Performing accountability in health research: a socio-spatial framework

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Abstract

The article explores how spaces aimed at improving accountability in health systems are socially produced. It addresses the implications of an initiative to promote patient involvement in government-funded research in the context of a large cancer research network in England. We employ a socio-spatial theoretical framework inspired by insights from Henri Lefebvre and Judith Butler to examine how professional researchers, doctors and patients understand and perform accountability in an empirical context. Our data reveals fundamental tensions between formally-required and routinely-enacted dimensions of accountability as these are experienced by patients. Consequently, our analysis argues for a need to augment abstract, professionalised discourse about accountability in health services by acknowledging embodied spaces of representation, in which patients themselves can contribute to making participatory accountability a reality. We suggest that such a shift will provide a more rounded appraisal of patient experiences within health research, and health systems more widely.

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Introduction

Strengthening accountability is one of the highest priorities, as well one of the thorniest issues, within publically funded health systems (House of Commons Health Committee, 2007). Seen as a means of addressing the persisting democratic deficits in planned health systems, the notion of accountability follows from the fundamental democratic principle that those who exercise political authority should be accountable for their actions (Bovens, 2007). Internationally (in countries ranging from Canada and the US, to Brazil, France and the UK), satisfaction of democratic accountability has been linked increasingly with policies that encourage wider citizen participation in health systems (e.g. Lehoux et al., 2012; Cornwall and Shankland, 2008; Potter, 2010; Rabehariosoa and Callon, 2002). In the UK's National Health Service (NHS), which constitutes the focus of this paper, this shift is reflected in the implementation of patient and public involvement (PPI) initiatives in decision-making processes, clinical and research governance structures. It has been argued that the emphasis on achieving participatory accountability via PPI in health is part of the wider government attempts to transform the 'political ordering of space' (Bradley, 2014; McDonald, 2016) within public services into new assemblages of 'distributed governance' (Allen and Cochrane, 2010; Swyngedouw, 2004), or what Fung and Wright (2003, p. 3) call 'empowered participatory governance'.

Reforms initiated by the 2012 Health and Social Care Act (Department of Health, 2012) blend two discourses in their promotion of 'PPI in research'. On the one hand, conventional policy exists around achieving more patient-centred outcomes, greater transparency in health research funding processes and more democratic clinical decision-making (Lofgren et al., 2011; Abelson et al., 2007). On the other hand, these reforms also promote explicitly

emancipatory discourses of bottom-up participation movements (Staniszewska et al., 2014; Fotaki, 2011; Martin, 2008), seeking to establish participatory accountability as a form of citizen-based evaluation to complement existing forms of accountability – for example the public administrative, managerial, and professional accountabilities (Hupe and Hill, 2007).

Linking accountability to publicly funded health research, which this article examines, has a long pedigree in public health policy aiming to promote patient participation and civic engagement; however, it also carries a heavy baggage of sociological critiques. Various studies have shown how government-convened spaces for 'participation' commonly exclude or reify patient experiences (Renedo et al., 2017), discounting them as 'unrepresentative' (Martin, 2008) or irrational (Komporozos-Athanasiou and Thompson, 2015; Renedo et al., 2017), serving ultimately to legitimate existing priorities and pre-decided agendas (Komporozos-Athanasiou et al., 2016). Moreover, in a field rich with history of bottom-up participation such as health social movements (e.g. HIV activism and the mental health movements of the 1980s), attempts to encourage accountability through deliberative governance fora such as PPI have been challenged as being at best ineffective, and more worryingly, as co-opting and neutralising more radical forms of civic involvement (Di Domenico and Phillips, 2009).

Such conflicts between top-down and bottom-up participation are further exacerbated by varying and complex accountabilities that come into play in the healthcare context: from the satisfaction of the Hippocratic Oath, summarised as 'first do no harm' (clinical accountability), to showing respect for the integrity and autonomy of patients (ethical accountability), as well as professional, legal and financial accountabilities. Drawing on ethnographic data, this article examines how introducing aspects of accountability into a publically-funded cancer research network (henceforth called 'the Forum') highlights the emerging tensions and power differentials as these unfold during cancer patients and doctors' interactions in formal meetings. We argue that increasing the participatory dimension of accountability (developed

by Huppe and Hill, 2007), is a matter not only of including patients' abstracted views as the users of research, but also of the ways in which patients *perform* accountability – spatially and bodily - by incorporating their lived experiences of disease. As a conceptual lens, performativity has been traced to Austin's (1962) description of powerful language games, where a performative utterance at the level of representation can lead to a material outcome by altering social reality (as in 'I now pronounce you man and wife'). In turn, such a lens demands increased attention to the organisational spaces that enable and/or constrain the way in which lived experiences are embodied and represented – since in framing performance, such spaces affect what is represented and thus contribute to unfolding social reality itself.

The article offers a new theoretical perspective on the enactment of this emerging form of accountability that highlights its spatial and performative constitution, driven by a motivation to understand more about 'the changing relations between participation, professional knowledge, and power' (Bell and Evans, 1997: 275). Existing spatial and performative perspectives have critically discussed such spaces and technologies of 'spatial governmentality' (Gibson, 2001), where participating citizens are increasingly expected to draw on markets to "regulate themselves through organizing their lives around the market" (O'Malley 1993:172-173). For Merry (2001:20), in spatial governmentality "the individual invested with rights is replaced by the individual who defines himself or herself by consumption". In the context of health research, these developments can be located within a shift to a consumerist framework where patients are increasingly thought of as customers and expected to reveal their preferences through choice (Mold, 2010; Fotaki, 2006), thus influencing research priorities.

However, existing approaches often regard patients as individuals abstracted from the collectivities to which they belong (Lie et al., 2009), tending to reify their experiences by considering them a 'resource' to be harnessed by researchers (Caron-Flinterman et al., 2014).

At the extreme, marketised approaches towards accountability often aim to 'improve efficiency, economy and effectiveness' (Boote et al., 2002: 222), by involving patients in 'research-style surveys' aimed at increasing the quality and 'user satisfaction' of the end product (of research) whilst not obligating institutions to do so (Boote et al., 2002: 223); nor do they offer patients significant power over resource allocation and social aspects of accountability (Metsch and Veney, 1976). In conceiving of patients primarily as consumers, and economic rather than political entities, it has been argued that their role is constrained to 'assembling health information' (Griffiths et al., 2012: 2234) - exacerbated by an inherent imbalance of knowledge and power between patients and health professionals, not least because of patient vulnerability, which often accompanies ill health (Fotaki, 2014). More broadly, material dimensions of illness often frame struggles and negotiations over access to, and mobility through, space (Harvey, 2000; Massey, 2005; Cornwall and Coelho, 2007), yet the importance of how time and space may be used in addressing such power imbalances in health care settings is often ignored with a few notable exceptions. For instance, Halford and Leonard (2006) explain how doctors and nurses creatively use space and time as different and distinctive resources, in relation to discourses of change and 'in the construction and performance of subjectivities' (Halford and Leonard 2006: 661). Others have emphasised the performative effect of the body in re/creating new socio-spatialities aiming to alter the flows of power in the context of social movements (Daskalaki and Fotaki, 2017).

In responding to these challenges, we develop our theoretical perspective by drawing on Lefebvre (1991) to explain the production of space in contemporary organisations through intersection of discourses, bodies and subjectivities. For Lefebvre 'society is a space and an architecture of concepts, forms and laws whose abstract truth is imposed on the reality of the senses, of bodies, of wishes and desires' (Lefebvre, 1991: 139), implying that bodies' wants and desires may differ from verbal accounts of workplace activity (McDonald, 2016). In this

view, social reality comprises contradictory information and opposing views held in tension, in the manner of a dialectic (McDonald, 2016). Lefebvre's spatial architecture resonates with Judith Butler's conception of the body in space: 'it would not be possible to speak about a body part that precedes and gives rise to an idea, for 'it is the idea that emerges simultaneously with the phenomenologically accessible body' (Butler, 1993: 59). Butler's insights enhance, and politicise, Lefebvre's ideas by introducing the notion of body/space performance to build an analytical framework capable of accounting for symbolic and material aspects of spatial performativity, where production of space both constrains and enables what is thinkable and thus possible. As philosopher Gillian Rose explains, these are shaped by relationalities between different embodied subjects which are 'inter- relational and performative' (Rose 1999: 247).

The concept of relationality as foundation of human subjectivity proposed by Butler is also key for understanding public health policies' role in dealing with our shared precariousness as sentient human beings (Fotaki, 2017). Put differently, Butler develops Lefebvre's (1990) political understanding of space as a product of power relations, elucidating how bodies give meaning to space and how the interrelations between them alter the notion of space itself by, for instance, appearing together in public space to protest against grave injustice - thus creating new relations in space, termed as socio-spatialities (Daskalaki and Fotaki, 2017). This is in line with thinking by postmodern urban theorists who further develop Lefebvre's ideas to develop the notion of spatialities as socially produced, concrete material reconfigurations of space around a set of relations between individuals and groups (Soja, 2010). We bring these ideas together to theorise the production of space in healthcare contexts, and propose that we cannot have participatory accountability in health without considering how bodies reform and perform relations in space. As we shall demonstrate, the dimensions of bodies and space are thus mutually constitutive: patients' and carers' physical experiences of illness enable and constrain what it is they feel, do, and say – and thus how the space is performed. In turn, acknowledgment

of these embodied and relational aspects of accountability demands attention to how spaces for accountability are actually produced, highlighting a need to complement abstracted metrics, such as performance indicators and clinical outcomes, with an attentiveness to patients' more subjectively experienced and performed realities. Furthermore, achievement of this aim entails recognition of the tensions arising between these various dimensions of accountability (e.g. Epstein, 2007; Pols, 2014) and between different perceptions/experiences of accountability as it is performed - by diverse actors including doctors or researchers in our case, as well as managers and patients.

To improve such recognition, we draw on rich ethnographic data documenting the *spatial production of accountabilities* - both professional and experiential - in a context of a national Forum for patient participation in clinical research. The Forum comprises patients, carers, health/clinical researchers, and third sector representatives, and exemplifies recent attempts to enable lay people and professionals to challenge and hybridise boundaries such as those between clinical, occupational and personal spatial domains (Minkoff, 2002), where lay and expert knowledge circulate simultaneously and 'hang together' (Mol, 2008). Such hybrid 'new democratic spaces' (Cornwall and Coelho, 2007) are situated at the interface between the state and society, and act as 'conduits for negotiation, information and exchange' (Cornwall and Coelho, 2007: 1).

In tracing the Forum's attempts to achieve the policy aim of 'participative accountability', we deploy the conceptual lens of performativity, enhancing this further with a specific examination of accountability's *spatial* performance. Our analytical framework reveals underlying tensions as these are experienced and negotiated by participants. In so doing, our study contributes to an important but relatively under-researched area of organisational space as dynamically produced rather than a static pre-given (Halford and Leonard, 2006; Wasserman and Frenkel, 2015) and more broadly to the emerging field of organisational

performativity (Cabantous et al., 2016; Wickert and Schaefer, 2015). In highlighting unfolding tensions between macro-level policy, organisational and subjective notions of accountability, we make a practical contribution to the claim that participants' unfolding experience, and negotiation, of such tensions constitutes a large part of the practice of 'patient participation'. Drawing on of Lefebvre's and Butler's political theories of space, we show how engagement with these tensions within health settings necessitates *a broader construct of participatory accountability* encompassing embodied and performed experiences of illness and care, and foregrounding patients' interests throughout. Our theoretical contribution is to propose a novel framework of performative accountability comprising material and symbolic aspects involved in co-producing organisational reality, where the material-discursive organisational space within which accountability is performed is illuminated as a *dialectical process* underpinned by power dynamics involving tensions, struggles and negotiations.

The remainder of the article is structured as follows. We briefly outline the background to PPI, and to the UK's publically funded health research platform (the Forum). We then present our empirical ethnography conducted in the Forum, and discuss findings of the research. We apply our proposed theoretical framework to show how our more spatially aware approach illuminates key aspects of participatory accountability that have been overlooked to date, foregrounding important tensions that underlie its day-to-day performance. We conclude by describing practical and theoretical implications as well as limitations of our study, and identify some directions for further research.

Patient and public involvement and the changing spaces of accountability in health research

During the 1990s, the political imperative to improve patient and public involvement (PPI) in the UK National Health Service led to the setup of INVOLVE, an advisory group to support PPI and promote research accountability. (Department of Health, 1993). At the same time, there had also been growing demands for accountability for research expenditure (Buxton and Hanney, 1996), as well as for better-coordinated research priorities between academics and industry (Oliver et al., 2004). The National Institute for Health Research (NIHR) began to demand that researchers 'demonstrate accountability' to the public by showing how they have involved patients in their studies after high profile scandals such as the Alder Hey Children's Hospital, and the Bristol Royal Infirmary (where ethical consent processes were bypassed respectively in research using children's body parts, and in the development of experimental treatments). Both were considered catalysts for PPI fora that would ensure health research was held to account transparently and democratically (Barnes and Cotterell, 2011).

However, despite various initiatives for promoting participatory accountability through establishing fora for PPI in health research (Fudge et al., 2008), the NIHR remains largely unsuccessful in addressing the deficit in democratic accountability (with some notable exceptions, e.g. Greener et al., 2010). This relative lack of success appears to be because accountability measures failed to capture the relational, and unequal, nature of public participation (Abelson et al., 2007; Cook and Brunton, 2015). A key reason for this can be linked to the dominance of 'choice' as a mechanism for participation which predominantly underpins accountability developments in health research, and fails to capture aspects of health care that do not fit with the consumerist model of patient choice (Fotaki, 2006, 2010). As Oliver et al. (2004: 1) discuss in their report on the NHS research and development strategy: 'Consumer involvement in identifying and prioritising research topics should be considered in the context of the increasing involvement of consumers in making decisions about their own personal healthcare and about the development and delivery of services'. Such developments

reflect the politics of the New Labour government in England during the late 1990s and early 2000s, which blurred boundaries between 'consumerist' and 'citizenship' approaches to accountability, even using the two terms interchangeably within 'patient-centred' discourse (Pickard et al., 2002). These were often underpinned by the discourse of accountability for how public resources are spent and what benefits these produce for the users of health services (Newman and Vidler, 2006).

More recently, there have been calls for greater attention to the practical experiences of the 'involved patient' role (e.g. Martin and Finn, 2011) – and more generally for a re-spatialisation of citizenship (e.g. Staeheli 2016; Vaiou and Kalandides, 2017) via participatory practices such as PPI. There is increased acknowledgment of the need to focus on the socio-spatial context of 'participation' and recognise "non-state-based material and locatable situated practices, memories, and imaginings" of involved citizen-actors (Kallio and Mitchell, 2016) via 'deterritorialised' networks of patients-professionals, based increasingly on 'diffuse and temporary platforms of interaction' (Griffiths et al., 2012: 2234). The spatial performance of these tensions takes various forms: for instance, tension between patients' desires to fulfil a social contribution, and their practical performance of rules and routines within professional spaces of participation.

Developing the notion of spatial performance beyond Lefebvre's and Butler's ideas, we build on Renedo and Marston's (2015) recent linking of accountability with notions of space in the health care context (as will be explained next), where '[p]olicy and academic discussions of participation are permeated with spatial metaphors (e.g. 'opening up', 'widening' 'arenas' and 'spaces' for public involvement, citizens gaining 'positions' of influence' (Renedo and Marston, 2015: 2). Renedo and Marston signal a 'sociological' concern with space as both medium and outcome of social relations and structure (e.g. Massey, 2005), which in turn enables a useful discussion of the struggles and negotiations that occur over performing lay

and professional roles, as framed by the materiality of space. If the dialectic between organisational and subjective notions of accountability within the materiality of space is socially generative (e.g. Kallio and Mitchell, 2016), we accordingly require a more spatial-theoretical understanding of accountability. To develop such an understanding, we draw on ethnographic fieldwork conducted over eighteen months in the large national cancer research platform, the Forum, involving various groups of participants (researchers, doctors, managers and patients). The methods used are presented next, followed by the analysis of findings.

Ethnographic study: a patient involvement forum in cancer research

The setting

Ethnographic research was conducted within the PPI Forum of a large clinical research network in the UK,[1] a partnership that brings together third sector funders and government departments to provide national coordination for cancer research. The Forum was created to progress the Labour government's desire for 'direct public accountability', involving collaborations with many charity organisations, and was further supported by the 2007 Cancer Reform Strategy. It promotes the view that scientific investigation should be informed and shaped by lay experiences, and that 'consumer groups' should be embedded in health research commissioning, to ensure funded studies are relevant and 'of importance to patients and to those caring for them' (Chalmers, 1995). The Forum has a national membership of 60-65 persons including cancer survivors and cancer carers, and was established in 2001 with two aims: a) to provide a space where service users meet, share experiences gained from their involvement locally, and organise learning activities and workshops; and b) to deliver patient representation across more than twenty two clinical research groups coordinating development of clinical trials that improve outcomes for patients within their field of cancer research.

In this study, we focus specifically on the activities of the clinical research groups: the formal spaces in the Forum where users encountered medical professionals. Groups were divided according to specific types of cancer, comprising high calibre clinical researchers, oncologists, epidemiologists, and psychologists, many of them university professors and medical consultants. Each research group met three times a year for a day in one of the buildings of a charity organisation in a major UK city, to discuss new research, design and commissioning of clinical trials, relevant policy change, and impact on services. These meetings were attended by two to four patient representatives, ten to fourteen clinical researchers on average, a manager representing the third sector partnership network, and an administrator. The vignettes presented discuss patient involvement activities that took place over a period of two years, between 2009 and 2011.

Methods

For a period of eighteen months, from December 2009 to June 2011, the first author followed the trajectories of the Forum group members, both as participant and non-participant observer, in fifteen formal and less formal events, national meetings, workshops and conferences, totalling over 100 hours of observation. In addition to field observation, 28 in-depth interviews were conducted following ethnographic observations with 25 members of the Forum: thirteen with clinical researchers, professionals and administrators, and fifteen with users (patients and carers). These lasted 60 minutes on average, and were recorded and transcribed verbatim. The observations were written up as ethnographic field notes.

Taking an abductive approach (Wodak, 2004), we began with a theoretical interest in the 'non-canonical' and less 'visible' dimensions of accountability that co-exist alongside more easily abstracted, managerial and professional dimensions (Hupe and Hill, 2007), which we hoped to illuminate within participants' ground level enactment of PPI. Hence when going into

the field, the first author looked for ways in which relations of accountability between various participants were formed and experienced through meetings and other interactions. More specifically, personal accounts and emotional experiences of participants were solicited to deepen our understanding of their transition from more traditionally understood roles as 'patients', 'carers' and 'clinicians', to professional 'representatives' and 'advocates' through PPI. In turn, this yielded a greater sensitivity to the formalisation of this process via a *complex spatial unfolding*: how material structures, such as agendas, minutes, and table and chair arrangements interacted with unfolding relations of accountability (e.g. Abram, 2014) encompassing a range of dimensions, from physical metrics to embodied, emotional and relational understandings. Together, this process suggested a more dynamic enactment of participatory accountability than is usually assumed in literature, a process that was fraught with tensions associated with competing demands experienced in the governance of clinical research.

The data was analysed in two rounds; the first author first read the field notes and interview transcripts, and used open coding (Strauss, 1997) and line-by-line analysis to generate thematic codes, which reflected participants' own experiences as they participated in performing accountability. Some of the codes included 'sharing personal experience', 'feeling out of place', 'questioning boundaries', 'enacting routines', and 'seeking consensus'. These codes were then tested with authors 2 & 3 for triangulation. In the second round of analysis, all three authors engaged iteratively in further coding of the data, which was framed in dialogue with social theories of space, specifically with the work of Lefebvre. Our iterative approach (Langley, 1999) is well tested in empirical studies that seek to make a rich conceptual contribution (e.g. Cutchin, 2003), and where researchers move backwards and forwards between data and theoretical literature in order to develop possible explanatory frameworks.

Whilst we had no prior intention to use a particular theoretical framework for data analysis, as we began to explore approaches to theorising our findings, we turned to both Lefebvre and Butler, whose work provided us with useful and complementary conceptual tools helping us to make sense of our increasing awareness of the differential spatial dimensions of performed accountability – and associated tensions therein. We explain our dialogue with these ideas more fully in the Discussion section, but in summary their theories provided us with a set of 'sensitising concepts' (Hammersley and Atkinson, 1995) enabling us to refine our thematic categories and foreground such tensions, and hence to 'open up' existing notions of accountability. Our use of Lefebvre's theory sensitised us to the political structuring of space (Elden, 2004) - the interrelationship between spatial dynamics and unfolding power structures - whilst Judith Butler's explication of how discursive performativity constitutes the possibilities for bodies to appear, become, matter (Butler, 1990, 1993), and interrelate, allowed us to appreciate how such spatial dynamics unravel in the context of illness and care (Fotaki, 2014, 2017).

Together, these approaches enable a view of space as the ongoing product of three co-constitutive dimensions: people's performative actions, involving personal experience, or 'spaces of representation' in Lefebvre's terminology; abstract representations, and established structures, of professional power, or 'conceived space'; and people's emergent understandings which inform their social expectations, or in Lefebvre's words: 'perceived space'. According to Butler, it is discourse that constitutes possible, viable or even liveable bodies: 'One is subjected and subjectified within discourses, and becomes a subject through performativity, which is not an act, nor a performance, but constantly repeated 'acts' that reiterate norms' (Butler, 1993: 12).

Our multi-dimensional outlook on the organisational material-discursive space within which accountability was performed in PPI foregrounded the less tangible dimensions of

accountability that exist in patients' personal experiences of illness and their social expectation of roles and relations, showing how these interact with abstract representations of managerial and professional accountabilities associated with organisational targets/indicators. As we will show, Lefebvre's tri-dimensional space enabled us to uncover hitherto invisible tensions between subjective, canonical, and socially-emergent registers of the unfolding performance of accountability in PPI – an appreciation that was further tuned via Butler's understanding of the physical subjectification involved in such performances – all the more poignant given the intensely debilitating nature of the physical illness that constituted its subject. This thematic framing involved constant comparison of Lefebvre's three conceptual categories, enriched by Butler's conception of performativity of the body, through iterative analysis as well as axial coding (Cutchin, 2003) in order to refine the different aspects of accountability, and importantly to unpick the tensions appearing between these. We identified three principal tensions in operation within the PPI Forum: i) between abstract representations and personal experience of accountability, which was often embodied; ii) between such personal experience of, and social expectations about, accountability; and iii) between participants' social expectations about, and abstract representations of accountability. We address each of these three tensions below.

Analysis

Tensions between abstract representations and personal experiences of accountability

The time and spatial arrangements of the research group meetings followed the tropes of conventional executive board meetings. They took place at in large, high-ceilinged

boardrooms, situated in Edwardian period-buildings in central London, which were owned by major third-sector organisations. Participants in these meetings were positioned around large oak boardroom tables, in seats that were pre-allocated by the organizers and indicated with name plates that were positioned before the meeting. This arrangement most often positioned the two or three patient representatives in a cluster, facing the rest of the participants around the table. The discussion followed a linear structure, which offered specified allocated time-slots to patients and professionals to make contributions to the Forum's unfolding debates. Discussions were always organised around meeting agendas that had been prepared and circulated by the organizers in advance of the meetings, and often involved high-level details of a range of planned research such as clinical trials.

Managers and facilitators responded to organisational issues by invoking pre-existing Lefebvrian representations of space within meetings; users sometimes struggled with the use of acronyms, combined with the highly specific and technical nature of information involved, which often seemed hard for them to follow. In such occasions it was apparent that some participants felt particularly uncomfortable in negotiating their own experience of disease or care, with their formal roles as patient representatives. There was a recurrent tension – a feeling of a lack of space for expressing their more visceral self-identifications as patients, requiring them to include their embodied experiences within the abstract framings of professional medical discourse expected by the organisation; other visible tensions experienced by participants were linked to the risk of them becoming 'professionalised' through the participation process (El Enany et al., 2013). This uneasiness was manifest in a sense of loss of control, as evidenced in Catherine's statement:

'I've become a lot more involved, properly involved, what some doctors like to call professional patient… Now, I'm not sure if I like that term because that carries with it

an element of truth, but it is also problematic. Because by calling a patient 'professional patient' you are immediately making them step over a dividing line, into a different arena. Now, for all we know why can't every patient be a professional patient, why should we not use that term? (Catherine, colon cancer survivor, patient representative)'

As users became more involved in the Forum's activities, they questioned simplistic distinctions concerning their various roles in performing accountability, such as 'professional' versus 'lay'/'experiential' - although they recognised, to some extent, the importance of both dimensions, as evidenced in the spatially aware vocabulary of 'stepping over a dividing line, into a different arena' (in Catherine's words). Similarly, professionals themselves did not always feel entirely comfortable within the Forum's formal accountability process - although, unlike patients, professionals' own vulnerabilities were shared privately (during the interviews) rather in their interactions with patients. Additionally, doctors and clinical researchers often appeared to be apprehensive about the abstracted representations of accountability around patient involvement, and uncomfortable with the expectation to demonstrate 'participatory accountability' within the Forum. Tim, a clinical psychologist in one of the research groups revealed:

'[PPI] is a game that I've even started playing. I've learned over my involvement in this group that when I put together funding applications, I need to name a patient on that, simply to tick that box… I think that's wrong. Before I got involved in these groups I spoke to patients as part of my research. . . And I think I was much more willing to involve them when it was of my own volition rather than now when it seems to be something that "I have to do", whether I think it is particularly needed or not.'

Tim was concerned about the ethical implications of drawing upon patients' experiential knowledge simply to meet the Forum's formal accountability requirements. He went on to clarify how conflict between these two domains of accountability was contingent upon the different physical spaces of participation, and in particular, the 'formality' that such spaces produced:

'I think the formality of the meetings, they [patient representatives] don't seem to get involved much. And I am not sure that is, I think the formality of it is possibly an aspect but I think more so is the fact that we simply don't have much to contribute given the topics that are discussed at those formal meetings. But a more informal basis [cites example of event] . . I went last year to the National Cancer Survivors Initiative, a consultation event on setting research priorities, [that has] much more informal discussion based sessions, and I think that is where users come in handy'

However, despite such misgivings about the effective organising of research practice, professionals usually felt unable to resist or challenge managers' demands to promote participatory accountability in the research group, fearing the impact this could have on their professional standing. As Tim described:

'I've never had conversations at the level of the [research] groups, with the [Forum's management], because quite honestly I think that'd be quite dangerous. From my perspective I think it could affect my chances of developing my career down the line…'

Such comments were representative of a commonly reported tension, as both patients and clinicians sought to reconcile the demands of *physically* defined, or represented, practices and

protocols with their unfolding *experience* of such practices. Revealingly, the 'common sense understandings' developed in meetings were often focused on responding to formal accountability demands – such as those posed by the research funding priorities, safeguarding the 'success' of clinical trials and researchers' 'career development', to use Tim's words. However, a relative invisibility of the more personal experiences of the research process generated tensions for all participants (both patient representatives and professionals), and a degree of dissatisfaction about levels of accountability achievable within the Forum.

Tensions between personal experiences of, and social expectations about accountability

Such personal experiences of performed accountability within the participatory space of the Forum lay in tension not only with formal representations (and measurements) of accountability, but also with some of the 'common sense understandings' of accountability emerging within this setting. As David, an oncologist chairing one of the research groups emphasised:

'[H]aving friendly PPI people on your side, you know, you can ride into battle with… you know, with the funders or whatever is of course…um, well for a [national] funding it's mandatory… and I'm not sure how much room that leaves --[laughs]--… for differences as it were…you know, where should the greater influence be: do you find people who agree with what the researcher wants to do or what… (David, consultant oncologist)'

Thus, securing research funding was considered a question of conforming to a set of specific cultural norms and expectations associated with physical, rather than experienced (constituting the Lefebvrian lived space) outcomes, such as 'group consensus'. Such discursively established behaviours within the Forum reflected professionals' view of patients'

as 'research subjects' rather than interlocutors, preventing clinical researchers from engaging more substantively with the experiential aspects of disease brought in by these users (Renedo et al., 2017). Accordingly, the more intimate type of engagement required for sharing patients' experiences was less discernible within the space of those routines, as is evidenced in David's statement above suggesting that these were useful if they fitted with helping to obtain research funding. Consequently, satisfying such experiential aspects of accountability were not seen as a priority in routine preparations for securing funding.

Participants' lived space - or Lefebvre's 'spaces of representation' - was different from professional 'representations of space': their conceived space. In recounting their hopes and expectations as 'patient representatives', users frequently drew on their lived experiences, emphasizing how these had profoundly impacted on their choices both in relation to their treatment and within the PPI context. When patient representatives pointed to the marks of illness in their bodies, they attempted to relate their lived, embodied experiences to their social expectations of their roles as patients' representatives, introducing another dimension of accountability:

> 'I am not the typical patient in asking questions – you'll see I've got a scar here [points to her neck] I have a thyroidectomy… I postponed that for a while because I thought… I think it's a bit akin to the prostate cancer situation, where you can roll along quite nicely without much risk… now I wasn't necessarily quite right there, but I used that experience to question people more closely. You have to have a certain amount of confidence to debate these things with consultants. (Trisha, patient and carer representative)'

Trisha, and other patients during Forum meetings, make frequent gestural references to their embodied subjectivity to their professional interlocutors, in an attempt to directly relate the physical traces of *their* cancer with the social expectations of PPI, thus calling for greater acknowledgment of the more viscerally inhabited dimension of their personal experience. Another patient, Jenny, reminded the Forum participants on how the diseased and disfigured body and (the reality of disease and dying) cannot be avoided by retorting to somewhat drastic measures:

> 'I've still got my stoma [an artificial opening on the surface of the patient's body]. I thought the show treatment is best… So I mentioned that, you know… And you can see in their minds and eyes that they hadn't actually thought… They wouldn't have noticed'. (Jenny, bowel cancer survival, patient representative)'

To recall Butler (1990), the patients' discursive performativity along with the body's own power to be 'noticed' made it possible for their bodies to appear, become and matter in these meetings. But such discursive performativity co-implicating their body, was also in evidence when patients participated in major research conferences and workshops in the Forum, where they often referred back to such experiences, even when this was not considered appropriate within formal discussions. New group members often introduced themselves at the meetings by describing experiences of illness, loss, and bereavement. On some occasions, these descriptions became particularly charged emotionally, and interrupted or diverted the meeting's discussion from the prescribed agenda:

> 'She (former user) died last week… she would write to me, we were exchanging emails until a couple of days before it happened. It wasn't entirely altruistic, but it was cathartic

for her… but really helpful. (Katy, breast cancer survivor, quoted in research group meeting)'

Katy's reference to another patient who had recently died was an example of how personal memories were drawn directly into the Forum's 'conceived' space, generating some awkwardness around the table. Nevertheless, the occurrence of such emotive references was met with a routine scepticism, where emotions were brushed aside in enactments of the professional dimension of accountability, mostly by senior clinicians in meetings. This was manifest, for instance, in comments about the lack of relevance of personal experience in formal procedures: as Chris, a clinical researcher remarked 'you don't want too much of that, because the emotion of the moment can hinder discussion.' Hence, consistent with Butler's analysis, even though performative acts of participation allowed patients materially to establish their complex and vulnerable subjectivities, these were ultimately shut down and they were forced to reiterate the routinely enacted norms of professional meetings.

Tensions between participants' social expectation and abstract representations of accountability

Emerging perceptions of participation by different actors involved were not always antagonistic to such more viscerally experienced accountabilities: in some cases, professionals suggested a shift within routinely enacted accountability to create more 'space' for accommodating personal experience. Here is what Robert, a clinical researcher said:

'I think for them it's almost a mission in life, and it's partly for them I guess trying to make sense or to, to redeem something from the tragedy that's happened, you know, the husband who died young or their daughter who died young, or whatever, and to use this

experience in a way of shaping something else. Providing one acknowledges that, and also acknowledges their vulnerability that at times the issues under discussion may be hugely emotionally charged for them, I think they can be, they can be very helpful.'

However, even when patients' experiential dimensions were initially accommodated into enacted participation practices and emerging routines and expectations, they remained ultimately in conflict with (pre-) established accountability structures, thus eliminating possibility for real change. While professionals often acknowledged the need to 'give some space' to patient experience in meetings, formal requirements for measures and structures of accountability appeared to contain and 'neutralise' such emerging consensus around listening to patients' voices. For example, when it became evident that conversations were deviating significantly from the set agenda, professionals articulated concerns about the importance of getting the job done in a timely fashion, avoiding distractions from achieving much-wanted agreements, and eschewing shifts in undesirable directions. Raising such concerns was an effective means for 'correcting' any divergences from the established discussions, and ultimately re-affirmed the organisational focus on a physically defined, top down notion of accountability expressed in metrics and targets.

Lefebvre was aware that language can be alienating in that it separates meaning from the body and everyday sensory experiences (McDonald, 2016). Language is 'dangerous' since it 'allows meaning to escape the embrace of lived experience, to detach itself from the fleshly body' (Lefebvre, 1991: 203). Nevertheless, the idea of performativity of language theorised by Butler suggests a more complex process in operation, where language has power to 'do[ing] things with words' (Austin, 1962). Accordingly, Butler's argument is that language and discourses have distinct performative effects as they literally materialise in space (Butler, 1997) imposing political constraints on bodies but also enabling for bodies to assert themselves

though their power of interrupting the dominant discourses. Sandra, a patient representative, captured this process of materialisation in her recollection of an incident from her early experience as patient representative at her local hospital. She described her experience in a specific meeting that was held in a room of a cancer outpatient clinic:

'We wanted to rearrange the chairs [they were in lines] in a more companionable setting within that confined space. They would not listen to us, they wouldn't do anything. One day, we went there in the evening and changed it. The next day they changed it back… … Finally, I discovered why the chairs wouldn't change. The senior registrar explained that before the outpatient clinic opens the consultant would brief all the doctors on the rounds so they would sit in rows, because that is the way they liked it, because they love hierarchy! So, I said to the senior registrar if they could move them back once they finish, and his response was: "Doctors don't move chairs!"'

This experience illustrates how established social expectations within the clinic were entangled with patients' emotional need for companionship, which prompted users to rearrange the layout of chairs – a rearrangement which ultimately could not be accommodated within the Forum, since it violated the invisible rules governing conceived space. By rearranging the chairs, patients attempted to reset these expectations - but failed to do so. This failure can be explained by the fact that a non-hierarchically arranged 'participatory space' contrasted with professionals' routinely perceived space of 'the clinic'.

Discussion: Towards a spatially-aware framing of accountability

Our case example presented and analysed different tensions characterising participants' experiences within the multidimensional performance of accountability in the Forum. The

presented ethnography illustrated the ways in which 'ends' such as research targets around the design of clinical trials (abstract representations) were emphasised and prioritised in the Forum's meetings, through the organisation of discussion space and time around strictly allocated slots and through exhaustive technical documentation. Overall, the article contributes to furthering our understanding of spatial accountability in three, linked, areas. Our first contribution is to foreground the hitherto invisible social spaces governing the appearance of accountability relationships between professionals and patients, by showing how material structuring involved in the development of PPI leads to newly emergent understandings of roles within participative fora – and associated tensions.

The underlying tension was primarily between abstract representations of discursive and physical space, defined by professionalised sets of rules and norms, and the social expectations around a more experienced/performed accountability that were experienced by patients and carers. Although 'controlled' in the production of PPI space, accountability practices also shaped the form and content of conversations, expectations and experiences of accountability in the research organisation (the Forum). Yet such arrangements were often incongruent with users' own ideas of appropriate practices, such as engaging in caring relationships and focusing on embodied, experiential aspects of illness and care. Patients attempted to challenge what they perceived as unhelpful arrangements by, for instance, removing chairs to enable them to be closer to each other during the meetings - only to see these rearranged back again in the same fashion. However, our conceptualistion of performed accountability as inhering in unfolding spatial and discursive tensions between Forum participants demonstrates some ability to challenge, and redefine, the symbolic norms that inform received notions of 'accountability' within conceived space. As Lefebvre's work suggests, language can inhibit the process of emancipation since it acts as an interstice which filters and distorts the emotional and sensory responses of lived space (McDonald, 2016). Butler's (1997) notion of iterability of language

and its embodied performativity in space supports this view by demonstrating how discourses create bodies which struggle to redefine space.

In foregrounding hitherto invisible social spaces within performative accountability, we have addressed calls (e.g. Martin and Finn, 2011; El Enany et al., 2013) for greater attention to the practical, lived experiences of the 'involved patient'. However, analysis of the evidence presented in our ethnography deepens existing understandings of this phenomenon, suggesting a changing landscape of patient-professional relations that comprises a *reciprocal social and material structuring* that is performatively enacted by bodies appearing in the interactive Forum space. As patients are increasingly called upon to participate in devolved PPI and other co-governance structures that require 'work in partnerships' and 'networks', they find themselves interacting with professionals in unfamiliar places outside of traditional health settings, such as conference centres, universities and business meeting rooms, accentuating the need to understand better how these more fluid spaces are enacted (Renedo and Marston, 2015) – as well as the social implications of this increased fluidity.

Our second contribution is a revealing of the dynamics of these less visible - yet particularly important - dimensions of the accountability process. In so doing, we complement existing attention within professional accountability to targets/indicators (the dimension of *abstract representations of spaces*), with an increased emphasis on two further dimensions: peoples' affectively-mediated *personal experience,* as well as *social expectations concerning the new embodied spaces of representation:* unfolding understandings amongst participating patients and professionals. The co-constitutive relationship between these three dimensions, corresponding to Lefebvre's conceived, lived, and perceived space respectively, is shown in Figure 1. Our tripartite model of accountability dimensions builds on existing acknowledgements, such as Hupe and Hill (2007), of the differences between public

administrative/managerial and participatory dimensions of accountability, by 'opening up' the latter to comprise personal (including embodied/affective) and social dimensions.

In turn, our tripartite dimensional framework enables our third contribution: an explanation of how *tensions* between the three dimensions of accountability in its unfolding performance mediate (that is, constrain and enable) participation in practice. The framework in Figure 2 enhances the dimensions in Figure 1, by drawing attention to the tensions *between* these three spatial dimensions, that may emerge from competing demands experienced during interactions between health professionals, managers, patients and carers as they seek to reconcile personal, social, and abstract dimensions of accountability. The framework combines physical and abstract with more experiential and material dimensions; measurements with narratives and accounts, which are viewed in turn as an indispensable means for bringing patients' input into enactments of participatory accountability:

INSERT FIGURE 2 HERE

Our framework is inspired by Lefebvre's political understanding of space as a product of power relations and Butler's notion of discursive/material performativity of how bodies matter in social spaces. Whilst these developments have influenced many investigations in health settings (e.g. Halford and Leonard, 2006; McDonald, 2016), the spatial and performed aspects of participatory accountability, the physicality of disease with its concomitant material alterations to patients' lives as whole people, and the spatial organisation of participatory (PPI) settings, have not yet been adequately considered (for a welcome exception see Renedo and Marston, 2015). Moreover, as illustrated, our approach is particularly sensitive to the *performative* dimension of this spatial enactment of tensions. Through a Butlerian understanding of personal experiences (especially those of physical and emotional

vulnerability in health care context – see Fotaki, 2014) we could add further nuances to the constitution of participatory accountability as being itself an iterative and conflicting process. For example, our empirical case study demonstrated how organisational members involved in PPI platforms had official roles ('lay' _versus_ 'professional') denoted in seating plans and meeting agendas (dimension of abstract representations) as reported by Sandra, how these were re-affirmed through a 'commonsense understanding' of their PPI roles (dimension of social expectation), and yet how these official roles and institutional expectations were often challenged and undermined in moments where emotions and memories of illness and care came to the fore (dimension of personal experience) in the accounts of users and carers (Trisha, Jenny and Katy).

We have therefore shown how traditionally recognised dimensions of organisational space sometimes rendered invisible, and were held to be unsupportive of, the personal experiences of individuals – both users and professionals – who often felt uncomfortable and dis-identified with the Forum's existing structures of accountability (which felt simultaneously too rigid and fuzzy). At times, routine social expectations that encouraged a box-ticking approach also seemed to produce user disengagement from the actual PPI process because they failed to resonate adequately with their own personal experience of the impact of disease on their lives. An example of such dis-identification were the many expressions of ambivalence and uncertainty around users' perceived roles in the organisation, which they felt were mis-represented by the lay/professional distinction.

Bringing together insights from Lefebvre and Butler, this study therefore contributes to the examination of how space is performed through micro-level tensions and contradictions in the context of health research platforms, by combining different actors and their divergent notions of accountability to develop a model how such interactions evolve (see Figure 2). Working round Figure 2, we were able to surface tensions at the empirical level _between_ social

expectation and abstract representations, abstract representations and personal experience, and personal experience and social expectation. Thus, beginning at bottom right of the triangle in Figure 2, we could see examples of where codified rules and structures (abstract representations) appeared irrelevant to emergent social expectations within the group (top of triangle). Beginning at bottom left of Figure 2, we could see where individuals disengaged unexpectedly or creatively from codified rules and structures (bottom right) which offered little resonance with their personal experience; and, beginning at the top of the triangle, we could see where social expectations and routines at group level provoked dis-identification at the level of personal experience (bottom left).

Our ability to recognise interdependence and tensions between the three dimensions of performed accountability enabled us to appreciate how such tensions were socially generative in the sense that much of the practice within PPI itself can – and perhaps should - be comprehended in terms of the various compromises that participants had to make. For instance, patients and professionals sometimes affirmed the dimension of abstracted organisational space (bottom right of Figure 2), avowing top-down expectations and role boundaries – for example in the case of professional researcher Tim in our study. Or they may become focally aware of the dimension of personal experience within organisational space (bottom left), prioritising emotional 'gut experience' over 'getting the job done' as evidenced in the account by another clinical researcher (Robert). Finally, they may submerge themselves in the routine practices, or 'social expectation' dimension of organisational space (top of Figure 2), avoiding altogether a choice of 'one option over another' but rather striving towards consensus as reflected by the oncologist David. An awareness of these tensions and compromises as experienced by 'whole people' in practice appears as a significant enhancement of more traditional, target-based measurements of accountability.

This finding is particularly important because rather than assuming a binary positioning of professionals and patients in the performance of accountabilities in PPI spaces, we showed that patient and professional roles are socially constructed *through* the negotiation and temporary resolution of tensions. Put differently, we suggest that far from occupying stable positionings, PPI participants with fluid identities may enact different roles in specific points/contexts in time and space, reflecting the malleability of their experiences and the possibility of change, thus making an empirical contribution to the emerging field of critical approaches to organisational performativity (Cabantous et al., 2016). We also do so in a way that is novel, by bringing together Lefebvre and Butler to discuss performativity in space in the context of participatory accountability (see also Tyler and Cohen, 2009 using similar framing in their research on gender in academic institutions; and Fotaki and Harding, 2017 drawing on Butler's performativity to examine pervasive forms of gendering in the workplace).

Implications, limitations and future research directions

There are potentially important practical implications emerging from this research. As our ethnography illustrates, holding clinical research accountable involves particular ethical responsibility because those benefiting from research outputs often lack a choice due to pre-existing socioeconomic and individual circumstances, and are frequently vulnerable. We have uncovered a continuing inequality of power in PPI settings between health researchers, managers and patients, seen in the dominance over the set-up and regulation of such meetings. It remains unclear whether patients had any substantive input into the research agendas or whether they were expected rather to acquiesce to professionals' priorities, as can be inferred from David's comments, without a major alteration in power relationships.

Our spatial focus offers opportunities to explore new accountabilities developed and performed in the continuous 'de-territorialisation' of governance structures in health research

(Gibson, 2001); seen in the break-up of traditional territorial boundaries such as the hospital, the clinic, or indeed the research lab, that is enabled by citizen participation (Häkli and Bäcklund, 2015). Future research can explore further how the constructs presented and discussed here on spacing dynamics might apply in other decentralised settings - for example, charity, community or grass-roots activist groups – which also depend, at least partly, on individuals' propensity to cooperate with others for the common good.

We acknowledge that the clinical research network that forms the setting for our study may differ from how participation unfolds in the context of health care provision and other public services more generally. That said, policy makers within other organisations adopting 'distributed governance' may wish to consider the inherent tensions at play in the spatial production of accountability – and the need to complement the target-driven approaches that characterise the measurement of accountability to date with a more nuanced, performed dimension that is better able to represent diverse experiences of, and tensions between, multiple stakeholders whose social roles are literally constituted within unfolding partnerships, networks and involvement fora. There is a need, we argue, to account for a variety of intense emotions present within the PPI encounter that are intrinsic to relations between patients and professionals, having their roots in dependency, vulnerability and precarity of the human condition.

Our study is not without some important limitations. For instance, much of the policy and discursive drive for participatory accountability has its origins in health services participation, rather than research, and the two areas differ in important ways. Through our ethnographic study of a research PPI Forum, we hope to have shown how pressures for participatory accountability have over the last decade been transferred into the field of health research. Future studies can explore the implications of our findings about the experiential/performative aspects of participatory accountability in the context of health services design and delivery.

In conclusion, discourses of accountability in health research have so far been couched in terms that imply a view of accountability as being 'demonstrable' through metrics, but seen through our framework, this appears to be a sleight of hand: we have proposed instead that PPI practices should be studied as specific performances of 'being accountable'. We believe our research is timely, given an increased blurring of boundaries between professional and lay roles in participatory models of health research – a blurring that removes many of the traditional protections of formal spaces of accountability, leaving both patients and researchers vulnerable to new metrics and forms of regulatory control or 'patient benefit' as narrowly defined by clinical outcomes. We thus seek more explicitly to acknowledge dynamics that affect the political ordering of space (Bradley, 2014). One such direction suggested in this paper would involve working to develop the links between such rationales and the particular performances upon which they often depend – performances that relate to how 'topics under research' are experienced by 'whole people'.

Funding

Note

[1] The name of the organisation is withheld to provide anonymity and will be referred to as the Forum.

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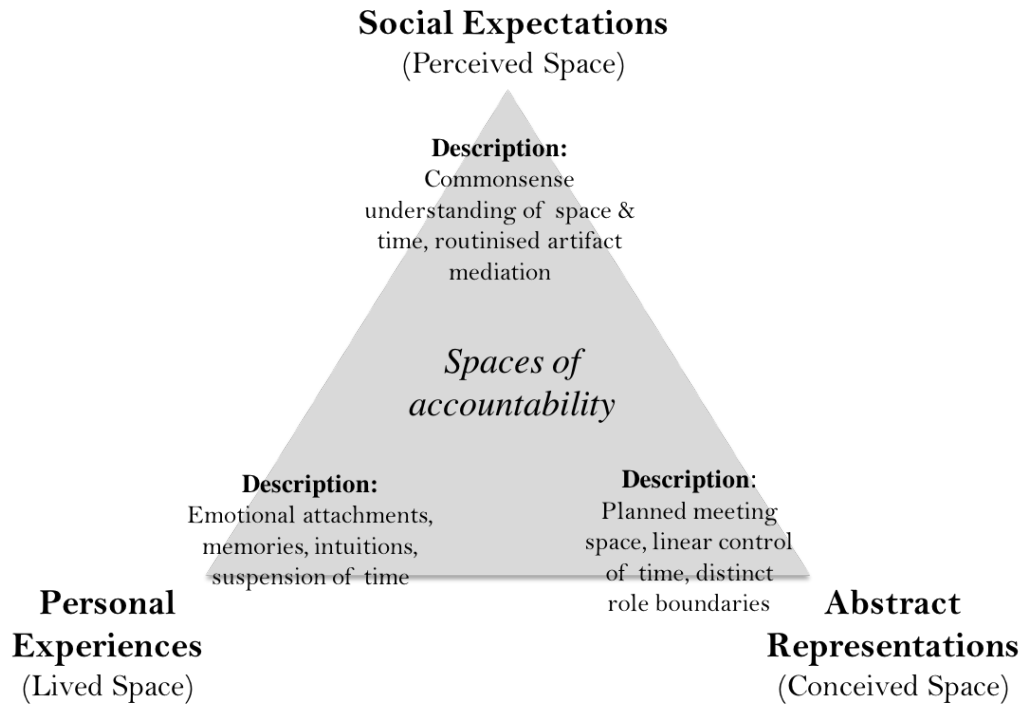
Social Expectations
(Perceived Space)

Description:
Commonsense
understanding of space &
time, routinised artifact
mediation

*Spaces of
accountability*

Description:
Emotional attachments,
memories, intuitions,
suspension of time

Description:
Planned meeting
space, linear control
of time, distinct
role boundaries

**Personal
Experiences**
(Lived Space)

**Abstract
Representations**
(Conceived Space)

Figure 1: the three dimensions of accountability spaces

Social Expectations
(Perceived Space)

*Spaces of participatory
accountability*

Tension:
Individuals appear disengaged from group
Understandings & routines

Tension:
Codified rules/visible structures appear
constraining/irrelevant to emerging group
consensus

**Personal
Experiences**
(Lived Space)

**Abstract
Representations**
(Conceived Space)

Tension:
Individuals appear constrained
by codified rules/visible
structures, and may disengage or
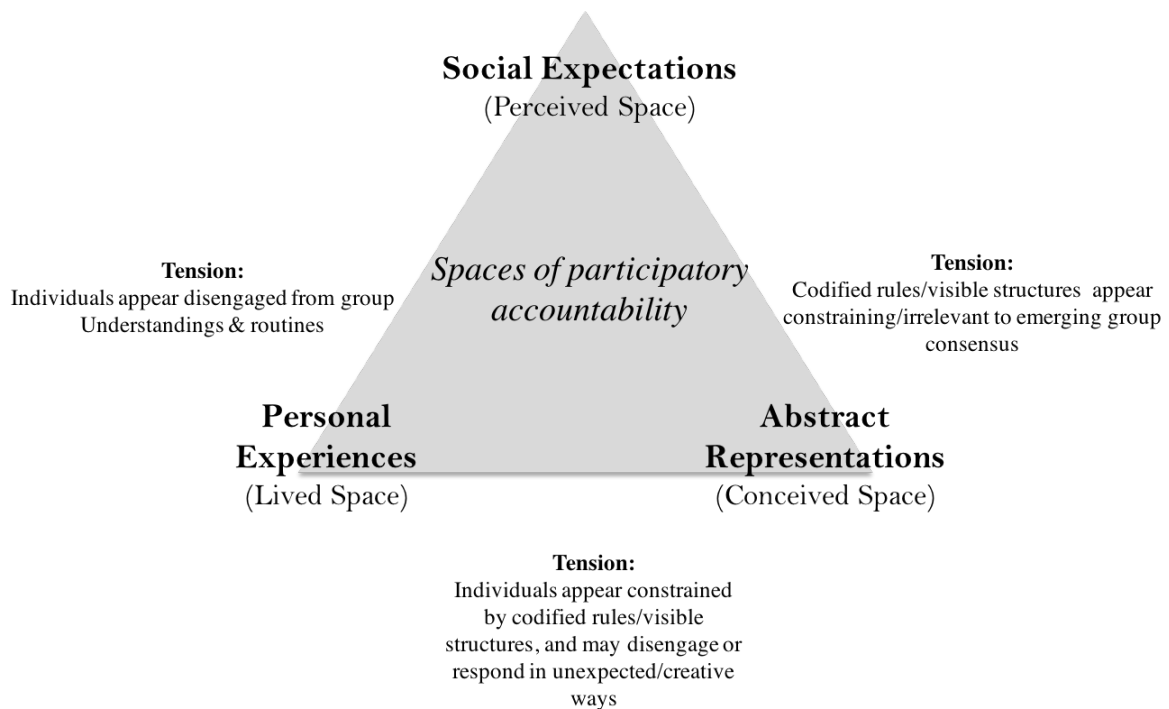respond in unexpected/creative
ways

Figure 2: the social production of participatory accountability through the enactment of tensions