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Citizen Participation as Political Ritual: Towards a Sociological Theorizing of 'Health Citizenship'

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Abstract

This article examines citizen participation in health research, where funders increasingly seek to promote and define 'patient and public involvement' (PPI). In England, the focus of our study, government policy articulates a specific set of meanings attached to PPI that fuse patients' rights and responsibilities as citizens, as 'consumers' and as 'lay experts'. However, little is known about the meanings those who take part in PPI activities attach to this participation. Drawing on ethnographic data of PPI in three clinical areas (stroke, cancer and pre-term birth) we investigate citizen participation in health research as political ritual. We identify tensions between policy-driven and ground-level performance of citizenship, and use ritual theory to show how such tensions are accommodated in participatory structures. We argue that the ritual performance of PPI neutralizes the transformational potential of citizen participation, and we draw wider sociological implications for citizen participation beyond the health arena.

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Introduction

Citizen participation is placed increasingly centre-stage in health work internationally. Within a range of health systems, such as those of Canada (Lehoux et al., 2012), Brazil (Cornwall and Shankland, 2008), the USA (Potter, 2010) and France (Rabehariosoa and Callon, 2002), the promotion of citizen participation in health emphasizes the realignment of relations between citizens and the state (Lehoux et al., 2012; Serapioni and Matos, 2014). A proliferation of 'citizen projects' has seen authorities recasting individual patients as politicized citizens, and devising new ways to act upon them (Rose and Novas, 2005). Citizen projects are explicitly associated with transformational agendas that advocate participative democracy, transparency and public accountability (Cornwall and Coelho, 2007; Martin, 2008). They are frequently viewed as a means of democratizing health and clinical research (Löfgren et al., 2011) as well as of enriching established evidence-based research practice (Boote et al., 2002).

In this article, we focus on citizen participation in health research in the English National Health Service (NHS) (Department of Health, 2006), commonly referred to as 'patient and public involvement' (PPI) (INVOLVE, 2012). This particular form of citizen participation presents a set of structural and political characteristics that make it a distinctive citizen project. In England, unlike other countries, PPI is organized centrally through well-defined structures and processes (including recommendations for job descriptions, person specifications, training and support), and integrated into the architecture of the NHS' research body, the National Institute of Health Research (NIHR). Formal recognition of patients' lived experience is viewed as an important resource for health research (Caron-Flinterman et al., 2005; Giarelli and Spina, 2014; INVOLVE, 2012). However, representation of such lived experience is hindered in practice by power and knowledge differentials between patients and clinical professionals (Martin, 2008), as well as by the increased professionalization of PPI roles (Komporozos-Athanasiou and Thompson, 2015). Lehoux et al. (2012) argue that overall an 'ontologically shallow understanding of citizenship seems to prevail' in PPI, with citizens often being prevented from articulating their positions in the bureaucratic structures of participative fora. This in turn undermines participants' ability to influence research and become 'legitimate spokespersons' (Lehoux et al., 2012: 1844).

Our article offers an analysis of three ethnographic studies representing PPI in health research, investigating how citizenship is performed in PPI activities. We first discuss existing conceptual approaches to citizen participation and review their relevance and limitations for the study of PPI. We then present findings from our ethnographic studies, showing how PPI participants' diverse performances of citizenship are couched on a set of powerful ritual structures that serve to legitimate policy-endorsed PPI aims and neutralize divergence from those aims. Finally, we provide a critical discussion of PPI's conservative role in the performance of citizenship, and conclude with some wider

implications for the sociology of citizen participation developed from our conceptualization of PPI as political ritual.

Conceptual Approaches to Citizen Participation

Citizen participation is increasingly seen as a way of re-imagining the relationship between citizens and state as synergistic, with the individual being recast as an 'active' and 'reflexive' citizen (Clarke, 2005; Martin, 2010). Sociological engagement with active citizenship as 'political participation' has been critical to this re-imagining (e.g. Contandriopoulos, 2004; Rose, 1996), with studies highlighting the inherent ambiguities contained in the 'active citizen' role, as well as the lack of real power transfer that would support it (Marinetto, 2003; Martin, 2010). Studies of 'active citizenship' can be divided into two broad categories: on the one hand, those that have considered its role in the containment and domination of one social group over another, discussing for instance how individuals become co-opted in nexuses of governmental power (e.g. Martin, 2010). On the other hand, those that discuss active citizenship as a form of 'bottom–up' empowerment that may emanate from the expression of social movements (Isin and Turner, 2002), or from the common, embodied experiences shared in a community (Rose and Novas, 2005).

Isin (2009: 369) argues that citizenship may, in fact, encompass both of the above positions, insofar as it is able to both solidify control of one group over another while also offering a potential for emancipation. Such co-existence of containment and potentiality is further sustained by the hybridity and variety of previously contradictory meanings attached to citizenship today (Cornwall and Coelho, 2007). Sociologists such as Schinkel and Van Houdt (2010: 698) explain the increased fusion of citizenship meanings through modes of neoliberal governance, in what they call 'neo-liberal communitarian governmentality', meshing citizens' individual responsibilities and communitarian values.

Patient and public involvement exemplifies many of these complexities and tensions in the enactment of citizenship in the health arena, where meanings attached to participation fuse patients' rights as citizens, as consumers *and* as embodied/experiential experts. Patients active in PPI fora might draw on their corporeal vulnerabilities, suffering and genetic risks to enact a form of 'biological citizenship' (Petryna, 2002; Rose and Novas, 2005), yet they also rely on notions of 'individual responsibility' and 'informed choice' (Schinkel and Van Houdt, 2010) to enact a form of 'consumer citizenship' (Khoo, 2012). Moreover, PPI participants are invited and positioned as 'experts' by government: they are called upon to realize a political project. Yet the spaces within which PPI is enacted (for instance government or charity organizations' boardrooms and office meeting rooms) transcend traditional clinical, market and civic society boundaries, and hence appear often unfamiliar to participating patients (Renedo and Marston, 2015), while professionals' control over the process is hardly relinquished (Fudge et al., 2008; McKevitt et al., 2010). This is in line with the progressive adoption of neoliberal forms of governance (Miller and Rose, 2008) in health systems, whereby citizen-patients are both dependent on the established medical/scientific apparatus *and* vulnerable to 'free markets' (e.g. Fotaki, 2006). However, participating citizens are not simply passive objects

of state or market intervention; 'health citizenship' can be articulated through biosocial technologies and markets, while at the same time being at odds with prescribed (state or market) versions of what participation means (Williamson, 2010) because participants bring their own meanings to participation.

Arguably then, when citizenship finds expression through health, the reality of citizen participation can be more complicated than the binary of co-option *versus* emancipation suggests. Our article explores *how citizenship is performed*, what is done and articulated in participation fora and to what effects. We are interested in digging deeper into the mechanics of such citizen performances through what Isin (2009: 379, emphases added) calls 'acts' and 'actions' of citizenship':

> How do we understand 'acts of citizenship'? The term immediately evokes such acts as voting, taxpaying and enlisting. But these are *routinized social actions* that are already instituted. By contrast, acts make a difference. We make a difference when we actualize acts with actions. We make a difference when we *break routines*, understandings and practices.

So what difference, however imperceptible, can citizenship acts make in the PPI context? We will argue that, although Isin's argument regarding the routinization of citizenship rings true for acts such as voting or taxpaying, his distinction between 'routinized actions' and 'citizenship acts' (which are assigned 'authenticity' in their ability to constitute citizenship through 'routine breaking') in participatory arenas such as PPI is too neat. Hence, while examining how PPI 'actions' become routinized in practice, we will also attend to the oscillations between this routinization and instances of 'routine breaking'. In challenging the binary of citizenship acts as either emancipation or co-optation we highlight the *hybrid nature of citizenship performances*, which are predicated on neoliberal governance and may combine both emancipatory and state-controlled meanings (Schinkel and Van Houdt, 2010).

Ritual Performance and Politics

Our empirical work readily suggested that the PPI fora we observed can be examined through the lens of *ritual*, a social form found not only in pre-modern societies (Durkheim, 1995) but also evident in the organization of advanced industrial societies (Lukes, 1975). Far from being restricted to expressions of religious thought, ritual is also a medium for the expression of social order in a wider secular and even political sense. Analytical approaches to ritual vary, from the Durkheimian, in which ritual serves to express social relationships and reinforce social cohesion, through to what Handelman (2005) terms the hegemonic approach which regards ritual as a means of representation of, according to Turner (2009: 50), 'beliefs, ideas, values and psychological dispositions that cannot be directly perceived'.

Ritual has been analysed in terms of its functions and in terms of its form. From the first perspective, the aim is to understand what social purpose ritual serves. From the second, the focus is on the performance of the ritual – what happens when people collectively act in a specific ritual. The latter orientation stems from an understanding that the meaning of the ritual is not necessarily fixed but may be contingent on, or even derive from the performance itself. As Moore and Myerhoff (1977: 5) argue 'ritual not only propagates social ideas but also shapes those ideas'.

The issue of meaning in ritual has been problematized for a number of reasons. For example, while a ritual can be directed towards specific collective aims, the extent to which individual participants share the purported aim or construe different meanings is unclear, since ritual as symbolic action can carry diverse intentions, desires and understandings. Secular rituals in particular are associated with 'back-stage' or 'off-script' meanings, which unlike religious ritual's explicit connection with the numinous, remain loosely and only implicitly connected with larger sets of habits and attitudes – open to an array of common understandings rather than one 'all-embracing ultimate universal' (Moore and Myerhoff, 1977: 11). Bloch (2010) emphasizes the need to understand ritual as the exercise of political power, arguing the impossibility of discerning the meanings individuals construe and noting ritual's linguistic restrictedness.

Lukes (1975: 301), writing in this journal specifically about political rituals, pointed to the cognitive role of ritual, which he defines 'as authoritative certain ways of seeing society'. This requires attention to how ritual performance is organized and prescribed, which groups authorize the collective representations rituals point to and how political rituals are used by different groups. Lukes (1975: 304) considers voting in a representative democracy (a 'citizen action' in Isin's terms) as a prominent example of political ritual 'partly because of their central place in the official ideology of such societies, partly because of the mass participation they involve'. Therefore through the ritual of voting citizens affirm their role within the 'political system', thus contributing to its stability, and re-enforcing the existing distribution of power within it. This view of political ritual is commonly described as 'agonistic perspective' (e.g. Roth, 1995), a view developed by sociologists aiming to study how certain social groups maintain their dominance over others. Some of this research (e.g. Di Domenico and Phillips, 2009) shows the nuances and dynamics of the ritualization process, for instance unpicking the role of 'transgressions' (actions that express resistance to a ritual norm) in maintaining (rather than fundamentally challenging) a ritual's dominance. This work shows how transgressions can themselves become ritualized and how the boundaries of ritual structures might remain fluid enough to endorse and neutralize any threats.

Our study draws on the concept of 'political ritual' to illuminate the processes by which PPI takes shape, as routine-breaking potential or routinized activity. Drawing on ritual theory, we investigate the complex and mediating role of routines and we attend to the articulation of seemingly conflicting ideologies of citizenship within PPI, such as those found in the biosocial and consumerist perspectives of citizenship. Importantly, our ritual theory perspective emphasizes the 'creative element' encompassed in routinization and highlights how the tensions between conflicting notions of citizenship meanings become veiled so that the overall purpose of 'participation' in health research work remains ultimately unchallenged.

Methods

Case Studies

We examine PPI activities in three areas: cancer research, stroke research and pre-term birth research, hereafter referred to as 'the cancer forum', 'the stroke forum' and 'the pre-term birth forum'. The three studies were selected because they represent a diverse

range of state-authorized PPI practice in England, different age groups and include both patients and carers. The studies represent a high level of professionalization of PPI, with a majority of middle-income and higher education participants.

The cancer forum is a nationwide partnership between 22 charity funders and government departments and has a membership of 60–65 cancer survivors and carers, with a wide age range of between 26 to 82 years (including a 'teenager and young adult' subgroup). Members of the forum attend meetings three times a year with professional researchers to discuss strategic priorities and the design and management of research projects across specific cancer areas. The stroke forum was established by a London university research group in 2005, as the policy to actively involve patients in research was gaining prominence. This forum is run by researchers and has a membership of around 20 stroke survivors and carers. Members are drawn from an ongoing epidemiological study that follows up individuals who have had a stroke from the time of their stroke until death. Commensurate with the profile of stroke survivors, members of the stroke forum have an age range of between 55 and 86 years and has members who have experienced a range of post-stroke disabilities, including communication and mobility disabilities. The stroke forum meets every six weeks to discuss grant applications and ongoing studies. The pre-term birth forum was set up in 2011 by a team of senior clinical researchers employed in a large inner city acute hospital, as a formal means to include the perspectives of women or couples in the design and completion of ongoing studies. It is one of two pre-term birth fora in the UK. It has 23 individuals registered as members and at its most active, five or six women or couples (from both the surrounding city population and across the country) attend each meeting, alongside six clinical researchers, including senior doctors and midwives. Some meetings host fewer women, couples or researchers with the group maintained by regular email correspondence through a senior research midwife.

Data Collection and Analysis

The three case studies were undertaken independently between 2009 and 2014. All three cases were studied ethnographically, which included extended periods of participant observation of the fora (totalling $N = 360$ hours, captured in 440 pages of field notes), semi-structured interviews with patients ($N = 31$), professional researchers ($N = 25$) and other professional staff ($N = 6$). The first author followed the activities of the cancer forum between 2009 and 2011; the second author conducted research within the stroke group between 2005 and 2008; the third author researched the pre-term birth group from December 2013 to March 2014. The fourth author supervised the latter two research studies. Initial discussion between the four authors on what kinds of citizen participation PPI might represent led us to realize the similarities between our respective studies, in terms of the importance of participants' meanings and understandings, despite these issues being largely absent from policy representations of PPI. The analysis presented here represents our shared research interest in the day-to-day performance of meaning in citizen participation (findings from each original study have been published elsewhere: e.g. Komporozos-Athanasiou and Thompson, 2015; McKevitt et al., 2010).

The innovative approach we developed utilizes a new analysis of the completed ethnographic research (rather than synthesizing existing thematic categories across the studies), providing cross-comparison across the three ethnographic cases and corresponding data sets, in order to address research questions that had not been envisaged or asked in the original research. We used iterative thematic analysis (Hammersley and Atkinson, 1995) drawing on field notes and interviews with participants in the three cases, in order to identify and examine the underlying motivations, perceptions and routines that mediated participants' interactions and guided PPI activities. Thus, the themes were developed inductively from the entire data set: interview transcripts and the authors' diary notes were reread to code specific patterns. Emerging themes were discussed and iteratively reviewed with the fourth author, whose distance from the primary data collection allowed better triangulation of findings.

Specifically, we looked for key issues of meaning of citizen participation as these emerged and were negotiated in everyday PPI practices across the three sites. Thematic analysis focused on three interrelated areas: (1) the structural arrangements of PPI, especially within the physical space of formal meetings; (2) participants' own perceptions of PPI practices and roles; and finally (3) evidence of how such practices and roles were legitimated or challenged in the fora. We identified a recurrent tension between what we found to be an attempt to maintain a 'scripted' version of PPI and the 'off-script' articulations of PPI work. Thus in our second round of coding we drew on ritual theory's two broad categories of '*structure*' and '*performance*', to unpack this tension. The following section discusses the findings from our case studies in detail.

Findings

Despite the differences across the cases presented here, all three PPI fora made use of formal 'meeting space' to perform PPI. Thus the first stage of our analysis is examination of the role of meetings as the social space for the performance of citizenship meaning, showing how the latter was construed as a ritual. Like all rituals, PPI can be seen as a form of collective action, formally organized, set apart from day-to-day life, and directed towards a range of ends. Although, for each of the three case studies, there were various 'official' documents prescribing both how PPI should be carried out and to what ends, we found that in all case studies PPI was not enacted as a direct representation of these texts, but as a series of emergent and 'slippery' articulations. Correspondingly, our findings are organized around two sections. First we identify specific ritual practices that structured the performance of citizenship in the PPI fora, including time control, agenda control and technical language. Second, we unpick the ways in which participants' performance in the ritual was used to articulate their own, often diverse sets of meanings. The verbatim extracts used to illustrate our findings are taken from field notes and interviews, and are sometimes lengthy in order to preserve context.

The 'Ritual Structures' of PPI

Across the three PPI fora we observed a set of routine practices that reflected similar arrangements in the organization of meetings involving professionals and patients. Such

routines usually followed a strictly defined schedule of arrival time, informal chat with tea, coffee and biscuits, welcome, agenda, discussion, thank you and timed close of meeting. Below we examine three central dimensions of this dominant ritual structure: 'time control'; 'agenda control'; and 'use of technical language'.

Time Control. In all three fora the control of meeting agendas by professionals was taken for granted. Although some time was afforded to public and patient participants for expressing views and sharing experiences, researchers often expressed impatience with personal reflections offered by patients, especially if these were lengthy. In the cancer forum, the agenda itself set specific 'time slots' for lay contributions in the meetings. When, on occasion, patients attempted to take extra time to expand on items beyond meeting agendas or to speak at length on a personal experience of illness, their role was seen as obstructive and as a result their legitimacy as interlocutors was undermined. Hence participants had to learn to be 'facilitating' and 'efficient' to be afforded legitimacy within the forum. Thus, Lucy, a manager in the cancer forum, described the importance of adjusting to the demanding time structures of a meeting, which must correspond to the pace of 'scientific knowledge':

> [patients should have] key issues to bring to that group or to use that group to benefit a whole range of patients […] I know there are particular real concerns about *delays* […] scientific knowledge is going to move on *faster* than what you currently know. (Lucy, cancer forum manager, emphases added)

The practice of time control to manage participation was also evident in the pre-term birth forum. Here meetings were tightly structured as mini-conference style events with scheduled research presentations arranged around short question and discussion times. Question and discussion time was directed by clinical researchers with the aim to elicit specific knowledge contributions from participants, leaving little space for them to question the rationale or outcomes of a research study. However, during refreshment breaks women took the opportunity to describe and discuss their pre-term birth experience and their own research interests to one another, and to interested research midwives, before they returned to the formal agenda and scheduled research presentations. Thus the meetings became divided into the tightly prescribed 'real work' of clinical researchers' knowledge and the socializing of women, with only the former contributions being endowed formal legitimacy (Moore and Myerhoff, 1977).

Agenda Control. Even in cases where time was more liberally allocated in PPI discussions, pre-set agendas ensured that such discussions did not 'go astray'. The meeting agendas in the stroke forum were set by the researchers who established and ran the group. Meetings often featured lively conversations between stroke survivors and researchers, with experiences of stroke, views of the NHS and life in the local area made public and shared. The focus of discussion would often stray away from the research topic of a study, as stroke survivors sought to narrate their own stories and experience, something that meeting organizers and presenters permitted, while gently trying to redirect discussion back to the formal agenda and research priorities. The content of their

contribution was multi-faceted yet, in most cases, professionals made the final decisions on what was most relevant to the existing research agenda, as this extract from field notes illustrates:

> During one meeting of the stroke forum, Pauline, a stroke survivor responded to a researcher's request for article suggestions for the next issue of the research newsletter, produced to demonstrate researchers' engagement. Pauline suggested the newsletter should include recipes, and as many older people live alone, she suggested that the recipes should include cooking for one with a microwave. She told the group that she had found a 'nice recipe for a cake that only takes four minutes in the microwave, although actually it comes out more like a pudding so you have to eat it as a pudding with jam rather than as a cake'. As she spoke other members of the group begun to look worried. Catharine, a stroke survivor who since having her stroke took a keen interest in healthy living, interjected and asked if this cake was designed for people who had had a stroke. Pauline replied that 'it was from a packet'. Whilst the stroke survivors attending that meeting dismissed Pauline's recipe as unsuitable for the newsletter due to its unhealthy nature, the researcher dismissed the recipe column in its entirety as not meeting the priority of disseminating research results.
>
> (Stroke forum meeting, June 2006)

Technical Language. Technical language use was prevalent in all PPI fora. In the cancer forum, meetings were structured around 'high-level' technical discussion of various clinical trials. The routine use of acronyms combined with the highly specific nature of details involved was challenging for the user participants (and the ethnographer) to follow. In the pre-term birth forum, 'work times' in a meeting were signalled by different researchers taking the floor before the audience of women and research colleagues, using PowerPoint presentations, with subsequent discussions continuing in the highly specialized language of research and of clinical medicine (e.g. with questions and discussions about the challenges of randomization and sample size as well as of bio-markers). Three of the women attending the group were from health professional backgrounds hence this language was familiar to them, while two other women remarked to one another: 'It's all really complicated.' Researchers in the stroke forum were attentive to the problem of language, striving to translate technical terms, and checking participants' understanding. They also asked external speakers to use accessible language but soon learned to check presentations before meetings after instances of speakers presenting their work in language that confounded participants. On one occasion Dorothy, a stroke survivor from a business background, challenged an external speaker over his use of 'jargon'.

Performance of PPI

From the perspective of clinical professionals involved in the three fora, the raison d'etre for participation was changing funding requirements, rather than an ideological commitment to a more democratic research paradigm. Although the groups were established to demonstrate 'active engagement' with patients as required by research funders, professionals used the structures provided to articulate a series of different aims. In the stroke forum, for example, researchers spoke of an ethical need to engage with stroke survivors

to ensure that research priorities were addressed in ways that went beyond superficial 'box ticking'. Thus one academic lead described:

> [there is an] industry of people developing very politically correct policies, which sure, you can implement. But you can implement very superficially and tick all the boxes. So in terms of [my research] I can have a government structure for user involvement that says, right, we have a user representative on the members council, and we will let them know about each theme and they can get involved as they want, and we'll have a report at the end of the year. We've ticked our box. But, actually what we do need is to get right underneath that and get really representative people who can be involved. But it's a question of what they're going to be involved in, because they don't have the skills to do a lot of the things that [researchers] might do. So I think it's about, does the question sound to them like a sensible clinical research question? And can they see the potential benefits of it? (Professor Barlow, researcher, stroke forum)

By using meetings to review grant applications and proposed data collection tools with stroke survivors, the researchers implicitly invoked the NIHR view of PPI as enhancing research quality. They also saw the potential in the forum itself as an opportunity for knowledge production, rather than simply for policy implementation. The pre-term birth forum meetings, for instance, were used to elicit aspects of women's experiential knowledge that were useful to a clinical study as well as to demonstrate and document that women were involved in research. At the same time senior research clinicians often reminded the group that they were 'only one of two nationally' and thus gave these researchers an important advantage in the competition for national pre-term birth research funding. Hence through relying on the ritual structure of meetings (in terms of orientation, time and content), researchers in the fora ensured that PPI was directed towards their own productive aims, invariably associated with generating grant income and research papers.

Yet our ethnographic findings suggest that patient participants too made use of the same ritual structures to perform PPI in their own ways. In doing so, they produced alternative social representations of 'health citizenship', relating to the emotion of illness experience, the need for sociality and the desire to comment politically. We now discuss these in turn.

Emotion. Emotions often appeared as participants sought to draw links between research under discussion and their personal experiences. Hence patient participants made reference to themes of illness and care, and spoke at length about the feelings that those experiences evoked for them. Rather than aiming to contribute explicitly to the stated aims and funding requirements of their organizations, they seemed to be motivated by a biographically informed need to relate the personal, 'lived experience' to the social networks of participation (Lehoux et al., 2012). This is what Nicholas had to say about what motivated his involvement in the group:

> The first thing is that I felt very alone with my experience, I was obviously very upset but I was also very angry, because I had a very strong natural instinct that things should have been better […] It was for me personally a useful way to channel this distress if you like, and that's what started me with patient advocacy. (Nicholas, patient rep, cancer forum)

As this interview extract illustrates, Nicholas' motivation serves neither the researchers' aim for useful and efficient participation, nor the wider institutional purpose of 'democratizing' research (e.g. Löfgren et al., 2011). For Nicholas, being 'actively' involved in research as a citizen suggests the motivation to produce an emotional performance of citizenship. Similarly, Sheila, a patient representative in the pre-term birth forum, described her fear and frustration at trying to communicate her felt risks of premature birth during her second pregnancy when she had already experienced such an event. Several times, between the formal presentations and group question/answer sessions, she spoke directly to the women seated next to her:

> You just never forget it do you? […] and like when the second time it happened and I said to the community midwife 'actually I know there's something not right […] you know with my waters going early and so I need antibiotics this time […] this is what happened last time and why I lost the baby' […] and she just said that 'it was fine' and that I was 'just worrying too much' […] and I said 'I know things aren't right' […] but she didn't really know the facts on this […] she was a local midwife […] not like this [the clinicians present in this research group]. (Sheila, patient rep, pre-term birth forum)

This narrative of personal experience, of the fears of pregnancy loss because of a 'local' (non-specialist) clinician's ignorance of newly discovered research evidence was a potent shared meaning for women of the group. Sheila searched for shared social belonging through establishing identification with those who had also experienced the enduring anxiety of threatened pre-term birth. At the same time both Sheila and other women were aware that they enacted the set meeting agendas affording support for pre-term research by their very presence, or ongoing longer distance involvement, at the meetings. In both Nicholas' and Sheila's narratives it is evident that the choices made by patients in the limiting space of PPI meetings, are critically bound to their illness and life trajectories (Lehoux et al., 2012) even though these matters were not recognized in the regulatory meanings embedded in participation structures.

Sociality. Participation in the ritual structures of the PPI fora provided patients with an opportunity to narrate (and strive to afford legitimacy) to public narratives of suffering and healing. Although the drive of 'sociality' is readily identified with family and friendship networks, our three case studies all highlight the issue of participants' desire for companionship through shared experiences and caring. This was particularly evident in the stroke forum where participants spoke of enjoying the opportunity to meet others in a similar situation, but also used meetings to ask others about their experience of accessing health and social care services and to exchange health-related information. Reflecting the variation and heterogeneity that illness and care experience can have, patients' personal narratives conjured different aspects of the stroke, cancer and pre-term birth experience. In the stroke forum, patients and carers repeated personal stories, word for word, numerous times over the course of observations, as if the urge to narrate and convey the story was beyond their control. Jim was a frequent raconteur of his stroke story, which would be told whenever the topic of physiotherapy arose in one of the stroke forum meetings:

> Well I keep plugging it, but I think my, the importance to me is the physio. I was stuck in a wheelchair when I was in X hospital and my sister came up to visit and she said to the nurse, 'Why isn't Jim having physio?' And she was told I'd never walk again. But when I left the hospital I went into a nursing home because I wasn't in a state to go home. So I was just stuck in a wheelchair and the only way of getting in and out of the wheelchair was in a hoist. And then I was referred to X Hospital where I met up with a physiotherapist, Ken. Saint Ken I call him. Three times a week he would put me on a tilt board, strap my legs down, as my hamstrings had shortened. It was very, very painful but I used to look forward to it because he was convinced he could get me walking, and he did.
>
> (Extract from interview with Jim, January 2006)

In the pre-term birth forum all women enjoyed the opportunity to compare their experiences of first time motherhood – particularly as motherhood was such a crucial achievement to each of them – as well as the doting and attention that midwives and clinical researchers lavished on their babies. For some women or couples (particularly those from health professional backgrounds themselves), ongoing ties with researchers were developed and sustained during national and regional fund-raising events for pre-term birth research and support work.

Political Concerns. Other participants seemed politically motivated to discuss their concerns with health care quality and perceived threats to health care, particularly in the light of ongoing service reforms and the government's economic austerity measures. In the stroke forum, concerns with the state of the NHS united the group, not only in relation to the quality of care individuals had experienced but also in relation to the financial status of the NHS and ongoing reorganization of specific services. Early on in the set-up of the stroke forum, members talked about becoming a 'campaigning group'. Improving stroke services was coupled with a larger desire to fight for the NHS, which Catharine, a stroke survivor, described as 'the only decent thing we have left'. Timothy, a stroke survivor and former naval officer, talked of the group becoming a 'ginger group', a group within a larger organization or movement seeking more radical change to the policies and practices of the organization or movement, while still supporting the general goals of the organization. While the forum's conveners sought to maintain a focus on research, participants frequently diverted the conversation to express concerns about the health service as well as to retell stories about NHS failure they had heard of in the media.

Similarly, in the cancer forum some patients took time outside formal meetings to discuss ways to intervene in a more political way, for example by communicating their collective views on, for instance, government planned changes in the commissioning system. Several forum members saw group meetings as an opportunity to foster support for cancer advocacy's struggle in the 'difficult times of spending cuts' as one of the patients put it. They discussed for instance the possibility of developing a case study that could generate media and general public interest, raising awareness around the importance of patient participation in the research network and opposing planned spending cuts in their group. One cancer survivor noted to that effect, that the forum's participants must resist condoning such top–down policies through 'slotting into the PPI structure'.

These political impulses were less evident in the pre-term birth group, which had been more recently established. Following the lead of the senior clinical researcher, forum participants focused their attention advising on research protocols for already formulated clinical research questions, securing longer-term advantage for this clinical team in research funding applications, and fund-raising to support wider advisory and support services provided by established charities. A few women indirectly challenged the compliance of the pre-term birth forum but with limited effect.

Discussion

Our article investigates an increasingly prominent form of citizen participation in health research: three 'patient and public involvement' fora, established by researchers to implement UK PPI policy. In doing so, we compare formally sanctioned meanings of policy with those constructed by professionals and laypeople participating in PPI activities. On the one hand, professionals were concerned to demonstrate compliance with PPI policy: to articulate an ethics of democratic participation in research, and in so doing ensure eligibility to compete in the research funding arena. Patients, on the other hand (and in contrast to Lehoux et al.'s (2012) view that they are 'prevented' from articulating who they are by PPI's 'bureaucratic structures'), found opportunities in forum participation to express a range of concerns: the public narrating of suffering, sociality and civic participation. Though divergent, these two sets of meanings did not appear to be in conflict. Considering PPI participation as a performance of political ritual explains why this might be the case, and makes two important contributions to the sociology of participation, and to citizenship studies more widely.

First, we argue that health can be considered a *site of citizenship*. In particular, our study shows that although PPI fora emerge as an arena promising to enhance consequential 'citizen acts' (Isin, 2009), in reality they only allow for routinized and already instituted 'citizen actions' (Isin, 2009). We trace out the subtle role of this 'routinization' process in PPI, reflected in the *co-constitution* of ritual by a set of off-script *and* on-script performances of citizenship (Moore and Myerhoff, 1977). We demonstrate, in particular, that off-script performances did not represent a 'deviation' from the policy-sanctioned, social representations of PPI; emotive interruptions of formal proceedings – such as Jim's repeated physiotherapy story, Nicholas' expression of distress or Dawn's attempts to lobby for research into a particular pre-birth condition – were readily managed by organizational structures, but not responded to explicitly. This containment became possible in the 'material conditioning' achieved through meeting rituals, the 'mundane technologies' (time and agenda control, the use of specialist language), on which participants relied to made sense of the organization and their role within it (Abram, 2014). Such 'transgressions' hence remained unthreatening to the overall process (Di Domenico and Phillips, 2009), since when carefully managed they did not challenge the priorities contained in the PPI 'scripts' invoked during meetings.

Second, and relatedly, we suggest that PPI should be examined in the context of increased dominance of statutory and regulated involvement predicated by current shifts to neoliberal forms of governance. These increasingly 'push 'citizen participation from the 'activist' to the 'active' end of citizenship, that is, further away from

self-organized projects and 'conventional' political engagement (Busse et al., 2015). Our findings make a significant contribution in showing that the routinization (and concurrent neutralization) of PPI operates in the (often under-explored) embodied and affective registers of participation. Wilkinson's (2010) research into community volunteering has shown how intimacy, sociability and civility become enmeshed in the public domain; the risk highlighted by our approach is that 'emotional citizenship' enacted by PPI participants may continue to converge seemingly contradictory 'communitarian values' of lay citizens with the neoliberal emphasis on individual responsibility and participation (e.g. Crow, 2002).

More worryingly, the state's (in our case represented by the NIHR) superficial endorsement of participating citizens' emotional experiences (manifest for instance in policy discourse emphasizing the utilization of 'patient experience' when re-designing care services (Department of Health, 2008)), could be criticized for manipulating participants by removing their need for more radical involvement that may take the form of confrontational activism – such as street protests. Such more radical forms of citizen participation correspond to what Di Domenico and Phillips (2009: 339) discuss as ritual transgressions of 'higher' order, which do not merely disrupt existing ritual elements, but 'involve more forceful and explicit strategies of resistance' that cannot be 'easily neutralized': these can include for instance '*nonparticipation*' (2009: 336, emphasis added).

Finally, the meta-ethnographic nature of our study, and its use of secondary analysis of rich contextual data, presents some challenges and limitations that need to be acknowledged. The discussions between the four authors during the data analysis, fuelled new and interesting interpretations of the independently collected data, however they inevitably further distanced the analytical process from the original ethnographic context and iterative quality of ethnographic fieldwork. Additionally, we must acknowledge that our original ethnographic data are only representative of a specific type of 'physically present' participation (involvement through meetings) and are thus not necessarily representative of other fora where participation may occur (such as virtual participation, through emails or social media). Ritualization will be different in such spaces, and citizenship performances such as 'sociality' likely to acquire different meanings as the digitalization of personal life continues (see Lupton, 2014). However, we believe that these very issues invite new, potentially exciting methodological work that can make use of meta-ethnographic methods to combine different researchers' insights and develop new understandings from existing ethnographic data.

Implications and Conclusions

Our article suggests that the vision of citizenship asserted by state-authorized PPI activities in health research, is a far cry from the transformation of knowledge production or the rebalancing of power differentials formally aspired to. If ritual is a medium through which ideology is expressed, then active citizenship can be seen as one such powerful and permeating government ideology. However, unlike community-based activism in previous decades – such as mental health movements in the UK (e.g. Crossley, 1999), or

HIV activism in the USA (e.g. Epstein, 1996) the 'active citizen spaces' of PPI allow little room for re-writing the rules of participation.

Hence, contrary to policy aims 'to transform' – to produce involved citizens, to improve research quality, to democratize clinical science – the ritual performance of citizen participation engenders a conservative form of engagement in health, and the corresponding forms of knowledge production involving the 'citizen-patient' present new challenges for sociologists: for instance, could a more 'activist' (rather than merely 'active') approach to knowledge production address systemic power differentials in today's health systems? Does active citizenship in the form of PPI weaken or delegitimize such more 'activist' types of citizenship (which could, for instance, take the form of 'non-participation')?

Such challenges resonate with long-standing epistemological and ethical debates about the role of research in the development of specific notions of citizenship and knowledge production. Brownlie (2009) problematizes participation in research as part of disconnected people's ongoing struggle to be recognized as citizens. Correspondingly, if the production of (medical) knowledge is to be 'participatory', it cannot dispense of the *collective* element underpinning our identified 'alternative orientations' brought into participation by citizen-patients. Our article underscores these risks, and warrants against the development of impoverished notions of 'active citizenship', promoted within neoliberal democracies yet veiled by the very rituals of participation.

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