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Exploring difference or just watching the experts at work? Interrogating patient and public involvement (PPI) in a cancer research setting using the work of Jurgen Habermas

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Abstract

Patient and public involvement (PPI) has emerged as a key consideration for organisations delivering health research and has spawned a burgeoning literature in the health and social sciences. The literature makes clear that PPI in health research encompasses a heterogeneous set of practices with levels of participation and involvement ranging from relatively minimal contributions to research processes to actively driving the research agenda. In this paper, we draw on the work of Jurgen Habermas to explore the ways in which PPI was accomplished in a cancer research setting in England. Drawing on ethnographic data with PPI participants and professional researchers, we describe the ways in which the life-world experiences of PPI participants were shaped by the health research system. We argue that PPI in this setting is less about exploring differences with regard to a plurality of expertise and more about simply watching or supporting the professional researchers at work.

Keywords (up to 8):

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Introduction

One important change in the work of statutory, voluntary and private sector organisations delivering health and health research over the last 20 years concerns the importance placed on involving patient and the public (Martin, 2008; Staley, 2009). Patient and public involvement (PPI) has had a complex and sometimes difficult relationship within the health research sector but has emerged as a focus of considerable attention for researchers working at the intersection of health services research and the social sciences and has spawned a significant body of work (Farrell, 2004; Martin, 2008; Staley, 2009; Boote et al, 2011; Brett et al, 2014; Thompson et al 2012; Thompson et al 2013). Such is the strategic commitment to PPI in the UK that the major health research funding body (National Institute for Health Research, NIHR) supports a national advisory group – INVOLVE - dedicated to supporting PPI in health and social care research (see invo.org.uk). How we might use insights from the work of Jurgen Habermas to understand PPI in one particular health research setting (the National Cancer Research Networks) is the focus of this study. Before we suggest how some of Habermas's ideas can help shed light on this area of activity, we sketch out the broad contours of PPI in its intersections with health research.

PPI can be viewed as a portmanteau term to describe a heterogeneous set of practices operating in a range of clinical and non-clinical settings, but which refer to "*research carried out 'with' or 'by' members of the public, rather than 'to' 'about' or 'for' them*" (www.invo.org.uk). To illustrate this heterogeneity, involving patients and the public in health research can mean professional researchers working with PPI representatives in a 'fully' participative sense, for example as co-researchers, commissioners and advisors on research projects (and the scale of involvement might include formulating questions, advising on methodologies, setting the context for the research, applying for funding, as well as collecting and analysing data and disseminating findings) (DH, 2006; INVOLVE, 2012).

There are well-known (albeit, rare) examples where lay groups have entirely reframed the research agenda in a challenging and scientifically engaged way, such as that described by Epstein (1995) in his study of HIV activists in the 1980s and 1990s. Within the field of disability studies, there have also been notable attempts to re-define debates about what meaningful participation in research constitutes (Charlton, 1998). At the other extreme, PPI can also encompass a professional researcher simply asking a PPI representative to 'review' a research protocol to indicate that the necessary involvement has been sought to ensure compliance with the requirements of a funding body (Brett *et al*. 2014). Across this continuum, there will be varying levels of involvement, but it needs to be emphasised that these activities necessarily take place within a health research system and an organisational context (Thompson et al, 2012). By health research system, we mean a setting where rules and practices are more or less codified and which are organised in meaningful ways to deliver specific outcomes for both professional and lay groups (Thompson et al, 2013).

The heterogeneity of involvement practices as referred to above, also extends to the claims made to justify the status of PPI in the broader policy arena (see www.invo.org.uk). For example, the need to undertake PPI is often justified in ethical or consequentialist terms, in the sense that meaningful PPI may render research more transparent, or address perceived 'democratic deficits' in policy formulation or those organisations funding and delivering research (Martin, 2008). It has been claimed that PPI confers authenticity and credibility to research organisations, in terms of both processes and outputs (DH, 2006). This authenticity, it has been argued, derives from the experiential expertise of patients, carers and members of the public, and can be set against the motivations of professional researchers who might have more instrumental interests with regard to the research they are pursuing (Rhodes et al, 2002). It has also been claimed that PPI settings are important since they provide a space for the "*exploration of difference, particularly the difference between lay and professional views*" (Farrell, 2004:41), which can lead to 'creative tensions' and more meaningful or relevant research. This exploration of difference might take place in existing knowledge spaces (for example with patients and carers invited to be part of a research project advisory group) or through the creation of new knowledge spaces (Elliott & Williams 2008) - for example the development of PPI forums that provide input into research but exist independently of any particular research project. Martin (2008) provides

a useful analysis of policies on participation in healthcare in England, highlighting an implicit tension between democratic and technocratic justifications for involvement. He suggests that what emerges out of this tension is an 'ideal' PPI participant, one who needs to – perhaps uncomfortably - inhabit both the 'ordinary' and the 'extraordinary', and who is at the same time both 'lay' and 'expert in laity'. Indeed, we have commented elsewhere (Thompson et al 2012; Thompson et al, 2013), that these tensions are often uncomfortable and difficult to negotiate for PPI participants, coupled with the fact that there is considerable ambiguity around what it means to be a 'credible' PPI participant, and what kinds of knowledge and expertise are brought to bear in accomplishing this task. Moreover, the PPI participant who becomes 'professionalised' through incorporation into the health research system also faces challenges and tensions in justifying their role and their relationship to their lay reference groups (Thompson et al, 2013).

In the broader field of science and technology studies, patient and public engagement (PPE) or 'citizen science' is used to describe the contribution of non-professional participants to the governance, regulation and translation of scientific development (Prainsack, 2014). There is some ambiguity about the difference between PPE and PPI and indeed there may well be overlapping activities within both camps. What unites both approaches is a commitment to 'open up' systems of knowledge production to 'other' forms of expertise beyond the notion of the singular professional expert. What appears to have been overlooked within these literatures, however, is how knowledge from the life-world sits – more or less comfortably - into these new knowledge spaces.

This brief overview highlights some of the tensions and challenges around PPI as it relates to health research. Given that both the policy and the social science literature pertaining to PPI contain repeated attempts to justify its existence, this in itself points to a level of conceptual and practical ambiguity with regard to its status in health research systems. In some ways, this ambiguity may simply reflect wider questions in relation to the vexed issue of incorporating or taking account of lay views and experiences within medicine and health care more generally (Popay & Williams, 1996; Williams and Popay, 2001; Greenhalgh, 2016). Bearing these points in mind, we focus here on exploring the ways in which PPI functioned within the National Cancer Research Network and Institute (NCRN & NCRI) in England.

Through an ethnographic exploration of PPI within these settings, we highlight some key dilemmas concerning how PPI participants constructed their role in what Habermas describes as the language of the life-world, i.e. contributing authentic knowledge to system-oriented discussions and processes. We illustrate some of the ways in which these lifeworld contributions appeared to be marginalised and we point to some of the ambiguities and difficulties associated with accomplishing a 'sharing of difference' in these settings (Farrell, 2004), or indeed 'opening up' health research settings to other forms of expertise. Before describing the methods used, we outline aspects of Habermas' work that are relevant to this paper.

Background

As Williams and Popay (2001) note, Habermas rarely focused on the everyday institutions (schools, hospitals, the police, the legal system and local government) within which actors routinely organise their lives. However, his ideas provide important traction for 'jobbing sociologists' (2001: 29) seeking to make sense of the social world. It is his arguments around the colonisation of the life-world by the forces of capitalism and the state that we deploy here. Habermas (1987) distinguishes between two spheres of social life; the system and the life-world. Within these he identifies two distinct forms of rationality: what he refers to as the life-world is governed by communicative rationality, orientated towards reasoning and achieving mutual understanding between actors (Scambler, 1987). The life-world is the sphere of social life where knowledge and understanding are culturally reproduced (Britten, 2008; Habermas, 1987). As Habermas (1987:138) states:

> *'The interactions woven into the fabric of everyday communicative practice constitute the medium through which culture, society and person get reproduced. These reproduction processes cover the symbolic structures of the life-world.'*

By contrast, the 'system' refers to areas of social life that are concerned with the material reproduction of society and are governed by a different form of rationality – instrumental rationality. Scambler (1987) identifies *'formal knowledge'*, the knowledge of professional experts, as constituting an example. Habermas points to the separation of the system and the life-world in modern societies and the increasing systemisation, or colonisation, of areas

of the life-world, and the distortions that can occur throughout this process (Turner, 2014). This colonization of the life-world can lead to raised public expectations about what the state and other systems organisations might deliver on; expectations that are not always met. As a counter to the colonisation of the life-world, Habermas (1987) proposes a deliberative ideal, based on new forms of participation and a rapprochement between system and life-world aims. It is not difficult to see how PPI might be considered as an expression of this.

At the micro level, Habermas (1987) proposes the theory of communicative action as a way to transform deliberation and participation in practice. Key to the theory of communicative action is open dialogue, or that which is free from the distortions of coercion or manipulation from particular interests, which can lead to more democratic decision-making. This would suggest that in making a decision each party would be entitled to present their perspectives and the outcome would be that the 'best' argument succeeds; this would constitute an 'ideal speech' situation, one based on the validity of the argument, rather than manipulation or strategic action. It is recognised that such a situation is an *ideal* and as such is unlikely to exist in this form (Barnes et al, 2006). However, it does provide a useful benchmark from which to assess communication patterns in system settings.

Drawing on his work in the context of doctor-patient encounters, Mishler (1984) refers to doctors and patients as residing within different orbits - the 'technical- rational' and the 'life-world'. He points to patterns of communication that often result in patients feeling alienated, misunderstood and ignored during medical consultations. His argument is that where doctors adopt technical rational language, they may overlook opportunities to engage with patients through stories about illness. Using Mishler's insights into the medical consultation, Barry et al (2001) identified four types of doctor-patient communication – 'strictly medicine', 'life-world blocked', 'life-world ignored' and 'mutual life-world'. For example, the 'strictly medicine' category was deemed 'successful' where consultations dealt with physical conditions and when the patients were happy to maintain the boundaries of communication within systems talk. However, the authors also highlight instances where patients expected that the consultation would address life-world issues. Within their study, the 'life-world blocked' and 'life-world ignored' categories involved communicative practices

where patients' life-world concerns were either ignored (or misread) by the GP or deliberately blocked, resulting in dissatisfaction. In contrast, where they found consultations in which both the GP and the patient spoke in life-world terms, they argue that not only did the patient feel heard but the communication was deemed successful (Barry et al, 2001).

Britten (2008) explored pharmacists and patients' perspectives on the use of pharmaceuticals within a Habermassian framework. One of her key arguments is that prescribing practices ignore patients' life-world concerns and with medicines information emphasising the potential benefits over harms, system imperatives therefore promote medicines usage. In seeking to re-claim aspects of the life-world, Britten argued that patients often disregarded professional advice concerning medicines usage. This was a key concern amongst health professionals, who viewed patient disregard for systems rationality as a challenge to their expertise. Britten's positive suggestion is that one way to re-couple system and life-world interests would be to enhance patient and public involvement in strategic decision-making bodies, such as the National Institute for Health and Care Excellence (NICE) and other research commissioning bodies, such as the National Cancer Research Networks in England. Her argument assumes that greater exposure at the strategic level of organisations between the voice of the life-world and the system may create opportunities for ideal speech situations, or more open dialogue.

Britten's positive assertion that greater patient and public involvement in decision-making bodies might offer a way for system and life-world interests to be re-integrated is not uniformly reflected in the small empirical literature in this area. Drawing on Habermas's theory of communicative rationality, Hodge (2005) explored service user involvement in a mental health forum that had been established by a mental health service in England. Hodge noted that communication appeared to be far from the Habermasian ideal speech situation, with service users' life-world contributions frequently restricted and bound closely to the remit of what was institutionally defined as 'acceptable' talk. She argues:

> '...the kind of discourse constructed by the system is far from communicatively
> rational. Participants are structured into adopting communicative roles that mirror
> the institutional identities created by the system, and these roles limit the forms of

knowledge that can be drawn upon by occupants of different roles in discourse"
(Hodge, 2005; 178).

Whilst demonstrating the pervasiveness of system imperatives within the communication dyad, Hodge (2005) also highlights a potential difficulty with Habermas' ideal speech situation, namely, the conceptualisation of 'competence' as unproblematic where all speakers are considered as equal. Such an analysis fails to account for the construction of what counts as competence within existing institutional power dynamics (Turner, 2014). For example, the dynamics between professionals and patients in the mental health forum studied by Hodge (2005) were often found to echo those in clinical settings where asymmetries of power, information and control have long been reported (Pilnick and Dingwall, 2011).

Returning to the case of PPI in health research there are no studies that we are aware of, that have utilised Habermas's notions of communicative rationality and the colonization of system and life-world. In this paper, we seek to do so, specifically in the context of PPI in cancer research settings. We now describe the setting and methods used in this study.

Research Setting and Methods

The setting for the research was the National Cancer Research Network and Institute in England (NCRN & NCRI) and the ethnographic data we draw on in this paper were collected between 2008 and 2009 by JT. The NCRN and NCRI provide the infrastructure for cancer clinical research in England and they state that:

> *'PPI is of key importance to both organisations based on the premise that the value and quality of cancer research can be improved through meaningful PPI'* (NCRI & NCRN, 2011).

Within the infrastructure of the NCRN/NCRI, there were 22 national clinical studies groups (covering different cancer specific groups), which oversaw cancer clinical trials and identified future research priorities for the network and beyond. Patient and/or carer members were part of each clinical study group, of which the remaining membership

consisted of clinical and professional researchers. At local level, many cancer research networks had established PPI panels, with individuals involved within research projects, local clinical trials steering groups, or providing advice to researchers. The aim of the ethnographic study was to understand the ways in which patients and carers were involved in the work of the NCRN/NCRI and to explore the barriers and facilitators to involving patients and carers, as revealed through interviews and observations with PPI participants and professional researchers.

Six clinical studies groups and one local PPI panel in England were studied over a year-long period using observation, interviews and analysis of key documents. Sampling was pragmatic and the chair of each clinical studies group was invited via email to be included as a case study. All six who responded were included. A local PPI panel was chosen largely because of its convenience geographically, as the site for more detailed ethnographic investigation. This was a well-established panel, which had been operating for over 5 years when data collection commenced and located within the region in which JT 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.

During the data collection period, non-participant observation of one full meeting for each of the five CSG case studies and two full day meetings of the CSG subgroup case study were completed between May and September 2008. Semi-structured interviews were undertaken with ten clinical and academic members, eight PPI members and two members of the management group. Documents including; minutes, agendas, role descriptions and person specifications were also analysed. Participant observation was undertaken with the local PPI panel (LRP) for the entire data collection period, with JT assisting the LRP for one day a week with administrative and facilitation tasks. Observational data collected included: weekly email and telephone contact with LRP members, at least a dozen informal meetings with the Chair, the academic facilitator and the clinical lead; four full day business meetings; two half day meetings and; two training days. Semi-structured interviews were conducted with four panel members, the panel secretary and two researchers who had worked with panel members on research projects. Documents analysed include: seven annual reports, minutes, person specification and role description and material from the LRP website.

The semi-structured interview guides were developed by drawing on the literature and in collaboration with the Project Advisory Group, which included a patient member (who was involved throughout the duration of the study from initial question development to interpretation of findings). A combination of telephone and face-to-face interviews were undertaken, dependent on the participants' preference and in consideration of practical constraints. The length of the interviews ranged from 30 to 90 minutes. Interviews were digitally recorded and transcribed verbatim by JT. Each transcript was anonymized, with the participant given a pseudonym and any identifying data removed. Interview, observational data (in the form of field notes, written accounts and reflexive journals) and documents were analysed using an interpretative thematic approach to analysis, as proposed by Seale (2004). This was a reflexive and iterative process with initial open coding followed by selective and more detailed coding, making links and comparisons between themes, across participants and with the wider literature and discussing findings with other members of the team as a fuller account for the data emerged. Initial and secondary coding practices were discussed between JT and PB and some of the data were recoded as a result.

Each member of the case study groups consented to the entire ethnographic study, with the understanding that they may be approached to take part in a more formal interview as part of the research. The project received NHS ethical approval.

Findings

Constructing competence in the NCRI setting

Habermas's theory of communicative action relates to the competence of each person in the relevant setting to speak. A question we explored with PPI participants focused on this issue and, in particular, what they thought they brought to the health research setting they were working in. Direct experience of cancer and cancer services (as a patient or carer) was (not surprisingly), referred to repeatedly and allowed participants to discursively differentiate themselves from what we refer to as the professional researchers, and also allowed them to claim an area of expertise, credibility and competence (Thompson et al,

2012). In this sense then, their competence to contribute within the research settings in which they were involved was constructed out of the 'authentic' embodied experiences of being treated for cancer, at the level of engagement with services and particularly around the quality of patient care. This can be seen in the extracts below:

> 'You know how you were treated. I have no complaint about my treatment at all. I had wonderful treatment, it wasn't nice but I can't fault how I was looked after and how I was dealt with. But because I had the experience personally of that, when they now start to talk about what they want to do with the patients in this group, I think 'would I have been able to have coped with that or would I have liked it done differently'. So I draw on my own experience which obviously nobody else can do' (Sheila, PPI participant, LRP).

Similarly, Fiona said:

> 'I think we bring a worldliness that is different from pure academics point of view. I think we can sometimes ask and answer questions that they don't know how to deal with. As a slight example of that I think sometimes professionals feel that they must treat continuously and that people want the maximum that they can. So they will keep doing it even though they know you're going to die and some of the implications are that the treatments will make you very, very ill. And that whole debate is about 'when do you stop'? And does that then create hopelessness in that person and then gives up 'they've told me there's no hope, it's kind of curtains here'. And I think sometimes as a patient you can say 'well this is my experience and this is how I would take it' and you can perhaps sometimes just give experiences about what it feels like.' (Fiona, PPI participant, LRP & CSG).

Both Sheila and Fiona privileged personal experience as the unique contribution they made to the research settings they were involved in. Their competence to contribute was based on their experiential evaluation of what felt acceptable to them as a patient. Here, embodied experience, or what we refer to here as life-world authenticity, when applied to the problematic issue of when to cease treatment, provided another window on the vicissitudes of living with cancer, and was seen as relevant to the workings of the system.

Yet, as a basis for establishing competence, this valorisation of personal experience was not necessarily shared by the professional researchers.

This latter group referred to constructions of the PPI role that overlapped with the sentiments identified above, but in rather different ways. Steven, a professional researcher, referred to PPI participants fulfilling a 'checks and balances' role, but one that was passive, and secondary to the systems oriented tasks:

> *'I see them probably more as a part of a checks and balances rather than a, because they obviously don't have the specialist knowledge or the knowledge of new treatment they are unlikely to be part of the initiation of a process. But I see them as an important part of the, an important check point that the proposed trial should go past, on the 'is this reasonable?', 'is this a fair question to present to somebody?' sort of level. So I think it's essentially a slightly passive role.'* (Steven, professional researcher, CSG4).

This downgrading of the knowledge of PPI participants was highlighted in other accounts from professional researchers, and points to the ambiguous nature of what PPI participants brought to this setting. What also became clear from the interviews with PPI participants, was that whilst they emphasised their experiential authenticity, this appeared to be an insufficient – or at least uncertain - basis for competence to participate in the NCRN meetings. For example, whilst PPI participants initially made claims about the different perspectives they brought to research settings, it became apparent that the articulation of these was shaped by a strong sense of what was considered appropriate in the system settings (Thompson et al, 2012). For example, many PPI participants made reference to what they thought constituted the 'right person' or the 'right kind of involvement' in these settings, with the articulation of what was described as a fresh perspective or a sense of 'naivety' contrasted against the advantages of being an 'established' or 'accepted' lay member. This latter group were able to draw on a range of system-oriented skills (including training in clinical trials, disease aetiology and treatment) and were able to 'fit into' NCRN PPI meetings, and communicate more effectively with the professional researchers. They were, in short, a quasi-professionalised group. There were also other tensions participants

identified, such as the need to separate out 'inappropriate' aspects of personal experience in NCRN settings.

>'Clare: But of course I have to be aware that I have to maintain objectivity. So it [personal experience] must inform my response but it must not be too much about my own experience.
>
>Interviewer: How do you do that?
>
>Clare: I have to be very careful and think about it carefully. There's always a desire to want to go 'it's been like that for me'. It's about not having one's own agenda. I have to be objective, and yet use my own background. So in a way it's more complicated and more demanding than for the researcher because one can be objective. So I have to use my experience although not emotionally in that it might skew my response...That is something I must remember, I'm there because of my experience but I won't become too personally involved. You know, to contribute out of one's experience but objectively not emotionally. Which goes back to the importance of training. I've benefitted from the training provided by the NCRN, previously from [a local cancer network], also from the Macmillan training and of course previously from the Community Health Council training as well. It is important…to remember… you know the clear path between patient and professional. We're in the middle.'
>(Claire, PPI participant, CSG group).

In this, and other accounts, we saw instances of monitoring and self-surveillance by PPI participants over what they felt they could and could not say, and their assessment of how emotional experience might be viewed. Competence to speak in NCRN settings, therefore, was not simply a case of expressing 'life-world' experiences and for these to be straightforwardly heard in this setting. Another way of putting this is that PPI participants appeared to have internalised the idea that communication around experiential authenticity had to be re-formulated to fit into the communication practices that were appropriate to the health research system.

The system hearing the life-world?

Something frequently identified by PPI participants as problematic was the use of technical and scientific language at CSG meetings. One approach to addressing this was to provide 'jargon buster' guides for PPI participants (lists of commonly used acronyms, definitions of research, treatments or trial terms) which were distributed pre-meeting. Whilst this was one of many efforts we observed within CSGs to facilitate a better understanding of clinical care, this interest was not reciprocated. There was variable interest from professional researchers' in understanding life-world perspectives on the experiences of cancer or its treatment. Some professional participants deemed it more important that systems talk was understood by the PPI participants:

> *'I think we've got to make sure our discussions are comprehensible for them and we're not getting carried away with political stuff within medicine and terminology. We've got to make sure that the language we use is understandable to them as well. And certainly if I think something is a bit esoteric is being discussed in our group I would normally stop and explain it. At least I hope I would'* (Mick, Professional researcher, CSG3).

Other professional participants showed less interest in ensuring their systems talk was communicated in a way in which PPI participants could comprehend:

> *'There's usually about 20 of us and if one turns up, there's one consumer and I'm afraid very quickly as far as I'm concerned, we forget if someone doesn't know our jargon if you like'* (Victoria, Professional researcher, CSG5).

It was also clearly evident that those PPI members who were able to converse with professionals in what we term 'systems talk' were those who were turned to by professional researchers for guidance on what were deemed 'PPI' matters (which consisted mainly of supporting the professional researchers with ensuring trial documentation had received input from PPI participants – for example, commenting on the appropriateness of patient information leaflets and consent forms). As we have already noted, some PPI participants

had spent long periods of time in this role and had benefited from training in medical statistics, trial methodology, systematic reviews and qualitative methods. However, this focus on the 'proto-professionalised' was not without its problems. This was seen most often within the local research panel (LRP), where there was far more vocal and forthright discussion amongst PPI participants about how they should work with professional researchers and whether 'experiential expertise' was valued. For example, during observation of a group discussion about research methods training there were clear differences of opinion, with some LRP members highlighting the positive aspects of attending training courses (increased confidence in research processes and understanding of clinical trials findings). However, those members who had not attended training courses began to question their own contribution within the LRP, with one group member (a carer) stating that she felt her lack of training left her with "*nothing to offer*". Another LRP member took a firm stance against this stating *"We are all here as people in our own right. Not to be experts in statistics and research".* One of the academic facilitators for the panel repeated that LRP members were not there to act as *'mini researchers'*, emphasising the importance of their experience as patients and carers rather than acquiring research skills. However, what appeared to occur overtime was that PPI participants qualified their input to meetings in line with what they thought the system required (an absence of emotion and limited input in terms of personal experience) and those that had the greatest amount of system-oriented training, felt able and willing to speak. Indeed, overtime we noted examples where LRP participants who did not undergo training, left the forum.

PPI as a new knowledge space?

A final theme we highlight is the potential of the CSGs to incorporate PPI in the form of the Habermasian deliberative ideal. We do this through documenting examples of communication in the CSGs. In principle, PPI was part of the standard agenda for each group meeting with PPI participants allocated time to bring their own issues to the table. Furthermore, PPI participants could, as any other member of the group, contribute to group discussion about any item on the agenda. However, in practice it was less clear that this happened and PPI issues tended to be secondary to the more instrumental concerns of the CSGs. During an interview with the Chair of a CSG study group, when asked about his

understanding of PPI he began by claiming that PPI members had a role to play in all areas of the group, and that they provided *balance* to the functioning of the group*:*

> '**Interviewer***: So what's your understanding then of why [lay people] consumers serve on the [case study groups]?*
>
> *Erm, well it's to, essentially it's to input the view of the consumers into, across the board. So from potential research questions, areas, priority areas for research, right up through conceiving and designing studies, asking relevant questions, to balance the way the studies are designed and to improve the interpretation of the data.'*

However, as the interview progressed it became apparent that he viewed PPI involvement as secondary, or subsidiary, to the other aspects of the group:

> *'I mean I have to say that involvement, that the involvement of the consumer representatives, is not at the top of the list of priorities at present…if you look at, sort of, what we're aiming for, which is essentially delivering studies, bringing in income, bringing in industry sponsored studies, interacting with other agencies, advising NICE running study days. All of those and, developing the role of the consumer representatives isn't at the top of the list of priorities.*

The agenda in meetings also appeared to limit the potential for genuine debate and the incorporation of a plurality of views and expertise (including those of the PPI participants). In this study, we witnessed several examples that were illustrative of the differing expectations of PPI participants and professional participants about the role of PPI within the case study groups. For example, one PPI participant described when she had attempted to introduce issues for discussion within the group that interested her as a patient.

> *I did manage to say something which had an effect…. it had something to do with the complementary therapies group and he asked did anybody want to go along to something that was happening with complementary therapies. And there was almost, you could almost describe it as a snigger went round. And it was so obvious*

that they dismissed it totally and nobody did want to go to this thing. So later in the meeting, the Chair, again doing a good job as a Chairman, turned to me, asked me to introduce myself to the group, which in itself was terrifying… So in this very peculiar voice that wasn't mine because I was so scared, I actually commented on the fact that I noticed the response to complementary therapies, and I was surprised that there was so little interest because certainly from the patient's point of view and my experience with other patients, complementary therapy plays a very important role in the path of their recovery.'

In this example, Anne had wanted to contribute practical rationality to the group, in this case the use of complementary therapies, rather than validating the existing work of the group. This could have been used as an occasion to discuss the basis for the efficacy of different treatments and to engage in mutual dialogue. Her reflections were also illustrative of the feelings of anxiety that were often associated with being involved in cancer research settings as a PPI participant and attempting to introduce practical rationality based on experiential expertise into systems orientated research groups - an issue raised by many that were interviewed.

Taken together, these findings illustrate the constraints and limitations of the PPI role within settings that were largely orientated towards achieving instrumental outcomes (i.e. more evidence) and the subtle mechanisms that regulated the communicative contribution PPI participants were able to make. We now discuss these findings further with reference to points made earlier.

Discussion

In this paper, we have reported on some of the ways in which the life-world experiences of a group of patients and carers were articulated and received in one particular health research setting. We are mindful that what we observed might not necessarily translate easily to other settings. Nonetheless, with this caveat in place, we would like to make some general reflections about PPI in health research settings. We then comment on the value of the Habermas's concepts of system and life-world as a framework for understanding PPI in this particular domain.

In relation to the former, as we saw, the majority of PPI participants initially highlighted what they saw as their contribution to this setting in life-world terms (that is, in terms of being able to speak about experiences of cancer and its treatment). However, there were also very clear caveats concerning how this life-world expertise could be articulated in this setting. For example, in reflecting on the need for and the impact of training for PPI participants and on the requirement for 'objectivity' when voicing personal experiences of cancer, there was a clear sense that lifeworld expertise had, at best, an ambiguous status in this setting. As we have noted, those participants who had undergone training in research methods could converse more fluently with the professional researchers, and this provided an important source of credibility in their encounters. Indeed, our study identified a number of participants who could be seen to embody Martin's (2008) ideal PPI participant – one who is both ordinary (by virtue of their laity) and extraordinary (in terms of their skill set and ability to negotiate techno-scientific discourses). But what was particularly stark, was the extent to which the articulation of personal or direct experience about cancer and its treatment, which one might imagine would be the primary *raison d'etre* for PPI in this setting, was viewed, not negatively, but certainly in ambiguous and uncertain terms, by professional researchers, and also by some PPI participants.

Returning to Habermas's and Britten's (2008) arguments presented earlier about the potential for PPI to lead to rapprochement between system and lifeworld, to what extent do we think this was successful in this particular setting? We have provided examples which illustrate how the voice of the life-world was included, blocked (overtly and covertly), disregarded and/or modified. By contrast, within some CSGs, there were instances when technical aspects of research were described in plain English for the benefit of the PPI participants. It is arguable that this was welcomed and facilitated an understanding of the NCRN mission. However, in the main it was clear that these communication practices facilitated largely one-sided encounters. In other words, in these system settings, PPI functioned such that participants were 'empowered' to understand the working of the health research system, but it was rare for two-way dialogue to occur, where professional researchers also acknowledged or reflected on the personal, embodied or familial dislocations and strains that result from living with cancer and its treatment. Indeed,

'successful' participation was routinely described (by both PPI participants and professional researchers) as providing input into trial documentation or making changes to information sheets and consent forms. This suggests that PPI in this particular system setting worked best where participants were willing and able to communicate in the language of the system. As a mechanism to re-couple system and life-world in dialogic terms, or as a means by which to accomplish the Habermassian deliberative ideal, PPI could not be said to serve this function.

PPI as manifested in this setting is perhaps less about challenging or broadening expert knowledge through the inclusion of life-world perspectives and more about PPI participants working with the experts on their own (system oriented) terms. These conclusions challenge those arguments presented by some about the role of lay knowledge in professional settings. For example, Hess (2004) suggests that lay people present an 'epistemic challenge' in the field of complementary therapy, and Williams and Popay (1994:120) have asserted that lay knowledge provides a challenge to the '*institutional power of expert knowledge*'. By contrast, our conclusions are similar to those of Kerr et al (2007), exploring lay/professional interaction in public forums about genetics. Highlighting the limited impact of lay voices in challenging professional expertise, Kerr et al (2007) conclude that they had reservations about the possibility that lay involvement in scientific debate might lead to more transparent decision-making or more deliberative forms of knowledge production. Similarly, Hodge's (2005) work on service user involvement in a mental health forum highlighted how institutional power dynamics placed boundaries around what was considered to be acceptable talk within that setting, limiting the potential for life-world perspectives to be voiced.

Hodge (2005) notes that applying Habermas's theory of communicative rationality within the mental health service user forum she was researching was conceptually difficult given the assumption that competence to speak is essentially unproblematic if we assume that all parties are treated equally. As she noted, this does not account for the *"underlying institutional and personal dynamics that operate within user involvement forums"* (Hodge, 2005: 180). In our study, similar dynamics appeared to be at work. Within the CSGs and subgroups communication appeared to be shaped by 'professional' voices and a systems

driven remit, and PPI members often questioned their competence and credibility based on life-world contributions alone (Thompson et al,2012). However, what was particularly notable was that this was also observed within the Local Research Panel, even though it comprised a majority of patients or carers (including the chair). In this setting, some PPI participants who had undertaken additional research methods training were observed to move the group discussion towards more formal systems talk and in the process alienating those who could not or did not wish to engage in this way. Clearly, 'competence', within the settings that we observed, was linked to additional skills and attributes beyond verbalising experiential expertise, most notably the ability to converse in techno-scientific language. We would argue, therefore, that whilst the health research system encouraged patients and carers to communicate with it on its terms, the reverse rarely occurred and it was difficult to see PPI as embodying Habermas's ideal speech act.

Conclusion

On the basis of this study, PPI remains an ambiguous area of activity within the health research system, one where communication is focused on systems oriented priorities, and does not appear to function as a space for the exploration of difference, as some authors have suggested (Farrell, 2004). Stilgoe et al (2006: 19) presciently ask: *"Are we opening up expertise to new questions and perspectives, or are we just letting people see the experts at work?"* For us, the answer seems clear, which returns us to a broader discussion of why we see these patterns of communication and interaction, and why PPI does not appear to act as a bridge between life-world and system.

Good (1994) makes the point that as a key institution at the heart of Western civilization and its claims to modernity, medicine privileges a soteriological vision, and a means by which to transform human suffering. In order to achieve this vision, the formal knowledge of medicine increasingly takes place in spaces where
"specialised forms of argumentation become the guarded preserve of experts and thereby lose contact with the understanding process of the majority of people" (Ray 1993:49-50). As numerous authors have noted (Frank 1995), it is in the enactment of this soteriological vision, that the nature of suffering, (or what we have referred to as experiential expertise), gets overlooked.

Having said this, we are not suggesting that PPI within health research is without benefits either for the system or the participants themselves. As we have argued elsewhere, PPI provides important opportunities for participants (where they are willing to converse on systems oriented terms) to re-configure and re-fashion new and positive self-identities following a diagnosis of cancer, whilst also providing an important space for re-establishing a sense of meaning in a world where domestic roles and the rewards from paid employment may have shifted significantly (Thompson et al, 2012). We acknowledge this, but would also caution against an uncritical assertion that PPI in health research settings can unproblematically bring life-world expertise into the realm of the system.

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