

# Healthcare Professionals' Representations of 'Patient and Public Involvement' and Creation of 'Public Participant' Identities: Implications for the Development of Inclusive and Bottom-Up Community Participation Initiatives<sup>†</sup>

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## ABSTRACT

Community participation is widely thought to be important in the improvement of healthcare delivery and in health equity. Yet there is little agreement about what 'participation' means in practice, or when it might be necessary. Drawing on the case of healthcare delivery in the UK, we examine key socio-psychological elements at the heart of community engagement with participatory processes. We explore the link between public participant identities and social representations of patient and public involvement (PPI) among healthcare professionals, and examine the role they play in supporting or undermining inclusive and bottom-up forms of PPI. The study is ethnographic, using in-depth interviews with public participants and healthcare professionals involved in PPI, and observation of PPI activities in London. We show that it is crucial to take account of more than individual participants' capacities in order to understand and improve PPI. Professionals' talk about PPI contains contradictory discourses about participant identity. These contradictions are reflected in involvees' self-understanding and experience as public participants, constraining their subjectivities and forms of knowledge, and crystallizing in their participatory practices. Involvees must negotiate professionals' negative discourses to develop self-images that reflect their own interests and projects, and that empower them to produce an effect in the public sphere. These processes can hinder successful participation even where there is an institutional infrastructure to promote civic engagement with healthcare. Understanding how involvees construct their own identities through engagement with professional discourses will help develop processes that are positive and enabling rather than negative and limiting. Copyright © 2011 John Wiley & Sons, Ltd.

*Key words:* community participation; healthcare; patient and public involvement; public participant identity; social representations

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## INTRODUCTION

Community participation is widely thought to be important in the improvement of healthcare delivery and in health equity (Department of Health, 1999; WHO, 2008; World Bank, 2006). Despite the apparent consensus, there is little agreement about what 'participation' means in practice, or when it might be necessary.

This paper draws on the case of healthcare delivery in the UK to examine key socio-psychological elements at the heart of participatory processes. We focus on the link between social representations of patient and public involvement (PPI) and public participant identities, and examine the role they play in undermining or supporting inclusive or community-orientated, 'bottom-up' forms of PPI. Participation in PPI can potentially provide a means through which ordinary people can exercise their citizenship in health services governance. In line with new approaches to citizenship (e.g. Barnes, 1999; Barnes, Newman, & Sullivan, 2004; Barnes, Auburn, & Lea, 2004), we view participation as a potential means of enabling 'citizenship in practice' (Barnes, Auburn et al., 2004). Within this framework citizenship is interactional, and constituted at the interface between public participants and official bodies/professionals through dynamic relationships between them (Barnes, Auburn et al., 2004). Citizenship not only involves civil rights, responsibilities or the internal attributes of individuals, but also opportunities to participate in systems of state governance (Barnes, 1999).

For more than a decade, the UK Department of Health has called for involvement of patients and the public in healthcare research and service development. Recent government policy has identified PPI as a way to promote citizen participation, to shape and improve organization and delivery within the National Health Service (NHS) (Tritter & Lutfey, 2009), despite the scarce evidence of impact on either healthcare research (Boote, Telford, & Cooper, 2002; Fudge, Wolfe, & McKeivitt, 2007; Oliver et al., 2004) or equitable access to improved services (Barnes & Coelho, 2009). Within the NHS, there is an emphasis on developing individuals' capacities for PPI (INVOLVE, 2010), yet this approach ignores the contextual barriers and facilitators to successful involvement.

There is still widespread disagreement between policy makers, healthcare professionals<sup>1</sup> and 'involvees'<sup>2</sup> about the definitions and rationales behind PPI and the role public participants should play. Contrasting policy-level rationales for public participation (e.g. technocratic excellence versus democratic accountability) and diverging discourses about the relationship between public healthcare services and citizens (Barnes & Coelho, 2009; Hogg, 2007; Martin, 2008), are re-interpreted by professionals in response to their own agendas and projects (Martin, 2008). This affects how PPI is implemented and experienced by involvees (Martin, 2008). Within the NHS there is no agreement over the expected roles of public participants, or the 'qualifications' they need (e.g. experiential knowledge of an illness, elected to represent the views of a particular community) (Barnes & Coelho, 2009; Hogg, 2007; Martin, 2009).

Barriers to successful PPI development include resistance within organizational cultures, and differing ideas of 'involvement' held by staff and 'involvees' (Daykin, Evans, Petsoulas, & Sayers, 2007). Participatory practices also tend to remain at the consultation level with professionals' decisions taking priority (Barnes & Coelho, 2009). In other words, individuals' capacities are far from the only limitation to the success of PPI.

One crucial area for understanding the social psychology of participation—the study of social identities of participants (Campbell & Jovchelovitch, 2000)—has to date been largely neglected in the PPI literature. This paper contributes to this neglected area of work.

Whatever form it takes, becoming a ‘participant’ is a way to assert your identity in the public sphere; to state who you are, what your knowledge is, and what your concerns are (Guareschi & Jovchelovitch, 2004). Individuals’ engagement with PPI processes, impact on decision making, and participation in collective action for social change all have an influence on—and are influenced by—those individuals’ social identities, self-esteem, and social recognition (Campbell & Jovchelovitch, 2000; Campbell & McLean, 2002; Campbell, 2005; Guareschi & Jovchelovitch, 2004). Similarly, and particularly in the absence of any general understanding of what ‘participation’ involves, relationships between involves and professionals are crucial in forming the backdrop against which individuals’ participation is ‘learned and actualized’ (Guareschi & Jovchelovitch, 2004, p. 314).

In this paper, we examine discourses about PPI among healthcare professionals in London, and explore how involves negotiate these discourses when making sense of themselves as public participants. Drawing on social representations theory (Moscovici, 1974/2007, 2000) and the concept of social identity (Duveen, 2001; Duveen & Lloyd, 1986; Howarth, 2002), we explore how professionals’ understandings of PPI contain discourses about the identity of the participant (i.e. who she is, how she should be/ behave), and the effects these may have on developing or hindering inclusive and bottom-up forms of PPI. Social representations theory enables us to study the relational and symbolic dimensions of participation (Campbell & Jovchelovitch, 2000) and thus can contribute to understanding citizenship as an ‘interactional matter’ (Barnes, Auburn et al., 2004) that is realized in the inter-subjective space between ordinary citizens and the state.

### *Social representations, identity and citizenship*

Social representations are systems of social knowledge collectively constructed and re-constructed in communicative interaction and social practices with others (Moscovici, 1974/2007). As common symbolic resources shared by members of a particular group to give meaning to their social and material world, and orient themselves within it, social representations inform the behaviours of that group (Moscovici, 1984). Their content and dynamics reflect their grounding in people’s positions in diverse socio-cultural and political contexts and the manifold dialogues with others through which they are constructed. Professionals’ representations of PPI (i.e. understandings, norms and practices) permeate interactions with involves and help constitute the symbolic environment within which involves organize their experience and construct their identities as public participants.

Identities are intersubjectively constructed through the interplay of the symbolic resources contained in others’ and own representations about self and our groups (Campbell & McLean, 2002; Howarth, 2002). Identities become meaningful in social interactions and practices through processes of positioning the self in relation to social representations circulating in our environment; appropriating, reworking and/or contesting these representations (Duveen, 2001). The availability of different identity positions in these networks of meanings is framed and constrained by contextual norms and values (Duveen, 1993). The relationship between how others represent the groups we belong to,

and how we construct ourselves, becomes clear in the case of minority and socially excluded groups (e.g. Hodgetts, Radley, Chamberlain, & Hodgetts, 2007; Howarth, 2002). More 'powerful' others' representations of 'us' (self and social grouping) constitute symbolic and material constraints which may restrict the extent to which we are able to produce positive identities and challenge identities that put our potential future achievements and interests at risk. Identities may thus play an important role in reproducing or transforming relations of power and constraining or enabling individuals' civic engagement (Campbell & Jovchelovitch, 2000; Campbell & MacPhail, 2002; Campbell & McLean, 2002).

In relation to health care, Campbell and McLean (2002) have shown that social representations of ethnic minority groups play a key role in constraining their engagement in grassroots community participation. Hierarchical identity positions between health visitors and members of the public can also constrain dialogue, for instance in terms of the extent to which they accept each others' input (Gillespie & Cornish, 2010).

In the case of PPI, public participants' and professionals' interactions in decision-making are asymmetric in terms of symbolic and material power (e.g. status, access to information), which may prevent involvees participating in ways that adequately reflect their own concerns and needs (Ansell & Gash, 2008; Barnes & Coelho, 2009). On the other hand, participants may exercise agency in their relationships with others, resist negative representations projected onto them, and develop alternative and more positive identities (Howarth, 2006, 2010).

For dialogue to exist in the encounter between the knowledge and projects of self and another, each must recognize the other as 'legitimate partners in interaction' (Jovchelovitch, 2007, p. 132).

## **METHODS**

This study is part of a larger ethnographic project examining the PPI activities of CLAHRC (Collaboration for Leadership in Applied Health Research) for Northwest London. CLAHRC is a 'five year nationally funded collaborative research improvement programme that will accelerate health research into patient care'<sup>3</sup>. CLAHRC funds approximately seven projects every 18 months, under two research themes: Acute and chronic care, while highlighting three cross-cutting themes (PPI, collaborative learning and delivery and evaluation). CLAHRC helps the projects translate research results into better patient care, using the cross-cutting themes as a focus, for instance, helping with PPI implementation.

We used an ethnographic approach, examining the whole of the CLAHRC. At time of writing, the work was ongoing and this paper focuses on the cross-cutting work rather than the individual projects. Here we draw on 27 in-depth 45–120 minute individual interviews and 82 hours of observation of PPI activities run by CLAHRC. Twelve interviews were with healthcare professionals affiliated with CLAHRC, and required to implement PPI—seven staff responsible for supporting and developing PPI, and five clinical researchers; 15 were with 'involvees'—service users or members of the public involved in CLAHRC PPI activities. All were audio-recorded and transcribed verbatim. Interviews covered general definitions and experiences of PPI in healthcare research and service improvement. Professionals also discussed public participants and their role. We asked involvees about

identity, e.g. how they saw themselves as public participants and how they defined their role, their interactions with professionals and perceptions of how professionals viewed PPI.

We used two parallel analytic strategies to examine representations and identities: (1) We used iterative thematic analysis to identify key themes (e.g. meanings, symbols) (Attride-Stirling, 2001), and (2) we examined the type of discourse through which the themes emerged in participants' construction of representations and identities (e.g. contestation, explanation, justification). Through these strategies we identified inter-relationship between themes (including their sequential relationship within the narrative) as well as the dynamics of the content within the themes. In the course of repeated rounds of analysis, we developed a coding frame of themes and sub-themes and identified the discursive patterns through which they arose.

### *Institutional context of the study*

In the UK, PPI is delivered within a complex institutional context across a number of agencies and characterized by ongoing abolition and replacement of constituent bodies (e.g. PPI Forums) (Hogg, 2007; Hughes, Mullen, & Vincent-Jones, 2009). In 2008, responsibility for PPI was given to 'Local Involvement Networks' (LINKs), which comprise various statutory agencies hosted by independent third sector organizations (Hughes et al., 2009). The LINKs aim to mediate between the NHS and the public, enable PPI in commissioning, scrutiny and provision of health and social care, and collect and represent the health-related views of the local population (Hogg, 2009).

CLAHRC works in collaboration with LINKs and other organizations in northwest London responsible for providing and commissioning care (e.g. primary care trusts, acute hospital trusts).

## **RESULTS**

### *Representations and identity*

Professionals' representations of the identity of the 'involvee' were plural and contradictory, reflecting the tensions and ambiguity of the context where these representations are produced and enacted. As we will see, this plurality and contradiction applied both to the content and dynamics *within* each of the three major co-existing themes which formed their shared representations, as well as to the dynamics *between* these themes. The representations were rooted in the competing values of liberal individualism and communitarianism, the tensions between citizenship equality and expert authority, the intricacies of reconciling private and public spheres, the relationship between biomedical and experiential knowledge-systems and the conflict between the right to raise one's voice and norms of civic engagement.

Professionals represented PPI through five co-existing discourses: (1) Discourses of epistemology, (2) discourses of civic engagement, (3) discourses of pragmatism, (4) discourses of democratic equality and (5) discourses of reflexivity. All were put to use to different ends and played out in diverse and opposing representations of the identity of the involvee, who emerged simultaneously as a technocrat patient, self-interested political agent and institutionalized reflexive citizen (see below). This set of representations contains internal paradoxes between different practices and constructions of who the involvee is and how she should participate.

For involvees in this study, entering the context of PPI entails participating in elite systems in which they must develop a new position as social actors and engage with the ways of thinking and norms of the environment. They must situate themselves within the network of plural and contradictory meanings (spoken, enacted and manifest) that comprise the 'culture' of PPI and in the process develop a sense of who they are as public participants.

Tensions were evident in involvees' identity positions, related to the contradictory ways they felt that professionals represented them and related to them. Involvees constructed and stated their identities through and against the voice of professionals/statutory others by assimilating, contesting and/or negotiating professionals' PPI-related practices and beliefs. That is, through and against their own perceptions of how professionals expect them to be and experiences of how they interact with them when participating. Involvees' identity work revealed self-other (professionals) tensions, framed by involvees' fight for social recognition and attempts to avoid the threats to the self posed by functioning within expert-systems as ordinary citizens.

#### *Professionals' representations*

*Technocrat-patient.* Professionals' accounts suggest a tension between the ideal of people as expert patient-advisors and the structural and symbolic realities of their lack of equality and agency when participating in expert-systems. There is a recurring dialogue in their accounts between epistemological discourses and civic engagement discourses, played out in the representation of involvees as technocrat-patients. The epistemological discourses construct the involvee as an outsider technocrat whose experiential knowledge as a patient/service user is a valuable asset for experts to enhance quality of research and services (Quote 1).

This representation is also anchored in images of involvees as lacking skills, and struggling to function in expert-institutional contexts. Professionals assert the need to improve involvees' knowledge through the development of their biomedical and research skills (Quote 2).

'We chose the word 'advisor' because we felt that what they were bringing was their understanding of the patient experience which would then provide some, almost advising the group [...] and that's all they can be, is experts in their own experience and that's really all we can expect of that person.'

#### Quote 1 (S<sup>4</sup>)

'It's [a public participant is] someone who's proactive, who's taken the time to learn about their disease or the healthcare they're involved in, who wants to learn more, wants to go on training, wants to understand about qualitative research methodology.'

#### Quote 2 (R<sup>5</sup>)

Involvees' experiential knowledge is 'first-hand' knowledge-in-context developed through subjective and bodily experiences that are often alien to professionals. To participate, the involvee must fit within particular expert categories of disease (e.g. HIV) and produce 'confessional tales' of her illness that threaten to confine her within the

'patient'/'user' category. Although she is encouraged to maintain her identity as an outsider so that her knowledge remains relevant, she is paradoxically asked to develop into a 'proto-professional' to overcome the 'shortcomings' arising from only having experiential knowledge, and also to ensure that her contributions are effective; for example, CLAHRC developed and implemented a training programme aimed to create 'effective' public participants. Discourses of civic engagement are used to claim that 'professional' skills would enable involvees to exercise their rights as consumers/citizens. The representation of the involvee as a technocrat-patient is translated into paternalistic practices of correction through which professionals carefully manage PPI and involvees' adjustment to the ways of acting instituted by the expert majority. Practices such as providing involvees with notes they can refer to at a scrutiny committee and explaining these prior to the meeting, are justified as a way to help them to move with confidence in challenging institutional contexts, but also encourage conformity with the practices within those contexts, such as waiting for the Chair to request an opinion 'as opposed to just shouting out your experience.' (Professional, S).

### *Self-interested political agent*

In professionals' accounts there is a conflicting dialogue between discourses of pragmatism and discourses of democratic equality, played out in representations of the involvee as a self-interested political agent. On the one hand, she is an engaged agent who embraces her right to raise her voice. On the other, she is self-interested and lacks the qualities of the 'good' civic-minded citizen. Her input is not granted validity as it is bound to personal experiences, and lacks objectivity and universality; as such it is not useful to experts as it ignores the realities of the NHS and its professionals' working lives. In drawing upon discourses of pragmatism, professionals position themselves as both responsible to PPI and as subject to institutional constraints in their attempts to implement participatory initiatives.

Political agency to raise one's voice, as well as motivation to be informed are qualities that the technocrat-patient needs to develop to become the kind of involvee professionals want. However, when adopted by the self-interested political agent, these can be seen as a threat and an illegitimate effort to 'push' a particular selfish agenda. Every citizen has the right to question the established order. However, when this is not done within the NHS framework and considering professionals' everyday realities, the involvee is regarded as a burden (Quote 3). Discourses of democratic equality are used to justify the controls professionals exercise on involvees' roles (e.g. turning down requests for greater involvement). Involvees' political agency needs to be 'domesticated' so that the collaborative and democratic nature of PPI is not jeopardized by unruly subjects (Quote 3, Quote 4). It is here where professionals voice their concerns about broadening the involvee population and refer to public engagement as a 'recruitment' process led by them.

'We've had a lot of challenges with that in the sense that [the involvee has] been frustrated, that he sees that we're spending a lot of time making decisions and not reaching consensus [...] 'I think we are wasting money' and 'I am going to go to [CEO name] and say this' [...]. So it's a huge risk. [...] This is causing tension amongst the team, where they don't want him on the team any more. And the other thing, he wants to do more, [...] and so that is an issue, it's how much [involvement opportunity] can we give [him]?'

Quote 3 (R)

'There needs to be something [in the training] about people who are involved in public involvement actually, extending [involvees'] reach so that it's not just about the individual.'

Quote 4 (S)

*Institutionalized reflexive citizen*

In discourses of reflexivity, the involvee is entitled to exercise her right to participate in the public sphere as a citizen, but this is a right that needs to be institutionalized. Paradoxically, she is free to construct the terms of her participation, yet is required to develop the type of agency and subjectivity permitted in the institutional environment. For instance, the ability to be self-critical and discover personal biases is important to ensure her disinterested participation (Quote 5). As well as conforming to institutional practices and bureaucracies, she must fulfil certain social obligations. Discourses of democratic equality assert involvees' responsibility towards others. In their role, they must constrain their subjectivities to become able to channel the views of the community they represent, and promote civic engagement to achieve 'bottom-up' PPI. The involvee is at the interface between expert systems and the lay community. Experts want a particular type of input which will benefit their projects, and when channelling public input, the involvee is governed by expert frameworks. However, involvees also have a communitarian duty to act in the interest of ordinary citizens (e.g. with respect to their health needs) (Quote 5).

'We have our kind of really active LINK authorized representatives where they will have gone through a period of training as well and they will understand about, and be fully aware of the code of conduct and the Nolan Principles<sup>6</sup> and what's expected in terms of representing the LINK in a public meeting or a stakeholder event where they have a responsibility to assess what the LINK view is in a particular issue and to bring that forward as opposed to their own personal interests.'

Quote 5 (S)

*Involvees' identity: Difference, congruence and regulation*

*Difference and congruence.* Paramount to the identity of the involvee is her situation as a dislocated outsider, a member of a minority group within an alien realm. The positions made available to her in the invitation to be a public participant and in the interaction with others from a majority out-group, are difficult to reconcile. On one hand, as an ordinary member of the public, she is called upon to exercise agency as a 'critical friend' and be a self-determined citizen/customer. On the other, she is aware of the norms of the expert system, where an agentic positioning may pose a threat to professionals' accountability and where the frailty of her knowledge in the encounter with the logic of experts might put her legitimacy at risk. Participants' identity strategies sought to achieve social recognition whilst bolstering their self-esteem, through continuous ontological and epistemological differentiation from both members of their 'lay-public' in-group and the type of common-sense knowledge that they hold (Quote 6, Quote 7). Strategies of differentiation emerged



hand-in-hand with strategies of ontological and epistemological similarity: Seeking congruence with the way of thinking and being characteristic of the 'host' environment (Quote 7). Involves critically engaged with the views and practices of professionals, contesting them both at interviews and at observed group discussions between public participants. However, the degree to which this happened at the performative level was framed by the norms and values of the system. The need for congruence with the alien institutional expert-system, guided their discursive and performative identity in the enactment of their PPI role.

Intra-group comparisons aimed at dealing with the negative representations of their social group were manifest in involves' assertions that they had education and/or a professional background that equipped them to do PPI. They also positively differentiated themselves from vocal members of the public with personal agendas that neglect the public interest. In unfolding this identity strategy they addressed professional/statutory others, contesting their potential doubts about the quality of their knowledge and the unrepresentative (biased, self-interested) nature of their contributions. They were careful to present themselves as having moved from this original position as patients/members of the 'lay-public' and gained forms of expertise characteristic of the 'host' context (e.g. biomedical, research-related). In this way they could assert 'insiderness' and thus protect themselves from the implicit meanings and practices that construct difference and separation from the expert majority and which are contained in professionals' invitation to the technocrat-patient. Those with long experience in PPI positioned themselves as quasi-experts through alignment with professional others and those others' expertise (Quote 6).

'I can go to [first name of researcher] and ask, 'do you think these people [other involves] that have been involved know what's going on? Have they got a clue?'

#### Quote 6

'I've had a good education, so I'm more than the average person off the street. If you have a degree you think systematically [...] You don't get taken on to a REC until you've had a testing interview, the most testing I've ever had, more testing than a job.'

#### Quote 7

Involves' search for similarity with the expert out-group existed in tandem with recurrent demands of the need to understand the complexity of host contexts (e.g. bureaucratic practices) (Quote 8). Common to all involves interviewed was the urge to become self-sufficient, i.e. able to move with agency and equal status to experts in the exercise of their civic engagement within this institutional context. This materialized at interviews and field observations in their frequent requests for information about the NHS (e.g. service commissioning). The identity strategy of positively differentiating from the lay in-group co-existed with the need to embrace the role of the 'technocrat-patient', which involved conforming to a position as a lay ordinary outsider. For instance, when introducing themselves at consultation meetings or PPI events, involves would open presentations with an apology for being 'just an ordinary person', or similar. At interview they explained that at these professional-dominated events, experts introduced themselves by their professional role, and so they felt they had no alternative but to present themselves as public/patient representatives.

'[...] you get confidence from knowledge and understanding the system, and what I found was that when you went to challenge someone initially they would try and tell you, you were wrong [...]

Quote 8

*Regulation*

As they embrace their role as public participants, involvees have to conform to the bureaucratic procedures and ways of being of institutionalized others. In our study, this was evident in the adoption of self-regulated and organization-related identity positions. These are linked to the democratic rationales behind PPI, where participation in 'public' forms of decision making requires involvees to embrace the role disinterestedly, as a civic duty. What emerged implicitly from participants' accounts and our observations was that involvees all had a 'passion' for a subject/patient group, which was linked to their private life-worlds and embodied subjectivities (e.g. illness). They were aware that this could threaten their legitimacy and often engaged in justificatory arguments of self-regulation, asserting their interests did not stem from their own socio-psychological context. Here, they engaged in identity strategies of alignment with the group they had to represent (i.e. local community) and sought to present themselves as detached from their own embodied self (Quote 10). In unfolding this strategy, participants appropriated and put to use discourses of democratic equality and identified themselves as conduits for communication of public healthcare needs. They asserted their community identity and drew upon local knowledge of health issues to underline the epistemological validity of their input.

Involvees constructed themselves as working for the public good via their struggles in manoeuvring through expert systems, adjusting to bureaucratic duties, and demonstrating their capacity to perform and deliver tasks with professionalism (Quote 9). They often referred to their experience as a battle to engage powerful others and treated their organizational belonging (e.g. LINK) as a resource to claim legitimacy in their attempt to develop 'high-end' connections with those others. They frequently adopted organization-related identity positions and aligned themselves with the organizational ethos and discourses (Quote 9).

'You have to develop relationships with people at high level, get high level buy in from the NHS, from the council, from whichever organisation you're dealing with so that they trust you basically as an individual, and if they trust you as an individual and they understand the structure of your organisation and how it functions and that you've got the right checks and balances and [...] it's very hard work to get them to accept a particular view from the public. They say they want evidence. When it suits them evidence can be 20 people sitting in a room verbally articulating their views, when it doesn't suit them, they want a ten page essay from each individual.'

Quote 9

'I just not only speak for myself. I speak for 200 elderly people where we live, and there are various issues where we have been very adversely affected by the government changing the whole structure of healthcare for elderly.'

Quote 10

**DISCUSSION**

This paper has explored how professionals' representations of PPI can constrain or facilitate formation of 'public participant' identities, which in turn may play an important

role in enabling or limiting civic engagement in healthcare. Examining these symbolic and relational factors in addition to individual characteristics is therefore crucial to understand why PPI processes work or do not work.

We have shown that being an involvee is about struggling first to assert a legitimate identity as a public participant, second to 'survive' as a lone outsider and a minority in complex expert-systems, third to exercise agency when having to adapt to institutional top-down forms of PPI, and fourth to cope with threats to lay identities and derogated common-sense knowledge. These struggles illustrate obstacles to involvees' developing self-images that reflect their own interests and projects, and that empower them to have an impact in the public sphere. They also point to the impediments they encounter when seeking to enact their citizenship and play a role in influencing healthcare. The experience of involvees includes having to question and reject their own subjectivities and belonging to private spheres, and simultaneously conform to institutionalized forms of PPI.

Involvees in our study made sense of their role and embraced participatory initiatives through and against their perceptions and experiences of how professionals saw them and related to them. We do not argue that professionals' representations have absolute power over involvees, nor that they are the only symbolic resources which involvees draw upon when constructing their identities. Nevertheless, this study shows that professionals are important significant others, and interactions with them are key relational contexts within which involvees define their experience and self-understanding. The interplay of these relational and symbolic aspects of participation enables us to unpack the mechanisms whereby the contradictions and disagreements around PPI (e.g. rationales, roles) identified in the literature (see Introduction) are crystallized in the subjectivity of involvees.

Our findings are derived from a specific programme in one city in the UK. While we do not claim that our sample represents PPI across the UK, our research provides insights into the dialogical nature of PPI and thus offers a novel way of understanding this phenomenon which is likely to be relevant more generally. We have shown that participation in PPI is a constitutive process through which the 'involvee' is constructed and realizes her role in dynamic relationships with public bodies and professionals. Assuming that involvees are separate entities, detaches them from the relational and symbolic processes through which they are constituted. Recognizing PPI's dialogical nature is therefore important since there is often much emphasis on the individual capacities of 'involvees'—in terms of adopting their PPI role, or of professionals—in terms of engaging the public. Our study suggests that current attempts to foster citizen engagement with healthcare may be unintentionally constraining the enactment of the subjectivities and forms of knowledge that ordinary people bring to the PPI encounter, consequently disengaging certain groups, and perpetuating the same inequalities that participation seeks to address. If we agree that participation in the public sphere is a practice inherently linked to the knowledge we have of our self and social group, of who we are and what our needs are (Campbell & Jovchelovitch, 2000), we should engage with involvees' different world views and ways of life. Our findings highlight the importance of being attentive to the link between representations and identity to further our understanding of how citizenship in PPI is not automatically conferred upon people by 'inviting' them to participate in the public sphere, but instead and in line with new approaches (Barnes, Auburn et al., 2004), is a dynamic relational practice, meaningfully constituted and negotiated through interactions between the state and citizens. We believe that the interrelated phenomena of social representations and identity are key elements in constructing a social psychology of citizenship.

There are a number of strategies that might mitigate some of the problems we identify. For instance, networking with others in similar roles might help with difficulties caused by involvees' identities as 'lone outsiders'. Involvees could be encouraged to take more control over PPI, perhaps by hosting particular activities on their 'home turf', or by engaging in peer-to-peer learning so that induction into complex expert systems are less likely to be experienced as 'correction' of individual shortcomings. Understanding how and whether such strategies work will be crucial to improve existing PPI systems.

National calls for public participation and top-down establishment of institutional infrastructure, e.g. LINKs to promote bottom-up active citizenship are not enough. Without understanding how involvee identities are constructed in participatory processes on the ground, we risk—with the best intentions—undermining the development and sustainability of truly inclusive participatory projects.

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