Defining Evidence
Involvement and Participatory Approaches in Applied Health Research

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Abstract: This article provides an account of service-user involvement in applied health research in the U.K., where such involvement is understood as research ‘with’ or ‘by’ service users. I reflect on some of the driving forces behind service-user involvement in health research and discuss the ways in which this kind of involvement has become systematised in a research context that values comparison and evaluation. I argue that the potential to conflate participatory research with service-user involvement may lead to participatory approaches – so often practiced by anthropologists – becoming described as forms of service-user involvement. Despite the systematisation of service-user involvement to meet the requirements of applied health research, service-user involvement is not viewed as providing research evidence. If participatory approaches become redefined as user involvement then there is a risk that evidence produced by disciplines such as anthropology are no longer viewed as ‘evidence’, and become unable to influence decisions about healthcare practice and policy. Sensitising anthropologists to this possibility may be a first step in identifying ways to ensure that results from participatory research retain a position as evidence.

Keywords: applied health research, evidence, participation, service-user involvement

The Context: Service-user Involvement in U.K. Applied Health Research

Applied health research often aims to inform healthcare practice and policy, and anthropologists across the U.K. are employed in this kind of research. To achieve impact on practice and policy, the research that we conduct must engage in expectations and norms of multi-disciplinary contexts and of colleagues, funders and policy makers. One of the key expectations is that research produces and delivers ‘evidence’ to inform practice and policy. Production of evidence is increasingly bound up with a drive to involve patients and members of the public (‘service users’) in the design, delivery and oversight of research. In this article, I describe and analyse the processes through which service-user involvement is becoming systematised, and try to understand this in the context of the idea of ‘evidence’ in applied health research. By focusing our attention on definitions of ‘evidence’ and by noticing parallels between participatory approaches and user involvement, it becomes clear that participatory approaches to research may become re-labelled as service-user involvement. I conclude with some thoughts about the risks that this might pose.

Support for service-user involvement is provided by national advisory group – INVOLVE – which is part of and funded by the National Institute for Health Research (NIHR). As an organisation, INVOLVE is the main source of information for the health research community about service-user involvement in re-
search, and it provides a repository of information and guidance documents, and holds events including an annual conference. INVOLVE describes public involvement in research as ‘research being carried out “with” or “by” members of the public rather than “to”, “about” or “for” them’ (INVOLVE 2012).

Service-user involvement activities in health research take several forms. Recent literature indicates the predominance of public or patient representation on project steering groups, and attempts by researchers to ensure that their overall project ideas as well as the detail of their design reflect the experiences, views and priorities of patients and the public (Barham 2011; Rowe and Frewer 2005). Much user involvement in research is achieved through ‘panels’ or ‘fora’, which comprise groups of service users convened by research groups to discuss specific research ideas, topic areas or projects. Over the past five years I have been actively working with one such forum, which was recently awarded an Engagement Award by our University. The forum comprises a group of people with personal experience of musculoskeletal health conditions who meet to discuss new research ideas and ongoing projects, and provide their views about the value and design of projects. The forum depends on group members’ own experiences of health, illness and healthcare and has inputted into the design of many new projects, all of which aim to improve healthcare for people living with musculoskeletal conditions (Gooberman-Hill et al. 2013a, 2013b).

Service-user involvement exists against a long-standing backdrop of participatory research hailing from diverse disciplines. Psychologist Kurt Lewin is often credited with first use of the term ‘action research’ in the 1940s (Lewin 1946) and anthropologists are usually familiar with Robert Chambers’ Participatory Rural Appraisal described in the 1980s (Chambers 1983). Sherry Arnstein’s widely cited model – ‘the ladder of participation’ – originated from community development in the 1960s (Arnstein 1969) and it has been suggested that INVOLVE’s perspective on involvement resonates with her model (McKevitt et al. 2010: 87). This ladder of participation states that degree of participation in any given activity can be defined and described as situated on a continuum ranging from ‘high’ to ‘low’ participation. Arnstein placed ‘citizen control’, ‘delegation’ and ‘partnership’ at the upper end of the ladder, and positioned ‘informing’, ‘therapy’ and ‘manipulation’ at the lower end of the ladder. In health research, the drive towards service-user involvement in research places value on forms of involvement that are situated at the upper end of the ladder, in which participation is ‘high’.

Broad driving forces for involving service users in research design and delivery include arguments about research quality and the rights of the public (Gibson et al. 2012; Mockford et al. 2012; Staley et al. 2012; Vale et al. 2012; Ward et al. 2010). User involvement is increasingly evaluated (Oliver et al. 2009), although it has also been acknowledged that impact of involvement on research quality may be hard to define (Fudge et al. 2008). The view that members of the public are the owners of publicly-funded research means that members of the public are also described as having the right to be involved in identification of research priorities as well as decisions about design and funding. It then becomes the responsibility of the research community to ensure that this happens. These arguments accord with ideas around citizen empowerment, which have been played out more widely through activities using methods of deliberative democracy to involve the public in assisting with policy decisions or priorities (Davies et al. 2006; Gooberman-Hill et al. 2008). The drive to ensure that user involvement takes place and has effect also contains moral overtones. As described by McKevitt and colleagues (2010), the moral status of involvement means that recommendations delivered through involvement activities may be afforded particular weight by the research community. Related to this and to the view that public rights are important and that researchers have responsibilities, the importance of respect for involved service users is emphasised in writing about conduct of involvement in research (Hewlett et al. 2006).

It is not necessarily the case that all anthropologists working in applied health research become engaged in service-user involvement. However, in my experience, researchers with a qualitative bent – such as anthropologists – are often those approached to conduct user-involvement activities. I have heard it said that this relates to the view that qualitative research and involvement activities both involve ‘being good with people’ and that the skill-sets required are similar or the same.

These ideas are not unfounded and I would suggest that many of the underlying principles of service-user involvement are well rehearsed within social sciences, not least anthropology. When asked at a public engagement event a few years ago if I was ‘new’ to service-user involvement work I immediately replied that I was not, explaining that anthropology and anthropologists conducting empirical fieldwork would usually (although not always) work in some form of collaborative engagement during conventional fieldwork, and that it was standard that I would normally...
try to align research questions and priorities with those of ‘participants’. In retrospect I now might answer such a question rather differently, not least as while I now think that the idea of collaboration may underpin many anthropologists' ethnographic fieldwork, any overemphasis or simplification of affinity between fieldwork practices and involvement in research may be unhelpful. In part this is because it may be important to understand service-user involvement in research as a growth area in its own right, to understand the prominence of involvement within current thinking about applied health research, and to consider what type of knowledge is produced by anthropology compared with that produced by user involvement.

The drive to conduct service-user involvement is taking place in the context of the imperative to deliver research findings that are grounded in public priorities and that are seen as reliable and verifiable. The credibility of research is assessed by reference to the hierarchy of evidence, on which systematic reviews and randomised trials are positioned as the most reliable form of evidence whereas case studies are seen as the least reliable form (Lambert 2009). The hierarchy of evidence is important within applied health research since if research is to influence policy, then a position higher up the hierarchy is more likely to achieve influence. I return to the relationship between the hierarchy of evidence and service-user involvement later.

### Systematising Service-user Involvement

Participatory approaches have a long pedigree and they usually take place in keeping with an ethos of partnership and collaboration. Partnership and collaboration is often also seen as a hallmark of good service-user involvement in research. Additionally, service-user involvement in health research has become a set of processes and practices in its own right, with underlying logic and driving forces. Recent years have seen the systematisation of processes for service-user involvement in health research. I would argue that in the context of broader discourses about public rights and the moral value of involvement, these serve to bolster the credibility of service-user involvement activities. The process by which this systematisation takes place includes broader work of organisations such as INVOLVE and the importance given to user involvement in assessment of grant applications, alongside standardisation of terminology and the development of guidance relating to conduct and dissemination of involvement.

Researchers applying for grant funding from many major funders must describe how patients or other members of the public have been involved in research design, and funders involve members of the public on decision-making panels. To enable researchers and members of the public to take part in involvement activity, there are guidance notes and publications, including notes about payment of involved members of the public, about how to write plain English summaries and about inclusive practice in involvement (Buckland et al. 2007; INVOLVE 2012). Guidance is publicly available, and within the involvement activity that I am engaged in we make extensive use of the material, including providing copies of INVOLVE’s documents to members of the involvement forum. We have also contributed to INVOLVE’s resources by providing examples of our practice for their website.

In describing and discussing service-user involvement in guidance or elsewhere, the language used is increasingly well defined and standardised, although some terms remain subject to debate. For instance, members of the public or patients taking part in involvement activities are not described as ‘participants’, but may be referred to collectively as ‘partners’ or ‘collaborators’. The term ‘service user’ has been debated and discussed at length, with research exploring how different stakeholders define ‘involvement’ (Rise et al. 2011). As INVOLVE suggests that researchers conducting service-user involvement should aim to work ‘with’ patients and members of the public, the language of collaboration and partnership is central to the idea that patients and the public should be equal stakeholders in publicly funded research. Standardisation of terminology has become part of the endeavour of service-user involvement; I would suggest that appropriate use of terminology is a mark of possession of expertise in service-user involvement.

Alongside debate and a degree of standardisation of terminology, researchers are encouraged to report service-user involvement activity with transparency, and a recently developed checklist provides a formal structure that researchers can utilise to guide this. The ‘Guidance for Reporting Involvement of Patients and Public’ (GRIPP) provides a list of items that the authors advocate should be included in descriptions of involvement work, for instance: level of involvement, process and economic information. The development of a checklist is part of a wider drive to evaluate the impact and value of involvement activities to research, as the authors argue that standardising reporting of involvement enables evaluation of ‘what [service-user involvement] works, for whom, in what circumstances and why’ (Staniszewska et al. 2011). Evalua-
tion of impact is increasingly part of the current agenda, and the Medical Research Council recently funded the development of the ‘Public Involvement Impact Assessment Framework’ (PiiAF 2014). PiiAF was designed to shape the design and subsequent assessment of public involvement in research.

The need to systematise service-user involvement may be best understood in the context of the environment of applied research in which it takes place. Applied research attempts to provide results that will impact on health and health care. Often conducted by multi-disciplinary teams including health professionals, such research will ultimately be assessed and implemented through processes of policy. In these processes, decisions about the relative reliability and therefore credibility of research are informed by the hierarchy of evidence in which some forms of evidence are deemed more reliable than others. The presence and application of the hierarchy is arguably one of the driving forces behind new approaches such as formalised synthesis of published qualitative research as well as the representation of research methods and findings in ways that accord with the style of clinical research. As part of the landscape of health research, involvement activity must show that it is robust and rigorous and can lend itself to comparison and evaluation. The systematisation of approaches is one way to work towards achievement of this.

**Research versus Involvement**

Guidance from INVOLVE makes it clear that members of the public who are involved in research are not participants, and should not be seen as such. Application processes for research funding also emphasise this distinction. However, my experience of health research is that there is frequent need to explain the difference between research and involvement, and this is particularly the case when describing qualitative research, much of which relies on eliciting the experiences of service users. When presenting qualitative research at clinical conferences, I have recently been known to start my talk by outlining the difference between research and involvement, and often return to this distinction in research project planning meetings.

However, in the context of the need to deliver research evidence that can be positioned on the hierarchy of evidence, there is another aspect to the affinity between involvement and participatory approaches that we should consider. For instance, within health research, ‘experience based co-design’ (EBCD) employs many strategies of participation and principles of collaboration to deliver research designed to improve healthcare (Bate and Robert 2007). As a form of participatory action research, EBCD involves a variety of methods, with the aim of ensuring that experiences of service users, healthcare professionals, friends and family experiences are at the core of service design. Alongside these types of approaches, as user involvement is increasingly systematised to ensure that it accords with the clinical research environment and policy decisions, there is also the possibility that involvement becomes conflated with research. I suggest this may mean that the outcomes of participatory research may become defined as non-evidence, therefore failing to be considered in the design of healthcare and related policy.

Helen Lambert (2009) has convincingly argued that evidence-based medicine responds to critiques by incorporating them, and that is why expert opinion is now featured on the hierarchy of evidence. However, with organisations such as INVOLVE and the NIHR couching service-user involvement as informing research rather than as research, it would perhaps be challenging for user involvement to be drawn into the hierarchy. Lambert also argues that anthropology needs to ‘claim legitimacy for our style of knowledge by making it more transparent just what our evidence consists of’ (2009: 20). If anthropology does not make notions of evidence explicit, then there is a risk that anthropological knowledge might not be seen as ‘evidence’. Taking the next step in this argument and in light of the emphasis placed on user involvement as a valid, morally appropriate endeavour, there is then the possibility that anthropological approaches that privilege co-working and partnership run the risk of becoming defined and described as forms of service-user involvement. Not only does this mean that anthropological evidence is then no longer able to influence policy, but this also means that the processes of knowledge production may be uncritically assumed to reflect a particular stance towards moral rights and responsibilities. Given the long history of participatory research and the way in which many participatory approaches are designed to effect change, it would seem a shame that they may become labelled as non-research and less able to influence decisions at national and international levels.

Service-user involvement is now a key part of U.K. applied health research, based on ideas of rights and ownership and bolstered by increasing systematisation. It is hard to argue with these as ideals, not least given the long history of collaboration and partnership in anthropological research. However, anthropologists may do well to consider where anthropological evi-
idence now sits on the hierarchy of evidence, as it would seem a shame if such carefully produced knowl-
edge – which is so often co-produced – no longer has the capacity to influence practice and policy.

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Acknowledgements

The ideas in this article were originally presented at the Annual Meeting of the American Anthropological Association, San Francisco, November 2012. Thank you to the panel organiser, Narmala Halstead, for the opportunity to do. Thank you also to the Medical Anthropology Group at Bristol, particularly Helen Lambert, for thoughts and input on an earlier version of the article.

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