

Developing the evidence base of patient and public involvement in health and social care research: the case for measuring impact

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Abstract

While patient and public involvement (PPI) in health and social care research has progressed successfully in the last decade, a range of difficulties with the evidence base exist, including poor understanding of the concept of impact, limited theorization and an absence of quantitative impact measurement. In this paper, we argue that a paradigm change towards robust measurement of the impact of involvement in research is needed to complement qualitative explorations. We argue that service users should be collaboratively involved in the conceptualization, theorization and development of instruments to measure PPI impact. We consider the key advantages measurement would bring in strengthening the PPI evidence base through a greater understanding of what works, for whom, in what circumstances and why.

Introduction

Over the last decade, there has been increasing focus on patient, public and service user involvement [patient and public involvement (PPI)] in health and social care in the UK and internationally (World Health Organisation, 2006; Staniszewska, 2009; Farrell, 2010). In addition to involvement in health and social care service development and design, patients and the public have become increasingly involved in health and social care research. Recently, Professor Dame Sally Davies, Director General of National Health Service Research and Development in England and Chief Medical

Officer, stated that PPI in health and social care research should be the norm, not the exception (Staley, 2009), to enhance the quality, relevance and acceptability of research. PPI in research has ranged from consultative forms of involvement to more collaborative forms, with service users as partners in the research process, to user-controlled research, where service users take the lead in a study (Hanley *et al.*, 2004; Faulkner, 2010; Morrow *et al.*, 2010). It is important to acknowledge the different terminologies used in this area. While PPI is a more common policy description, individuals involved in research often describe themselves as service users rather than patients or the public, particularly as they are often not

patients during their involvement. We will refer to 'service users' to reflect this perspective and PPI when describing the area more broadly.

The involvement of service users in health and social care research has been embedded into all aspects of the research cycle. This has ranged from the prioritization of research topics, development of research focus and questions, to the analysis and dissemination of research findings and follow-up action. This successful embedding of PPI is reflected in the research funding application process, where researchers are commonly asked to demonstrate how they will involve service users in their studies. For example, the National Institute of Health Research in England routinely requests that researchers include plans for involvement in their protocols (National Institute for Health Research Website, 2011).

The evidence base of PPI

While PPI in health and social care research has progressed successfully in the last decade, the evidence base underpinning this activity remains partial and often lacks coherence (Crawford *et al.*, 2002; Staniszewska *et al.*, 2008; Brett *et al.*, 2009; Mockford *et al.*, 2009; Staley, 2009). A range of difficulties exists, including poor conceptualization, limited theorization, little attention given to the quantitative measurement of impact and poor reporting (Mockford *et al.*, 2009; Brett *et al.*, 2009; Staniszewska *et al.*, 2011a). Concepts have been used interchangeably, with PPI variably defined and often poorly described. As a result, it is difficult to judge the conceptual equivalence of studies, that is, whether they are focusing on the same concept or different but related ones (Staniszewska *et al.*, 2008; Brett *et al.*, 2009; Mockford *et al.*, 2009). Concepts are also important because they form the building blocks of theoretical models or frameworks (Boote *et al.*, 2006). Progress on developing a strong theoretical underpinning for PPI has been variable, and there is no one agreed theoretical framework that adequately captures its essence. Theoretical frameworks are important because they can provide a detailed blueprint of a phenomenon that can guide instrument development (Nunnally and Bernstein, 1994). The application of theoretical frameworks is illustrated by the field of patient-reported outcomes (PROs). Ware and Sherbourne (1992) theorized that quality of life is made up of eight dimensions, which should always be included in any attempt to measure patients' perceptions of their quality of life. They operationalized their theoretical framework in the development of the Short-Form 36 health survey, which measures eight dimensions of health (Ware and Sherbourne, 1992). While the content is not directly relevant to PPI, the methodological approaches utilized by patient-reported outcome measures (PROMs) have relevance to PPI. For example, the psychometric methods used to develop robust measures could be applied directly to PPI. Concepts such as reliability and validity are also relevant in ensuring the robustness of measures.

In addition to difficulties with conceptualization and theorization of PPI, there has been little focus on measuring the impact of involvement. Recent reviews have found that impact tends to be reported qualitatively; reporting is variable in content and often poor in detail, making the evaluation of impact very difficult (Oliver *et al.*, 2004; Brett *et al.*, 2009; Mockford *et al.*, 2009; Staley, 2009). The inconsistent and often poor reporting of impact

data perhaps reflects the lack of reporting guidance, although work is now under way to develop such guidance in order to create the consistency required for a strong evidence base (Staniszewska *et al.*, 2011a). While we have seen the development of quantitative forms of measurement in areas such as PROs and in patient experience, there has been little parallel quantitative thinking in PPI, or any significant attempts to develop instruments that measure impact (Brett *et al.*, 2009; Mockford *et al.*, 2009). As a consequence, there has been little discussion of the need to involve service users collaboratively in the methodological development of instruments – neither have users been involved – or in defining the content of instruments that should measure the impacts of importance for both service users and researchers, with some exceptions that have explored the potential for service users to lead or collaborate on the development of instruments (Rose *et al.*, 2011).

While interest in such possibilities has emerged, some have argued that PPI is derived from a democratic right. For example, the United Nations Convention on the rights of persons with disabilities states that 'considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them' (United Nations, 2006).

However, other pragmatic arguments acknowledge the need to justify expenditure on PPI in times of fiscal constraint, as well as practical insights as to what appears to work best and for whom and in what context (Staniszewska, 2009). While some may view the interest in measurement of impact as primarily the focus of researchers, it is important to recognize that many service users view this as an opportunity to identify the impact they make and to add to our understanding of the value it brings (Brady *et al.*, 2011). In addition, many service users involved in research are keen to see the direct impacts of their involvement. In one study, the young people involved in a group wanted to see direct, practical results soon after their inputs into a project (Pear, 2010). The debate around measurement of impact provides a reminder that any form of measurement sits within a political or ideological context that cannot be ignored. It is important that the developing discussion of ideological differences around user involvement in research is considered as part of this debate (Beresford, 2007).

While acknowledging the important contribution PPI makes to the broader democratization of research, in this paper we argue for the need to move beyond guidance on how to do PPI or capture impact, to the development of instruments that measure the impact of PPI. We recognize this is a significant paradigm change in this area, but one that is needed to enhance our understanding of the difference PPI makes to research.

The importance of collaborative PPI in instrument development

While service users have often been involved in instrument development in the field of PROs as sources of data, for example, by being interviewed about what it is like to live with a condition, examples of more collaborative involvement in the development of PROMs are rare. Concerns expressed about the extent to which PROMs actually focus on outcomes of importance to patients (Haywood *et al.*, 2010, 2011; Rose *et al.*, 2011) have raised the need to consider more collaborative forms of involvement in PROM development which might be more effective in ensuring

instruments include outcomes of importance to service users (Staniszewska *et al.*, 2011b). These issues have resonance for the development of instruments that aim to measure the impact of PPI. As we are now poised to develop such instruments, the case for collaborative user involvement in this process has never been stronger.

The evolution of measurement

The art and science of measurement is a vital part of many forms of research, whether they are in the natural, social or health sciences. Measurement in the laboratory sciences has played an essential role in developing scientific understanding. Many aspects of laboratory science can be measured without inherent difficulty through the development of appropriate instruments, although error in measurement is rarely eliminated (Streiner and Norman, 2008). In the last few decades, clinical research has become more complex. The impact of treatment on quantity of life has been partly replaced with an interest in quality of life. In order to evaluate quality of life, attention was given to trying to measure elusive concepts that had appeared impossible to measure and to assess them in a reproducible, feasible and valid way. Since then the field of PROs has emerged with a plethora of instruments designed to capture more subjective impact of treatments on individuals. While the move from more 'scientific' to subjective measurement may have seemed very difficult, it may not have been as formidable as first thought, as psychologists and educators have been grappling with such issues for many years, culminating in the development of very thorough and carefully considered psychometrically derived methodologies (Fayers and Machin, 2007; Streiner and Norman, 2008; Hobart and Cano, 2009).

Concerns raised in the past about the measurement of quality of life have also been seen in the field of PPI, with some questioning the feasibility of measuring some aspects of PPI (Barber *et al.*, 2011). Our response is that by drawing on experiences from fields such as psychology, education and PROs, meaningful measurement of PPI impact is feasible. However, one important difference, as already discussed, is that service users must be collaboratively involved in instrument development to ensure measurement is meaningful. We need to move away from models of working where service users only contribute to the content of instruments, to one where service users are part of the research team and contribute collaboratively to all aspects of instrument development. In this paper we argue the case for developing instruments to measure the impact of PPI by identifying some of the potential benefits it could bring.

Developing robust measurement

As already outlined, measurement of subjective and often elusive concepts has become feasible over the last few decades. Psychometrically derived approaches utilized in areas such as PROs offer much potential for the development of instruments to measure the impact of PPI. While we acknowledge that qualitative approaches can provide a vital and rich insight into impact, our position is that well-developed instruments can provide a quantitative assessment of a qualitative construct, and so can add to knowledge in a number of ways. One way is through utilizing measurement approaches to tap into the complexity of involvement. The field of

health measurement has long recognized that it is not enough to ask one question to capture a complex concept, and the use of rating scales made up of multiple items (questions) has evolved, in which each item addresses a different aspect of the same underlying construct (Streiner and Norman, 2008). The advantages of such approaches can be transferred to the field of PPI, where they could work well in unravelling some of the complexity of PPI impact. The use of psychometrically derived measurement approaches would enable the development of instruments with known performance properties, such as reliability and validity. Using such instruments would enable us to understand how well we are measuring the concept of interest, how much error exists in the measurement, how robust an instrument is and so how much confidence we place in the results.

Developing conceptual and theoretical clarity

The development of an instrument to measure the impact of PPI would need to be based on a theoretical model or framework that captures all aspects and dimensions of the concept, including the different levels of involvement. This in itself would provide an opportunity to start clarifying some of the ambiguity that currently exists in parts of the evidence base, for example, by identifying the areas of impact that should be included in an instrument to ensure its content validity. It would also offer the opportunity of explaining how important elements such as the context and process of PPI are considered in the development of an instrument and in the evaluation of impact.

PPI as a complex intervention

Any theoretical model of PPI underpinning instrument development would need to consider involvement as a complex intervention. The Medical Research Council Complex Interventions Guidance (Craig *et al.*, 2008) defines complex interventions as having several interacting components, which can present special problems for evaluators. Many of the problems relate to the difficulty of standardizing the design and delivery of such interventions, their sensitivity to features of local context and also the length and complexity of the causal chains linking interventions with outcomes. All of these elements resonate with PPI, which is made up of many interacting components, can differ according to local context and can be very complex as an activity, all of which make consistent evaluation difficult at present. Considering PPI as a complex intervention at the start of theoretical development would offer the opportunity of embedding this into the instrument (or instruments), further promoting the possibility of meaningful measurement of a complicated phenomenon. This may mean that instrument development needs to consider not only the content of an instrument (that is the items, questions or dimensions used to measure a concept), but in the case of PPI, it could also measure other components such as the context and process of involvement, elements that are important in the evaluation of impact (Brett *et al.*, 2009).

Impact for whom

In developing instruments to measure impact, it will be important to recognize that there are different audiences and purposes for

measuring impact. For service users, it may be about demonstrating that they can make a difference and raise the quality of research. For researchers and research funders, it may be about persuasive evidence that effective PPI improves the quality of research by making it more relevant to the needs of the people it is intended to benefit and so theoretically have more impact on their health and well-being.

Understanding the nature of impact

Utilizing a theoretical framework when developing an instrument to measure the impact of PPI would be helpful in considering which aspects or dimensions of impact need to be included in the content of an instrument. Recent synthesis of systematic review data from two studies that aimed to assess the (1) impact of PPI on research (Brett *et al.*, 2009) and (2) impact of PPI on health and social care (Mockford *et al.*, 2009), has found that the content validity of studies is often very poorly reported (Staniszewska *et al.*, 2011a). Content validity is a judgement of whether an instrument samples all the relevant or important content or domains (Streiner and Norman, 2008). It is not always clear whether studies have focused on certain areas of impact or whether they examined a number of areas and only reported on what they found. Such ambiguity in reporting could be very effectively addressed by using instruments that measure well-defined areas of impact and through more complete reporting of findings from such measurement, whether there was evidence of impact or not.

Understanding the extent of impact

Recent reviews have identified a range of impacts that have resulted from PPI (Brett *et al.*, 2009; Mockford *et al.*, 2009; Staley, 2009). These reviews focused on identifying the impact of PPI on health and social care services (Brett *et al.*, 2009; Staley, 2009) and the impact of PPI on health and social care services (Mockford *et al.*, 2009). However, the descriptions of impact contained in these reviews are often brief and provide limited evidence of impact. Longer qualitative descriptions often provide a better insight into impact. However, while such descriptions can be very valuable, they provide no indication of the extent of impact or its magnitude or how it compares across different areas of impact. Measurement of impact would provide this opportunity and as such would enable a clearer landscape of PPI impact to emerge. Over time such measurement studies would contribute to enhancing this evidence base.

Understanding impact for different stages of research and different groups

Measurement of the impact of PPI would enable us to consider how different PPI activities impact at different stages of the research process in a consistent way, helping to develop a clearer picture of where particular forms of PPI have a greater impact than others, in what contexts and with which processes. In addition, it would allow us to explore how PPI impacts on different groups, including both service users and researchers. The nature of measurement would allow us to explore whether impacts are negative

or positive, which is particularly important when considering that negative impacts are often under-reported (Staniszewska *et al.*, 2011b).

Understanding what works, for whom, in what circumstances and why

Our ultimate aim is to develop instruments that can measure the impact of PPI and so allow us to develop a more comprehensive understanding of what PPI works, for whom, in what circumstances. The development of these instruments would be underpinned by a realistic evaluation approach in order to capture the complexity of PPI (Pawson and Tilley, 1997). The application of robust instruments to measure PPI impact would add a further layer of understanding that could complement our qualitative understandings and would enable an exploration of the influence of different factors on impact.

Utilizing scarce resources

The utilitarians among us might argue that in a time of fiscal constraint, it becomes even more important to utilize scarce resources well, and understanding what forms of PPI might work better in certain contexts might enable us to achieve this. The pragmatists among us might argue that such evidence becomes a necessary form of protection in a society which might only fund involvement when there is some evidence of benefit. While we would not necessarily support this very pragmatic approach, there is no doubt that strong evidence would provide further support for the continued funding of PPI in research at a time of unprecedented fiscal pressures.

Building good quality PPI

While this paper has focused on the need for measurement, it is important to recognize that PPI activity needs to be of good quality to provide the potential for impact to occur. Understanding the context and process of PPI is a vital element in the interpretation of impact (Brett *et al.*, 2009). Thus, we need to reflect on and build an understanding of what good PPI looks like (Telford *et al.*, 2004; Boote *et al.*, 2006; Morrow *et al.*, 2010; Wright *et al.*, 2011).

The future

In this paper, we have argued for the need to collaboratively develop quantitative instruments to measure the impact of PPI in research. While we value and acknowledge the contribution that qualitative data make to our understanding of impact, we also believe that quantitative forms of measurement would strengthen our evidence base. We recognize that the development of instruments to measure impact does represent an important change in the field of PPI. However, we would describe it as an evolution rather than revolution, moving it from an area that primarily relies on qualitative and retrospective evidence, narratives and case studies to one that also draws on principles of robust measurement and collaborative involvement. This will, we believe, enhance our understanding of the difference PPI makes to research and its benefit for patients and the public.

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