interpretive analysis, drawing heavily on *open coding* and *categorization* procedures of grounded theory, although we did not adopt a 'grounded theory approach' in a prescriptive sense. After all transcripts had undergone open coding, we grouped conceptual labels under common themes which were modified to accommodate negative or deviant findings. Of course the key themes that 'feel right' for one analyst may not always concur with those of another with entirely different assumptions brought to the interpretation or indeed with those of the participant (Opie, 1992). In the few circumstances where there were differences in interpretation, we discussed these in light of our theoretical and ideological frameworks, and acknowledged the different interpretations in the final analysis. Indeed, these ‘qualifiers’ to the process of analysis can be viewed as enriching and illuminating rather than necessarily problematic as they highlight the complexities of social research and the world it investigates.

Findings

The findings presented in this paper need to be situated within the broader findings from this study, which can be found in a sister paper (Thompson et al. 2009). Essentially, the sister paper reveals that overall, the study participants had only a limited knowledge and understanding of the relevant policies regarding consumer involvement in research, although the participants from health services and public health research generally a greater awareness of the policies than researchers from biomedical research. Study participants also had differing working practices with regards to ‘involving’ consumers in their research, ranging from non-involvement of consumers (generally in laboratory-based research) through to the lower rungs of Arnstein’s ladder (Arnstein, 1969), whereby consumers were often involved in a minor or superficial way (e.g. having consumers on steering groups, getting consumer to review questionnaires or repots to make then understandable to lay audiences etc), rather than engaging in a power-sharing exercise resulting in ‘participation’. These findings are similar to recent findings on user involvement in health service development (Fudge et al., 2008).

The ‘know-do’ gap

Across all interviews, there was consensus on the importance of involving consumers in research in general. Participants talked about the potential for consumer involvement to help with accessing/recruiting participants, disseminating findings and making the research more 'real' (the notion of 'lived experience' in collaboration with 'professional/technical experience'), in addition to improving the research in terms of validity, applicability, accountability, transparency and transferability. These reasons fit within the methodological imperatives for involving consumers (Nilsen et al., 2006), but are primarily focused on improving the research and research outputs, rather than engaging in a two-way empowering relationship with consumers. However, there were a number of statements about consumer involvement being *'a good thing'* whereby consumers had a '*right*' to be involved in research as members of a democratic society (akin to the New Left ideology around consumerism), although this 'ideal research situation' was always contrasted with the 'reality of research'.

In terms of research ethics, participants talked about both general ethical principles of doing 'good research' in addition to the requirements and formalities of RECs. Participants were generally cognisant of ethical principles in researching with humans and regarded involving consumers in their research as adhering to these. The following quote builds upon the ethical imperative further by suggesting that involving consumers can also act as a mechanism of empowerment:

> *'…..from an ethical point of view….I think there's an ethics for research which is, says we should be involving people who are affected by our research in designing and conducting that research. But at an earlier stage than just involving them as kind of research subjects. So I suppose that's linked to sort of discourses of empowerment'* (Participant 7)

Whilst in certain research studies (particularly in the social sciences) the empowerment imperative of involving consumers would hopefully be the case, evidence of this actually occurring within our participants' research studies was limited. The limited engagement with 'consumer involvement in research' has also been found in other quantitative (Barber et al.,

2007) and systematic review evidence (Oliver et al., 2008). In fact, this particular participant went on to say that in reality, her experience was that it did not happen a great deal, in part due to the epistemological dissonance (see below). A number of participants cautioned against what they regarded as 'complete' consumer involvement in all stages of all areas of research, stating that it should not be seen as a panacea. However, the counter point was also put by one participant who said:

> *'I don't think there should be any area* [not subject to consumer involvement in research], *if you can't provide a rationale that a group of patients or users will accept as being a reasonable rationale then you should severely question the research'* (Participant 6)

This participant was not advocating for consumer involvement in all stages of all research projects, but rather that on a rights-based, moral level, all research needs to be both understandable and defensible to lay audiences.

In terms of the requirements of RECs (and research governance frameworks, research funders and health policy more generally), there were numerous statements about the *'need'* to involve consumers in research. Whilst having 'consumer involvement' as one of the elements of the research ethics and funding processes actually means that researchers have to engage at some level with involving consumers, there was a fear within some of the participants of tokenism (i.e.being pressured into involving consumers), with some participants talking about it as a *'tick-box exercise'*, similar to recent findings elsewhere (Oliver et al., 2008). Whilst we would not advocate a tokenistic approach to involving consumers in research, it is not surprising, given that "professionals are hierarchically socialized and organized to view themselves as authorities" (Nilsen *et al* 2006: 2) and that client-oriented perspectives on consumer involvement are limited by organizational power relationships and decision making (Cawston & Barbour (2003: 716) – this can result in "difficult relationships" (Crawford *et al* 2002: 1264).

The following quotes highlight participants' anxieties about the potential for tokenism in the ethics review process (first quote) and in response to requirements of funding bodies (second quote):

> *'Well certainly I think it's a good thing in theory, I think the difficulty is doing it in some sort of meaningful way really, and getting over the tokenism business. I think that's the difficult bit'* (participant 9)
>
> *'Well it sort of, it forms part of most grant proposals now doesn't it? But I wonder whether sometimes when you read proposals, because we have had a few, the sort of the extent of their user involvement is like a token one…my concern would be that it's tokenism.'* (Participant 10)

Indeed, one participant made the comment that these ethical and funding frameworks are *'almost telling you that you* ***should*** *and you* ***must*** *involve consumers'* (Participant 13, emphasis added) and in a similar vein, another participant talked about consumer involvement being *'a requirement rather than a philosophy'* (Participant 1). This provided incentives in the form of an 'ethical imperative' to be a 'good, ethically sound researcher' and a threat of failing to get through the ethics review process (or even before that, to secure research funding in the first place). This goes to the heart of the problem for assessing the nature and extent of consumer involvement, since consumers may be constructed as being 'involved', but are not empowered to 'participate', which highlights Arnstein's warning about the "empty ritual of participation" (Arnstein 1969: 216).

Whilst participants talked lucidly about the benefits of involving consumers in research, this was often in a generalised and idealized context. When it came to talking about their actual experiences of involving consumers in their research or research conducted in their academic departments, the old adage of ‘rhetoric vs reality’ came to the fore, as can be seen in the following quote:

> *‘I don’t think we’re there [involving consumers fully in research], I think we are a million miles away from getting there at the moment, but I think that’s a nice utopia to aim for. But yes, I’m convinced by the hypothetical arguments, I just think we’re a long way from having any sort of infrastructure in place that would allow that to happen very easily’* (Participant 3)

Even those participants that were passionate advocates for consumer involvement and bought into its underlying philosophy felt that the reality did not match up to the rhetoric. As outlined in the above quote, a lack of supportive infrastructures was often cited as one of the main difficulties in realising the potential of consumer involvement. A further complication centred around the increase in commissioned and service/priority driven research, which reduced the possibility for involving consumers in research. Factors such as short and often immovable deadlines, lack of time, limited budgets that do not have in-built finances for consumer involvement, and lack of researcher training were the most often cited barriers. The following quote highlights these well:

> *‘Research is still driven from project to project so it’s a last minute scramble to put in a funding bid and that doesn’t promote effective involvement of the public unless you already have existing networks there’* (Participant 6)

At one level, this quote and the other barriers referred to above seemed ‘reasonable’ in terms of the authors’ experiences of undertaking contract research, but at another level, they uncover a lack of investment in the underlying philosophy or ideology of consumer involvement by both these researchers and related funding agencies. This is not a deleterious attack on either the researchers or funding agencies, but does beg the question ‘what can be done to provide supportive environments for active engagement with consumers who wish to become involved in research?'

In terms of service or priority driven research, the participants here were referring to situations where the research questions and to a certain extent, methodological design were already developed and researchers were responding to the needs/wants of organisations. The task of the researcher in this context was to write a grant proposal to fit into a number of *a priori* assumptions, meaning that consumer involvement was potentially already limited. In the UK, there is increasing national funding for health related research which is open, allowing researchers to set the research question and design and (to some extent) the time-scale of the proposal submission. In theory this should allow greater scope and flexibility for public involvement in research and it would be interesting to see whether this is realized.

A concern of some of the participants revolved around the ways in which researchers and the mechanisms/frameworks involved in facilitating and promoting consumer involvement in research placed 'research' at centre-stage and made (implicit) assumptions that consumers 'should' want to be involved (what might be termed 'researchism'). This fits with the notion of the reflexive consumer who has enough information to 'shop around' and make choices. The issue here relates to the extent to which research can be viewed like any other commodity in the marketplace whereby consumers have both a demand and willingness to become involved. For example, this particular participant had been working with a marginalised group who experienced multiple forms of deprivation:

> *'I suppose it's about how important it* [the research study] *is in what else is going on in their lives… and I know there is so much going on in their daily lives, that this* [the research study] *is a very low priority. You know if you've got to worry about all sorts of*

> *big issues, you're going to be least concerned about going to some research meeting that doesn't directly seem to affect you'* (Participant 1)

The above quote questions the centrality of research involvement within the life-worlds of members of this particular group and leads us to question the representativeness of consumers who choose to get involved in research, which is taken up in the next section.

Concerns about epistemological dissonance

In response to questions about the barriers to, and negative experiences of, consumer involvement, participants often talked about consumers bringing different forms of knowledge to the research process. Whilst in much of the sociological literature on 'lay knowledge' or the sociology of science, this would be seen as a positive and enlightening scenario, the participants in this study did not construct it in that way. Whilst the participants did not use the term, they were engaged in an epistemological dialogue about the validity or authenticity of 'consumer/lay knowledge' *vis a vis* 'professional/academic knowledge'. The following quote relates to a quite specific area of health services research, but nonetheless highlights the fundamental issue for a number of participants in this study:

> *'I think if we're honest, we have some very basic beliefs about what causes distress in our communities. And I think it's those that are in conflict. So for instance, say you are a psychiatrist who believes passionately that mental illness exists and it's a neurological problem and we just need to find the bit of the brain that's not working and correct that and you're sitting around a table trying to do collaborative research with say service users who think that's rubbish. You have underlying belief differences'* (Participant 2)

This type of debate will be very familiar to people in medical sociology and public health who have been involved in advocating for lay voices to be both heard, recognised and acted upon as valid forms of knowledge, rather than as they were hitherto constructed as irrational beliefs (Williams, 2003; Williams, 2000). However, what is new here is the context in which this debate is being played out, whereby researchers are defending their ‘professional boundaries’. Indeed, one participant talked about consumer involvement being a one-way transference of information (‘imparting knowledge’) from researcher to consumer which is *‘good for the general public to actually know what’s going on’* and *‘might make them more compliant’* (Participant 8). These comments are not necessarily dismissive of the validity of consumer involvement, but suggest a lack of reflexivity about the potential for researchers to learn something from consumers or to share in new forms of knowledge construction (i.e. the lower rungs of Arnstein’s ladder (Arnstein, 1969)). Much like the critiques within the literature on ‘lay knowledge’, participants constructed consumers as docile or vacuous bodies just waiting to be filled by academic knowledge, which fails to recognise the whole point of consumer ‘involvement’ whereby the researcher and research process can and should get a great deal out of involving consumers by virtue of the development of a multi-knowledge conglomeration or *bricolage* (Busby, Williams, & Rogers, 1998).

In terms of laboratory-based medical scientists, it is less surprising to find epistemological dissonance given that such research is usually quite far removed from social interaction with consumers. Therefore, they often found it hard to conceive of points in the research process where consumer involvement could be useful. However, given the increased consumer involvement in the research commissioning process, we specifically asked about the value or utility of consumer involvement in terms of research agenda setting. However, this was met with debate and criticism at the level of epistemology, with comments such *‘their experiences cannot outweigh my academic qualifications or knowledge’* (Participant 12).

In order to explain and defend these more generalised constructions of epistemological dissonance, a number of participants operationalised their criticisms by questioning the objectivity and representativeness of consumers who choose to be involved in research. In this way, participants raised important points about the notion of a homogenous ‘consumer voice’ when many research studies claimed to involve consumers *per se* but actually included individuals from particular segments of society. The issue of the ‘representativeness’ of consumers has been raised in relation to involvement in health service planning (Contandriopoulos, 2004; Fudge et al., 2008), although given the inherent difficulties in recruiting consumers for involvement in research studies, it seems that the focus might be placed on inclusion and diversity of consumers, rather than representativeness *per se* (Beresford, 2007).

Most participants recalled stories of ‘professional lay-people’ who seemed to occupy the role of consumer or layperson on numerous committees and are often constructed as representing the ‘consumer voice’, which has also been noted elsewhere (Telford et al 2002). However, these people were seen to be located in a hinterland between ‘lay’ and ‘professional’ and were often constructed as having been professionalised, thereby questioning the authenticity of the (consumer) knowledge they hold. The following quote came from a health services researcher who was talking about a consumer representative on a recent study, *‘well of course we didn’t get Joe Bloggs off the street, we basically got a retired university researcher who happens to have back pain’* (Participant 9). Selecting consumers with professional status, may partly be a reflection of researchers attempt to overcome practical difficulties (such as the consumer’s perceived ability to contribute in formal meetings) but there is also the possibility that the researcher’s acceptance of the consumer’s academic or intellectual expertise increases the value of their experiential knowledge to the researcher

Given the resources, confidence, social status and time required to act as a ‘consumer’ in research studies, a number of participants were resigned to the unrepresentative nature of consumers, with comments such as *‘they are more representative than nobody’* (Participant 3) being common. In contrast to the constructions of consumers as unrepresentative and ‘biased’, there were also a number of reflections on the ways in which researchers are also biased and bring personal and pre-set agendas to research. Whilst this was not vocalised by all participants, it is still an important point to keep in mind.

Concluding comments

We conclude with three key points that seem worthy of further discussion. The first point relates to the veneration of research (or ‘researchism’) – the idea that consumers recognise both the importance of research and can/want to become involved in research. The idea of increasing ‘research literacy’ was suggested by some participants as a way of helping consumers to develop a ‘better’ understanding of the research process and to engage in a meaningful and empowered relationship with researchers. Such a process would need to be ‘democratic’ in order to increase research literacy across social milieu and hence allow the possibility of consumers other than just the ‘professional lay person’ to be involved in research. However, this idea is rooted in a model in which consumers want to engage with and be involved in research and does not account for a structural patterning of reflexivity, or ‘stratified reflexivity’ (Ward & Coates 2006; Ward 2006).

In addition, the veneration of research does not take into account the notion of ‘functional knowledge’ and ‘functional knowledge deficits’, (Ungar, 2008) which pertains to those forms of knowledge required to undertake one’s daily tasks or perform one’s roles in society. For example, the kinds of functional knowledge required by a sociologist in order to undertake and perform their role within a University is quite different (although no more or less important) to that required by a plumber or a parent. Given that the functional knowledge of a researcher will be expected to be different to that of a consumer, this raises questions about the assumed willingness of consumers to want to get involved in research studies.

Moreover even if access to research information was increased, the effects of such access are unlikely to be socially neutral, for example Shilling states that *“different patterns of socialization result in class-based orientations towards symbolic knowledge which affect the degree to which the social world is seen as open to individual intervention”* (Shilling, 2002 p.634). Thus, it seems likely that those with the economic, cultural and social capital will remain more likely to get involved in research. Indeed, given that the rise of consumerism is often seen as part of ‘reflexive modernisation’ (Beck et al., 1994; Giddens, 1994), the question becomes, how far are consumers engaged in a project of the self or treated as reflexive actors? It seems from our study that there is an ‘ideal research situation’ whereby researchers buy into (at least at some level) the New Left ideology and perceive methodological benefits of involving consumers. However, the reality is that the researchers in this study were not really engaging on the higher rungs of Arnstein’s ladder (Arnstein, 1969) and in a reciprocal relationship with consumers. Researchers were (maybe unconsciously) working along the lines of ‘in what ways can the consumers help my research study?’ rather than with the question ‘what can the consumers also get from being a part of the research study?’.

The second point is around the value of ‘lay knowledge’ in relation to researchers’ views, which often lead to a tokenistic engagement with consumers. Epistemological dissonance centres around a lack of recognition that consumers can bring valid forms of knowledge to bear on the research process. Of particular relevance here are issues around lay-professional knowledges and the privileging of ‘expertise’ over ‘experience’ (Glasby & Beresford, 2006; G. Williams & Popay, 2001), the ways in which lay knowledge is blocked or incorporated (Barry, Stevenson, Britten, Barber, & Bradley, 2001; Scambler & Britten, 2001), and more abstract issues around how epistemological divides are constructed to defend boundaries and reconstruct lay and professional identities (Irwin & Michael, 2003; Wynne, 1996). The notion of ‘epistemic violence’ (Spivak, 1988) may be used as a way of further understanding this, which positions the researcher in the position of the ‘knower’ (Lewis, 2007) and the consumer in the much less powerful (or powerless) position of the ‘docile body’, ready to be filled with expert knowledge from researchers.

The final point (which is embedded in the second point above) is around the ‘professionalising strategies’ employed by researchers to maintain their power/status and promote the authenticity and primacy of their knowledge *vis a vis* consumer or lay knowledge. Whether researchers can actually be regarded as being part of a profession is a mute point and cannot be explored here. In fact, some would say that the definition of a profession lacks explanatory power and is a ‘time-wasting diversion’ (Evetts 2003) and it has even been suggested that none of the current ‘professions’ such as medicine, law and engineering are ‘true’ professions but are actually ‘expert occupations’ (Sciulli 2007). Nevertheless, researchers appear to be engaged in a process of boundary defense and maintenance that mirrors the processes being undertaken within the healthcare professions (Hibbert et al., 2002). The issue for the future of the research relationship is whether a similar set of ‘boundary clashes’ will occur between researchers and consumers, potentially impacting on the nature and extent of ‘real’ consumer involvement in research and the (re)negotiation of the notion of the ‘researcher’ and the ‘consumer’.

References

Aldridge, A. (2003). Consumption. Cambridge: Polity Press.

Arnstein, S. (1969). A ladder of citizen participation. *American Institute of Planners Journal,* 35, 216-224.

Barber, R., Boote, J., & Cooper, C. (2007). Involving consumers successfully in NHS research: a national survey. *Health Expectations,* 12, 380-391.

Barry, C. A., Stevenson, F. A., Britten, N., Barber, N., & Bradley, C. P. (2001). Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. 53, 487-505.

Bauman, Z. (2001). The Individualized Society. Cambridge: Polity Press.

Beck, U., Giddens, A., & Lash, S. (1994). Reflexive Modernization. Politics, Tradition and Aesthetics in the Modern Social Order. Cambridge: Polity Press.

Beresford, P. (2007). User involvement, research and health inequalities: developing new directions. *Health & Social Care in the Community,* 15, 306-312.

Boote, J., Telford, R., & Cooper, C. (2002). Consumer involvement in health research: a review and research agenda. *Health Policy,* 61, 213-236.

Bourdieu, P. (1984). Distinction: A Social Critique of the Judgement of Taste. London: Routledge.

Busby, H., Williams, G., & Rogers, A. (1998). Bodies of knowledge: lay and biomedical understandings of musculoskeletal disorders. In M. A. Elston (Ed.), The sociology of medical science and technology. Oxford: Blackwell Publishers.

Cawston, P. G., & Barbour, R. S. (2003). Clients or citizens? Some considerations for primary care organisations. *British Journal of General Practice,* 53, 716-722.

Charles, C., & DeMaio, S. (1993). Lay participation in health decision making: a conceptual framework. *Journal of Health Politics, Policy & Law,* 18, 881-904.

Contandriopoulos, D. (2004). A sociological perspective on public participation in health care. *Social Science & Medicine,* 58, 321-330.

Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N. *et al.* (2002) Systematic review of involving patients in the planning and development of health care. *British Medical Journal*, **325**, 1263-1265.

Department of Health. (2005). Research Governance Framework for Health and Social Care. London: Department of Health.

Dyer, S. (2004). Rationalising public participation in the health service: the case of research ethics committees. *Health & Place,* 10, 339-348.

Edgell, S., Hetherington, K., & Warde, A. (1996). Consumption Matters: The Production and Experience of Consumption. Oxford: Blackwell.

Evetts, J. (2003). The sociological analysis of professionalism. Occupational change in the modern world. *International Sociology,* 18, 395-415.

Falk, P. (1994). The Consuming Body. London: Sage.

Featherstone, M. (1991). Consumer Culture and Postmodernism. London: Sage.

Fudge, N., Wolfe, C., & McKevitt, C. (2008). Assessing the promise of user involvement in health service development: ethnographic study. *British Medical Journal,* 336, 313-317.

Gabe, J., & Calnan, M. (2000). Health Care and Consumption. In S. J. Williams, J. Gabe & M. Calnan (Eds.), Health, Medicine and Society. Key Theories, Future Agendas. London: Routledge.

Giddens, A. (1994). Risk, Trust, Reflexivity. In U. Beck, A. Giddens & S. Lash (Eds.), Reflexive Modernization. Cambridge: Polity Press.

Glasby, J., & Beresford, P. (2006). Who knows best? Evidence-based practice and the service user contribution. *Critical Social Policy,* 26, 268-284.

Hanley B, Bradburn J, Barnes M, Evans C, Goodare H, Kelson M, Kent A, Oliver S,Thomas S, Wallcraft J (2004) Involving the public in NHS, public health, and social care research: Briefing notes for researchers, 2nd edn. Eastleigh: INVOLVE.

Harrison, S., Dowswell, G., & Milewa, T. (2002). Public and user 'involvement' in the UK National Health Service. *Health & Social Care in the Community,* 10, 63-66.

Henderson, S., & Peterson, A. (2002). Introduction: Consumerism in Health Care. In S. Henderson & A. Peterson (Eds.), Consuming Health: The Commodification of Health Care. London: Routledge.

Hibbert, D., Bissell, P., & Ward, P. R. (2002). Consumerism and the work of the community pharmacy. *Sociology of Health and Illness,* 24.

Hill, S. (2007). Involving the Consumer in Health Research. In M. Saks & J. Allsop (Eds.), Researching Health. Qualitative, Quantitative and Mixed Methods. (pp. 351-367). London: Sage.

Hobsbawm, E. (1999). The New Century. London: Little, Brown and Co.

INVOLVE. (2007). INVOLVE - promoting public involvement in NHS, public health and social care research. http://www.invo.org.uk.

Irwin, A., & Michael, M. (2003). Ethno-epistemic assemblages: heterogeneity and relationality in sceintific citizenship. Science, Social Theory and Public Knowledge (pp. 111-136). Maidenhead: Open University Press.

Lasch, C. (1980). The Culture of Narcissism: American Life in an Age of Diminishing Expectations. New York: Abacus.

Lewis, L. (2007). Epistemic authority and the gender lens. *The Sociological Review,* 55(2), 273-292.

Lupton, D. (1997). Consumerism, reflexivity and the medical encounter. *Social Science and Medicine,* 45, 373-381.

NHMRC and Consumers' Health Forum of Australia (2004) A Model Framework for Consumer and Community Participation in Health and Medical Research., Canberra: NH&MRC Council.

Nilsen, E. S., Myrhaug, H. T., Johansen, M., Oliver, S., & Oxman, A. D. (2006). Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. Cochrane Database of Systematic Reviews.

O'Donnell, M., & Entwistle, V. (2004). Consumer involvement in decisions about what health-related research is funded. *Health Policy,* 70, 281-290.

Oliver, S., Rees, R., Clarke-Jones, L., Milne, R., Oakley, A., Gabbay, J., et al. (2008). A multidimensional conceptual framework for analysing public involvement in health services research. *Health Expectations,* 11, 72-84.

Opie, A. (1992). Qualitative research, appropriation of the "Other" and empowerment. *Feminist Review,* 40(Spring), 52-69.

Scambler, G., & Britten, N. (2001). System, lifeworld and doctor-patient interaction: issues of trust in a changing world. In G. Scambler (Ed.), Habermas, Critical Theory and Health. London: Routledge.

Sciulli, D. (2007). Paris visual Academie as the first prototype profession. Rethinking the sociology of the professions. *Theory, Culture & Society,* 24(1), 35-59.

Shaw, I., & Aldridge, A. (2003). Consumerism, health and social order. *Social Policy & Sociology,* 2, 35- 43.

Shilling, C. (2002). Culture, the "sick role" and the consumption of health. *British Journal of Sociology,* 53, 621-638.

Sklair, L. (1998). The Transnational Capitalist Class. In J. Carrier & D. Miller (Eds.), Virtualism: A New Political Economy (p. 140). Oxford: Berg.

Spivak, G. (1988). Can the subaltern speak? In C. Nelson & L. Grossberg (Eds.), Marxism and the Interpretation of Culture. Basingstoke: Macmillan.

Telford, R., Beverley, C., Cooper, C., & Boote, J. (2002). Consumer involvement in health research: fact or fiction? *British Journal of Clinical Governance,* 7(2), 92-103.

Thompson, J., Barber, R., Ward, P.R., Boote, J., Cooper, C., Armitage, C. *Jones G.* (2009) Researchers' attitudes to public involvement in health research. *Health Expectations* 12, 209-220.

Ungar S (2008). Ignorance as an under-identified social problem. *British Journal of Sociology* 59, 2, 301-326.

Veblen, T. (1899/1970). The Theory of the Leisure Class: an Economic Study of Institutions. London: Allen and Unwin.

Ward, P. R. (2006). Trust, reflexivity and dependence: a 'social systems theory' analysis in/of medicine. *European Journal of Social Quality,* 6(2), 143-158.

Ward, P. R., & Coates, A. (2006). "We shed tears but there is no one there to wipe them up for us": narratives of (mis)trust in a materially deprived community. *Health: An interdisciplinary journal for the social study of health, illness and medicine,* 10, 283-302.

Williams G (2000). Knowledgeable narratives. *Anthropology & Medicine* 7:135-140.

Williams G (2003). The determinants of health: structure, context and agency. *Sociology of Health & Illness* 25:131-154.

Williams, G., & Popay, J. (2001). Lay health knowledge and the concept of the lifeworld. In G. Scambler (Ed.), Habermas, Critical Theory and Health. London: Routledge.

Williamson, C. (1995). A manager's guide to consumers. *Health Services Journal,* 105, 28-29.

Williamson, C. (2001). What does involving consumers in research mean? *Quarterly Journal of Medicine,* 94(12), 661-664.

World Health Organisation. (2005). Bridging the "Know-Do" Gap. Meeting on Knowledge Translation in Global Health. Geneva: WHO.

Wynne, B. (1996). May the sheep safely graze? A reflexive view of the expert-lay knowledge divide. In S. Lash, B. Szerszynski & B. Wynne (Eds.), Risk, Environment and Modernity: Towards a New Ecology. London: Sage.

Table 1

ID*	Gender	Research Background	Academic discipline
1	Female	Health services research (qualitative)	Social science
2	Female	Health services research (qualitative)	Social science
3	Female	Clinical trials (quantitative)	Medicine
4	Male	Health services research (mixed methods)	Public health
5	Male	Health services research (quantitative)	Psychology
6	Male	Health services research (quantitative)	Psychology
7	Female	Health services research (mixed methods)	Public health
8	Female	Laboratory research (quantitative)	Biomedicine
9	Male	Primary care research (mixed methods)	General practice
10	Female	Laboratory research (quantitative)	Biomedicine
11	Female	Clinical Trials (quantitative)	Medicine
12	Female	Population based research (mixed methods)	Nursing
13	Female	Health services research (mixed methods)	Public health
14	Male	Laboratory research (quantitative)	Biomedicine
15	Female	Medical statistics (quantitative)	Statistics

* The ID number is used within the paper to identify particular quotes.