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Can the Experience of Participatory Development Help Think Critically about 'Patient and Public Involvement' in UK Healthcare?

David Mosse

SOAS University of London, UK

Email: Dm21@soas.ac.uk

Abstract

The expansion of spaces for 'patient and public involvement' (PPI) in health systems in the UK is a relatively recent phenomenon, and yet 'participation' as a principle for planned interventions in international development is well established as a field of practice and controversy. Development workers and scholars have passed through moments of enchantment and disenchantment with the idea that the true source of innovation, expertise and workable (and sustainable) solutions is to be found not in the professionals but in communities of experience. Making 'local knowledge' the basis of interventions has proved unexpectedly problematic. How could incommensurable forms of knowing, across steep gradients of power be bridged? This article describes a decade-long experiment in participatory development in a remote Adivasi (tribal) region of western India in order to suggest the relevance of this experience for the very different context of PPI in healthcare settings. In particular, it highlights some general points about knowledge practices at the interface, and the human tendency to adjust, mirror, mimic, loop and in other ways make the ‘patient-professional’ interface itself hard to navigate. The article suggests that self-reflective insight into these social processes is necessary for effective ‘engagement’ by professional and lay actors alike.

Keywords

Participation, patient and public involvement, citizen engagement, development, India.

Introduction

The expansion of spaces for ‘patient and public involvement’ (PPI) in health systems in the UK is a relatively recent phenomenon, and yet ‘participation’ as a principle for planned interventions in international development is well established as a field of practice and controversy. This article considers the relevance of critical reflection on participatory development for researchers and practitioners of health systems PPI, given the shared idea that innovation and workable solutions to intractable problems require the engagement of communities of experience, and parallel struggles with the paradoxes of managed citizen engagement, and state-driven community/citizen control.

There is also, of course, a shared political context in neoliberal trends that, from the 1990s, brought new interest in citizenship as a resource for governments under fiscal pressure and committed to reform of public services and welfare. Alongside ideas of citizen activation and empowerment –'expanding the reach of choice and voice' of consumer-citizens – came 'responsibilization' (Clarke, 2005: 449). Responsible citizens make the right kind of choices (ibid: 451). It is in this context that citizen engagement is regarded as a form of governance as much as power-sharing.

Enrolling participants with the rhetoric of partnership or local ownership is often understood in terms of Foucault's notion of governmentality in which individuals constitute and discipline themselves, their desires, aspirations and interests 'in terms of the norms through which they are governed' as 'free' agents (Shore and Wright, 1999: 560). Certainly, the rise of the discourse of participation in international development coincided with the era of 'good governance' as a policy agenda, achieved through self-governing disciplines of 'capacity building' thorugh which, paradoxically, international agencies, increased intervention in the internal affairs of developing countries. Critical analysis of user-engagement has, in parallel, found this associated with a dispersal of state services to private providers. I will not in this article focus on the wider political economy of participation, but rather turn to a more close-up view of practices of participation significant across the wide stretch to PPI.

I will, first, point out some fairly obvious parallels in the language and principles of PPI and participatory development, outlining the shifting moments of enchantment and disenchantment within the latter. Second, I will consider the knowledge processes involved in professional-lay interactions, taking a case from rural India. I will not imply direct parallels between citizen participation in Indian agricultural development and UK healthcare, but rather point to looser resemblances. Indeed, it should be clear that this article is not written on the basis of work in UK healthcare settings (except to the extent explained in the postscript). I cannot therefore make the explicit comparisons that readers are encouraged to draw. The agricultural story should thus be read as a kind of allegory. Third, I turn to the 'disciplinary' aspects of participation in this project, and fourth to its enabling effects. Finally, I ask how favoured models of participation can come to be sustained as representations independent of practice. In a postscript, I offer a perspective from the different subject position of a space-claiming participant and citizen. The aim throughout is to demonstrate how critical analysis of the processes involved can enable learning, adaptation and change in practice so that the claims for PPI/participation are not only tested, but made more credible because grounded in social realities. A precondition and means for this is reflective awareness (in different roles) of the often unnoticed (and unintentional) effects of power, identity and knowledge at the professional-lay interface.

PPI and participatory development

Reading the literature on PPI (especially in the field of mental health) as an anthropologist of development made me aware of the resemblances between the two contexts and the underlying claims, in both, to rearrange the gradients of power between providers and recipients, professionals and patients, service users and commissioners, among others. I am, of course, thinking about what is well known to those involved in PPI: that a distributed idea of knowledge inclusive of 'expertise-by-experience' is involved; that services are 'co-produced' with users drawing on their existing capacities (rather than deficits) and are in the jargon 'asset-based'; and that a mutuality blurring the lines between 'professional' and 'lay' is required. The now well-established claim is that when medical professionals are *facilitators* of patients' self-directed care — that is, recovery-oriented approaches, personalised services—established power inequalities are challenged; and that apart from intrinsic merits of equity and social justice, these models make for more effective, usable, relevant, or just better services and research. And, of course, in UK healthcare research, patient involvement has become a legal requirement. In mental healthcare, for instance, involving people in co-production is understood to: increase respect and reduce stigma within healthcare systems, including among professionals; strengthen patients' social networks and positive social belonging; improve skills and employability; reduce dependence on acute services by enhancing prevention; and foster well-being (Slay & Stephens 2013).

This PPI discussion is fairly easily read across to claims about the benefits of people's participation as an alternative to 'top-down' approaches to development in the 1990s and the goals of empowerment through the work of people like Robert Chambers (1997) and the subsequent Sustainable Livelihood Analysis framework with its emphasis on local assets and the pentagon of capitals: human, social, natural, physical and financial (Carney, 1998). Alongside the goal of participation, came its differentiation as practices were judged to be nominal participation, instrumental participation (e.g., a matter of cost-efficiency, customer-orientation), representative participation (a means to express local voice), or transformative participation (collective action, control from below) (White, 1996). A parallel separation marks out PPI approaches that inform, consult, empower through shared leadership; or research that graduates from user consultation or collaboration to research that is user-controlled (McKevitt, 2013).

As in healthcare, these degrees of participation might be expected at different 'levels' of development systems, distinguishing, with Carman et al. (2013), engagement directly in the design/delivery of services (say, agricultural or healthcare) from engagement in organisational design and governance, or broader policy-making. The range, from control over particular ‘treatments’ to representation in decision-making over the allocation of resources, also invokes different kinds of identity: the patient/farmer service user, on the one hand, and the public citizen, on the other. And these – both contained in the term ‘PPI’ – imply different justifications for engagement. While patients, farmers or consumers might be mobilised on the basis of their *expertise* or experience (to improve services), citizens are to be engaged (consulted or empowered) on the basis of their *representativeness* in relation to characteristics of society. However, as Martin (2008) points out (with reference to public participation in healthcare in the UK), this bifurcation of technocratic and democratic rationales breaks down in practice. Engaging lay ‘expertise’ overlaps with concerns about representativeness, hard-to-reach groups or a need for ‘ordinariness’ among those through whom state systems seek to know their constituencies or share leadership; while justifications based on social representativeness give way to the pragmatic need for the representation of specific discursive positions or experiences, often self-honed into expertise (Martin, 2008).

Differing rationales and characteristics of involvement are also sources of contention. By the late-1990s, participation in development had become widely criticised for having lost touch with its radical (democratic) roots in social movements, conscientisation and action research; becoming depoliticised with its (technocratic) incorporation into the aid industry, including expert procedures of the World Bank (1996), becoming by 2001 a ‘*new tyranny’* to quote the title of a landmark critique published that year (Cooke and Kothari, 2001). Yet three years later, participation’s transformative potential appeared reinstated with the follow-on volume, *From Tyranny to Transformation* (Hickey and Mohan, 2004). Of course we know that the politics of participation is such that all its forms can be manipulated and co-opted by interests from the top, but also from the bottom (White, 1996). In the development lexicon, ‘participation’ became one of the most prevalent buzzwords; or fuzzwords, given its amorphous and ambiguous meanings (Cornwall and Brock, 2005). This is a challenge to anyone wanting answers to the question, *does participation work*? – subtitle of a recent World Bank publication (Mansuri and Rao, 2012) – to which I return.

Knowledge processes in participation

Taking a development example, I turn first to the knowledge processes involved in the interface of lay-professional expertise. During the 1990s and early-2000s, I worked on an official-aid DFID[1]-supported participatory livelihoods project with upland Adivasi or ‘tribal’ farmers in western India – people who cultivated food grains (producing less than could feed them) from steep and eroded hills with almost no external inputs (fertiliser, irrigation). We had to ask a question, just as planners of health services might: who are the experts here? Is it those with lived experience of survival in complex and difficult circumstances with limited resources; or is it those who organise this experience into a general scheme, with the power to make a diagnosis, identify a problem or propose the remedy in general and scientific terms?

In this case, until recently, it was clear where the expertise lay. It lay with agricultural science and engineering which would provide the much-needed technological interventions to address the problems of failing subsistence agriculture: improved seeds, soil and water conservation, farm implements, inputs such as fertiliser, credit and so forth. As with bio-medicine, there were also broad schemes (in India) such as the World Bank’s National Agricultural Research Plan in which problems and their treatments were defined with reference to a scheme of agro-ecological zones and farming situations into which local conditions were organised, and state resources, research priorities and official recommendations for cultivation defined. As perceived by experts, the failings of impoverishing upland subsistence farming made it an arena for almost unlimited improvement and potential.

However, in the 1990s, following years of failed top-down expert interventions, a new participatory 'farmer first' approach (Chambers et al., 1989) refused to trace problems to farmer ignorance, or the deficiencies of traditional agriculture. On the contrary, indigenous farming practices were considered sophisticated adaptations to complex and risky environments. Farmers were the true experts and experimenters deriving knowledge from lived experience on how to work the land with meagre resources. The real problem was not farmer ignorance but the lack of knowledge among the scientists in the regional research centres about farmers' lives and agricultural practices, and the inappropriate official recommendations, treatments and technology that resulted (Mosse, 2005: 30–5). Drawing a parallel with the discourse on global mental health, attention was turned from the 'treatment gap' (limited access to biomedical treatment) to the 'credibility gap' (inappropriate use of specialist diagnostics and interventions) (Patel 2014). We had concluded that scientifically credible and successful agricultural development needed directly to involve farmers using their expertise to develop and adapt new agricultural technology.

So, this aid project involved a programme of participatory crop development taking place on farmers' fields and involving their fine-grained judgements in breeding, testing and popularising new crop varieties (Mosse, 2005: 138–142). This was somewhere between collaborative and user-controlled research at the level of treatment design or direct 'care'; and as an intervention it was an instance of 'co-production' (doing-with, rather than doing to, or for) albeit of the professional-designed-user-delivered variety (Slay and Stephens, 2013: 3–4), while also training a cadre of local ‘barefoot’ agricultural ‘peer’ experts.

The project had the hallmark of success. It rearranged knowledge hierarchies –elevating farmer experience and demoting professional expertise – while building this into regulatory frameworks. It provided a scalable, cost-recovery-generating model. However, after five years, impact studies showed some of the crop varieties developed by this method, while initially successful, were now scarcely to be seen in the fields as farmers reverted to their older ones (Mosse, 2005: 205–29; Patel, 2007).

Accounting for disappointment in a client-led intervention opens up paradoxes of knowledge across the lay-professional boundary. In the simplest terms, the scientific expertise of the research-station was initially discredited because it was too embedded in a given organisational culture and authority structure, unable to respond to farmer realities and promoting inappropriate high-input-dependent technologies.[2] Farmers with their expertise honed by experience were the true scientists; enrolled as such on our participatory designs to make judgements about crop performance from paired comparisons and controlled crop-cutting experiments. But in being made experts in this way, farmers were themselves removed from the social context of *their* knowing. Their knowledge was disembedded. Once the new crop varieties were re-embedded in the complex social relations and micro-environments of their everyday lives — not just the fragmented plots, steep slopes and water scarcity, but also the conditions of seed supply, networks of obligation, deficits or debts, family relations, market connections or migrant labour — the scientifically proven yield advantages failed to appear as livelihood benefits (Mosse, 2005: 205–14).

Our participatory techniques also carried meta-assumptions about farmers' knowledge practices, among them that farmers lived in a world of choice, and that when faced with a harsh and variable ecology they just needed more choices (crops, varieties etc.). But when it came to the maize staple crop farmers could not imagine themselves in a supermarket of varieties. They adapted environments to cultivate one preferred type of maize that suited food habits and nutritional needs. Each season they would select seed corn to preserve the quality of grain in ways that deployed a very different experimental method from that of the plant breeders/geneticists running the participatory trials.

What is important here is not the detail (see Mosse, 2014: 514–5; Patel, 2007) but that, broadly, we faced two kinds of knowledge difficulty. First, platforms (farmer-participatory experiments) for involvement intending to draw on lay experience and knowledge actually required a disembedding and decontextualisation of that knowledge such that its judgments were no longer sound or relevant, or not adequately so. Second, there was an incommensurability in the underlying knowledge practices of the 'patients' (the tribal farmers) and the professionals. One might add that in this development case, it was not easily understood why sincere participatory approaches had failed to make the research and the interventions more relevant or effective. In fact, commitment to the value of farmer-participatory approaches led to resistance from the professionals to the idea that this was not working; an issue to which I return.

Relating this to PPI in UK healthcare, if what constitutes 'expertise by experience' is the understanding of symptoms, diagnoses, medication-effects or care relationships similarly woven into the fabric of everyday social and material life, then it is not difficult to see how modes of engagement with lay people – the consultations, surveys, committee structures, even diagnostic settings, through which that expertise has to be articulated – might (re)frame, constrain or shape the knowledge that is shared such that it loses some of what is important. Furthermore, aspects of contextually-shaped, relational or subjective experience of health or related conditions remain unheard because incommensurate with the procedural forms that produce lay 'expertise' and count it as relevant for health service planning or delivery; and in consequence the effectiveness and efficiencies expected from PPI are not always forthcoming.

A current innovation in mental health crisis care (pioneered in Finland and under trial in UK) addresses the problem of the clinical disembedding of patient experience and makes social networks the context and foundation of treatment. In addition, in this Peer-supported Open Dialogue (POD) model, mental health service users ('experts by experience') join the therapeutic teams as peer-workers.[3] The relationship between professional and patients is reconstituted and different kinds of knowledge rendered commensurable by not prioritising clinician-defined diagnosis, tolerating uncertainty and encouraging multiple voices in 'network meetings' including patients, family members, social workers and service-user 'peers'. And a clinician stance of 'not knowing' and equal attention to the utterance of all participants (including those made in psychotic speech), in principle, allow new meanings and openings out of crisis to emerge for patients *within* their social networks (Anderson and Goolishian, 1992; Razzaque and Stockmann, 2016; Seikkula and Olson, 2003). This is not the place to further explore POD and its challenge to existing health-service organisational culture (the author is currently developing ethnographic work in collaboration with POD services in the UK that are simultaneously subject to the first randomised controlled trial), suffice it to note the centrality of knowledge processes (and of language) in shifting lay-professional relationships and innovation on intractable problems.

Processes of participation and engagement

Participation that disciplines

Perhaps the challenges of ‘patient engagement’ (from care delivery to policy-making) arise from power inequalities in participation’s ‘invited spaces’ (Cornwall, 2002); that is spaces established by authorities into which people are invited as ‘guests’ (clients, users etc.) rather than ‘claimed/created’ through direct assertions, such as farmer protests against hybrids/GMOs, and the disability or psychiatry survivor movements demanding ‘nothing about us without us’ (McKevitt, 2013).

Returning to our Indian project, we discovered that in all its programmes (crops and others), the best available techniques of participatory mapping, modelling or livelihood analysis (oriented now to design and planning levels), and the work of dedicated community workers, could not resolve some intractable obstacles to designs and interventions being truly citizen-controlled. First, the venues of engagement (of participatory planning) – because of their medium, methods, location and publicness— gave better access to the voices of the privileged. Our methods implicitly required a certain cultural capital such as possessed by Adivasi male lineage heads (as equivalently, white educated middle-class patients in UK), and inadvertently deployed self-fulfilling stereotypes about the capacity and contribution of different types of people. While the women, the aged or inferiorised groups lacked voice, powerful individuals had the capital of authority to have their private interests registered as public needs (Mosse, 1994). Also, it was only certain kinds of knowledge that could be articulated at these venues: knowledge that was public, explicit, codified and recognised as such. Knowledge apart from practice. But much experience and expertise (in cultivation as in health) did not take such form. It was not mediated by language could not be represented apart from practice-experience (ibid).[4]

Second, the tools and techniques of participation at different levels — crop development or Participatory Rural Appraisals (PRA) – were less a means for people to articulate *their* knowledge so as to design the intervention, and more the means by which they (Adivasis here) could acquire a new kind of ‘planning knowledge’; that is, bring about a change in their own knowledge (and in themselves), so as to engage with outsiders in the outsiders’ terms, as proper patients or beneficiaries, as indigenous experts with appropriate knowledge, needs and ambitions (those normatively modelled for them by the lifestyle of outsider non-Adivasi community workers). Some, including women who articulated their needs in terms that were too large or too small – as the need for a hospital or help for an ailing family member – were unable to express themselves as the project required.

Lay participants in health systems too have to gain familiarity with the institutional arrangements, categories and language (that is discourse) necessary to speak, and much of their knowledge work is oriented to this task rather than (or at least alongside) the articulation of their experience. And there will be those excluded, not socially or by geography, but because they cannot speak in the terms expected or will not identify as patients – perhaps for reasons of stigma or trauma born of violence, abuse, neglect or loss. The key point is that the professional-lay interactional context is itself likely to shape the outcome of public/patient involvement — what and how people speak, and how they identify themselves and their concerns. People adapt or change towards the terms, identities, labels and diagnoses (etc) by which they are ‘hailed’ (to invoke Althusser’s [2006] idea of interpellated subjects) in patient engagement as much as in treatment settings; something familiar to medical anthropologists, and linked to philosopher Ian Hacking's (1995) idea of the 'looping' effects between people and their diagnostic labels. The identity categories of people and experiences here are interactional, and co-constituted; perhaps as an unconscious and passive adaptation to the terms of engagement, but also through active even ironic performances of professional terms of address or diagnoses (as medical anthropologist Emily Martin [2009] explores in her book *Bipolar Expeditions* drawing on her experience of her own diagnosis). There are particular challenges where PPI requires a transformation of diagnosed illness into deployable expertise by peer workers who find themselves having both to overcome *and* retain their 'patient' identity (e.g., in mental health, see Cubellis, 2018).

Returning to our project, the third point is that the hiatus between participatory moves and local interests allows some villagers' responses to engagement to be strategic. Farmers acquiesced to the professionals' schemes and technologies, or anticipated them by re-articulating their needs in outsiders' terms, simplifying them or presenting a consensus, which hid/muted divergent perspectives. Sometimes this was to secure known short-term benefits (wage-labour, loans, capital investments in small-scale irrigation); but equally, adapting to the project's schemes was the best strategy to maintain a relationship with the project as service provider and resourceful agent of influence: a patron and protector. Indeed, Adivasi citizens disrupted and transformed a neoliberal participatory development concern with technology choice, local voice and low-cost self-reliance, into the acquisition of patrons, social protection and investment in assets. This was a more relevant approach given their structural conditions of vulnerability, exploitation and dependence on external mediators of rural livelihoods (see Mosse, 2005). For these actors, participatory development was the means to quite different ends. PPI initiatives also occur within contexts that exceed the initiating health system's purposes, so that citizen engagement is used to promote investment rather than cost-efficacy in services, or interests in fields as varied as employment, housing or reputation building; and the interests that patients and families occupying different structural positions (sometimes privileged ones) pursue are not necessarily disruptive or misaligned to neoliberal citizen participation goals even though working to parallel and separate ends.[5]

Participation that enables

Spaces of 'participation' can also create genuinely new possibilities, meanings and social performances, as non-hegemonic heterotopia in Foucault's (1986) terms. I would point to three kinds of discussion here: the fostering of new thinking, social solidarities and reshaping the participatory process itself.

First, back to the Indian project, the new planning knowledge Adivasi farmers acquired as they unpacked practical experience into words, or PRA maps or matrices to communicate with outsider-professionals, or participated in structured crop trials, allowed for novel reflection on experience, and for problem-solving and innovation. Growing improved seeds, project-delivered with inputs (fertiliser etc.), separated decisions about cropping from the normal constraints of relations with kin and moneylenders in ways that could be liberating. Participation brought new knowledge and experiences.

Second, participation creates new solidarities. Citizen engagement with professional systems may allow people to shape or re-claim those co-produced beneficiary or patient identities (of need or suffering) and to generate new solidarities around them that are productive of positive meaning and agency, and hence are (in a health context) therapeutic. In Open

Dialogue therapy, an inner monologue is reoriented to ‘the outer social dialogue’ and building a social network (Seikkula and Olson, 2003: 405). We can also think of advocacy groups, alliances/networks or peer-support groups that play a role in (and are partly shaped by) initiatives and experiences of engagement. They involve new knowledge and connections, and entail social exchanges through which individual, subjective, and fragmentary experiences acquire language, objectivity and social recognition. Through repeated collective/inter-subjective (interactive) processes, group members acquire from each other a shared narrative that influences experiences and gives meaning to the suffering of a given symptom or syndrome. And this might protect against the re-traumatising effect that articulating patient experience might otherwise entail.

The transformation of the ‘clinical’ (individual) patient identity to an ‘engaged’ (social) patient identity (or from the private experience of distress to its social meaning) necessarily involves change in the relationship with the ‘clinician’ and therefore of the professional’s identity as well; mediated by their own collectives/networks necessary to managing shifts in boundaries, accountability and risk-holding. Inverting the issue, one could say that patient or citizen (or professional) identity has to be produced socially before it can be ‘engaged’ or changed (cf. Martin, 2009).

In a different context the development project also demonstrates the solidarity effects of participatory processes. Consider the women’s savings and credit groups set up by the project, which even though they failed in their micro-finance objectives (for particular cultural reasons, Mosse, 2005: 118-22, 222), were judged especially important by Adivasi women for the new form of sociality (mutual support and problem-solving) they offered women from scattered hamlets. This licensed collective action independent of existing ritual and reciprocal obligations that were experienced as burdensome, especially for the poorest with weak social networks. Moreover, these project spaces of engagement and the disciplines they involved (the order of schedules, ledgers, minuted resolutions, rules and fines) repudiated existing forms of collective action mediated by feasting and especially alcohol, which women connected to ill-health, debt, conflict and especially domestic violence.

Let me make a further observation here, tangential to the point about new solidiarities produced by participatory approaches but pertinent to the broader discussion of their contradictory effects. It was not expected or desired that project venues of participation would offer freedom from existing social capital (mediated by alcohol) in the way just mentioned; neither was it anticipated that engagement with the project would become part of wider-ranging cultural reform and the embrace of 'the modern' through changed dress, diet, meetings and other forms of 'self-betterment'. But, in effect, participatory mechanisms that were intended as the means to give voice to 'the local' or 'the indigenous' and to transform outsider development approaches were precisely those through which Adivasis sought a self-transforming route to become 'developed' (less stigmatised as 'tribal') in the manner modelled by outside project workers. Contrary to its self-representation, participatory development (at least here) empowered people not by giving them local voice, but by enabling 'relationships with outsiders having better access to resources; and not through validation of their existing knowledge and actions, but by seeking out and acknowledging the superiority of modern technology and lifestyles, and by aligning themselves with dominant cultural forms' (Mosse, 2005: 218). Equally, for their own unanticipated reasons, patients and citizens in any context might discover aspirations, identities or hope through the public 'venues' onto which they are enrolled, and so actively cultivate these connections and networks, and inhabit/adopt professionally-defined worldviews.

As a third transformative effect citizens find various ways to re-shape the participatory process itself so as to pursue their particular (group) interests – raising awareness, improving services, setting research agendas and bringing about change to the system. It could be argued that Adivasi villagers had repurposed (even subverted) participatory development to their different ends: the pursuit of clientship and capital investment. We did not at the time perceive or examine these as strategic forms of engagement, which they may have been; but there *is* now a body of work more focused on the intentional and strategic performances and spaces of citizen engagement. Renedo and Marston (2015), for example, use Egin Isin's ideas on deliberative 'acts of citizenship', and Doreen Massey's analysis of space to explore how citizens create new 'scenes' of action, new openings, ruptures or beginnings in order to bring about change in existing arrangements.

Patient-citizens learn to conform to institutional conventions while at the same time 'plotting' — in the double sense of mapping and scheming — so as to create opportunities to bring the change or resources that they desire (Renedo and Marston, 2015: 6–8). Or they may leverage influence through forging transient connections between spaces; or create more durable formations (patient groups, inter-agency strategy groups) (2015: 9–11). There is clearly much to explore here in terms of the way citizens find/or compel an authority for their voices: as collectives, making reference to policy, or through organised roles in health charities or other bodies.

Crucial in this repertoire for communication and persuasion is the force of emotion grounded in personal experience — in what Komporozos-Athanasiou and Thompson (2015) call 'biographical affect'. Such emotion often may drive the uptake of opportunities for citizen engagement in the first place, and is key to its meaning in the personal narratives of those involved; but also to the interface with organisational structures. Emotion (or reactions to emotion) can be a route out of pre-defined agendas (the discursive space of the say-able and do-able), but can equally arouse judgement and dismissal as institutional schemes sort out 'the rational' and 'the irrational'. The exhibition of authentic feeling that communicates may of course have other kinds of effects (positive and negative) on those seeking to persuade and their audiences; and in view of this is likely to be highly modulated by context.

Evidently, the dynamic of citizen engagement comes from the positionality of actors and their claims to represent a group, a network, a charity, a diagnosis, an individual experience as sufferer or survivor, from, as Bruno Latour puts it, 'the swelling or shrinking of the relative size of [the] actors' as individuals (citizens, patients) find authority for their voices and actions in varied ways. The citizen actor, like the development brokers I have written about, 'is a person of constantly shifting size and institutional position' (1996: 45).

Does 'it' work?

Finally, I turn to assessment of the impact of citizen participation on the effectiveness of the various systems, schemes and services involved. What is the relationship between strong policy advocacy of participation and actual practice and outcomes?

The first point, as the above-mentioned World Bank review (Mansuri and Rao, 2012) discovered, is that findings from econometric analyses and the insights from qualitative or ethnographic analysis of participatory development programmes are equivocal. Much depends upon circumstances and the contingencies of social/institutional setting. Different kinds of citizen involvement or participatory intervention will work, or not, for different reasons in different places and times. The sheer variability of practice under a common description — as ‘participation’ or ‘PPI’— the diversity of settings, and the multiplicity of combinations of factors affecting outcomes, raises questions about the meaningfulness of the question (does it work?) or the coherence of the categories of practice under investigation. And here, as Cornish (2015) points out, the conclusions and claims from systematic reviews of such fields have limited reliability. The evidence is context-sensitive: cut out the noise and you miss the point (2015:6).

Secondly, an idea as vague but politically mobilising as participation or citizen engagement throws light on the complex often disjunctive relationship between policy intention and institutional practice – a ‘loose coupling’ as Rottenburg puts it (2009: 69 et seq.). Despite uncertainty about the evidence for causal pathways from citizen involvement to better outcomes — in fact because of this uncertainty— participation in development (to take that example) becomes important as a valued approach, a strategy, a replicable model, and as I show in *Cultivating Development,* ‘participation’ was even produced as a transacted commodity (Mosse 2005; cf. McKevitt 2013). The function of this policy model in the project on which I worked was not in reality to guide practice (nor was it a description of practice) so much as to enrol political support for the project and its interventions; that is to legitimise rather than orientate action. In fact, the ambiguous ‘participatory approach’ was so successful in enrolling such a diversity of agencies, with conflicting interests and expectations, and the project was in consequence so full of contradictions, that the participatory model *could* not be implemented (see Mosse, 2005).

A good deal of actual practice contradicted the farmer-driven community-control model; or as Cornish & Ghosh say of a community-led HIV prevention project in Kolkata, 'the "community" that leads this project is much wider than a local grouping of marginalised sex workers […] given existing power relations, the engagement with other interest groups was necessary to the project's success' (2007: 496). In the rural development project, the delivery of programmes and expected outputs — technologies, water-conservation schemes, forestry – was in fact far too important to be left to *participatory* (i.e. farmer-managed) processes; hence the strong vertical control of activities and implementation backed by systems of reward and punishment (Mosse, 2005, 161).

Nonetheless, staff at all levels (and villagers too) worked hard to promote the view that successful activities and outcomes were indeed primarily the result of a farmer-led (or equivalently sex-worker-led) approach. The validating participatory model stabilised the meaning of events for the various publics (donor, managers, politicians); establishing the causal link between desired outcomes (better targeting, efficient delivery etc.) and practices of 'participation' that was absent (or hard to verify) in practice (Mosse, 2005: 162).

Here 'participation' provided the framework for interpretation of diverse activities and happenings, made more important by the complex and uncertain actual route to improved outcomes (rural livelihoods etc.). Success was a matter of keeping this framework in place. Working for a decade in this project system as a 'participation expert', I realised that my own 'expertise' increasingly failed to direct practical action and was instead directed towards the more urgent task of refining this authoritative framework of interpretation, linked to higher policy. It did not precede but followed action. The greater the need to sustain a policy model, the greater is the need for supporters to 'contextualise' it, in Latour's (1996) sense of constantly ‘translating’ project goals and intentions into the diverse interests of bureaucrats, charities, user-groups, politicians or suppliers so as to stabilise a ‘community of interpretation’. Success is thus not just a matter of representation or ‘social construction’, it entails an array of social actions, including the maintenance of networks of support that enrol different interests, creating a public audience for the work of transformation through participation, that *make* participatory initiatives successful, and without which they will fail. The story of how a post-1990s aid policy shift produced project *failure* and the disassembling of networks around participation as a policy model only underscores this point (see Mosse, 2005: 184-204)

Being alert to the social processes of model-making and the packaging of complex professional-patient relational dynamics, and attentiveness to the actual routes to desired outcomes, is something equally relevant to PPI initiatives. This changes the question from *whether* PPI works, to *how*; or what happens under that description, and with what effects? This suggests the value of an inductive ethnographic perspective. But this has its own challenges. There may be significant political, professional and moral/personal investments in patient/citizen engagement policies, which make social science descriptions difficult if not threatening. The ethical and epistemological challenges of contending with participant objection (to analysis or publications), and the implications for participant-controlled or collaborative social research are issues discussed at length elsewhere (Mosse, 2006).

It is important to emphasise that I am not at all suggesting that policy ideas and categories of participation or citizen engagement are merely abstract ‘mist and fog, infinitely changeable and concealing behind them the “true” face of power’, since there is always a ‘touching ground’ (Galley, 2011: 274), that is ‘solid points of contact between obfuscated or tangled arenas of policy-making, service-delivery and human rights' and the real life of people, directing resources, shaping relationships and changing outcomes (ibid). My own experience convinces me that even over-ambitious policy goals create space for new impactful acts of citizenship. Too much has changed in the UK (as elsewhere) to slow the momentum of expectations of patient involvement; but the ends that are possible are still ill-defined, and transformative visions too often unsupported by parallel attention to the relationships and organisational processes through which they become real.

Postscript

I was invited to contribute to this discussion on citizen participation on the basis of my experience of decades of work promoting participatory approaches to rural development and bringing a (self-)critical reflection to bear on this practice, sometimes going against the tide of policy enthusiasms. The positions of professional and anthropological critic in this work did not make available the subjective experience of the invited or space-claiming participant, patient or citizen. Over the past five years or so, personal and family circumstances have unexpectedly given me a set of new roles as lay member, lived-experience representative, expert-by-experience or peer-supporter in a variety of national and local forums for policy or programme development in mental health. For example, I currently serve as a lay member on a Public Health Advisory Committee of NICE (National Institute for Health and Care Excellence) – a national policy body; I chair a borough-level multi-agency strategic planning body, participate in mental health expert reference groups, user forums and serious incident reviews; I joined mental health research advisory boards, and have membership of national networks and alliances. I respond to calls to speak to public policy forums, an all party parliamentary group, and public/mental health professional teams; and I convene and co-lead peer-support services; all on the basis of personal ‘lived experience’. What does it mean to turn from promoter and critic of participation to being a citizen called upon and engaging with public services (in this case mental health)? What have I learned from subject positions that were novel to me, and from the interfaces of citizen participation?

It might be claimed that there is so little in common between the contexts of international development and citizen engagement in UK healthcare that drawing parallels is fruitless; and mine is anyway only one specific kind of experience having more to do with a self-driven desire to engage with and influence health systems and public policy in response to personal anguish; creating platforms for action as much as being subject to a scheme of patient and public involvement. Nonetheless, the claim that I have been making throughout this article is that, without overdrawing parallels, the interactional and knowledge processes of a development project do offer something useful with which to think about any form of citizen engagement and PPI. My claim is further that the issues discussed thus far offer some guide to salient features of my own experience of such involvement.

Certainly, I became aware that, as with participatory development, public involvements such as mine take place within and are anticipated by a strong normative discourse on citizen participation in health planning, on the gains from co-production, and on including lay voices; a discourse that often runs ahead of practice. Then, recalling White’s (1996) distinctions, it seemed that my participation in public health policy might occasionally be described as ‘token’; it is sometimes ‘instrumental’ (such as when a local authority Commissioner refers to me as a ‘community asset’ having relieved the council of certain public health functions); often it is ‘representative’ (of the cause of a particular condition/need for which I act as ‘champion’); and occasionally ‘empowering’ through an assertion of citizen control.

The spaces of involvement are also differentiated. The ‘invited space’ of lay membership of a NICE guideline committee involves formality, is managed by the Public Involvement Programme, has an induction process, guidance on how to engage in committee meetings and mentoring by a Public Involvement Advisor. Lay full membership of the expert committee is recognition that all evidence requires interpretation, and that producing policy (recommendations) from evidence is a complex matter of ethical and social value as well as scientific judgements, and that this is a process of negotiation (NICE, 2008). Similarly, in other invited spaces (mental health policy forums, review boards, working groups) as a lay outsider to the healthcare system, I can be a heterodox presence, juxtaposing person to protocol, subjectivity to system, often thorough ‘biographical affect’. Sometimes as lay observer, I am better positioned to notice the blindspots, gaps and disarticulations, and how action/inaction is driven by implicit ‘system goals’ directed towards the protection of institutions, professionals, rules or administrative order, rather than patients (e.g., in risk management) (Mosse, 2005: 103–4), or by the impact of resource cuts on these; or experience might make it be more apparent to me the way categories (e.g., ‘mental capacity’, or diagnostic categories) hide the lives behind them; or how work patterns or schedules are ill-matched to preserving the quality of therapeutic relationships. My simultaneous identification and distanciation in relation to the health system brings an orientation that is ethnographic.

Sometimes the citizen space is ‘claimed’, or perhaps more accurately it is an *occupied* space. The hiatus between the ambitions of national strategy or public health guidelines, on the one hand, and the diminished capacity of deficit-managing local authorities with looming cuts, on the other, creates vacant spaces into which issue-focused citizen activists can move. It is in these terms that I ‘occupied’ a space by adopting a convenor role that brought together statutory and voluntary sector actors and concerned citizens on a key social and mental health issue in a London borough. This involved a new ‘scene’ of action, an ‘opening’, ‘plotttings’ (Renedo and Marston, 2015) and a durable formation (that now features in local authority organograms). My citizen voice acquires authority by reference to official best-practice guidelines, although there is constant tension between citizen action that challenges and changes the system, and that which substitutes for (and hence stabilises) official (non)responsibilities. Other spaces through which I move are more clearly ‘claimed’, being created by and for affected people, venues for innovation, campaigning, lobbying or devoted to giving voice to a critical issue.

Some light can be thrown too on the knowledge processes of my citizen involvement with reference to the case of participatory development. Without question, the venues of engagement in which I participate give me privileged access on the basis of social characteristics and cultural capital (education, class, profession, gender, race etc.). They also allow (indeed require) the articulation of only certain kinds of knowledge or accounts of experience that have been honed or narrativised in particular ways so as to be publicly recognised. Much will be silenced by the implicit rules about what or how experience can be expressed. To engage with the health policy system, I need to articulate personal experience as the general and the generic; as an instance of a category of experience, and thus as multiple rather than singular, systemic rather than contingent. My idiosyncratic experience has to be aligned with others’ so that I can report on a category of experience, a client group, a diagnositic or service user category.

My world is, of course, far removed from that of the Adivasi villagers engaged by the project I worked for. But just as I saw our participatory planning venues being for them more about the acquisition of new ‘planning knowledge’, I discover in my own experiences of public engagement that a primary task is to acquire new knowledge, to learn how to become an ‘expert-by-experience’ and to re-frame experience in terms that are legible to the health systems in which I ‘participate’. Acquiring ‘health system’ knowledge is a matter of vocabulary, understanding institutional systems, and social-professional relations; it is self-tutored through observation, mimicry and performative experiment. I learn what can or cannot be heard or taken note of, what is significant and what is ‘noise’, and what in any given system separates the relevant from the irrelevant, while also pushing these boundaries. Competence in these performances opens other spaces; just as incompetence, and the failure to speak experience as required in order to be heard, closes them down. I have been in admiration of mental health service users with highly-developed skills in talking to the system.

It would be unsurprising if I did not myself adapt to the terms of engagement as I inhabit what were entirely novel categories (e.g., ‘lived experience’ expert), and adapt the expression of experience or acquired knowledge to the strategic purpose of influencing services, plans or policy. And to remain in such spaces of engagement requires the work of maintaining relationships, which in turn reflexively constitute my identity in a universe of patient and public engagement, and beyond. Different from my Adivasi aid project subjects, but not entirely so, I too discover that citizen engagement allows new ways to process experience, new knowledge and new solidarities. From development experience, I am also alert to closures from the top that might arise from claims to success on the basis of policies of citizen engagement. So I can, at least in these ways, say that experience of participatory development helps think critically about 'patient and public involvement' in UK healthcare.

References

Althusser L (2006) Ideology and ideological state apparatuses. In: Sharma A and Gupta A (eds) *The Anthropology of the State: A Reader*. Oxford: Blackwell Publishers, pp. 86–111.

Anderson H and Goolishian H (1992) The client is the expert: A not-knowing approach to therapy. In: McNamee S and Gergen K (eds) *Therapy as Social Construction*. London: Sage Publications.

Carman KL, Dardess P, Maurer M, et al. (2013) Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs (Project Hope)* 32(2): 223–231.

Carney D (ed.) (1998) *Sustainable Rural Livelihoods: What Contribution Can We Make?* London: Department for International Development.

Chambers R (1997) *Whose Reality Counts?: Putting the First Last*. London: Intermediate Technology Publications.

Chambers R, Pacey A and Thrupp LA (1989) *Farmer First: Farmer Innovation and Agricultural Research*. London: Intermediate Technology Publications.

Clarke J (2005) New Labour's citizens: Activated, empowered, responsibilized, abandoned? *Critical Social Policy* 25(4): 447–463;

Cooke B and Kothari U (eds.) (2001) *Participation: The New Tyranny?* Zed Books.

Cornish F (2015) Evidence synthesis in international development: A critique of systematic reviews and a pragmatist alternative. *Anthropology & Medicine* 22(3): 263–277.

Cornish F and Ghosh R (2007) The necessary contradictions of 'community-led' health promotion: A case study of HIV prevention in an Indian red light district. *Social Science & Medicine* 64(2): 496–507.

Cornwall A (2002) *Making spaces, changing places: Situating participation in development.* IDS Working Paper 170. Brighton: Institute of Development Studies.

Cornwall A and Brock K (2005) What do buzzwords do for development policy? A critical look at 'participation', 'empowerment' and 'poverty reduction'. *Third World Quarterly* 26(7): 1043–1060.

Cubellis L (2018) Care wounds: Precarious vulnerability and the potential of exposure. *Culture, Medicine, and Psychiatry*: 1–19.

Foucault M and Miskowiec J (1986) Of other spaces. *Diacritics* 16(1): 22–27.

Galley A (2011) *Colombian Refugee Migrant Experiences of Health and Social Services in Ottawa, Canada: Navigating Landscapes of Language and Memory*. PhD Thesis. McMaster University, Hamilton, Ontario.

Hacking I (1995) The looping effects of human kinds. In: Sperber D and Premack A (eds) *Causal Cognition*. Oxford: Oxford University Press, pp. 351–383.

Hickey S and Mohan G (2004) *Participation: From Tyranny to Transformation: Exploring New Approaches to Participation in Development*. London: Zed Books.

Komporozos-Athanasiou A and Thompson M (2015) The role of emotion in enabling and conditioning public deliberation outcomes: A sociological investigation. *Public Administration* 93(4): 1138–1151.

Lambert H (2006) Accounting for EBM: Notions of evidence in medicine. *Social Science & Medicine* 62(11): 2633–2645.

Latour B (1996) *Aramis, or the Love of Technology*. Cambridge, Mass: Harvard University Press.

Mansuri G and Rao V (2012) *Localizing Development: Does Participation Work?* World Bank Publications.

Martin E (2009) *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton, NJ: Princeton University Press.

Martin G (2008) ‘Ordinary people only’: knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health & Illness* 30(1): 35–54.

McKevitt C (2013) Experience, knowledge and evidence: A comparison of research relations in health and anthropology. *Evidence & Policy*. 9(1): 113–130.

Mosse D (1994) Authority, gender and knowledge: Theoretical reflections on the practice of Participatory Rural Appraisal. *Development and Change* 25(3): 497–526.

Mosse D (2005) *Cultivating Development: An Ethnography of Aid Policy and Practice*. London: Pluto Press.

Mosse D (2006) Anti-social anthropology? Objectivity, objection, and the ethnography of public policy and professional communities. *Journal of the Royal Anthropological Institute* 12(4): 935–956.

Mosse D (2014) Knowledge as relational: Reflections on knowledge in international development. *Forum for Development Studies* 41(3): 513–523.

NICE (2008) *Social Value Judgements: Principles for the development of NICE guidance. Second edition*. London: National Institute for Health and Clinical Excellence. Available at: https://www.nice.org.uk/Media/Default/About/what-we-do/Research-and-development/Social-Value-Judgements-principles-for-the-development-of-NICE-guidance.pdf (accessed 15 February 2018).

Patel K (2007) *Cultivating Diversity on Farm: Examining de facto Conservation of Agrobiodiversity in a Tribal Region of Western India*. PhD Thesis. University of Guelph, Canada.

Patel V (2014) Rethinking mental health care: Bridging the credibility gap. *Intervention* 12: 15.

Razzaque R and Stockmann T (2016) An introduction to peer-supported open dialogue in mental healthcare. *BJPsych Advances* 22(5): 348–356.

Renedo A and Marston C (2015) Spaces for citizen involvement in healthcare: An ethnographic study. *Sociology* 49(3): 488–504.

Rottenburg R (2009) *Far-Fetched Facts: A Parable of Development Aid*. Cambridge, Mass & London, UK: MIT Press.

Seikkula J and Olson ME (2003) The Open Dialogue approach to acute psychosis: Its poetics and micropolitics. *Family Process* 42(3): 403–418.

Shore C and Wright S (1999) Audit culture and anthropology: Neo-liberalism in British higher education. *The Journal of the Royal Anthropological Institute* 5(4): 557–575.

Slay J and Stephens L (2013) *Co-Production in Mental health: A Literature Review.* London: New Economics Foundation. Available at: http://b.3cdn.net/nefoundation/ca0975b7cd88125c3e_ywm6bp3l1.pdf.

White SC (1996) Depoliticising development: The uses and abuses of participation. *Development in Practice* 6(1): 6–15.

World Bank (1996) *The World Bank Participation Sourcebook*. 15363. The World Bank. Available at: http://documents.worldbank.org/curated/en/289471468741587739/The-World-Bank-participation-sourcebook (accessed 12 February 2018).

NOTES

[1] UK Department for International Development

[2] A parallel critique of established clinical expertise as too embedded in professional authority presaged the drive towards evidence-based medicine (Lambert, 2006: 2639–40).

[3] Peer-supported open dialogue draws on Intentional Peer Support developed in the 1990s, growing out of the psychiatric survivor movements of the 1960s and 70s (Cubellis, 2018).

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[4] A reviewer observed that addressing the question here, ‘who is missing?’ ,depends on whether the justification for engagement is a matter of democratic representativeness or of instrumentally mobilising lay expertise (here, rather inseparable).

[5] As a reviewer noted.

Author biography

David Mosse is a Professor of Social Anthropology at SOAS University of London. He has conducted research on the anthropology of international development, Indian caste society, religion, and environment. His current interests include work on Dalit activism, citizen engagement, and mental health in India and the UK. His books include *The Rule of Water* (2003), *Cultivating Development* (2005), *The Aid Effect* (co-ed. 2005), *Development Brokers & Translators* (co-ed. 2006), *Adventures in Aidland* (ed. 2011), and *The Saint in the Banyan Tree* (2012).