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

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Keyword:	Consumer involvement in research, Consumerism, Qualitative analysis < Data analysis, Epistemologies
Abstract:	<p>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.</p>

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

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

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3 should be involved in all stages of research, although this paper is focused on the views of other
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5 health and medical researchers who may not share our view.
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10 Despite such strong imperatives and policy directives to involve consumers in research
11 (Department of Health 2005; NHMRC and Consumers' Health Forum of Australia 2004), recent
12 studies (Barber, Boote, & Cooper, 2007; Telford, Beverley, Cooper, & Boote, J. 2002) have
13 provided evidence of a gap between policy and practice that we refer to as the 'know-do gap'
14 (World Health Organisation, 2005) whereby researchers are involving consumers much less
15 than the policy makers would hope for. Whilst this provides some quantitative evidence on the
16 prevalence of consumer involvement in research, little work has been undertaken to explore
17 researcher perspectives on both the policy and practice of consumer involvement in health
18 research (Telford *et al*, 2002). The present paper reports data from a qualitative study of
19 researchers about their perceptions and experiences of consumer involvement in research. Our
20 data focused on the nature and extent of consumer involvement in health research in the UK,
21 and the implications for the future of the research relationship. However, we begin the paper by
22 exploring the relationship between wider movements of consumerism and commodification
23 within research, definitions of consumers of research and what does/might consumer
24 involvement mean in/for research?
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45 **The nature and extent of consumerism in research**

46 There has been a great deal of sociological writing around the rise of consumerism in general,
47 and some specifically related to health and healthcare (Gabe & Calnan, 2000; Hibbert, Bissell, &
48 Ward, 2002; Lupton, 1997; Shaw & Aldridge, 2003). There has been less sociological work on
49 the rise of consumerism specific to research, although the sociological and health-related
50 literature has explored constructions of 'consumers' (Cawston & Barbour, 2003 and the shifting
51 relationships with professionals (Lupton, 1997; Scambler & Britten, 2001). Consumerism in
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3 health has led to increased calls for equal weight to be given to lay voices *vis a vis* those of
4 health professionals. In relation to research, a similar call for consumer involvement is evident in
5 health policy and the requirements of a number of research funding bodies, Research Ethics
6 Committees (RECs) and research governance frameworks (Department of Health 2005).
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14 Theories of consumption have a long history in the social sciences. Some of the earliest work in
15 this area was Veblen's 'conspicuous consumption' (1899/1970) and Marxist conceptualizations
16 of, and distinctions between, production and consumption. In more contemporary times,
17 consumption has been theorised as both a form of distinction within 'consumer society'
18 (Bourdieu, 1984) and between consumers and professionals (Campbell, 1987; Falk, 1994;
19 Lupton, 1997). There have been arguments made about the 'commodification of the body'
20 (Falk, 1994) and post-modern theories on consumerism (Bauman, 2001; Featherstone, 1991).
21 These theoretical frameworks set up some important issues for researchers involved in
22 'consumerism in research', such as the changing relationships between the production and
23 consumption of research, and between researchers and consumers, the nature and extent of the
24 commodification of research (indeed, research as a commodity within a marketplace) and the
25 shifting place or importance of research within late modern society. This latter point is
26 particularly pertinent, given that the process and outcomes of consumerism may rest on
27 individuals (re)producing self and identity, meaning, wellbeing and/or psychic security (Lasch,
28 1980) within the process of reflexive modernisation (Beck, Giddens, & Lash, 1994) – the role
29 that research, as a consumer commodity, can play in this intersubjective process is yet to be
30 understood.
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53 In one sense, consumerism could be viewed as a step towards greater inclusion, empowerment
54 and participation, notions that are believed to be intrinsically positive, emphasizing choice and
55 consumer rights (Shaw & Aldridge, 2003). Using this definition 'consumerism' and 'citizenship'
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3 are often seen as closely linked terms. However, as has been pointed out (Aldridge, 2003),
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5 citizenship implies much more of a reciprocal relationship based on rights and responsibilities,
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7 whereas consumerism is merely concerned with rights, with one commentator (Hobsbawm,
8
9 1999) going further to suggest that consumerism constitutes a threat to citizenship. The
10
11 important point to take from this, are that consumers and citizens are seen to occupy different
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13 functional roles within society, which therefore begs the question, what are the responsibilities
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15 with respect to consumer involvement in research (on the part of both the consumers and
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17 researchers)?
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23 Whilst the role of consumers may have an overarching definition, such as “acquiring and/or
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25 using goods or services for their own benefit” (Gabe & Calnan 2000; 255), there seem to be two
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27 major ideological strands that have implications for the researcher-consumer relationship,
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29 particularly given that “the culture-ideology of consumerism is the fundamental value system that
30
31 keeps the system intact” (Sklair 1998: 140). Gabe and Calnan (2000), following on from others
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33 (Edgell et al., 1996), make the case that New Right and New Left agendas both promote
34
35 consumerism, although for differing reasons, and with differing implications for the future of the
36
37 research relationship. The ideology underpinning the New Right push for consumerism rests on
38
39 the neo-liberal values of the centrality of the market, self-reliance and individual choice. The New
40
41 Left push for consumerism is based on the rights of individuals and groups to have a voice, with
42
43 underpinning values of equity and advocacy. Both of these ideologies imply ‘choice’, although
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45 the ability to make choices actually demands some knowledge and an understanding of
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47 available information (Lupton, 1997). The ‘consumer’ is therefore framed as an active participant
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49 who engages with the available information to make rational and educated choices, in line with
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51 the notion of the ‘reflexive actor’, a central plank in the reflexive modernisation thesis (Beck et
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53 al., 1994).
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3 In terms of consumer involvement in research, it is more difficult to see relevance of the New
4 Right ideology, given that consumers are not really looking ('shopping around') for research
5 studies to be involved in (even though researchers may be 'shopping around' for consumers to
6 be involved in their research). It seems more likely that consumer involvement in research will be
7 based around the civil and human rights of consumers and the advocacy roles of consumer
8 groups to both shape research and benefit from their findings (Harrison, Dowswell, & Milewa,
9 2002).

20 **Conceptualising consumer 'involvement' in research**

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

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42 There have been some attempts at providing a definition or taxonomy of consumers, with
43 respect to both healthcare and health research (Boote et al. 2002; Williamson 1995). **With**
44 **respect to research, three types of 'consumer' have been identified: individuals, local groups,**
45 **and national or international organisations (Boote et al., 2002). Examples of individual**
46 **consumers may include service users, carers, patient representatives and members of the public**
47 **who are potential users of services. In terms of local consumers groups, this may include**
48 **support groups, self-help groups and pressure groups. National and international consumer**
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3 organisations may include charitable organisations, non-governmental organisations, statutory
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5 bodies and global pressure groups.
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10 In UK health policy and research governance, the term 'patient and the public involvement' is
11 used rather than consumer involvement, although the latter terminology is the term preferred by
12 the Cochrane Collaboration and in Australian health policy. The term 'patient' has "historically
13 been seen as occupying a subject position, with implications of dependency and unquestioning
14 compliance" (Hibbert et al., 2002; 47). In traditional Parsonian terms the patient refers to a
15 person occupying a sick-role which may not be the case for people (consumers) involved in
16 research. The term 'public' may make sense in terms of general policy – after all it could be
17 argued that we all 'consume health' (Henderson & Peterson, 2002) and can be seen as having a
18 stake in research on health. However in order to actively involve people in the research process,
19 researchers need to be more discerning in their choice of who to involve.
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33 In terms of providing clear guidance to researchers about the nature and extent of 'involvement',
34 some of the most useful definitions make explicit reference to changing power relationships
35 between researchers and consumers, whereby involvement becomes active rather than passive
36 (Williamson, 2001; INVOLVE, 2007), for example "doing research with or by the public rather
37 than to, about or for the public" (Hanley et al 2004) or "where consumers and researchers work
38 in partnership with one another to shape decisions about research priorities, policies and
39 practices" (NHMRC and Consumers' Health Forum of Australia, 2004). Both of these definitions
40 use the term 'involvement', but seem to suggest 'participation', whereby consumers engage in
41 some level of power sharing or empowerment, rather than solely being 'involved'. A definition
42 used in UK health and social policy renders the roles of consumers in research even more
43 explicit, stating that "Relevant service users and carers or their representative groups should be
44 involved wherever possible in the design, conduct, analysis and reporting of research"
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3 (Department of Health, 2005). This provided both the policy context within which our study was
4 undertaken and the definition we gave to study participants; we asked study participants to
5 reflect on their experiences of involving consumers across all of these domains of research (i.e.
6 from design through to dissemination) and then to talk about the barriers and facilitating factors
7 to enabling such 'consumer involvement in research'.
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16 Whilst these definitions start to allow researchers and consumers to negotiate their respective
17 roles and responsibilities, it is also useful to highlight some potentially useful conceptual models
18 of involvement or participation. Williamson (1995) distinguishes between 'overt' and 'covert'
19 involvement: 'overt consumers' get involved because they are motivated through personal
20 experience or health issue, whereas 'covert consumers' bring particular skills as part of their role
21 (e.g. member of a relevant NGO or patient support charity). An early model was Arnstein's
22 'ladder of citizen participation' (Arnstein, 1969) which provides eight symbolic rungs of citizen
23 participation, moving from the first rung (non-participation), through rungs relating purely to
24 informing and placating, onto the higher rungs of partnership, delegated power and citizen
25 control. The key aim of current policy is to move 'consumer involvement in research' further up
26 the ladder, away from 'non-participation' in research and towards creating and maintaining
27 partnerships with researchers. There have been attempts at refining the model, combining other
28 conceptual frameworks and developing new conceptual models (Charles & DeMaio, 1993; Oliver
29 et al., 2008), although the important point to take from these is that there are differing levels of
30 consumer involvement, which will be socially, culturally and politically contingent (INVOLVE,
31 2007; Nilsen et al., 2006).
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53 In addition, consumer involvement as a 'tick box exercise' (on whatever rung of the ladder) is
54 very different to 'real' involvement, as Arnstein argues: "there is a critical difference between
55 going through the empty ritual of participation and having the real power needed to affect the
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3 outcomes of the process” (1969: 216). This brings up the issue of ‘tokenistic’ involvement of
4 consumers, which has been highlighted by other studies in relation to involving consumers in
5 healthcare planning (Nilsen et al., 2006), but has not been empirically studied in relation to
6 consumer involvement in health research. In addition, little is known about researcher
7 perceptions or experiences of consumer involvement in health research which is particularly
8 important if we are to both understand current practice and overcome any identified barriers.
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18 **Methodology, method and analysis**

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20 The research methods most commonly associated with a qualitative methodology were
21 considered to be, not simply most appropriate, but particularly sensitive in their nature and ‘fit’
22 with the research aims and objectives. In the present study, we used semi-structured interviews,
23 which allowed for explorations and discussions of relevant experiences and perceptions of
24 consumer involvement in research, in addition to creating an atmosphere conducive to an open
25 and uninhibited flow of conversation. The interviews were regarded as a social encounter in
26 which knowledge was constructed and not simply an occasion for information gathering.
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38 The sample population for the study was University health researchers in England and Wales.
39 Potential university departments were identified from their websites and information about the
40 department staff and their current research interests and projects were reviewed. In total 18
41 University departments were chosen to reflect diversity in terms of geographical location,
42 academic discipline and type of health research. We received 22 responses from University
43 researchers willing to participate in the study, and of those, fifteen interviews were undertaken.
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3 Table 1 shows details of the 15 study participants, in terms of their gender, research background
4 (and primary research methodology) and academic discipline. We hypothesized that
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6 researchers would be likely to view 'consumer involvement in research' differently, and also
7
8 have differing experiences of involving consumers in their research, so we aimed for a diverse
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10 sample. In terms of research background, we had a mix of health services, public health and
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12 primary care research (both qualitative and quantitative) through to clinical trials and laboratory
13
14 research. In terms of academic disciplines, we had social and behavioural sciences, medical
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16 and health sciences (public health, nursing and general practice) and biomedical sciences.
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18 Therefore, our findings need to be contextualized within the context of these diverse research
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20 and academic backgrounds.
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27 TABLE 1 ABOUT HERE

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31 A broad topic guide, derived from a comprehensive review of the literature, was endorsed by the
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33 research team and pilot interviews. The topic guide covered issues such as the scope,
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35 limitations, key purpose, experiences and arguments in favour or against consumer involvement
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37 in research. Throughout the interviews, participants were asked to provide examples of any
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39 experiences they had to illustrate their thoughts and opinions.
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44 All interviews were tape recorded and transcribed verbatim. All transcripts were analysed
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46 separately by both PW and JT, and the codes and categories discussed and refined over a
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48 number of meetings. The transcripts were analysed using interpretive analysis, drawing heavily
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50 on *open coding* and *categorization* procedures of grounded theory, although we did not adopt a
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52 'grounded theory approach' in a prescriptive sense. After all transcripts had undergone open
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54 coding, we grouped conceptual labels under common themes which were modified to
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56 accommodate negative or deviant findings. Of course the key themes that 'feel right' for one
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3 analyst may not always concur with those of another with entirely different assumptions brought
4 to the interpretation or indeed with those of the participant (Opie, 1992). In the few
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6 to the interpretation or indeed with those of the participant (Opie, 1992). In the few
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8 circumstances where there were differences in interpretation, we discussed these in light of our
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10 theoretical and ideological frameworks, and acknowledged the different interpretations in the
11
12 final analysis. Indeed, these 'qualifiers' to the process of analysis can be viewed as enriching
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14 and illuminating rather than necessarily problematic as they highlight the complexities of social
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16 research and the world it investigates.
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20 21 Findings

22 The findings presented in this paper need to be situated within the broader findings from this
23 study, which can be found in a sister paper (Thompson et al. 2009). Essentially, the sister paper
24 reveals that overall, the study participants had only a limited knowledge and understanding of
25 the relevant policies regarding consumer involvement in research, **although the participants from**
26 **health services and public health research generally a greater awareness of the policies than**
27 **researchers from biomedical research.** Study participants also had differing working practices
28 with regards to 'involving' consumers in their research, **ranging from non-involvement of**
29 **consumers (generally in laboratory-based research) through to the** lower rungs of Arnstein's
30 ladder (Arnstein, 1969), whereby consumers were often involved in a minor or superficial way
31 **(e.g. having consumers on steering groups, getting consumer to review questionnaires or reports**
32 **to make them understandable to lay audiences etc),** rather than engaging in a power-sharing
33 exercise resulting in 'participation'. These findings are similar to recent findings on user
34 involvement in health service development (Fudge et al., 2008).
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51 52 53 The 'know-do' gap

54 Across all interviews, there was consensus on the importance of involving consumers in
55 research in general. Participants talked about the potential for consumer involvement to help
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3 with accessing/recruiting participants, disseminating findings and making the research more
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5 'real' (the notion of 'lived experience' in collaboration with 'professional/technical experience'), in
6
7 addition to improving the research in terms of validity, applicability, accountability, transparency
8
9 and transferability. These reasons fit within the methodological imperatives for involving
10
11 consumers (Nilsen et al., 2006), but are primarily focused on improving the research and
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13 research outputs, rather than engaging in a two-way empowering relationship with consumers.
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15 However, there were a number of statements about consumer involvement being '*a good thing*'
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17 whereby consumers had a '*right*' to be involved in research as members of a democratic society
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19 (akin to the New Left ideology around consumerism), although this 'ideal research situation' was
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21 always contrasted with the 'reality of research'.
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27 In terms of research ethics, participants talked about both general ethical principles of doing
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29 'good research' in addition to the requirements and formalities of RECs. Participants were
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31 generally cognisant of ethical principles in researching with humans and regarded involving
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33 consumers in their research as adhering to these. The following quote builds upon the ethical
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35 imperative further by suggesting that involving consumers can also act as a mechanism of
36
37 empowerment:
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40 *'.....from an ethical point of view....I think there's an ethics for research which is, says we*
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42 *should be involving people who are affected by our research in designing and conducting*
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44 *that research. But at an earlier stage than just involving them as kind of research*
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46 *subjects. So I suppose that's linked to sort of discourses of empowerment'* (Participant 7)
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51 Whilst in certain research studies (particularly in the social sciences) the empowerment
52
53 imperative of involving consumers would hopefully be the case, evidence of this actually
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55 occurring within our participants' research studies was limited. The limited engagement with
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57 'consumer involvement in research' has also been found in other quantitative (Barber et al.,
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3 2007) and systematic review evidence (Oliver et al., 2008). In fact, this particular participant
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5 went on to say that in reality, her experience was that it did not happen a great deal, in part due
6
7 to the epistemological dissonance (see below). A number of participants cautioned against what
8
9 they regarded as 'complete' consumer involvement in all stages of all areas of research, stating
10
11 that it should not be seen as a panacea. However, the counter point was also put by one
12
13 participant who said:

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16 *'I don't think there should be any area [not subject to consumer involvement in research],*
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18 *if you can't provide a rationale that a group of patients or users will accept as being a*
19
20 *reasonable rationale then you should severely question the research'* (Participant 6)
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25 This participant was not advocating for consumer involvement in all stages of all research
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27 projects, but rather that on a rights-based, moral level, all research needs to be both
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29 understandable and defensible to lay audiences.
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34 In terms of the requirements of RECs (and research governance frameworks, research funders
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36 and health policy more generally), there were numerous statements about the 'need' to involve
37
38 consumers in research. Whilst having 'consumer involvement' as one of the elements of the
39
40 research ethics and funding processes actually means that researchers have to engage at some
41
42 level with involving consumers, there was a fear within some of the participants of tokenism
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44 (i.e. being pressured into involving consumers), with some participants talking about it as a '*tick-*
45
46 *box exercise*', similar to recent findings elsewhere (Oliver et al., 2008). Whilst we would not
47
48 advocate a tokenistic approach to involving consumers in research, it is not surprising, given that
49
50 "professionals are hierarchically socialized and organized to view themselves as authorities"
51
52 (Nilsen *et al* 2006: 2) and that client-oriented perspectives on consumer involvement are limited
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54 by organizational power relationships and decision making (Cawston & Barbour (2003: 716) –
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56 this can result in "difficult relationships" (Crawford *et al* 2002: 1264).
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6 The following quotes highlight participants' anxieties about the potential for tokenism in the
7 ethics review process (first quote) and in response to requirements of funding bodies (second
8 quote):
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11 *'Well certainly I think it's a good thing in theory, I think the difficulty is doing it in some*
12 *sort of meaningful way really, and getting over the tokenism business. I think that's the*
13 *difficult bit'* (participant 9)

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18 *'Well it sort of, it forms part of most grant proposals now doesn't it? But I wonder whether*
19 *sometimes when you read proposals, because we have had a few, the sort of the extent*
20 *of their user involvement is like a token one...my concern would be that it's tokenism.'*
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25 (Participant 10)

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29 Indeed, one participant made the comment that these ethical and funding frameworks are
30
31 *'almost telling you that you **should** and you **must** involve consumers'* (Participant 13, emphasis
32 added) and in a similar vein, another participant talked about consumer involvement being *'a*
33 *requirement rather than a philosophy'* (Participant 1). This provided incentives in the form of an
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3 departments, the old adage of 'rhetoric vs reality' came to the fore, as can be seen in the
4
5 following quote:

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7 *'I don't think we're there [involving consumers fully in research], I think we are a million*
8
9 *miles away from getting there at the moment, but I think that's a nice utopia to aim for.*
10
11 *But yes, I'm convinced by the hypothetical arguments, I just think we're a long way from*
12
13 *having any sort of infrastructure in place that would allow that to happen very easily'*

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16 (Participant 3)

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20 Even those participants that were passionate advocates for consumer involvement and bought
21
22 into its underlying philosophy felt that the reality did not match up to the rhetoric. As outlined in
23
24 the above quote, a lack of supportive infrastructures was often cited as one of the main
25
26 difficulties in realising the potential of consumer involvement. A further complication centred
27
28 around the increase in commissioned and service/priority driven research, which reduced the
29
30 possibility for involving consumers in research. Factors such as short and often immovable
31
32 deadlines, lack of time, limited budgets that do not have in-built finances for consumer
33
34 involvement, and lack of researcher training were the most often cited barriers. The following
35
36 quote highlights these well:

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38
39 *'Research is still driven from project to project so it's a last minute scramble to put in a*
40
41 *funding bid and that doesn't promote effective involvement of the public unless you*
42
43 *already have existing networks there'* (Participant 6)

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48 At one level, this quote and the other barriers referred to above seemed 'reasonable' in terms of
49
50 the authors' experiences of undertaking contract research, but at another level, they uncover a
51
52 lack of investment in the underlying philosophy or ideology of consumer involvement by both
53
54 these researchers and related funding agencies. This is not a deleterious attack on either the
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56 researchers or funding agencies, but does beg the question 'what can be done to provide
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3 supportive environments for active engagement with consumers who wish to become involved in
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5 research?’
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10 In terms of service or priority driven research, the participants here were referring to situations
11 where the research questions and to a certain extent, methodological design were already
12 developed and researchers were responding to the needs/wants of organisations. The task of
13 the researcher in this context was to write a grant proposal to fit into a number of *a priori*
14 assumptions, meaning that consumer involvement was potentially already limited. In the UK,
15 there is increasing national funding for health related research which is open, allowing
16 researchers to set the research question and design and (to some extent) the time-scale of the
17 proposal submission. In theory this should allow greater scope and flexibility for public
18 involvement in research and it would be interesting to see whether this is realized.
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31 A concern of some of the participants revolved around the ways in which researchers and the
32 mechanisms/frameworks involved in facilitating and promoting consumer involvement in
33 research placed ‘research’ at centre-stage and made (implicit) assumptions that consumers
34 ‘should’ want to be involved (what might be termed ‘researchism’). This fits with the notion of the
35 reflexive consumer who has enough information to ‘shop around’ and make choices. The issue
36 here relates to the extent to which research can be viewed like any other commodity in the
37 marketplace whereby consumers have both a demand and willingness to become involved. For
38 example, this particular participant had been working with a marginalised group who
39 experienced multiple forms of deprivation:
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51 *‘I suppose it’s about how important it [the research study] is in what else is going on in*
52 *their lives... and I know there is so much going on in their daily lives, that this [the*
53 *research study] is a very low priority. You know if you’ve got to worry about all sorts of*
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3 *big issues, you're going to be least concerned about going to some research meeting*
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5 *that doesn't directly seem to affect you'* (Participant 1)
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10 The above quote questions the centrality of research involvement within the life-worlds of
11 members of this particular group and leads us to question the representativeness of consumers
12 who choose to get involved in research, which is taken up in the next section.
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17 **Concerns about epistemological dissonance**

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20 In response to questions about the barriers to, and negative experiences of, consumer
21 involvement, participants often talked about consumers bringing different forms of knowledge to
22 the research process. Whilst in much of the sociological literature on 'lay knowledge' or the
23 sociology of science, this would be seen as a positive and enlightening scenario, the participants
24 in this study did not construct it in that way. Whilst the participants did not use the term, they
25 were engaged in an epistemological dialogue about the validity or authenticity of 'consumer/lay
26 knowledge' *vis a vis* 'professional/academic knowledge'. The following quote relates to a quite
27 specific area of health services research, but nonetheless highlights the fundamental issue for a
28 number of participants in this study:
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40 *'I think if we're honest, we have some very basic beliefs about what causes distress in*
41 *our communities. And I think it's those that are in conflict. So for instance, say you are a*
42 *psychiatrist who believes passionately that mental illness exists and it's a neurological*
43 *problem and we just need to find the bit of the brain that's not working and correct that*
44 *and you're sitting around a table trying to do collaborative research with say service*
45 *users who think that's rubbish. You have underlying belief differences'* (Participant 2)
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55 This type of debate will be very familiar to people in medical sociology and public health who
56 have been involved in advocating for lay voices to be both heard, recognised and acted upon as
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3 valid forms of knowledge, rather than as they were hitherto constructed as irrational beliefs
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5 (Williams, 2003; Williams, 2000). However, what is new here is the context in which this debate
6
7 is being played out, whereby researchers are defending their 'professional boundaries'. Indeed,
8
9 one participant talked about consumer involvement being a one-way transference of information
10
11 ('imparting knowledge') from researcher to consumer which is *'good for the general public to*
12
13 *actually know what's going on'* and *'might make them more compliant'* (Participant 8). These
14
15 comments are not necessarily dismissive of the validity of consumer involvement, but suggest a
16
17 lack of reflexivity about the potential for researchers to learn something from consumers or to
18
19 share in new forms of knowledge construction (i.e. the lower rungs of Arnstein's ladder (Arnstein,
20
21 1969)). Much like the critiques within the literature on 'lay knowledge', participants constructed
22
23 consumers as docile or vacuous bodies just waiting to be filled by academic knowledge, which
24
25 fails to recognise the whole point of consumer 'involvement' whereby the researcher and
26
27 research process can and should get a great deal out of involving consumers by virtue of the
28
29 development of a multi-knowledge conglomeration or *bricolage* (Busby, Williams, & Rogers,
30
31 1998).
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38 In terms of laboratory-based medical scientists, it is less surprising to find epistemological
39
40 dissonance given that such research is usually quite far removed from social interaction with
41
42 consumers. Therefore, they often found it hard to conceive of points in the research process
43
44 where consumer involvement could be useful. However, given the increased consumer
45
46 involvement in the research commissioning process, we specifically asked about the value or
47
48 utility of consumer involvement in terms of research agenda setting. However, this was met with
49
50 debate and criticism at the level of epistemology, with comments such *'their experiences cannot*
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52 *outweigh my academic qualifications or knowledge'* (Participant 12).
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3 In order to explain and defend these more generalised constructions of epistemological
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5 dissonance, a number of participants operationalised their criticisms by questioning the
6
7 objectivity and representativeness of consumers who choose to be involved in research. In this
8
9 way, participants raised important points about the notion of a homogenous 'consumer voice'
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11 when many research studies claimed to involve consumers *per se* but actually included
12
13 individuals from particular segments of society. The issue of the 'representativeness' of
14
15 consumers has been raised in relation to involvement in health service planning
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17 (Contandriopoulos, 2004; Fudge et al., 2008), although given the inherent difficulties in recruiting
18
19 consumers for involvement in research studies, it seems that the focus might be placed on
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21 inclusion and diversity of consumers, rather than representativeness *per se* (Beresford, 2007).
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27 Most participants recalled stories of 'professional lay-people' who seemed to occupy the role of
28
29 consumer or layperson on numerous committees and are often constructed as representing the
30
31 'consumer voice', which has also been noted elsewhere (Telford et al 2002). However, these
32
33 people were seen to be located in a hinterland between 'lay' and 'professional' and were often
34
35 constructed as having been professionalised, thereby questioning the authenticity of the
36
37 (consumer) knowledge they hold. The following quote came from a health services researcher
38
39 who was talking about a consumer representative on a recent study, *'well of course we didn't get*
40
41 *Joe Bloggs off the street, we basically got a retired university researcher who happens to have*
42
43 *back pain'* (Participant 9). Selecting consumers with professional status, may partly be a
44
45 reflection of researchers attempt to overcome practical difficulties (such as the consumer's
46
47 perceived ability to contribute in formal meetings) but there is also the possibility that the
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49 researcher's acceptance of the consumer's academic or intellectual expertise increases the
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51 value of their experiential knowledge to the researcher
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3 Given the resources, confidence, social status and time required to act as a 'consumer' in
4 research studies, a number of participants were resigned to the unrepresentative nature of
5 consumers, with comments such as *'they are more representative than nobody'* (Participant 3)
6 being common. In contrast to the constructions of consumers as unrepresentative and 'biased',
7 there were also a number of reflections on the ways in which researchers are also biased and
8 bring personal and pre-set agendas to research. Whilst this was not vocalised by all participants,
9 it is still an important point to keep in mind.
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20 **Concluding comments**

21 We conclude with three key points that seem worthy of further discussion. The first point relates
22 to the veneration of research (or 'researchism') – the idea that consumers recognise both the
23 importance of research and can/want to become involved in research. The idea of increasing
24 'research literacy' was suggested by some participants as a way of helping consumers to
25 develop a 'better' understanding of the research process and to engage in a meaningful and
26 empowered relationship with researchers. Such a process would need to be 'democratic' in
27 order to increase research literacy across social milieu and hence allow the possibility of
28 consumers other than just the 'professional lay person' to be involved in research. However, this
29 idea is rooted in a model in which consumers want to engage with and be involved in research
30 and does not account for a structural patterning of reflexivity, or 'stratified reflexivity' (Ward &
31 Coates 2006; Ward 2006).
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49 In addition, the veneration of research does not take into account the notion of 'functional
50 knowledge' and 'functional knowledge deficits', (Ungar, 2008) which pertains to those forms of
51 knowledge required to undertake one's daily tasks or perform one's roles in society. For
52 example, the kinds of functional knowledge required by a sociologist in order to undertake and
53 perform their role within a University is quite different (although no more or less important) to that
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3 required by a plumber or a parent. Given that the functional knowledge of a researcher will be
4 expected to be different to that of a consumer, this raises questions about the assumed
5 willingness of consumers to want to get involved in research studies.
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11 Moreover even if access to research information was increased, the effects of such access are
12 unlikely to be socially neutral, for example Shilling states that "*different patterns of socialization*
13 *result in class-based orientations towards symbolic knowledge which affect the degree to which*
14 *the social world is seen as open to individual intervention*" (Shilling, 2002 p.634). Thus, it seems
15 likely that those with the economic, cultural and social capital will remain more likely to get
16 involved in research. Indeed, given that the rise of consumerism is often seen as part of
17 'reflexive modernisation' (Beck et al., 1994; Giddens, 1994), the question becomes, how far are
18 consumers engaged in a project of the self or treated as reflexive actors? It seems from our
19 study that there is an 'ideal research situation' whereby researchers buy into (at least at some
20 level) the New Left ideology and perceive methodological benefits of involving consumers.
21 However, the reality is that the researchers in this study were not really engaging on the higher
22 rungs of Arnstein's ladder (Arnstein, 1969) and in a reciprocal relationship with consumers.
23 Researchers were (maybe unconsciously) working along the lines of 'in what ways can the
24 consumers help my research study?' rather than with the question 'what can the consumers also
25 get from being a part of the research study?'.
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46 The second point is around the value of 'lay knowledge' in relation to researchers' views, which
47 often lead to a tokenistic engagement with consumers. Epistemological dissonance centres
48 around a lack of recognition that consumers can bring valid forms of knowledge to bear on the
49 research process. Of particular relevance here are issues around lay-professional knowledges
50 and the privileging of 'expertise' over 'experience' (Glasby & Beresford, 2006; G. Williams &
51 Popay, 2001), the ways in which lay knowledge is blocked or incorporated (Barry, Stevenson,
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3 Britten, Barber, & Bradley, 2001; Scambler & Britten, 2001), and more abstract issues around
4
5 how epistemological divides are constructed to defend boundaries and reconstruct lay and
6
7 professional identities (Irwin & Michael, 2003; Wynne, 1996). The notion of 'epistemic violence'
8
9 (Spivak, 1988) may be used as a way of further understanding this, which positions the
10
11 researcher in the position of the 'knower' (Lewis, 2007) and the consumer in the much less
12
13 powerful (or powerless) position of the 'docile body', ready to be filled with expert knowledge
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15 from researchers.
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20 The final point (which is embedded in the second point above) is around the 'professionalising
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22 strategies' employed by researchers to maintain their power/status and promote the authenticity
23
24 and primacy of their knowledge *vis a vis* consumer or lay knowledge. Whether researchers can
25
26 actually be regarded as being part of a profession is a mute point and cannot be explored here.
27
28 In fact, some would say that the definition of a profession lacks explanatory power and is a 'time-
29
30 wasting diversion' (Evetts 2003) and it has even been suggested that none of the current
31
32 'professions' such as medicine, law and engineering are 'true' professions but are actually
33
34 'expert occupations' (Sciulli 2007). Nevertheless, researchers appear to be engaged in a
35
36 process of boundary defense and maintenance that mirrors the processes being undertaken
37
38 within the healthcare professions (Hibbert et al., 2002). The issue for the future of the research
39
40 relationship is whether a similar set of 'boundary clashes' will occur between researchers and
41
42 consumers, potentially impacting on the nature and extent of 'real' consumer involvement in
43
44 research and the (re)negotiation of the notion of the 'researcher' and the 'consumer'.
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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.