DOI: 10.1177/0038038516664683

K w

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

C A C

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’

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

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.

[illegible]

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).

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 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'.

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.

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

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,

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 '[redacted]' (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 citi-

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 delegiti-

Crossley N (1999) Working utopias and social movements: An investigation using case study materials from radical mental health movements in Britain. 33(4): 809–830.
Crow G (2002) : , *I* *C* . Buckingham: Open University Press.
Department of Health (2006) , , : *A* - (Vol. 6737). Norwich: The Stationery Office.
Department of Health (2008) *H* : *NH* Norwich: The Stationery Office.
Di Domenico M and Phillips N (2009) Sustaining the ivory tower: Oxbridge formal dining as organizational ritual. *J* *M* *I* 18(4): 326–343.
Durkheim É (1995) *E* *F* *L* . New York: Free Press.
Epstein S (1996) *I* : *AID* *A* , *K* (Vol. 7). Berkeley, CA: University of California Press.
Fotaki M (2006) Choice is yours: A psychodynamic exploration of health policymaking and its consequences for the English National Health Service. *H* 59(12): 1711–1744.
Fudge N, Wolfe CD and McKevitt C (2008) Assessing the promise of user involvement in health service development: Ethnographic study. *BMJ* 336(7639): 313–317.

M A is Research Fellow in the Faculty of Nursing and Midwifery, King's College London. She is a social and medical anthropologist. Her research interests include patient and clinician voice in clinical and health service research and innovation

C M K is Professor of Social Sciences & Health in the Faculty of Life Sciences and Medicine at King's College London. After completing a PhD in social anthropology at the London School of Economics, he began working in health research and activism. His research interests include emergent forms of knowledge production and citizenship.

Date submitted December 2015
Date accepted July 2016