6 | *Patient and public involvement in research*

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Contextualizing patient and public involvement in research

The increased interest internationally in patient and public involvement (PPI) in health and social care research cannot adequately be understood in isolation. It needs to be seen in the context of broader social and political developments. Emergence of PPI in research reflects major changes in both national and supranational politics and in grassroots social movements. Putting it in context allows us to move on from the tendency to treat participation at all levels in warm terms as like 'mom and apple pie' (Beresford & Croft, 1993). However, the complexity and ambiguity of both the practice and the conceptualization of participation also make it essential to problematize it.

This is reflected in the most recent expression of participatory democracy at the time of writing this chapter: the public referendum decision for the United Kingdom to leave the European Union. It is difficult to see how this outcome of public participation is likely to serve the economic, political or social interests of most of those who voted for this option. We perceive PPI in research as inseparable from the larger societal context in which it emerges. PPI is closely inter-related with and no less problematic than participatory democracy, or as Madden & Speed (2017) put it:

> "The normative shift toward PPI has taken place within a neoliberal policy context, the implications of which need to be explicitly considered, particularly after the Brexit referendum which has left policy makers and researchers wondering how to better appeal to a distrustful public subjected to 'post-truth' and 'dog whistle' politics."

It is important to note that there has not been one single driving force behind PPI in research. Instead at least two key sources of interest can be identified: the state and its policy-makers on one side and service users and their organizations on the other. These have emerged at different times and with different underpinning ideologies and principles.

145

One of the obstacles to the development and implementation of PPI in research has been the tendency to confuse and conflate these main two drivers, which can be seen to have different aims and processes. Both are critically linked with political changes taking place in the latter part of the 20th century, that is, the shift away from post-war policies of state intervention, welfarism, statist service provision and aspirations to reduce social and economic inequality, towards a more neoliberal, market-driven, globalized and individualistic politics (Beresford, 2016).

It is impossible to approach the topic of PPI in research from any neutral perspective and one can only make one's own standpoint transparent. Our approach is greatly informed and influenced by our long-term engagement in the disabled people's movement including federal and international organizations of patients, mental health service users and psychiatric system survivors. Our efforts to understand and advance PPI in research originate much more from the experiences and lessons learned from being involved than from involving. We hope that our critical approach towards various activities termed as PPI will foster further analysis, rethinking and strengthening of PPI initiatives.

Competing approaches to involvement in research

The UK has played an important pioneering role in the development of both the democratic (Beresford, 2002) or rights-based (Madden & Speed, 2017) and the consumerist (Beresford, 2002) or pragmatic and outcome-oriented PPI (Madden & Speed, 2017). However this is not to say that these two developments have not blossomed much more internationally or indeed globally.

The first of these developments was the emergence in the UK during the 1970s of emancipatory disability research (Hunt, 1981; Campbell & Oliver, 1996; Barnes & Mercer, 1997). This grew out of disabled people's dissatisfaction with their treatment at the hands of state welfare policy; their rejection of their inferior status in society; and the barriers and discrimination they faced. It resulted in the creation of the disabled people's and then other welfare service users movements (Campbell & Oliver, 1996). It was also associated with their distrust of conventional research which they saw as on the side of service providers, advancing the existing research agendas, rather than service users being able to articulate and follow their own research priorities. This model was first

advanced by the disabled people's movement and relates to feminist and community education models of research (Reason & Rowan, 1981; Roberts, 1981; Oliver, 1983; Maguire, 1987; Oliver, 1990). It has had three key concerns:

- to equalize the relationships of research production between researcher and researched;
- to support the empowerment of research 'subjects' shifting their role to that of participants; and
- to achieve broader social and political change in line with the rights, demands and interests of such groups and constituencies.

The second driver of public and patient involvement in health and social care research came much later, from mainstream researchers and the service system. A significant indicator of the emergence of this interest was the establishment in 1996 of the governmental National Institute for Health Research body INVOLVE, committed to this goal (INVOLVE, 2015). Originally it was called *Consumers In NHS Research*, a title that reflects the prevailing ideological origins of such state or service system interest in public involvement in research. This approach and its ideological basis have predominated in state- and service-led approaches to user involvement in research and other aspects of social work and social policies. It is not difficult to see also how this can be consistent with market-led and even neoliberal ideological approaches to politics and policy, with both sharing consumerist values.

The first ideological approach to user involvement in research can helpfully be described as an empowerment or democratic one, where the aim is the redistribution of power and authority, away from researchers and research funders, to serve a liberatory purpose for research participants. The second is appropriately understood as a consumerist/managerialist one (Beresford, 2002). It tends to be based on the argument that it is important to include the perspectives of people on the receiving end of research to ensure that the consumer voice is included to ensure greater research efficiency and effectiveness and to gain the benefit of user views. So here the service user and their opinions serve as an additional helpful data source for shaping and undertaking research.

If the first approach is essentially about empowerment, the second is more concerned with extraction. But confusingly, both approaches use the same language, the same terminology, the same rhetoric. This may help explain why there are so many misunderstandings, damaged

hopes and unfulfilled expectations in relation to PPI in research. The reality is that it is a very different matter to be involved in research in an advisory or consultative role than it is in a controlling one and betokens very different research ends and means.

Thus PPI may be seen to serve both regressive and progressive roles in population health improvement. So, for instance, pharmaceutical companies use individual patient testimonies to maintain a narrow emphasis on treatment with medication, while user-led organizations have highlighted holistic and social approaches. How these roles of PPI are understood is also conditional on the ideological and political perspective adopted. Consumerist user involvement research, with its emphasis on consultation, market research and intelligence gathering, readily serves the purposes of outsourcing, privatizing and choice agendas, with their commitment to audit, satisfaction surveys, outcome measures and regulatory frameworks (Simmons, Powell & Greener, 2009). The same is not necessarily true for user-controlled research. Its democratizing impulse and commitment to redistribute power can lead to conflict with prevailing policy and research agendas and a sense among its advocates of being tokenized rather than truly involved. This happens when service users are expected to serve pre-defined research purposes and acquire smaller technical roles within traditional research scenarios (Russo & Stastny, 2009). We will consider these issues in more depth when discussing different forms of PPI and efforts to understand and measure its impact.

Note on terminology

Public and patient involvement is an umbrella term for activities and efforts taking place under different frameworks such as civil society and service user/consumer involvement or participation in research. The term 'patient' is often not a term of preference among those attempting to acquire other roles in research than that of the research subject. Furthermore, different understandings and practices of PPI often find their expression in the terms used. In order to present and discuss those different approaches we decided to keep those different terms throughout this chapter rather than impose consistency. The terms involvement and participation are used interchangeably in this chapter to mean the same.

PPI initiatives in research: a summary overview of selected examples

The World Health Organization's Declaration of Alma Ata from 1978 appears to be one of the first international policy documents with an explicit statement that "[t]he people have the right and duty to participate individually and collectively in the planning and implementation of their health care" (World Health Organization, 1978). As described in Chapter 5 of this volume, the uptake of this idea has been very uneven across different countries and regions, not least because of the lack of service users' and patients' organizations in many parts of the world. In those countries where such representative organizations exist, the development of PPI can primarily be traced in the implementation and evaluation of health care and is far less present in research and knowledge production (World Health Organization, 2006). The degree of inclusion of civil society and in particular patient representatives in research also varies. While in some countries PPI remains a foreign concept, in others we can already talk in terms of the 'mainstreaming' or even 'institutionalizing' of PPI in research, and we illustrate this with selected examples below in order to provide a sense of how different structures or initiatives to foster PPI emerge and what their work can look like. We choose to describe briefly two national organizations, one international, academic initiative, one international research project led by a patient organization, and one value framework developed by a national service user organization. Later on we will refer to these examples and their different purposes and origins when discussing the overall impact and future of PPI.

NIHR INVOLVE, UK

The already mentioned organization NIHR INVOLVE is a national advisory body based in the UK (INVOLVE, 2015), although its future is uncertain. Funded by the National Institute for Health Research (NIHR), this governmental initiative is unique not only because it is almost certainly the longest-established organization of its kind (founded in 1996) but also because of its international visibility, expertise and number of resources produced over the years. INVOLVE's main goal is to "support active public involvement in social care and health research" (INVOLVE, 2015) and

its webpages include a rich collection of publications, webinars and clips that speak to different audiences including researchers, research funders and commissioners as well as those interested to influence research as public or patient representatives. These various resources cover a broad spectrum of topics such as guidance on how to start PPI in research and how to create training and support packages, advice on payment and recognition of public involvement, debates on assessing the impact of PPI, and others. Use of accessible language and their free availability make INVOLVE materials a helpful starting point for individuals and organizations interested in PPI in the UK and beyond. The materials include briefings for researchers about how to work in participatory ways, a toolkit for planning the cost of involvement, issues around including black and minority service users in research, a jargon buster, explanations of user-controlled research and other resources. Additionally, INVOLVE provides a directory of organizations interested in PPI, including some based outside the UK; it organizes regular conferences and provides advice. The very existence of this unique organization continues to impact internationally. INVOLVE has, for example, had an important role in developing the framework for user involvement in research in Denmark (Hørder, 2012), where the Knowledge Center for User Involvement (ViBIS) was established in 2011. Materials produced by INVOLVE also supported and under-pinned early claims of mental health service users in Germany for their involvement in research (Russo, 2004).

The Patient-Centered Outcomes Research Institute (PCORI), USA

The US-based Patient-Centered Outcomes Research Institute (PCORI, 2011–2017) is a federal, non-governmental initiative. Unlike NIHR INVOLVE, it has the aims of funding health research projects that are relevant to patients in terms of the initial research questions, engaging with public and patient representatives throughout the research process, and also ensuring that the relevant outcomes will be accessible to patients to help inform their decisions. Patient and carer representatives are involved in the studies' review process together with other experts; the funding decisions are made by the organization itself with limited patient involvement. PCORI supports patient-centred outcomes research and comparative clinical effectiveness research. The research studies within

these two categories tend to be conventional in their methodology. They include randomized controlled trials, pragmatic clinical studies, and observational and methodology studies. Participatory approaches, community action and collaborative research are not explicitly mentioned. PCORI started funding research in 2012 and the full list of 570 projects that this Institute had funded by the end of 2016 can be found on their website (Patient-Centered Outcomes Research Institute, 2011–2017). One investigation of the projects that PCORI funded in its early years (2011–2014) has opened up significant dilemmas about whether the scope and the mission of this organization are actually reflected in its allocation of grants (Mazur, Bazemore & Merenstein, 2016).

PCORI has also provided funding to the US Cochrane Center's initiative, Consumers United for Evidence-Based Healthcare (CUE), to help building the PCORI community among other aims (Box 6.1) (CUE, 2017).

The *Governer Board* of PCORI is in part appointed directly by the Comptroller General of the United States. It has a total of 21 members, three of whom have to be patient/consumer representatives. Additionally, PCORI has a number of committees including, for example, the Methodology Committee which "defines methodological

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Box 6.1 Consumers United for Evidence-Based Healthcare (CUE)

CUE is a national coalition of health and consumer advocacy organizations, which was established in 2003 on the initiative of the US Cochrane Center. It comprises about 40 member organizations, which are not supposed to be dominated by pharmaceutical companies or any other commercial interest. CUE seeks to promote the health of populations and the quality of health care through "empowering consumers, public health policy makers, and healthcare providers to make informed decisions" (CUE, 2017), based on the best available evidence through research, education and advocacy.

CUE focuses on training and empowering patients and their organizations in order to foster their partnerships with policymakers. They offer a number of useful online resources such as free online courses, webinars, lectures, video summaries of Cochrane reviews, etc.

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standards for PCORI-funded research and guides healthcare stakeholders towards the best methods for patient-centered outcomes research". We were not able to identify any patient representatives on this or any other committees, nor any related rule.

International Collaboration for Participatory Health Research (ICPHR)

The International Collaboration for Participatory Health Research (ICPHR) started in 2009 with the goal of strengthening participatory approaches to health research in terms of its definition, enhancing its quality and reinforcing its impact (International Collaboration for Participatory Health Research, 2014). Besides members from Europe, Australia, Canada, New Zealand and the USA, it brings together academic researchers also from Bangladesh, Brazil, Ghana, Mexico, Peru and Thailand. They all address health inequalities in their work, focus on voicing the needs of disadvantaged communities, and work in a participatory manner. ICPHR has its head office in Berlin, Germany, and holds annual working meetings and scientific seminars. Additionally, it provides training in participatory health research. ICPHR collaboratively issues position papers on topics relating to defining participatory research, its main ethical principles, and so on. The network is coordinated by a consortium of nine academics, none of whom represents the marginalized communities that are its main concern.

Value+. Promoting Patients' Involvement in EU-supported Health-related Projects

Funded by the European Commission's Public Health Programme, this two-year inquiry (2008–2010) coordinated by the European Patients' Forum (2017) aimed to enhance understanding of what constitutes meaningful involvement of patients' organizations in European Union-supported health projects at EU and national levels. It started with the mapping of patient involvement in such projects, but then evolved into a broad consultation exercise with a variety of stakeholders that led to the production of comprehensive resources specifically tailored to different audiences, including patient organizations, health project leaders and policy-makers (European Patients' Forum, 2010a; 2010b; 2010c). What was unusual about this project, in relation to other EU-funded actions, was

the leadership of patient organizations, both in its consortium and among its various partners. The outputs of *Value+* not only make a strong case for patient involvement but also explain all the requirements and steps in such processes. This project produced a range of documents including a handbook for project leaders (European Patients' Forum, 2010a), a toolkit for patient organizations (European Patients' Forum, 2010c) and policy recommendations (European Patients' Forum, 2010b). It is unclear whether and how the main messages from this unique project have been followed up in the practice or distribution of European health research funds.

4PI National Involvement Standards, UK

This framework addresses different areas of user involvement in health and social care including research and evaluation. It was developed by a group of UK mental health service users and carers (Faulkner et al., 2015a; Faulkner et al., 2015b) as a part of the *National Involvement Partnership* project (NSUN). Funded by the Department of Health, this three-year project (2012–2015) also promotes the adoption of 4PI standards by a wide range of organizations as "a means to enable services, organisations and individuals to think about how to make involvement work well" (p. 5). Based on the vision 'Nothing about us without us', this simple five-point framework easily translates across disciplines and geographic areas while addressing core issues of involvement (Box 6.2). By 2017 more than 60 UK organizations had endorsed the standards (National Survivor User Network, 2017).

Concluding observations about reviewed PPI initiatives in research

As the initiatives described above illustrate, PPI in research can be based on different points of departure and have different scopes. A top-down character is typical for the largest and most influential of such initiatives, such as PCORI in the USA. Notably, despite their best intentions, the described initiatives sometimes fail to ensure sufficient inclusion in their own work of the voices and perspectives that they seek to strengthen. This is probably most obvious in purely academic efforts such as ICPHR. On the other hand, the rare PPI projects initiated by patient organizations themselves, such as *Value+*, tend to lack the means to formally influence the decision-making processes of

Box 6.2 4PI Involvement Standards (NSUN)

PRINCIPLES: Meaningful and inclusive involvement depends on a commitment to shared principles and values. This includes valuing the contribution of service users and carers equally to those of professionals.

PURPOSE: The purpose of involvement should be clear and clearly communicated to everyone involved in the activity as well as the wider organization.

PRESENCE: A diversity of service users and carers should be involved at all levels and all stages of an organization or project. The people who are involved should reflect the nature and purpose of the involvement. Service users and carers should have the opportunity to be involved separately as they may have different priorities.

PROCESS: The process of involvement needs to be carefully planned in terms of issues like recruitment, communications, being offered appropriate support and training and payment, so that service users and carers, including those from marginalized communities, can get involved easily and make the best possible contribution.

IMPACT: For involvement to be meaningful, it needs to make a difference to the lives or the experiences of service users and carers.

mainstream research (Beresford & Croft, 2012; ENUSP, 2009). The 4PI standards of involvement provide an example of a bottom-up approach to conceptualizing involvement, which demonstrates the relevance and the potential influence of user-led involvement projects when they are adequately supported. The differences in actual power to initiate and influence changes need to be considered when assessing the impact of PPI in research because regardless of the quality of the PPI process itself, not everybody is in a position to make a real impact.

Levels of PPI in research

NIHR INVOLVE has identified three levels of PPI in health and social care research, based on the formal role of service users/patients in the research process (Royle et al., 2001). These are:

- consultation, where the input of service users is optionally added to the existing structures of research;
- collaboration, where service users and their representative organizations jointly undertake research with researchers and their organizations; and
- control, where service users design and undertake research and it is under their control throughout the entire process.

These levels have often been seen as forming a continuum from less to total user control. However, this is open to question, given the different, conflicting values that can underpin each of these approaches to PPI. Sweeney & Morgan (2009) have highlighted the shortcomings of these categories in real collaborative scenarios and include 'contribution' as an additional category, which refers to "research where service users/survivors make a significant and meaningful contribution to research but with power and decision making still residing with traditional researchers" (p. 29). Their analysis was offered in the context of mental health research, but the unequal value and status of different sources of knowledge and the resulting hierarchies in research conduct are demonstrated in all health and social care research (Glasby & Beresford, 2006). The dominance of professional expertise is an important part of the dynamics of involvement at all these levels. This dominance also extends to user-controlled research, which was historically the first way in which former research 'subjects' started taking an active part in knowledge production (Russo, 2012). Even though consultation and collaboration emerged later on, user-controlled research projects are the most difficult to find because what started as user control was often subsequently channelled into lower degrees of involvement.

The different modalities of participatory health and social care research continue to be judged against traditional criteria of what constitutes good (natural) science (Rose, 2008). Within such a working context, which extends from applications for funding to academic dissemination of findings, the greater levels of participation are frequently granted less scientific value (Beresford, 2003; Rose, 2009).

Co-production has recently been introduced as an additional concept in the development of health and social care services in order to address the power imbalances of collaboration. Adopting principles of co-production is among the explicit recommendations from the independent strategic review of public involvement in the National

Institute for Health Research (National Institute for Health Research, 2015). Advocates say:

> "Co-production is not determined by what the professional or service wants but focuses on the equal contribution of service users and communities. To ensure full collaboration, the co-production process should be about achieving equality and parity between all those involved" (National Development Team for Inclusion, 2016, p. 1).

Co-production is a concept which is applicable to research, especially regarding its main principles, including a commitment to equality, diversity, accessibility and reciprocity, as for instance elaborated by the Social Care Institute of Excellence in the UK (2013/2015). At the time of writing this chapter, INVOLVE led a project that aims to "identify how the discourse, elements and principles of co-production could be used to evolve and improve patient and public involvement in research" (INVOLVE, 2016, p. 4).

PPI at different research stages and in research structures

We have seen that PPI can be of different intensity in terms of the level of involvement. In this section we look at PPI in different phases of the research process and in related structures. The potential reach of PPI is broad; it can extend through the whole process of research, from its initiation to the dissemination of its outcomes and beyond, including:

- Identifying the topic of research and research questions
- Commissioning research
- Seeking, obtaining and managing research funding
- Undertaking the research
- Organizing and managing the research
- Collating and analysing data
- Reporting findings
- Producing publications and other outputs
- Developing and carrying out dissemination activities
- Prioritizing the outcomes and undertaking follow-up actions.

There may be PPI in none, some, or all of these stages. There may also be different degrees of such involvement, ranging from low to high. Sweeney & Morgan (2009) developed a two-dimensional illustration of the different levels of involvement at particular research stages, which offers a comprehensive overview of how user involvement can be implemented in practice. Figure 6.1 shows an *abbreviated* version

Figure 6.1 Levels and stages of service user involvement in research

Source: adapted from Sweeney & Morgan, 2009, pp. 32–3

of this model. The combinations between stages of research (vertical axis) and the intensity of user involvement (horizontal axis) may result in a multitude of research scenarios.

Public and patient involvement may not only take place in research projects, but also in the structures and institutions of research. Arguably, ensuring more of the latter is a key way of advancing the former. This can include ensuring PPI in the following research-related activities and structures:

• Identifying and setting research agendas and research priorities
• Developing research methods and methodologies
• Research funding organizations and funding decision-making processes
• Research organizations' governance
• Research training and education
• Recruitment, supervision and promotion of researchers
• Academic institutions' research strategy and research assessment
• Peer review and other selection processes for research publications/outputs
• Editorial roles in research journals and other publications
• Organization of research events and conferences
• Speaking on research platforms.

Although examples of each of the above can be found, their occurrence is uneven. A 2015 study from England and Wales investigating PPI in different parts of the research process reported that the 'most common PPI activities' that were undertaken were being a member of the research project's advisory or steering committee and involvement in developing or reviewing patient information leaflets (Wilson et al., 2015). This suggests that PPI in research is still some distance away from being comprehensively and systematically in place, or that it represents an accepted feature of the research landscape.

With regard to different levels and stages of PPI, we wish to emphasize that none of these is more or less important than the others. If undertaken with due consideration and commitment, each of these PPI activities can significantly shift the overall quality of research both in terms of its process and its outcomes. Or as Staniszewska & Denegri (2013) put it:

> "It may be that real progress will only be marked when poor PPI is seen as a fatal flaw in a research study, something which fundamentally undermines research quality, as opposed to an optional extra" (p. 69).

Understanding the impact of patient and public involvement in research

Research impact ideally relates to changes perceived as positive in health or social care that result from research and it is usually understood as something that occurs (or does not occur) *after* a research project has been completed. In participatory research, impact additionally includes the impact of the *overall process* on those involved or as Wadsworth (1998) noted: "Change does not happen 'at the end' – it happens throughout". Generally, there is much more emphasis on positive impacts although it is known that some research can impact negatively or lead to retrograde developments in health and social care policies (Cotterell et al., 2011). The decisive question in the assessment of research, including the assessment of PPI, is about who defines the desirable impact of research. Another important aspect is the actual formal power of those in charge of research to inform and influence the practice of service delivery and enact change. Researchers frequently have little say or control in such areas.

There are opposing views on the overall impact of PPI in research. When articulated as a question whether PPI impacts the research process, the assessments are more positive. For example, the RAPPORT study of PPI in research identified "PPI related outcomes" in all of its eight case studies in different health fields, such as defining the research question, changes to study design, improvements to recruitment materials, and dissemination (Wilson et al., 2015). However, when placed in a broader context of growing health and other inequalities, the overall role and purpose of PPI is subject to growing criticism. Thus, commenting on recent developments in PPI in research in the UK, Madden & Speed (2017) noted that the range of PPI activities can be seen "as a form of busywork in which the politics of social movements are entirely displaced by technocratic discourses of managerialism" (p. 5). They concluded that PPI formed "part of a wider politics of knowledge in which patient groups, clinicians and universities are co-opted into a corporatized health research agenda […]" (p. 5).

Different perspectives on the impact of PPI in research and its assessment are closely related to the overall approaches to participation and understanding of its scope. Perspectives range from equating impact with the number of publications in scientific journals to the issue of how empowering and transformative the overall process has been for all

involved (Staley, 2009). Box 6.3 provides two examples that illustrate differences in understanding of what constitutes a good outcome of participation and collaborative research work.

Participation can be positioned within the conventional understanding of research as a primarily clinical enterprise and applied as a tool to improve specific aspects of conventional research conduct. Conversely, Oliver (1992) emphasized the social relations of research production and that these can have lasting transformative effects on everybody involved. It points to the understanding of impact as a less measurable phenomenon that can question and alter the entire research process.

Existing systematic reviews of the impact of participation in research are largely based on academic papers focusing on discussions of the impact of PPI. Although such systematic reviews can include service users in advisory roles (Brett et al., 2014b), the perspectives of those actually involved in studies within the review remain largely absent. This highlights that assessments of PPI impact tend to remain expert-dominated.

Box 6.3 Understanding the impact of research participation

Based on an analysis of patient involvement in 374 studies in mental health research in England, Ennis & Wykes (2013) highlighted the utility of patient involvement for the successful undertaking of research, noting that "[s]tudies that involved patients to a greater extent were more likely to have achieved recruitment targets (χ^2 = 4.58, P < 0.05), defined as reaching at least 90% of the target" (p. 1).

In comparison, the disability theorist, activist and researcher Oliver (1997) emphasized the experiences of all participants as well as the broader social relations of research. His discussion of the emancipatory potential of research reminds us that impact is not a matter of easily identifiable aspects nor that there can be ready-made recipes of how to achieve research impact:

"[…] the question of doing emancipatory research is a false one, rather the issue is the role of research in the process of emancipation. Inevitably this means that research can only be judged emancipatory after the event; one cannot 'do' emancipatory research (nor write methodology cookbooks on how to do it), one can only engage as a researcher with those seeking to emancipate themselves" (p. 25).

The systematic review of PPI impact undertaken by Brett et al. (2014a) provided clear evidence that PPI impacts on all stages of the research process, from its initial stages all the way through to the implementation and dissemination stages. However, the review identified both 'beneficial' and 'challenging' impacts at all stages. In light of the above discussion about different perspectives on impact it seems notable that the review interpreted the finding that PPI "led to research findings being disseminated before the academic papers are published, thereby jeopardizing academic publication" (p. 644) as having a 'challenging' rather than a 'beneficial' impact. This takes us back to the question of whose perspective and ultimately whose interests are prioritized when assessing the impact of research. Judgements of the impact of PPI on a research process are normative.

A subsequent international systematic review of the impact of PPI focused for the first time on people involved in the research process (Brett et al., 2014b). It demonstrated that in reporting the impact of participatory research there was notably more emphasis on the personal benefits to service users directly involved in the research process than reports about how PPI might affect the larger communities that the research is about. The review highlighted the importance of both the process and the context within which PPI takes place, which may lead to positive as well as to negative impacts on people involved. These include the planning, training and adequate funding of PPI.

In this context, we wish to come back to the aforementioned framework for user involvement in health and social care including research and evaluation, the *4PI National Involvement Standards* (Faulkner et al., 2015). We find this framework helpful for the discussion of the impact of PPI not only because it centres on the perspectives of those involved but because it regards impact as part of involvement standards. As noted in Box 6.2, the framework comprises five elements or principles on which to "base standards for good practice, and to measure, monitor and evaluate involvement" (p. 8), which comprise shared values and principles; a clear purpose; the presence of service users from different backgrounds at all levels and in all aspects of the activity; carefully planned involvement process; and impact. With regard to the latter, the authors emphasize: "We are not interested in involvement for its own sake; for involvement to be meaningful, it must make a difference" (p. 11). Furthermore, the framework suggests that the impact of involvement can be continuously monitored throughout a given project, as

well as assessed at the end. The framework can also helpfully be read in association with the findings on enabling fully inclusive and diverse involvement (both in research and in evaluating impact) offered by the UK Shaping Our Lives, *Beyond the Usual Suspects*, user-controlled research and development project (Beresford, 2013).

At the end of this brief overview of different understandings of PPI impact and its assessments, we wish to stress the importance of centring on the perspectives of those actually involved in the research and disrupting the dominance of solely academic and researchers' discourses on impact. The question of whether PPI will have impact or not is inseparable from the timely assessment of the entire approach to the research process, in regard to its structures and its context and the degree to which these can enable or inhibit such impact.

Methodological challenges posed by PPI in research

Neither user-controlled research nor other participatory approaches to research are narrowly associated with any particular research method. The position of the International Collaboration for Participatory Health Research (2013) is that "participatory health research is a research *approach*, not a research *method*" (emphasis in original). Participatory approaches are much better understood through their specific values and principles, which in consequence do have implications for research methods and guide the whole research process. These values and principles refer to transparency, democratizing research, equalizing research relationships and supporting change and empowerment.

As noted earlier, PPI in research has become more established in recent years. For example, in the UK many statutory and independent funders require evidence of PPI in grant proposals and research projects they support. However, there still seem to be unresolved tensions between conventional research values on one side and the idea inherent in all forms of user involvement in research on the other, namely that it is important to engage with service users'/research subjects' experience and knowledge. Traditionally research has been understood as the most systematic, rigorous, indeed scientific way of generating knowledge. It has been conceived of as an activity exclusively undertaken by people with professional expertise in the methods and methodology of research. Such research has been particularly associated with the values of neutrality, objectivity and distance from its subject (Beresford, 2003).

The 'unbiased value-free' position, based on the professional exper-
tise of the researcher, is seen as a central tenet of such research. By
claiming to eliminate the subjectivity of the researcher, the credibility of
the research, and the rigour, reliability and replicability of its findings
are seen to be maximized. The introduction of *experiential knowledge*
into research that came about with PPI, to which traditional research
principles grant less value and credibility, can be seen to be at odds
with such thinking. Experiential knowledge is understood as knowl-
edge that comes from lived experience rather than from professional
training or research and experiment. This type of knowledge can take
individual and collective forms. Its inclusion in research continues to
be a major challenge to the acceptance of PPI in research, particularly
user-controlled research, with its overtly political purposes of bringing
about change in line with the rights and needs of research participants
as law and the participants themselves define them.

At the same time, the devaluing of experiential knowledge in much
traditional research has increasingly come to be seen as problematic.
This issue of marginalizing the knowledge of particular vulnerable
groups has begun to be talked about in terms of 'epistemic violence'
(Liegghio, 2013) or 'epistemic injustice' (Fricker, 2010), meaning
devaluing and marginalizing the knowledge of people who suffer
abuse, discrimination and oppression. PPI in research thus raises the
uncomfortable issue of including experiential knowledge centrally
and on equal terms with other kinds of knowledge. It means working
towards achieving epistemic justice and ensuring that everybody can
contribute to creating a general knowledge base and that perspectives
of entire social groups are no longer excluded from that process. We are
beginning to see the real involvement of ordinary and disadvantaged
people in research, for example people with learning difficulties, who
communicate differently or experience dementia (Faulkner, 2004). There
is also a growing body of, and discussion about, user-controlled research
where people who have traditionally been the objects of research are
now carrying out their own research and so restoring their epistemic
existence (Beresford & Croft, 2012).

However, if PPI in research is to develop effectively as part of the
mainstream, then it will need to be evaluated carefully and thoroughly
and from different perspectives. It is only in this way that we are likely
to receive a reliable picture of its strengths and weaknesses and poten-
tial impact. This needs to be a process of evaluation in which service

users, their organizations, research participants and user researchers, alongside other stakeholders, are involved fully and equally drawing on their plural criteria. Such comprehensive assessment of participation should extend to exploring developments internationally, considering specific political, economic and cultural contexts.

Ensuring diverse involvement in research

One reason for the development of schemes for participation has been the realization that less powerful groups and groups facing discrimination are often excluded from conventional arrangements for political and policy decision-making. However, the evidence indicates that the same problem arises with arrangements for involvement. The aforementioned UK Shaping Our Lives project (Beresford, 2013) has highlighted just how many groups tend to remain excluded from participatory initiatives. Five key groups of service users were identified, excluded on the basis of:

- *equality issues*, for example, in relation to ethnicity, gender, age, sexuality, disability, culture, class or faith;
- *where they live*, for example, if homeless, in the penal system, without citizenship rights or in residential institutions;
- *communicating differently*, for example, non-verbally, through sign language or where the national language is not their first language;
- *the nature of their impairments*, if these are complex, multiple or seen as costly to ensure access; and
- *being seen as unwanted voices*, who may express critical or negative opinions.

In the context of research, there still seem to be major barriers in the way of some groups of service users undertaking or being involved in research, reflecting broader problems in user involvement. At the same time the argument that service users are not a homogeneous group and the issue of representativeness (Crepaz-Keay, 1996) continues to be used by critics of PPI research.

There is particularly a need for work on improving access to undertake such research with older people, ethnic service users from racialized groups, and refugees and asylum seekers. These are important gaps, first because older people are the largest and fastest growing group of health and social care service users and second, because people from black and minority ethnic communities are known to have poorer access to

health and social care support and to be more likely to receive devalued and compulsory services than valued and highly regarded ones (Care Quality Commission, 2010; Centre for Social Justice, 2011). The use of the term 'hard to reach' has been thoroughly criticized in this context and in relation to public involvement more generally (Brackertz, 2007; Kalathil, 2013). Rather than focusing on factors that foster or inhibit involvement, identifying certain groups and communities as 'hard to reach' locates the problem within those groups and communities. Kalathil (2013) analyses such an approach and its ultimate implication that "they are the problem and not the ways in which the involvement is defined or undertaken" (p. 123). We agree with this author in her conclusion that

> "No communities are, by definition, 'hard to reach'. However, [...] there are practices, prejudices, belief systems and experiences that collude to create exclusion of some communities from involvement initiatives [...]" (p. 131).

Shifting the culture of participation – always thinking in terms of whose voices are absent or treated as if they are 'hard to hear', and what needs to be done in order to reach and include them on equal terms – remains one of the central tasks for the future of public and patient involvement in research.

Next steps for PPI in research

Public and patient involvement in research has emerged as a significant new research approach internationally in a relatively short time. It has pioneered research in new areas and resulted in a very diverse range of research projects, involving a wide range of citizen and service user groups (Faulkner, 2010). At the same time, it continues to face major practical, theoretical and philosophical challenges. Serious questions are still raised about both its quality and sustainability. Strategies will need to be developed to address issues of its current limited credibility, its inadequate and inferior funding and what have been described as 'incidents of direct discrimination during the course' of research projects (Beresford & Croft, 2012). A series of steps can be identified for placing PPI research on a firmer, better established and better evidenced basis. These include:

- *strengthening the theoretical basis of research with PPI* to better address criticisms of its principles and approach;

- *building research education and training*, both to support the development of PPI and user-controlled research and to help those likely to be affected by research more generally gain a better understanding of such participatory approaches;
- *rationalizing welfare benefits.* Although involvement in research can offer some service users routes into paid and unpaid work, the direction of travel of the benefits systems currently increasingly obstructs rather than supports this and requires reform;
- *equalizing access to funding.* At present, PPI research, particularly user-controlled research, receives a disproportionately low level of funding and this needs to be reviewed in the light of what it may have to offer;
- *comprehensively evaluating PPI in research and especially user-controlled research*, involving service users and their organizations in the process to gain a better understanding of these approaches, including in an international context;
- *addressing diversity.* There still seem to be barriers in the way of many groups of people becoming involved in research, reflecting broader problems in participation work. More needs to be done to improve access to undertake such research for older people, black and minority ethnic service users, and refugees and asylum seekers;
- *fostering user-controlled organizations.* User-controlled organizations provide a particularly supportive home for user-controlled research. At present they are under-developed, under-resourced and insecure. Creating policy to strengthen their position is key to securing the development and future of PPI and user-controlled research;
- *ensuring greater PPI in research structures.* Its proponents need to be ensured equal access to research publications, peer review processes, grant funding systems, and identifying barriers and ways of overcoming them; and
- *building alliances and sharing knowledge.* There is a need to improve the sharing of learning from PPI and user-controlled research. Building new networks and relationships and enhancing means of exchange across countries is likely to help with this.

Taken together, these proposals offer a set of building blocks for developing a strategy for critiquing, evaluating and advancing patient and user involvement in research, a strategy which must itself be fully and equally participatory.

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