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Barriers and Enablers to Optimal Consumer Involvement in Research: the Perspectives of Health and Medical Researchers in the UK

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Numerous reasons exist for involving consumers in research, falling mainly into three categories: moral/ethical, methodological and political (Boote, Telford, & Cooper, 2002). 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 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). The political imperative is centred on current policy directives in addition to requirements by research funding agencies, research governance organisations, research ethics committees (RECs) (Oliver et al., 2004; Oliver, Rees, Clarke-Jones, Milne, Oakley, Gabbay et al., 2008).

Despite such strong imperatives and policy directives to involve consumers in research (and healthcare planning and provision), recent studies have provided evidence on a gap between policy and practice (referred to as the 'know-do gap' in this paper (World Health Organisation, 2005), whereby researchers are involving consumers much less than policy-makers would hope for (Barber, Boote, & Cooper, 2007).

Who is a consumer of research?

Whilst the role of consumers may have an over-arching 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). 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. This consumerist movement is tied up with notions of market ideology, professional accountability and individual choice, and is essentially a managerially driven concept (P. Beresford, 2007). The New Left push for consumerism is based on the rights of individuals and groups to have a voice, within underpinning values of equity and advocacy.

Both ideologies outlined above 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. However, as Lupton (1997) argued, this leaves little room for an understanding of the consumer engaging in a dynamic and inter-subjective socio-cultural

process, rather than as an outcome of an individualised calculation.

Given the issues raised above, using the term 'consumer' in relation to consumer involvement in research is therefore not an uncontested term and reflects various political, economic and social assumptions that are culturally and historically contingent (Boote et al., 2002; Henderson & Peterson, 2002; Hill, 2007). The notion of 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.

Conceptualising consumer 'involvement' in research

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); for example, "doing research with or by people who use services rather than to, about or for them" (INVOLVE, 2007)1. Such definitions use the term 'involvement', although they seem to be suggesting 'participation', whereby consumers are involved in some level of power sharing or empowerment, rather than solely being 'involved'.

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' getting 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).

In addition, consumer involvement as a 'tick box exercise' is very different to 'real' involvement, as outlined by Arnstein (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 (Crawford, Rutter, Manley, Weaver, Bhui, Fulop et al., 2002; 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 help to overcome any identified barriers.

Methodology, method and analysis

In this study, we used semi-structured interviews, which allowed for explorations and discussions of relevant experiences and perceptions of consumer involvement in research.

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; of those, 15 interviews were undertaken. Data collection ceased after 15 interviews because it was believed that data saturation had occurred.

Findings

The findings presented in this paper need to be situated within the broader findings of the study, in which researchers had only a superficial knowledge of the relevant policies regarding consumer involvement in research and had different understandings and working practices with regards to 'involving' consumers in their research. These working practices ranged from not involving consumers at all, through to the lower rungs of Arnstein's ladder whereby consumers were often involved in a superficial way, rather than engaging in a power-sharing exercise resulting in 'participation'.

The 'know-do' gap

Across all interviews, there was complete 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 its validity, applicability, accountability, transparency and transferability. These reasons fit within the methodological imperatives for involving consumers (Nilsen et al., 2006), but are primarily focussed 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' and that 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 counter-argued on the basis of what was constructed as the 'reality of research'.

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 held by some participants of tokenism (i.e. being pressured into involving consumers), with some participants talking about it as a 'tick-box exercise'.

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 seems to be akin to the carrot and stick analogy, whereby the carrot is the 'ethical imperative' to be a 'good, ethically sound researcher' and the stick being the potential not to get through the ethics review process, or even before that, to not get funding for the research 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 openly about the benefits of involving consumers in research, this was often in a generalised and idealised context (an 'ideal research situation'). 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, it was stated, 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 barriers most often cited.

A concern of some participants revolved around what we call the reification of research. By that, we mean the way in which researchers and the mechanisms/frameworks involved in facilitating and promoting consumer involvement in research all place 'research' at the centre, thereby making (implicit) assumptions that consumers 'should' want to be involved (i.e. a central function of 'the consumer'). 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)

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. Whilst 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)

What is new here is the context in which 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 are possibly more the product of 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. low rungs of Arnstein's ladder).

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 were raising important points about the notion of a homogenous 'consumer voice' and the validity of stating that research studies involve consumers, when in reality it is individuals from within particular segments of society.

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'. 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 bear. 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).

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 not unbiased 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

Whilst we provided some discussion around key findings within the previous section, we feel that a number of areas are worthy of further discussion here.

The first point relates to consumer 'research literacy', which indeed was suggested by some participants. This, it may be argued, would facilitate 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 milieux and hence allow the possibility of consumers other than just the 'professional lay person' to be involved in research.

However, even if access to research information were democratically increased throughout society, the effects of its access are unlikely to be socially neutral. It may only be those with the economic, cultural and social capital who are most likely to get involved in research (Fuller, 2000; Lupton, 1997; Ward, 2006). It seems there is an 'ideal research situation' whereby researchers buy into (at least at some level) the New Left ideology in addition to the 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 and are therefore not working in a two-way relationship with consumers—in the end, researchers were (maybe unconsciously) working along the lines of 'in what ways can the consumers help my research study?' rather than additionally working with the question 'what can the consumers also get from being a part of the research study?'

The second point is around the value or worth of 'lay knowledge' in relation to researchers' views, which often lead to a tokenistic engagement with consumers. The whole notion of epistemological dissonance was centred around the 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 favouring of 'expertise' over 'experience' (P Beresford, 2002; P. Beresford, 2007; Busby et al., 1998; Glasby & Beresford, 2006; G. Williams & Popay, 2001), the ways in which lay knowledge is blocked or incorporated.

The final point (which is embedded in the above point) 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.

Endnotes

1 INVOLVE (www.invo.org.uk) is an organisation that was set up by the UK Department of Health to promote public involvement in health research. However, this is distinct from another organisation also called involve (www.involve.org.uk) that is more broadly engaged in advocating for, and providing resources to enable, public participation in decision-making.

References

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

- Baggot, R. (2005). A funny thing happened on the way to the forum. Reforming patient and public involvement in the NHS in England. *Public Administration*, 83, 533-551.
- 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.
- Beck, U., Giddens, A., & Lash, S. (1994). *Reflexive Modernization. Politics, Tradition and Aesthetics in the Modern Social Order*. Cambridge: Polity Press.
- Beresford, P. (2002). User involvement in research and evaluation: liberation or regulation? *Social Policy and Society*, 1, 95-105.
- 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.
- 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.
- 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.
- Flynn, R. (1992). Managed Markets: Consumers and Producers in the National Health Service. In R. Burrows & C. Marsh (Eds.), *Consumption and Class: Divisions and Change*. Basingstoke: Macmillan.
- Fudge, N., Wolfe, C., & McKeivitt, C. (2008). Assessing the promise of user involvement in health service development: ethnographic study. *British Medical Journal*, 336, 313-317.
- Fuller, S. (2000). *The Governance of Science*. Buckingham: Open University Press.
- 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.
- 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, 46-65.

- 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.
- 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 scientific citizenship. *Science, Social Theory and Public Knowledge* pp. 111-136). Maidenhead: Open University Press.
- 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.
- Milewa, T., Valentine, J., & Calnan, M. (1999). Community participation and citizenship in British health care planning: narratives of power and involvement in the changing welfare state. *Sociology of Health & Illness*, 21, 445-465.
- National Medical and Health Research Council 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., Clarke-Jones, L., Rees, R., Milne, R., Buchanan, P., Gabbay, J., et al. (2004). Involving consumers in research and development agenda setting for the NHS: an evidence based approach. *Health Technology Assessment*, 8(15).
- 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.
- Shilling, C. (2002). Culture, the "sick role" and the consumption of health. *British Journal of Sociology*, 53, 621-638.
- Strauss, A., & Corbin, J. (2004). *Open Coding*. In C. Seale (Ed.), *Social Research Methods*. London: Routledge.
- 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.
- Ward, P. (2006). Trust, reflexivity and dependence: a 'social systems theory' analysis in/of medicine. *European Journal of Social Quality*, 6(2), 143-158.
- 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.
- Williams, S. J., & Calnan, M. (1996). The 'limits' of medicalization? Modern medicine and the lay populace in 'late' modernity. *Social Science and Medicine*, 42, 1609-1620.
- 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.