Exploring the Impact of Patient and Public Involvement in a Cancer Research Setting

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Abstract

An enduring theme in the literature exploring patient and public involvement (PPI) in research has been the focus on evaluating impact, defined usually in terms of participants' practical contribution to enhancing research processes. By contrast, there has been less emphasis on the perspectives and experiences of those involved in PPI. Drawing on qualitative data with people involved in the National Cancer Research Network in the United Kingdom, we report on what motivated participants to get involved and their experiences of involvement in this setting. We highlight how those involved in PPI often espoused the notion of the "good citizen," with PPI in research being a natural extension of their wider civic interests. However, our findings also highlight how PPI was an important resource, utilized by participants to make sense of living with chronic illness. We suggest that PPI in research also offers spaces for the reconfiguration of self and identity.

Keywords

illness and disease, experiences; interviews; lay concepts and practices; research participation

Within the United Kingdom, patient and public involvement (PPI) in health and social care research is regarded as a prerequisite for studies funded by the National Health Service (Department of Health, 2006), the National Institute for Health Research (NIHR), and increasingly for research proposals submitted to research councils and charities. In short, PPI is now a more-or-less accepted aspect of the architecture of research governance within many countries, although the extent to which it is viewed in genuinely positive terms by professional researchers is rather more open to question (Thompson et al., 2009). Consequently, there is now a burgeoning literature that focuses on the impact of PPI in research, with the emphasis often on discrete and measurable areas of research, such as improvement in trial recruitment process and patient information leaflets.

As we set out in our short review below, the emphasis on documenting the measurable impacts of PPI and the justifications for PPI suggest a crisis of legitimacy in this sphere, and this again has been one of the common themes within the literature. In this article, however, we seek to address another set of points that we believe have been overlooked in much of the debate about PPI in research. These concern motivations for involvement and experiences within PPI settings. We argue, on the basis of a case study conducted within the National Cancer Research Network in the United Kingdom, that PPI might better be understood within the context of the sociological literature on chronic illness. We show how PPI in research was drawn on by participants in this study as a means of reconstructing or reconfiguring aspects of self and identity, and was viewed largely as a positive outlet for individuals who had experienced chronic illness.

Understanding of PPI From the Published Literature

Broadly speaking, PPI in research refers to the active inclusion of patients, carers, service users, and/or other relevant stakeholders in research processes, with PPI participants providing experienced-based perspectives alongside the "expert" perspectives of researchers (INVOLVE, 2012). Within the literature there are numerous examples of PPI in health and social care research at national and local levels, including developing good practice guidelines for health technologies, clinical practice and public health, prioritizing research ideas and reviewing research funding proposals (Oliver, Armes &

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Gyte, 2006), contributing to research bids, design, analysis, and dissemination (Ross et al., 2005), and designing patient information sheets and advising on recruitment (Koops & Lindley, 2002). Tellingly, within many policy documents and published articles are justifications or rationalizations for PPI in research, and the literature is now replete with examples of how it can be conceptualized (Thompson et al., 2009).

One broad set of justifications stems from moral or political arguments with a focus on rights, citizenship, and democracy. For example, it is suggested that as citizens and taxpayers, the public has a democratic right to influence research that is publicly funded or advanced in the name of the public good (Thompson et al., 2009). Relatedly, PPI has also been framed as a mechanism to address a perceived "democratic deficit" within research and policymaking, or as a way of shedding light on previously esoteric research practices, and thus addressing transparency and accountability issues in the process (Martin, 2008).

In terms of what are referred to as the consequentialist arguments used to justify PPI in research, it is most commonly proposed that PPI can enhance the credibility, relevance, and acceptability of research among patient groups, and indeed the population more broadly (Thompson et al., 2009). For example, it is suggested that the public brings unique perspectives to research through their personal knowledge and experience of a particular condition, health service, or treatment modality. Their perspectives on these matters are argued to provide balance, or a "reality check," in research settings that are typically dominated by professionals. In this vein, O'Donnell and Entwistle (2004) argued that when PPI is utilized during the early prioritization and review stages of research it can enhance public confidence as to whether research funds have been allocated equitably. Hence, PPI in research might be regarded as a legitimizing tool for researchers, validating the applicability and acceptability of their work (Thompson et al., 2009).

Other authors have argued that PPI might be empowering for those involved (INVOLVE, 2012), seeking to address (often unstated or weakly conceptualized) power differentials between researchers and the researched. However, as we have argued elsewhere (Thompson, Bissell, Cooper, Armitage, & Barber, 2012), empowerment in relation to PPI is an ambiguous and multifarious concept, and simply stating that the public are empowered as a result of their involvement does not appear to do justice to the complex and varying personal impacts on those involved. Indeed, in this article we seek to address this point by positing that PPI in research might offer spaces for the reconfiguration of identity rather than empowerment.

This seems to us to be an important, albeit largely overlooked feature of the literature about the evaluation of the impacts of PPI in health and social care research. Few studies have succeeded in capturing and evaluating the added value and impacts of PPI in research on participants themselves (Williamson, Brogden, Jones, & Ryan, 2010). Inconsistencies in terms used to describe PPI in research and difficulties in reporting and publishing this work are identified as key factors (Staley, 2009). Furthermore (and of particular interest with regard to this article), rationalizations for PPI are primarily concerned with what the public might contribute to research and the impacts of involvement on research systems. Rather less is known about the impacts of involvement on those PPI participants who become involved with health and social care research. This includes motivations for involvement, experiences of the process, and the potential outcomes of their involvement, particularly in terms of impacts to self and identity (Conklin, Slote Morris, & Nolte, 2010; Cotterell et al., 2010; Williamson et al., 2010).

Authors of two review articles synthesized the limited literature regarding motivations for PPI (Tarpey, 2006) and impacts of PPI for researchers, PPI participants, and research (Staley, 2009). Tarpey suggested that PPI participants' motivations can be grouped into social and personal categories. Social motivations refer to notions of altruism, influencing research and changing services for the benefit of others. Personal motivations include opportunities for individuals to develop confidence, learn new skills, and derive positive outcomes from their ill-health experiences. In terms of the positive impacts of involvement, Staley reported that these might include opportunities to acquire new skills and knowledge, building support networks and friendships, personal enjoyment and satisfaction, and financial reward.

Negative impacts of involvement include the potential for emotional burden and experiences of disillusionment with research processes and outcomes (Staley, 2009). Authors of both reviews suggested there is an added value for PPI participants from being involved in research—in terms of personal development and social networks—while also reminding us that these elements might not be consistently perceived as positive (for example, the emotional burden of PPI work). However, beyond describing themes, there is little thick description (Geertz, 1973) of the impact of PPI and how it might connect with notions of self and identity, and indeed, how it might relate to the literature on the sociology of chronic illness as it connects to self and identity (Bury, 2001).

With reference to PPI in cancer research, Cotterell and colleagues (2010) reported on one of the few studies to focus primarily on the impacts of involvement on PPI participants themselves. Like Tarpey (2006) and Staley (2009), they suggested that participants' motivations include a desire to improve health and social care services, whereas other impacts include improvements to participants' experiences of living with cancer in terms of

enhanced self-confidence, friendship and support, and a sense of personal achievement. Cotterell et al. highlighted a need to explore this area in more depth so we can begin to understand the wider implications of involvement.

Barnes and colleagues developed a more nuanced account of motivations for understanding older peoples' involvement in health forums (Barnes, Harrison, & Murray, 2012) and broader notions of participation in community and neighborhood organizations (Barnes, Newman, & Sullivan, 2006). Drawing on the volunteering literature, they suggested that a number of commitments are evident among individuals who get involved in aspects of participatory governance, including a commitment to a place or specific group of people, a commitment to a cause(s), and commitment to a set of values and personal experiences (Barnes et al., 2012). They highlighted that beyond simplistic descriptions of volunteers as "the usual suspects," we should try to understand the complex interplay between personal, social, cultural, political, and spatial factors that underlay an individual's motivation to become involved (Barnes et al., 2012).

In previous work, Barnes et al. (2006) usefully drew on social movement theory as a framework through which to explore issues of identity and participation in local initiatives. Defining identity as "an active process of making sense of oneself and one's connections to others" (p. 201), they argued that individuals' decision to become involved is mediated through consideration of what action might achieve change, how this makes sense in terms of their own perceptions of self and society, and their personal values. This framework provides a useful starting point for exploring PPI and identity, and for the study described here.

PPI in health and social care research requires huge personal investments (time, emotional, financial), not only by research organizations and research teams, but also by the patients and the carers who get involved. Given recent calls to demonstrate the impact(s) of PPI in research (Staniszewska et al., 2011), it seems particularly important to understand what motivates some individuals to get (and remain) involved in PPI work whereas others do not, and to understand the potential impacts of PPI on those involved. Furthermore, understanding why people get involved in research and what they stand to gain (or lose) might assist us in maintaining sustainability of approaches and broadening the reach of PPI initiatives to include individuals from seldom-heard groups. In this article we seek to address this gap in the knowledge by providing findings from interviews with patients and carers involved in cancer research settings as PPI participants. We highlight how PPI in research can provide spaces for expressions of agency and the reconfiguration of participants' sense of self and identity. This, we believe, remains a key impact of PPI in research, one which is often overlooked.

Methods

The data reported here form part of a larger ethnographic study conducted between December 2007 and March 2009 (Thompson et al., 2012). The study explored rationalizations, roles, and relationships in PPI within the framework of the National Cancer Research Network (NCRN), which provides the infrastructure for cancer clinical research in England. Within this infrastructure there are 22 national clinical studies groups (covering different cancer-site-specific groups) that oversee cancer clinical trials and identify future research priorities. Patient or carer members are part of each clinical study group, of which the remaining membership consists of clinical and research professionals. At the local level, the majority of cancer research networks have established PPI panels, with individuals involved within research projects, local clinical trials steering groups, or providing advice to researchers; for example, this includes reviewing patient information sheets, consent forms, and interview questions.

For the ethnographic study from which these data were taken, six clinical studies groups and one local PPI panel in England were studied over a year-long period using observation, interviews, and analysis of documents (Thompson et al., 2012). The sampling was pragmatic, with the chair of each clinical studies group invited via email to be included as a case study; all six who responded were included. The local PPI panel was chosen largely because of convenience. It was a well-established panel operating within the region in which the first author was based. Every member of each case study group gave informed consent to be involved with the ethnographic study, which included consenting to take part in an interview if requested by the researcher. The aim of interviews within the broader context of the ethnographic study was to explore individuals' perceptions of their roles, rationalizations, attitudes, and experiences of PPI, and to obtain their perspectives on some of the observational data and emerging themes.

Purposive sampling was used to approach case study group members to take part in a semistructured interview, 14 of whom were PPI participants. These individuals had experience of cancer (11 patients, 3 carers) and were involved in a range of activities, with each participant acting as an advisor on at least one research advisory group, reviewing patient information sheets and consent forms and advising on the acceptability of research protocols. Four of the participants were men; 1 participant was aged over 65 years and the remainder between 55 and 65

years. All but 1 of the participants had a professional background requiring higher education. Ethical approval was formally received for this study from a National Health Service Research Ethics Committee.

The interviews were conducted during the first half of 2008, using a combination of telephone and face-to-face approaches, dependent on participant preference and time/resource constraints. All interviews were conducted by the first author and lasted about an hour. Interviews were digitally recorded and transcribed verbatim by the first author (at which point the recordings were deleted). Each transcript was anonymized, with the participant being given a pseudonym, and any identifying data was removed. An interpretative thematic approach to analysis was used (Seale, 2004). This was a reflexive and iterative process with initial open coding followed by selective and more detailed coding. Links and comparisons were made between themes, across participants, and with the wider literature. Findings were discussed with other members of the team (which included a patient member) as a fuller account for the data emerged. Initial and secondary coding practices were discussed between the first author and second author, and some of the data were recoded as a result.

Findings

In the section that follows we outline and describe broad themes regarding motivations for and impacts of PPI in cancer research. We begin by suggesting that individuals involved in PPI share certain social and value-based characteristics, particularly in terms of their professional backgrounds. PPI in research is often a continuation of their involvement in other areas of civic engagement. We highlight participants' initial claims that they were motivated to engage in PPI for altruistic reasons. We then report and discuss additional claims made by participants about the impacts of PPI, referred to here as reconfiguring the self and identity, and suggest that these offer more nuanced insights into participants' accounts about their motivations for involvement in health research. We suggest that PPI in cancer research might offer an important space for narrative work involving the reconfiguration of self and identity in the light of ill health.

The Good Citizen

Congruent with studies that have explored PPI in other settings (Campbell, 2005; Martin, 2008), we found that the majority of participants in our study were highly educated, with professional or managerial backgrounds (although their careers had often ended prematurely because of ill health or caring commitments). We would suggest that there were clear parallels between our participants and Campbell's notion of the "good citizen": likeminded individuals from well-educated backgrounds with disposable resources (time and money). Some participants also had professional connections to health care, health research, or service improvement. For example, prior to their experience of cancer, Sheila and Ruth were both health professionals (a general practitioner [GP] and a nurse, respectively), and Fiona and Ben had worked in social services.

There also existed other similarities between participants in terms of their values and their attitudes toward wider civic engagement. A couple of participants spoke of their PPI in health research as almost a natural extension of their participation in other areas of civic society, beyond those associated with research. This included Clare, who had a history of involvement in voluntary-sector organizations, and Ben, who had been involved in various service improvement projects over a number of years:

> I became involved in the [name] user group on the voluntary side. I was already involved in various initiatives in my home area, building on my past in the voluntary sector and as a member of a community health council. (Clare)

> Well I think generally I'm obviously interested in, if you like, giving a voice to people who have experiences of services and the NHS. . . . And there are also lots of other roles that I've been involved in over the past few years, [and they] have largely been about bringing my experiences to them and trying to influence services to make improvements. I just saw this [his role in cancer research] as actually a natural extension of becoming involved and trying to influence. (Ben)

Similarly, both Alan and Hannah were founding members of cancer support groups:

> I'm one of the founding members of [name] cancer support group. . . . So that was sort of the start of it, and from there I got an invitation to see if I would sit on the cancer patients and carers forum. So I was a member of that forum. So then I was asked to join this and that. So I sit on probably half a dozen groups. (Hannah)

As can be seen from these quotes, for many participants PPI in cancer research was one dimension in a range of support-related activities in which they were engaged. Other participants in this study were actively involved in the infrastructure for local and national health services or research decision-making groups. For example, one was a member of a national research regulatory body, another sat as a member of a local research ethics committee. These findings suggest that for the majority of the participants PPI in research was congruent with a

broader set of professional and civic commitments. It is therefore of little surprise that two of the principal motivating factors for PPI in research suggested by participants were expressions of altruism and reciprocity.

Expressions of Altruism and Reciprocity

An ostensible reason for involvement advanced by the majority of participants in this study was that of altruism. This was often implicit within participants' statements about their desire to improve health care systems for the benefit of others, or to repay the health services and staff for the treatment they (or an individual they had been caring for) had received. For example, Ruth said,

> I think [I got involved for] a lot of reasons, really. One of them was that, to try and make things better for other patients. That was one of the big reasons. And also to try and give back something because they've treated me and I thought that's one way of giving something back. And also with [my type of cancer], it's such a rare cancer and often people are diagnosed very late, so that was an impetus for me, really. There's a lot of research into other cancers but because [my cancer] is so rare there's not much known about it, and the survival rate has not really improved over the last thirty years. That was another reason.

Ruth's account highlighted a complex interplay of factors. First and foremost, she suggested altruism as her primary motivation for getting involved in research. Additionally, she recalled her sense of gratitude for the treatment and care she had received, with her involvement in research seemingly an expression of reciprocity and a mechanism through which she could repay the system. Like Ruth, Mary also initially reported altruistic motivations for her PPI in research before also alluding to a sense of gratitude for her continued survival. When asked about how she felt her involvement in research had benefited her in any way she replied,

> I think it's more to do with how it has benefited them, really. I hope anyway. I mean I'm there for their benefit, not for mine. . . . Yeah, I like to think that I'm helping. I think I'm still here, which is highly unusual for someone who's had [my type of] cancer. And so I erm, you feel grateful that you were well treated, And I was on a trial, which, okay, I might well have survived without the trial; I'll never know. But you just feel as though you want to give something back. You want to help others. I suppose that's it.

Unlike, Mary and Ruth, William identified his poor experiences of health care as motivating his desire to improve services for others through PPI in research:

> I didn't have a particularly good pathway but I didn't want that to be the, you know, I didn't want to just moan about that. I've actually written my letter of complaint about the hospital and realized that nobody took a blind bit of notice unless you actually had something serious or died. So it was a case of trying to change things before they actually became as bad as, you know, that kind of situation.

William's involvement appeared to offer a cathartic outlet for his poor experiences of treatment. He felt he was working toward improving health care services for the benefit of others, while being enabled to articulate his complaints over his own treatment and care. Whereas expressions of altruism were often stated as initial motivations for PPI, it was clear from the participants' accounts that other factors were important, and we have framed these around notions of reconfiguring the self.

Reconfiguring the Self

It was apparent to us that participants in this study valued the opportunities they had for taking part in cancer research, and the skills and knowledge they acquired as a result of their involvement. Common to the majority of participants was a desire to take on and acquire new skills. For example, Alan spoke of his "enjoyment and intellectual stimulation from the challenges of research," whereas Fiona reflected on the critical thinking and appraisal skills she had developed as a result of her involvement in research:

> I think I am starting to get a lot more awareness about what research actually means. And for me, I like learning, and it's very interesting to see where the research is coming from and actually understand a bit more about the process [that contributes to] what twaddle comes on the telly [television] and the papers, and the underlying messages from them. . . . I think one of the things I learnt was that in order to determine what treatment I had, I had to negotiate with the people who were doing my care. And I had to go very quickly from having no knowledge at all of cancer to be able to critically evaluate what people wanted to do for me.

Through PPI in research, Fiona had come into contact with a greater range of technical and scientific information, which appeared to provide her with a greater sense of agency, especially in managing an illness that was often outside of her control. She talked in some depth about the impact her increasing knowledge about treatment, medication, and cancer, obtained through her active involvement in research, had had on her ability to cope with the disease. We would argue that the skills and knowledge development that often accompanied the PPI we observed in our study was one way some participants reconfigured aspects of their identity, often along more active and critical lines.

Fiona was by no means the only example of this, and the data highlighted how PPI in cancer research provided an important framework for meaning making in participants'

lives. As discussed, the majority of the participants were well educated—with managerial or professional backgrounds—most of whom had prematurely ended (or postponed) their career as a direct result of their experience of cancer. This marked a significant loss for many participants and was often referred to in terms of loss of structures of relevance in their daily lives.

Seen against this backdrop, PPI in research was often described in terms of attending to the gap left by the loss of work or career. It was common to hear from participants that PPI provided forms of meaning, or a new coherence, in what were clearly altered lives. For example, Ruth noted, "I've had to give up work and it [PPI] was another way of giving meaning to life, really," whereas Sandra said, "I retired on ill health, and so I suppose part of me thinks I retired five or six years too early. So I do feel I'm giving a little bit back, there." Anne, too, highlighted the importance of her career in her life before illness struck, and how PPI provided some limited compensation for experiencing the vicissitudes of chronic illness:

> So I had quite an exciting career where there were lots of things going on and life was very full and my brain was constantly been challenged and everything. And then along came cancer which, you know, stops you short, really, and my cancer was a cancer that I wasn't really expected to survive from and, touch wood, I am still surviving, but it's obviously made me look very differently at life. And I was getting older, and after having six months off . . . I started to go back part time and I started to build up my workload. And it just became evident, really, that it wasn't working . . . and I wasn't able to work one hundred percent. So the decision was taken that I would finish, which I did. And at first that was fine, it was really exciting. It was, "Oh, I've got all this time. Isn't it wonderful?" . . . but after having the sort of life I had had, I think I just started feeling a bit as if I wanted to do something. Didn't know what I wanted to do. . . . And I was just sitting in the garden one day reading *The Guardian*, and here was an advert [advertisement] for, request for consumer members on the National Cancer Research. And I thought, "Gosh, that looks interesting. Maybe I should just find out about it." And it was all very tentative really. And I did find out about it and thought it sounded just my cup of tea. So I decided to apply for it.

Anne's experience of cancer impacted her life in such a way that she questioned her taken-for-granted assumptions, including her ability to engage in her former (pre-cancer) career. PPI in research thus offered a route by which she could exhibit a degree of agency in the face of an illness that had forced her to give up her working life. Similarly, it was apparent that Sheila's involvement in research had enabled her to retain aspects of her former professional identity as a GP. No longer practicing medicine on account of her experience of cancer, Sheila had kept a professional (and personal) interest in the area through her work in the PPI sphere, and thus continued to display and utilize aspects of her professional skills and knowledge. When asked about her motivation for getting involved in PPI, Sheila replied,

> To improve the services available. . . . It's quite interesting from my point of view, because with the medical background that I've got, although obviously through ill health I no longer practice, I'm still very interested as to what my colleagues have to do to jump through the hoops to get their pay at the end of the day.

Another participant, Robert, never directly referred to the loss of career as having impacted his decision to get involved in PPI, However, Robert's account showed that he had effectively built a new career (paid employment) through his PPI in research. During an interview with him, it was noted that this appeared to have become a full-time occupation, to which he replied,

> Well, I'm all over the country talking about user involvement in cancer research. . . . So, it [involvement in research] has become [a full-time job], yeah. But I was in a position where that could happen because of the way my life had panned out. I had time to give to it. Fate, I suppose, to some extent. But yeah, fate cast me upon this beach and here I am building a sandcastle.

The findings suggest that Robert had re-established a quasiprofessional identity built around his significant PPI roles. Consequently, it would appear that the PPI we observed in our study might provide a framework through which participants were able to develop new skills and knowledge and to renegotiate aspects of their self and identity along more positive or constructive lines.

Discussion

In this article we have described participants' reported motivations for PPI in cancer research in England and suggested some of the ways their involvement impacted on self and identity, areas which to date have witnessed relatively little attention in the PPI literature. The findings we report need to be placed in the context of increasing calls to document the demonstrable impacts of PPI in research and to provide empirical evidence beyond philosophical rationalizations for PPI itself (Brett et al., 2012). We would argue that the findings provide a counterpoint to the impact literature, which fails to address how PPI shapes accounts of self and identity.

Our findings suggest that a range of factors motivated individuals to get involved in research. In line with the work of Cotterell et al. (2010), Tarpey (2006), and Staley (2009), our findings highlight the importance of altruism,

reciprocity, personal development, and satisfaction as important motivational factors for PPI. However, what our study adds is a more nuanced understanding of the ways PPI appeared to provide a focus for participants to reflect on and come to terms with the impacts of chronic illness on their life. We would suggest that PPI provided one means of establishing meaning, or as a way of redefining self or identity, whereby established patterns of meaning making had been challenged or lost—in particular a professional career—often as a result of ill health. Our central point would be that if we wish to extend our understanding of PPI in health research, we need to see it as a resource that individuals actively utilize or shape in the light of their experiences of chronic illness.

Barnes and colleagues (Barnes et al., 2012; Barnes et al., 2006) identified personal, social, cultural, and political factors underlying individual motivations for involvement in aspects of participatory governance, and it was apparent that many of these applied to participants in our study. In relation to the work of Barnes et al. (2006), we have argued how, culturally and politically, many of the participants in our study discussed their trajectories into PPI as congruent with their wider interests in public involvement in civic society, and altruistic reasons were frequently given as primary factors for PPI. Consequently, PPI in health research might be considered an expressive act, one in which individuals with shared values and beliefs have an "opportunity to express political identity and belonging" (Conklin et al., 2010, p. 3), thus building a collective identity based on these values.

These findings echo the findings by Barnes et al. (2006) in their work on citizen participation in a range of local governance initiatives. Furthermore, as shown, the majority of participants in our study had professional backgrounds, many of whom had retired; accounts from these individuals appeared to suggest involvement as an extension of their professional lives. For some, PPI provided opportunities for developmental impacts (e.g. skill and knowledge development), often replacing opportunities lost through the ending of a career. For other participants, PPI enabled them to maintain links (although often indirectly) to their profession, and for a small number of participants, their PPI had become a profession in itself. Through their involvement activities they were developing new, quasiprofessional identities as PPI panel members, as coresearchers, and for some, as called-on experience-based experts in the field.

In a previous article (Thompson et al., 2012) we discussed PPI in health research and (what we have argued to be) some of the problematic aspects of professionalization. By this we referred to patients and carers who engaged in a range of research-related training to the extent that they might have lost their experiential expertise as they became more sensitized to research processes and engaged with dominant techno-scientific discourse. From a poststructuralist perspective, others have argued that notions of participation within the broader discourses of public health might be regarded along more critical lines; for example, as a mechanism to promote surveillance and to subtly govern health behaviors at a population level (Lupton,1995). Indeed, one can make the same point with regard to PPI in research.

The findings we report on in this article, however, highlight an important (and overlooked) aspect of PPI: its transformational function. We suggest that PPI activities can provide spaces for identity work, with some individuals actively redefining aspects of self and identity along much more positive lines. It is perhaps not surprising that we identified this thread within PPI when exploring the experiential aspects of involvement. Identity work is a relatively common theme now within the sociology of chronic illness (Bury, 2001; Frank, 1995; Thomas, 2011; Williams, 1984), and asking participants to narrate their experiences allows them to identify a position in relation to powerful discourses and practices, such as biomedicine.

Indeed, what the accounts presented here remind us of most powerfully is the work of Arthur Frank (1995), who has argued that stories about illness are not simply telling about experience; they also allow individuals to demonstrate agency and moreover, they might constitute aspects of the narrative repair work that might need to be undertaken when chronic illness strikes. In many ways, in the data presented here we see what might be described as "quest narratives"—those that involve self-transformation at some level, and the offering of help to others. Along similar lines, Crossley (1998), in her work exploring the experiences of people with a diagnosis of HIV, referred to redemptive narratives that focus on illness as involving transformations to the self and the essentially therapeutic notions contained here. In our view, this is the novel contribution of this study, in terms of the connection between PPI and the sociology of chronic illness.

We would caution against the adoption of a perspective in which PPI is seen as offering unproblematic access to spaces whereby certain aspects of identity can be simply and easily reconfigured in positive terms. As Crossley (1998) pointed out, one of the drawbacks of the therapeutic or healing narrative, although useful at an individual level, is that it can also draw attention away from the more political or structural determinants of ill health. What was very apparent in our study was that those drawing on a quest or redemptive narrative when framing their accounts about PPI were largely the well-educated, articulate, former professionals. These individuals still had space or resources in their lives to engage with PPI and to use agency to fashion PPI to their own ends—in this case, for the production of redemptive narratives.

Although PPI might have been experienced positively by the majority of participants in our study, it could be considered as a policy that exacerbates inequalities, potentially limiting involvement to those who fulfill the criteria of the "good citizen" and who have the resources and abilities to take part. It was highly telling that almost all of the participants had professional backgrounds and found it helpful in some ways to redefine their professional lives through PPI. We would welcome research that explores the extent to which those from different social backgrounds are able to exploit the opportunities for career and identity development.

Overall then, our study findings suggest that although much of the existing literature on PPI privileges moral, political, and consequentialist rationalizations for involvement (in terms of impacts to research processes and systems), the act of being involved as a PPI participant has quite fundamental impacts on the identities of those involved. We argue that PPI provides a framework for sense making in late modernity, one in which participants are able to exhibit a degree of agency through their choice to participate in these roles, to develop research knowledge and skills, and to re-establish (or maintain) the professional self. We suggest that this should be considered as an important impact of PPI in research, albeit one that is in some ways distant from the often instrumental tasks of reviewing patient information leaflets, or commenting on trial recruitment processes.

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