Measuring something real and useful in consumer involvement in health and social care research

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Abstract

Actively involving service users, patients and carers in the creation and development of health research in the UK has recently come under pressure to articulate why involvement is a good use of resources. This has led to a growing interest in creating ways to measure the impact of involving patients, service users and carers in research. However, there is a concern that fundamentally important issues about why we should meaningfully involve service users, patients and carers are missing from the current measurement discourses and activities undertaken in relation to measurement. This paper argues three distinct points, and is based on the experience of the authors working with Folk.us as well as other fields of involvement. Firstly, there should be an open and honest debate about what is meant by the need to measure and assess the effects of involving people in research, addressing issues such as who benefits from the measurement and assessment and why the involvement is being done. Secondly, if at the conclusion of the debate it is deemed necessary to measure and assess, there must be a full and frank discussion about what criteria are appropriate for the proper reporting of involvement activities. This discussion would need to include the less obvious activities that are crucial to active involvement, such as administrative tasks, and where such activities would sit within these criteria. Thirdly, we will consider when such criteria should be applied, at the beginning or end of projects and, indeed, whether one can categorize the 'beginning' or 'end' of involvement.

Introduction

Over the last 12 years in the UK, an increasing number of policies regarding government-supported health care require the bodies responsible for delivering health care and health services research to involve patients and the public. (Department of Health, 1999; Department of Health, 2006). In England, the National Health Service's (NHS) research governance, which is the guidance governing all research where the NHS plays a role, states that 'consumer involvement should exist at every stage of research where appropriate' (Crown, 2005). The term 'consumer' refers to patients, service users, parents and guardians as well as carers of people who use services, and is distinct from being a 'participant' or 'subject' in the research. The political backing for involving consumers can be seen with the continued funding of INVOLVE as a national advisory group, which supports greater public involvement in the NHS, public health and social care research (INVOLVE, 2004). The National Institute for Health Research (NIHR), the umbrella organization for health and social care research programmes, established research design services to help researchers engage with clinicians and members of the public to design proposals for submission to national funding competitions for applied health or social care research (NIHR, 2011). All NIHR research calls are now emphasizing the requirement for involvement in the proposed research, and funding committees are also encouraged to have involvement in the decision making. Similarly, anyone seeking NHS ethics approval needs to detail their involvement activities regardless of methodological or disciplinary standpoint on the national research ethics application form (Integrated Research Application System, 2011).

Consumer or public involvement in research has been defined as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public (INVOLVE, 2004). INVOLVE defines 'public' as patients and potential patients; people who use health and social services; informal carers; parents/guardians; disabled people; members of the public who are potential recipients of health promotion programmes, public health programmes and social service interventions; groups asking for research because they believe they have been exposed to potentially harmful substances or products (e.g. pesticides or asbestos); and organizations that represent people who use services. (INVOLVE, 2004; NIHR, 2011) Involvement in health care and health services research is still largely conceived and defined in terms of 'consultation, collaboration or user control'. These definitions are based on Arnstein's ladder of citizen (public) involvement in civic planning processes, published 40 years ago (Arnstein, 1969). The model of

the ladder is essentially linear – each step, or rung, on the ladder represents another stage on a linear continuum of engagement, leading towards ever greater degrees of citizen power. Implicit in this model is the notion that involvement is hierarchical in nature with citizen control held up as the ultimate 'goal' of participation – an assumption that does not always align with individuals' own reasons for engaging in decision-making processes (Tritter and McCallum, 2006).

Measuring involvement

Several guidelines and examples of involving people in research have been produced (Hanley *et al.*, 2003; Telford *et al.*, 2004); however, recently, the debate has shifted with calls for evidence of the impact of involving people in research. Implicit in this debate is the concept of a 'quality assessment' or set of criteria with which to judge involvement activities; Wright *et al.* have produced appraisal guidelines against which the quality and impact of involvement can be assessed and with this argue that 'service users should be involved in health research only where they generate real benefit and the nature of the user involvement must not be detrimental to either the user or the research quality' (Wright *et al.*, 2010). The recent structured literature review *Exploring Impact* commissioned by INVOLVE (Staley, 2009) highlighted the need for a 'clear structure for describing involvement at the same time as reporting the outcomes of research'. Staley argues that without reporting on the process of the involvement in the research, causal claims regarding its effectiveness cannot be determined.

Why measure or assess involvement?

Even at the very beginning of this discourse there is a problem, because there is no universal definition of what is meant by 'involvement' in the English NHS. There has never been any requirement on any organization or researcher to define or articulate any theoretical or principled position at the outset saying what 'involvement' is; therefore, it is in danger of being whatever anyone calls it. This presents a major issue when considering the effectiveness or impact of involvement. It is very possible that there is no intention for the involvement to have any impact on the services or research or lead to notions of enhanced citizen power as suggested by Arnstein. It is possible that researchers or organizations define a set of activities as involvement, only to satisfy a criterion or requirement of the funding. This would mean involvement is not failing if it has no impact on the actual research or work, as it was never intended to. The only intention for this involvement is that it simply fulfils a requirement for funding. This is clearly a problem if the drive is to measure or assess its impact without a definition of what involvement is. In many ways, this issue highlights a possible benefit in requiring the involvement to be measured or assessed as it may address the real possibility of involvement being translated into anything people want it to be. Therefore, it would be helpful for involvement to have a shared meaning. However, there is a tension between bringing involvement into research and making involvement a subject of research. These are very different things and have different implications. 'Research can be defined as the attempt to derive generalizable new knowledge by addressing clearly defined questions with systematic and rigorous methods' (Crown, 2005), whereas involvement, as

discussed earlier, is about how research is carried out 'with' and 'by' not to or for (INVOLVE, 2004); in other words, we are asking to *research* a way of *doing* research, which seems to assume that involvement is a method. It is interesting that an online resource of NHS Evidence in May 2009 decided 'not to continue with a separate collection for public and patient involvement (PPI) but to address this area and the communities served through incorporating relevant material from NHS Evidence – patient and public involvement into the other specialist collections'. This could be read as an indication that PPI is now considered to be part of good research practice and is not for special note.

There continues to be an issue if there is no stipulation in the first place that involvement should have an impact on what actually happens, then it is difficult and unfair to retrospectively apply a notion of impact that no one knew they were working towards. This would not be such a major sticking point in this debate if the differences and anomalies in involvement practices were not so great. However, the guidance and policy positions on involvement in these organizations do allow for great variations in practices. Many organizations suggest using job descriptions for service users, whereas others, such as Folk.us, do not. Some organizations pay expenses on the day, whereas others have different arrangements. In many ways, this debate could be seen as being the wrong way around, notwithstanding the need for involvement to be organic and self-determining, it would perhaps be better to focus on what is required from the endeavour, in short, to work out what involvement is for before the guidance and policies all appeared. Without some stated aims, it would seem unrealistic to make any meaningful or sensible judgement about its value or success.

One of the reasons why it is important to seek an understanding and shared view of what involvement is, is because involvement is unlike most other activities in health or social care organizations and research. The reason for this is that successful involvement could potentially result in the failure of a project, scheme or plan. If the patients involved thought the research idea to be unnecessary or the design inappropriate, then they many turn down the work.

If involvement is about sharing power, then where people reject ideas or proposals, or say 'no', and what effect this has on the outcome of the proposal or research, is a crucial factor in measuring the success of the involvement. However, again, there is no agreement on whether power is a major element of involvement in terms of policy or practice.

In many ways, the juxtaposition of Arnstein and Wright *et al.* highlights a need for clarity about the intentions of involvement activities; organizations such as Folk.us (2011) take the view that the intention to have an impact is a primary element of involvement and that activities that are not undertaken on that basis cannot be considered as involvement. However, the difficulty this brings is that the impact may not always bring the outcomes as described by Wright *et al.* In a number of NIHR programmes that have patient and public involvement, there have been debates between the patient and the public members about whether poor involvement in a proposed research project is a ground enough to turn down the research for funding. It is often difficult to see what actual power patients or the public have within a structure or process, even those with good guidance such as the *Research for Patient Benefit* (NIHR, 2011) do not say much about the influence of patients within actual process. This is an ongoing debate that does highlight the impact issue; if poor involvement is not a

ground for rejecting a project, then what does that imply about what impact involvement is really expected to have? Possibly very little. However, if the project is sound in all other ways, then does that fit in with the assertion of Wright *et al*. that the project should succeed in being funded? The difficulty with all of this is that involvement that is free to grow and develop may not deliver what policy makers or research managers actually want or what they have set it up to do as, by its very nature, it may challenge the status quo. However, the counter-argument is that involvement might well deliver something much better than was originally proposed. Good involvement can, and sometimes should, result in what could be considered by policy makers or research managers to have the opposite effect to what was intended. One of the reasons for this is because involvement is limitless in what it can achieve; it is the structures and systems that seek involvement which set the limits. The need for involvement to have the potential to challenge and even contradict what it is set up to do and what it can do means that the discussion on measuring and assessing its impact needs to be very careful to ensure it does not result in a set of criteria that imply involvement, which is at odds with those seeking it, is not of necessity considered to be bad or to be failing. To this end, we need to move away from the notion that involvement is a static activity whose outcomes can be determined from the outset, and hence captured using traditional research methods. Folk.us sees involvement as a dynamic process within which the researchers and the service users interact to shape and affect the research. There is a need to determine a shared understanding of involvement not as an outcome-based or measurable activity, but as an understanding of why it is crucial to health care services and research development.

From what point of view can involvement be measured or assessed?

So the next question would need to address the basis on which we make the judgement as to what involvement is and why it is necessary. For example, the models and concepts underpinning social movements where pioneers have reclaimed research, which is defined by themselves. Here, feminism, Black people's activism and disabled people's activism would be obvious sources. To take one very briefly, disabled people's activism, as with all of these movements, grew from the poor treatment of people, which was particularly highlighted in places such as residential care homes in the 1960s and 1970s. Hunt's (1981) 'Settling accounts with the parasite people: A critique of *A Life Apart*' was a piece of research carried out at the residential home where he lived. The research undertaken was in his view and many others, so weighted and designed to prop up the existing system and agree with the staff, that the residents felt completely betrayed. The residents felt the researchers had no idea about their lives and their words and views had been translated into existing prejudices and views, which were commonly held by non-disabled people about disabled people. In many ways, it was this that propelled the argument for, and development of, disability emancipatory research. The explicit aim of disability emancipatory research is that research about disabled people is for the furthering of their rights and self-determination. This approach creates questions about who can do such research (Hunt, 1981), and moreover, can this sort of research ever really be achieved in a research culture where funding and approval is

mostly, if not exclusively, presided over by non-disabled people (Barnes, 1996; Oliver, 1997). A contrasting model is that of citizens' juries, which are made up of a 'best fit' (demographic) sample of 12–16 members of the public and are used where there is a 'live' contentious issue to be debated. The concept of the citizens' jury is to help work towards a decision where the way forward has not been decided or where workable policy options have been developed by policy makers about how to respond to the issue in question. The underlying belief is that citizens' juries can deliver decision making, which better reflects the public's views, and are a high profile example of public engagement (People and participation.net: Citizens' Jury, 2011). This is a model where census is of key importance in finding a response to public issues and does not explicitly seek to enhance the circumstances of the individuals within the process. Arguably, all these debates are evolving and changing and their very existence shows that research has moved a long way because Hunt's experience and the move towards notions of involvement are definitely evident in all the references within this paper and the hundreds not mentioned here.

Heading towards a shared understanding

The questions outlined here remain very pertinent, and clearly highlight where the debates are in patient and service user involvement in health research. If there is not a clear understanding of why patients and service users are involved in research development and design, then it is premature to discuss how to measure or assess its impact. These are issues that need to be addressed if there is to be any real sense of what it is that is measured or assessed. Folk.us would align themselves with the view that involvement in research should provide an opportunity as well as the support for patients and service users to undertake their own research, which leads to some furthering of their own situation. However, whether this aim is one that is shared with the involvement activity across NIHR or the NHS is not clear.

Similarly, if guidelines or checklists for reporting and assessing involvement in research are to be developed, these have to be grounded in what the purpose of the involvement is to begin with. For example, if the function of involvement is to alter the research design, then the process of involvement would need to ensure that this can happen by, for example, making sure there are accessible spaces to meet and paying people's travel and time. There is good, reliable information about involvement practices. One good source is the *Route map* (TwoCan Associates, 2010). Practical issues of involvement have long been debated. However, the practice and purpose of involvement cannot be separated if a judgement is to be made as to whether the involvement was 'good' or not. Any measure or assessment of impact would have to have been explicitly linked to the theoretical standpoint, which is guiding involvement activities. At the moment, there are involvement activities that are not grounded in purpose or theory, resulting in the possibility that measurements or assessments are applied to only one aspect of involvement, the way it is done and not *why* it is done. Perhaps, more critically, the way involvement is done invariably affects its purpose, which would be limiting, and hence diluting of the possible effect involvement could achieve. In essence, involvement could become defined by what it is not and cannot achieve rather than the scope of its aspirations.

Involvement activities should allow the research to be shaped and evolved according to people's views. However, how these decisions are approached and what barriers are overcome within the process may well depend on what purpose the involvement has in the first place. If involvement is about empowerment and equality, then it stands to reason that any barriers or difficulties to involving people would need to be challenged and resolved. If not, it is unlikely to achieve its outcome. However, if the purpose is to reach an agreement that is acceptable to the researchers, then perhaps there is less emphasis on or need to challenge any difficulties that arise. The judgement about impact would be focused on the consensus that is achieved and not the process.

The final issue is that what can be measured or assessed is not 'involvement', because as already said, involvement is not static, it is not actually really an activity, it is people's lives. It is the structures, systems and projects that can be measured and assessed. People's involvement does not stop simply at the end of a project or initiative. It is only the project or initiative that stops. So if criteria or assessment are agreed, working out when and where it would be applied will be just as difficult.

In summary, any measure of involvement must depend on what involvement is for, and while the debate about how to measure and assess involvement continues, there needs to be an accompanying discussion about the need for researchers, commissioners and policy makers to be explicit about who is to be served by involvement and what the process is supposed to achieve, and whether any contradictions are considered an acceptable, indeed essential, part of the endeavour. It is very unlikely that involvement will deliver both agreement and citizen power at the same time as these are, by nature, different; hence, one or the other has to be the ultimate aim. In turn, the aim dictates the approach taken. It is the aim that will give confidence to those supporting involvement to demand and create the appropriate changes in systems and structures to allow involvement to be embedding into NHS research practices. As it stands, involvement is being 'shoehorned' into existing ways of workings, which means it achieves little.

The authors of this paper recognize that they have characterized the arguments in uncomplicated terms, and that the portrayal of models has been simplified and limited. Indeed, there are many models of involvement that have not been mentioned or described here. Also, the examples given have not included all the nuances that exist in reality. In essence, the debate laid out is somewhat 'black and white'. However, for many working in the field of involvement, the reality is the choice between serving those involved or the needs of the system or structure they are working in, and these two things are rarely, if ever, the same. There is little guidance on which takes priority. As already said, this poses a major issue for measurement and assessment of impact.

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