

Putting the Politics Back into “Public Engagement”: Participation, Mobilization and Citizenship in the Shaping of Health Services

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Introduction

Concerns with public participation, health service user involvement and citizenship have figured large in recent debates about health policy across the world. These debates have given new political currency to older ideas that emphasised the need to involve people in the design and delivery of health services. Indeed, the roots of contemporary efforts to institutionalise public involvement in health go back many decades and include a series of radical experiments, from barefoot doctors to community health agents to participatory health councils who would monitor the delivery of health services and ensure that services were reaching people in the communities they were serving. Thus the World Health Organization sought to mark the 30th anniversary of the Alma Ata Declaration on Primary Health Care with a new resolution with a strong emphasis on the promotion of inclusive models of service delivery, allowing for individual participation and local community mobilization.¹ In the UK, debates about community participation in health as much as in other areas of service delivery have been reinvigorated in the UK Prime Minister David Cameron’s 2010 proposals for a ‘Big Society’.

¹ Stephan Vandam, WHO, on The Role of Community at the Heart of Primary Health Care, speech to the interactive conference ‘Community Participation in health and sustainable development’, April 2009.

This article draws on research carried out as part of a ten-year long collaborative international research programme, the Citizenship Development Research Centre.² It seeks to offer reflections on some of the emphases and silences in contemporary debates about public participation in the delivery of primary health care services. Through case studies from a diversity of global contexts, we reveal and explore a series of themes with high salience for contemporary debates, which have been underplayed in mainstream understandings of public engagement in health. In part this reflects a persistent disconnect between literatures and understandings of institutionalised participation in the governance and management of health, and of mobilization and activism - a division which this article suggests is unproductive and needs to be overcome. As our cases show, practices and trajectories of public engagement and citizenship in relation to health are necessarily plural, contingent and constantly being negotiated across different spaces and in different encounters and engagements.

We begin by considering some of the ways in which publics and citizens and their involvement have been framed in debates about health in the global north and the south. This leads us to identify four themes. The first is the importance of recognising the multiple sites in which public and citizen engagement takes place, beyond the official spaces into which citizens are invited to participate.

² The Development Research Centre on Citizenship, Participation and Accountability (Citizenship DRC) is an international research partnership exploring new forms of citizenship that will help make rights real, working with research institutions and civil society organizations in Angola, Bangladesh, Brazil, India, Nigeria, South Africa and the UK (http://www.drc-citizenship.org/About_us/index.htm.) The Citizenship DRC is based at the Institute of Development Studies (IDS), University of Sussex and funded by the UK Department for International Development (DFID).

The second is the need to look more closely at cultures, contexts and practices of engagement, including a sharper focus on tactics and styles. The third is the significance of recognising differentiated notions or 'summonings' (Newman and Clarke 2009) of publics, and 'differentiated citizenships' (Holsten 2009). The fourth is the importance of the politics of knowledge, both in terms of the framing of health issues and what kinds of knowledge are valued and legitimised in different fora. We then elaborate these themes through a series of health-focused case studies from Bangladesh, Brazil, South Africa and the UK. We conclude by exploring some of the challenges for negotiating health citizenship.

Understandings of Health Citizenship

Two broad, parallel literatures have addressed questions of public engagement and citizenship in relation to health. The first focuses on mechanisms for engaging citizens, generally as 'users' or 'consumers', in the delivery of primary health services. These include a relatively long-standing strand of work on 'community participation' with its roots in 1980s efforts to reform the delivery of basic health services, and the emergence of policy concern with 'public involvement' over the last decade or so. More recently, this has come to be complemented, mainly in literatures from the US, Canada and Europe, with a focus on public participation and deliberation in higher-level health planning processes. The second focuses on health activism and mobilization. This ranges from the documentation of activist experience, to applications of social movement theory to health activism. More recently, there has been an emergence

of interest in 'therapeutic citizenships' and in work addressing questions of identity and knowledge in an era of bio-politics.

Public health, almost by definition, involves ideas and issues that have been made public – but in diverse ways, as mediated by diverse sets of political actors and institutions, and involving diverse representations (Nichter 2008, Parker and Harper 2006). 'Publicness' in health refers to how particular combinations of things, ideas, issues, people, relationships, practices and sites have been made public, and 'publics' refers to those identifications with or membership of the collectivities that form the subjects expected to take an interest in such public issues (Newman and Clarke 2009: 2). The meanings and implications of health publicness and their specific publics (subjects) are channelled through particular sets of political and discursive practices geared to particular health-related and governance projects.

The publics invoked in primary health care and debates about service delivery are at once universal and highly specific. Thus the WHO slogan 'health for all' images a concerned public of all people, everywhere entitled to accessible, affordable health care. At the same time, publics are often portrayed as the people or citizens of a nation, both in arguments for strengthening national health systems and in discourses which connect the economic and political strength of a nation to the physical health of its people. Publics are also defined in terms of specific, located communities. Thus the tiered organisation of preventative, curative and referral services in many national health systems, with village or district primary health posts and centres served by regional and

national hospitals, administrative and supply points, is replicated in definitions of particular publics as the 'target populations' or 'users' served by each of these levels. At the base are notions of community, frequently imaged as distinct, located collectivities.

Arguably, and especially for government actors, primary health care services remain intimately entwined with narratives of coherent, structured nation states, even as their delivery has come to involve a far wider range of private, non-governmental and hybrid actors. Distinctions between public and private health institutions are commonplace in discussions of health systems and -seeking practices, reproduced in notions of public-private partnership. Yet as Bloom and Standing (2008) argue, these categories do not reflect the realities of contemporary health delivery in many settings, where there is a pluralised mix of state, private and non-profit providers, of informal private activity by state employees. Amidst shifting negotiations of provision and access, images of neat, ordered hierarchies of state provision provide a potent symbol – or vain aspiration – of government order and control, in which healthy bodies are served by and contribute to a healthy body politic. As we show later, public involvement takes place and involves interactions across a far greater variety of spaces.

If 'publicness' and 'publics' refer to collectivities taking an interest in matters of broad public concern, citizenship carries stronger connotations of rights claiming in relation to the provision of care. Citizenship has of course been theorised in many different ways, and is a normative concept around which there is

substantial contestation. Citizenship may be represented in liberal terms, with a focus on the individual's (health) rights and entitlements, and the citizen as consumer. Or it may be represented in more communitarian terms as engagement as a member of a community with mutual responsibilities as well as rights (e.g. Sandal 1998). By contrast, civic republican views emphasise the interface between citizens and governance institutions, including those of the nation state (e.g. Habermas, 1984, 1996; Miller, 1988). Claims and participation are not confined to representative political systems as in liberal thought; rather civic republican thought promotes deliberative forms of democracy as a complement or alternative (e.g. Dryzek, 1990, 2000; Bohman and Regg, 1997). In recent work, these perspectives have linked with those on social difference, identity and subjectivity (e.g. Young, 1989; Philips, 1995; Mouffe, 1995) to show how these engagements involve multiple and often shifting forms of solidarity that emerge around particular issues of concern (Ellison, 1997; Leach et al 2005).

Amidst a growing acknowledgement - with origins in previous decades - of the importance of eliciting public involvement in health policy and planning as well as in needs assessment and evaluation of service provision (Rifkin 1996, Mitton et al. 2009), recent years have seen a shift from an emphasis on techniques to more concern with the quality of participation, and the broader contributions that greater public involvement and citizen participation might make to democratizing governance (Gaventa 2006). The literature on 'invited participation' in health - that is, on forms of participation that are regularised, routinised, institutionalised - speaks to a broader set of concerns with reforming the governance of sectoral service delivery (Cornwall and Coelho 2007). There

has been a coming of age of institutionalised forms of participation that came out of the experiments with sector reform in the 1980s and 1990s. Institutional and methodological innovation has given rise to a variety of forms and opportunities for citizen engagement, including experiments in deliberative public participation (see, for example, Lenaghan 2001; Newman, Barnes, Sullivan and Knops, 2004).

A substantial literature now exists in which documentation of examples, lessons and implications from efforts to elicit public involvement can be found. And yet, Mitton et al. (2009) contend, there has as yet been little in the way of systematisation of the varieties of forms and kinds of public involvement found in the health sector – such that, as they note, there is ‘no clear consensus in the literature on when public engagement should be sought, how it should be obtained, or how it might be incorporated by decision-makers into priority setting and resource allocation processes’ (2009:220). Amidst a focus on methods and mechanisms, there has been little systematic consideration in the literature of the extent to which efforts to engage publics in health policy processes actually give rise to changes in health policy.

A prevalent concern in the literature on institutionalised mechanisms for public involvement is with questions of representation, inclusion and voice. In the north, the discourse of public involvement is peppered with terms like ‘ordinary people’ and ‘usual suspects’, reflecting the efforts made by those inviting participation to grapple with the difficulties of ensuring broad-based representation. In their review of 1108 studies of public involvement in health,

Crawford et al. (2003) note that 'statements about representativeness are very common in the literature but the meaning of the term is rarely considered' (cited in Martin 2008:36). In the south, concern is more often with the participation of particular social groups – such as 'women' – and with mechanisms that can ensure compliance with attempts to enforce some measure of diversity in contexts where historically rooted forms of social marginalization act as potent barriers to participation. Political theorists have grappled with the kinds of questions of representation, identity and difference (see, for example, Mansbridge 1999, Young 2000, Dryzek 1996) that are now such live issues in debates about institutionalised participation in health policy institutions in the south (Cornwall and Coelho 2007), to which the studies we draw on in this article have sought in particular to contribute.

Developing largely in parallel with these literatures on institutionalised public engagement and participation have been streams of work considering more self-organised forms of activism and mobilization in relation to health-related issues. Much of this literature consists of descriptive accounts and documented experiences of health activism, from a variety of social science disciplines and including the accounts of activists themselves. This has not generally engaged directly with debates about primary health care delivery, but offers prospects to enrich these debates in a number of important ways. Such accounts document activism around a wide range of health issues, from women's health (Ruzek 1978; Ruzek, Olesen and Clarke 1997, Morgen 2002); mental health (Brown 1984), disability (Shapiro 1993, Fleischer and Zames 2001) and AIDS (Epstein 1996) to environmental health and toxic waste (Brown and Mikkelsen 1990, Szasz 1994),

asthma (Bullard 1994, Shepard *et al.* 2002), breast cancer (Brenner 2000) and occupational health and safety (Rosner and Markowitz 1987). They illustrate activism directed at both government agencies and private companies, and at local, national and global institutions.

Brown et al. (2004) note that despite this vibrant documentation, there has been little systematic study of health activism from a social movements perspective, and social movement theory has hardly been applied explicitly to health issues. In a rare attempt to do so, Brown et al. (2004: 52) define 'health social movements (HSMs)' as 'collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and informal organisations, supporters, networks of co-operation, and media. HSMs' challenges are to political power, professional authority and personal and collective identity.' This broad definition reflects and encompasses a wide variety of forms of mobilization, from informal and networked alliances to more bounded organisations. Brown et al. (2004) also distinguish: *health access movements*, which seek improved provision and more equitable access to healthcare services; *constituency-based health movements* which address health inequality, whether along lines of race, ethnicity, gender, class or sexuality, and *embodied health movements* which address disease, disability or illness experience by challenging science on aetiology, diagnosis, treatment and prevention routes, with groups organising to achieve medical recognition, treatment and/or research. The case studies we consider below variously involve elements of each of these goals and activities.

Treating health-related mobilization in terms of social movements makes relevant the rich seam of literature theorising what holds movement collectivities together, and the processes of activist engagement. There are many strands of debate, and many ways of categorising these (for recent reviews, see e.g. Fransman and Miroso-Canal 2004; Edelman 2001; Tarrow 1998). Thus resource mobilization theory (e.g. McCarthy and Zald 1977) takes a rational actor perspective to address the balance of costs, rewards and incentives that provide people with the motivation to become involved in struggle. A particular focus has been the creation of professional movement organisations, and how personal resources, professionalisation, and external financial support have made these possible. Political process theories have built on these to explain mobilization processes and their success or failure by reference to the political and institutional context. They stress the significance of strategic interaction, and response to the political environment and the 'political opportunity structures' made available, as well as the culturally-encoded repertoires through which people interact in contentious politics (Tilly 1978, Tarrow 1998, McAdam 1982). A further dimension in the study of social movements acknowledges their embeddedness in space and place, arguing that social movements flow out of the interplay of space, power, framings and resources, so that an understanding of spatial location and context becomes critical to seeing why mobilization processes unfold as they do (Miller, 2000). Recent literatures also highlight that the spatial context of contemporary mobilizations is frequently wide and diffuse, involving multi-layered forms of networking and alliance (Edelman 2001, Appadurai 2000), and linkages between participants in diverse local sites across

global spaces, constituting forms of 'globalisation from below' (Falk, 1993; Appadurai, 2002).

Taking a different perspective, theories of framing (Benford and Snow 2000) emphasise how mobilization takes shape around and actively involves the construction of, particular ideas, meanings and cognitive and moral constructions of a 'problem'. In this view, mobilization involves struggles not just to promote a given social, political or health agenda, but to establish and promote certain meanings and problem-definitions as legitimate as against those who would dispute them. Such struggles over framing become integral to the political process of mobilization (McAdam, Tarrow and Tilly 2001). Finally, other strands of social movement theory highlight issues of identity, and how identities shape, and are formed and re-negotiated, through mobilization processes (Melucci 1989, Castells 1997). Studies of mobilization around health issues that engage with social movement theory generally suggest that all these emphases are significant, requiring an integrated understanding (e.g. Brown et al. 2004, Epstein 1996, Leach and Scoones 2007).

The changing, more pluralistic, politics of knowledge in the health field are linked with the emergence of a wide variety of citizen and advocacy groups and governance networks (Bloom et al. 2007). These often draw on critical 'lay' perspectives and forms of experiential expertise (Collins and Evans 2002). Some are constituted around 'citizen science' (Irwin 1995), where people conduct their own investigations and assemble evidence in accordance with their own experiences and framings of the issues concerned - as, for instance, in cases of

popular and epidemiology around environmental health issues (e.g. Brown and Mikkelsen 1990). Such forms of action reveal active citizen engagement in the politics of knowledge around issues involving science, technology and health (see Leach et al. 2005). Several recent analyses suggest that knowledge, identity and bodily experience may be coming together to create emergent forms of subjectivity, collectivity and engagement centred on illness and treatment. Thus Petryna (2002) coined the term 'biological citizenship' in relation to victim identities, experiences of environmental health and claims on a range of social protection mechanisms in the case of the Chernobyl nuclear disaster. Nguyen, in analysing AIDS activism in Burkina Faso, describes a 'biopolitical citizenship' that he calls 'therapeutic citizenship' which encompasses 'claims made on a global social order on the basis of a therapeutic predicament' (2005:126).

Mobilization processes, in such analyses, are shaped by and take place within a political field which is at once bio-political. Biopolitics has been understood as involving both an extension of biomedical concepts, jurisdiction and forms of disciplining of both individual bodies and populations (Foucault 1978), and important limits to such medicalisation – not least as exerted and claimed through mobilization around alternative and 'lay' knowledge and perspectives (Williams and Calnan 1996, Leach and Fairhead 2007). These strands of literature thus draw attention to the importance of identity and representation in health-related mobilization processes, as well as to questions of bodily and biological experience, knowledge and power.

Across these literatures, several key themes come into view. Our first theme picks up on the significance of a more nuanced and open understanding of spaces of engagement. This would require a greater appreciation of the plurality of sites in which health issues are framed, negotiated, contested and experienced. These sites are part of complex landscapes that encompass the local and the global, the formal and the informal, the 'invited' and the claimed, raided and conquered (Cornwall 2002). What comes into view across our cases is the observation that trajectories of engagement over time may involve shifting between and across different spaces, which a focus on particular spaces as sites in which participation takes place would obscure. Our second theme recognises the multiplicity of tactics and styles involved in citizen engagement on health issues. This transcends boundaries between institutionalised participation and self-organized mobilization, and includes the use of different media and repertoires of cultural symbols, tactics of argumentation, tactics for managing whether, when and who enters particular invited spaces and when pressure can be more effectively levered through engagement in other arenas, such as mobilization of public protest or litigation.

Our third theme highlights a core concern that has emerged around efforts to democratise decision-making over access to health services: questions of representation. Both attempts to produce inclusive institutional designs and processes social mobilization have run up against the challenge of differentiation across multiple axes of identity and subjectivity, bringing into question notions of 'community' and of singular categories such as 'women' (Young 1989, 2000). There is a growing awareness of the exclusionary potential of purportedly

'inclusionary' participatory institutions and social movements claiming to represent particular interests around issues of difference (Cornwall and Coelho 2007). This raises key questions about who speaks for whom, and who represents whom, which are crucial in relation to health citizenship. Fourth, the importance of framing and the politics of knowledge comes into view across these literatures. Especially given the continued dominance of biomedical framings in the health field, questions about what kinds of knowledge and expertise can be brought to bear effectively in different fora, about what is up for deliberation and what is black boxed, and what viewpoints are deemed legitimate, loom large.

Participation and Mobilization in the Shaping of Health Services: Case Studies

The cases we consider here are drawn from across a range of sites, north and south – from remote regions of rural Bangladesh and Brazil to metropolitan centres in the UK and South Africa. They encompass a range of health issues from the governance of primary care through to specific concerns with access to treatment and prevention. They examine these issues through a range of different methodological lenses, from fine-grained ethnographic studies of issues and institutions, to participatory studies in which health citizens and activists helped shape the questions, to formal surveys which sought to generate comparative data on engagements in multiple sites. We provide here a brief synopsis of the cases.

In Bangladesh, Simeen Mahmud (2004, 2007) explores the dynamics of inclusion and exclusion in the creation of institutionalised mechanisms for the governance of health services. This is set in a context in which health sector reforms have been driven by external institutions, such as the World Bank, in attempts to address the perceived failings of a weak and paternalistic state, poor health services coverage and the persistence of a range of basic health problems. At the same time, Bangladesh has experienced a proliferation of NGOs reaching into all regions and sectors, including health. Mahmud's work is based on in-depth interviews with health service users, non-users, health committee members and members of health watch committees. It contrasts the health user committees institutionalised as part of sector reform programmes with NGO-led health watch committees established as a mechanism for enhancing the accountability of health services delivered by the state.

In Brazil, Alex Shankland, Vera Schattan Coelho and Andrea Cornwall and colleagues (Cornwall et al 2006; Coelho 2007; Coelho et al. 2009; Shankland 2010; Cornwall and Shankland 2008) offer different perspectives on a set of common institutions: participatory health councils. Created as part of wide-ranging reforms in the governance of services in Brazil and at each tier of government, health councils serve as an interface between the state and organized civil society. More than twenty years of democracy after authoritarian rule have given rise to exciting innovations in citizen engagement, led by pioneering work in the health sector. Brazil's inequalities produce a complex picture for health service delivery, with a mix of services and conditions more similar to the US and Europe than developing countries, alongside the persistence of basic health

problems amongst poorer and indigenous communities. The three studies are located in the poorest regions of the country, the North and North-East and in the metropolis of Sao Paulo, and draw on a range of methodologies, from ethnographic research to large-scale survey methods. These studies address questions of representation and voice in these fora, and explore some of the implications of competing notions of democracy and legitimacy in health policy.

In a series of studies of AIDS treatment politics in South Africa, Steven Robins and colleagues (Robins 2004, 2005 a and b, Robins and von Lieres 2004, Robins 2009) document the shifting engagements of a particular social movement, the Treatment Action Campaign. This is in the context of a strong state with a rights-based constitution that faces significant challenges in the delivery of basic services in a country with persistent inequalities. This case study, based on ethnographic research and in-depth narrative interviews with movement leaders and service users, highlights a plurality of engagements across time and space over a period where the issues of concern have shifted from the fight to access anti-retroviral drugs to their distribution, take-up and effects, as health policy debates have moved from AIDS-denialist controversy to the economics of managing HIV infection as a chronic illness in a context with the highest rate of HIV infection in the world.

In the UK, Melissa Leach and colleagues (Leach 2005, Leach and Fairhead 2007, Poltorak et al 2005) address the dynamics of mobilization by parents in the UK around the concern that MMR vaccination was producing autism-like illness in their children. In the context of a strong and centralising state where high

immunisation coverage is iconic of effective public health delivery, the implications of parental anxiety about and refusal of the MMR vaccination were disturbing and profound to government agencies. Her work is based on ethnographic research with organizations and support groups of parents who felt their children to have been damaged by the MMR vaccine, and on ethnography, narrative interviews and a large-scale survey of vaccination reflections and decisions amongst parents in the city of Brighton and Hove. It documents the spaces of engagement, uses of different media and legal fora, the relationships between knowledge and expertise, and the processes of framing which proved significant in this heated and high-profile controversy amongst citizens, medical and public health scientists and professionals, and UK government institutions.

Dynamics of health citizenship: Spaces, tactics, representation and framing

In this section, we go on to consider how these cases shed light on some of the dynamics of health citizenship. In particular, we focus on the insights they provide in relation to the four themes we identified above, dealing respectively with spaces, tactics, issues of representation and of framing.

Spaces

Even though many of the cases appear to focus on a particular kind of space as their site of interest – a particular organizational forum, a deliberative process, a committee – engagement in other spaces is part of the story. In some cases,

trajectories of engagement move across and between different kinds of space over time. In the case of the Treatment Action Campaign, Robins shows how claiming space in the streets, the shebeens, the courts and the clinics gained visibility for the campaign, giving it both local buy-in and international reach. Robins also shows how over time and with the adoption of anti-retroviral roll-out as part of formal government policy, TAC activists along with other civil society groupings took on other roles within more formal policy fora and in relation to institutions for delivering treatment. Similarly, the MMR mobilization in the UK involved parents as citizens engaging through demonstrations and protests, through the media, through hospital spaces in alliance with particular doctors, in the courts and over the internet. What they requested, but were never granted, was access to a deliberative space in which they could air and debate their concerns openly with Department of Health officials and public health professionals.

Shankland's (2010) study in Brazil shows how indigenous leaders combined engagement in officialised participation spaces with forms of insurgent activism that drew on powerful cultural symbols to demand that their concerns be heard. Shankland describes an incident in which indigenous leaders held health post staff hostage with bows and arrows to demand a meeting with local health managers, and another where Brazilian state attempts to engage them as participants were accompanied by forays into town to occupy Ministry of Health buildings. These shifts from participation to protest and back again become part of the process of engagement to such a degree that they gain an almost ritualistic

nature, defining moments within the experience of engagement in which spaces are occupied and captured, as well as simply taken up.

The ways in which matters of health are discussed in different kinds of spaces also make possible – and preclude – particular kinds of engagement. Mahmud shows how in rural Bangladesh, poorer participants in the health committees feel themselves unable to contribute meaningfully, where the language of meetings is so markedly middle-class and requires being versed in the right kind of way of presenting issues, or even having basic information about how the system works. How people engage in the spaces that are made available to them or in interfaces with the state may be mediated in ways that constrain or even preclude the expression of certain concerns or interests. And yet Mahmud shows how the very women who appear to sit passively through committee meetings may be the first to take to the streets.

Activists might combine action in a plurality of sites, but also emphasise some rather than others at any particular time depending on how favourable the conjuncture is for achieving their aims. It may also be the case that it is through backstage action outside the space that success is achieved in influencing agendas and decisions. The Brazilian case studies illustrate the density of social networks, sites of engagements, affiliations and alliances that span the institutional spaces in Brazilian municipalities; the health council becomes one site amongst others in which agendas can be advanced, through connections and contests in other spaces. There may be a need to ‘hold the space’ for a while when nothing seems to be possible, just to keep a seat at the table; there may be

at other times a need to mobilize other forms of action around taking up that seat, such as using the media or other forms of publicity.

The creation of spaces for participation needs to be contextualised in broader shifts in policy and institutional arrangements, which may emanate from other sites and have a trajectory that needs to be understood historically – such as the influence of the World Bank on health sector reform in Bangladesh or of the *movimento sanitaria* on the creation of health councils in Brazil. In this respect, a recent trend has been the rise of big philanthropic and public-private organizations whose funds dwarf those of public sector organizations and are arguably now calling the shots in the development of health systems, services and treatment/prevention options across the world. These institutions, like older ‘global’ institutions such as the World Bank, are accountable to nobody and do not have any formal accountability mechanisms but are claiming to embody participatory procedures. What makes them different is the fact that they operate almost entirely outside states.

Public and citizen engagements thus involve moving across and between spaces, in ways that confound the distinctions between spontaneous mobilization and orchestrated formal participation constructed in the literatures considered earlier. Attending to the variety of these spaces, backstage as well as frontstage, and situating them in a shifting landscape of other institutional arrangements and opportunities therefore becomes critical to understanding how citizens influence the shaping of health services.

Tactics

The literature on health related social movements illustrates a rich repertoire of tactics and practices through which citizens have used their agency to influence health policy. Examples from our cases include direct action and demonstrations, letter writing, petitioning, and internet campaigns, strategic non-participation, subversion of official attempts to gather information, pursuing claims in the courts, strikes, occupations, taking officials hostage to make demands and a variety of non-violent forms of protest and resistance. In the UK, for example, parents mobilizing around the concern that the MMR vaccination had caused illness in their children combined demonstrations in front of Parliament, website campaigns, the enlisting of journalists to write supportive newspaper articles, deliberately filling in Department of Health information request forms in a false and jokey way, and pursuing their claims through a class action against the pharmaceutical companies that had manufactured the vaccine. In South Africa, TAC activists drew on these and other tactics, which made use of cultural repertoires that included imagery, songs and dances that had been part of their earlier experiences in the struggle against apartheid.

Whereas it is sometimes assumed that such tactics take place separately from and outside more orchestrated forms of participation, the case studies blur these distinctions, showing that creative agency and tactics are very much a part of citizen engagement processes even in more formalised institutions. Thus for example, in Brazil, Cornwall shows how activist groups sent different 'players' into official participation spaces depending on particular moments in the

political process and judgements about what was needed at that moment, whether sending a leader in to give weight to a position or sending a younger person to learn the arts of negotiation – or indeed making space for other, smaller, local organizations to get a seat at the table. Those who enter these spaces from activist movements and organizations often bring with them a style of argumentation and alliance-building that is more consonant with the habitus of a social movement than of a bureaucratic institution. Again in Brazil, Shankland and Cornwall both narrate examples of the kinds of speeches and appeals made by activists within health councils, which owe their tone, style and content more to social movement and left political party styles of seeking to influence debates. Gustavo Esteva (1985) once commented that institutionalised participation meant ‘democracy becomes bureaucracy’. But our cases reveal that regularising participation through the creation of ‘invited spaces’ does not always succeed in disciplining unruly citizenship practices. And these forms of ‘unruliness’ are not only tactical accompaniments to engagement in institutionalised participation, they may at times be an intrinsic part of citizen engagement in these spaces.

The cases also highlight how the tactics that people bring to bear in exercising – or feeling unable to realise - health citizenship are strongly shaped by earlier histories of engagement and of relations between people, the state and international institutions. It is not just the history of state-society relations and of particular movements that is important to take into account here. Many of those involved in the movements discussed in the case studies have longer histories, including in other movements. They may draw upon experiences around other

issues, bringing in particular ways of working and forms of protest that resonate with other periods or actions. This is particularly evident in South Africa, where the anti-apartheid struggle has lent generations of activists a powerful set of tactics that continue to be used, even by those within the current government. But it is also very visible in other countries in which there has been a history of mobilizations and trajectories of activism that span civil society and the state. Thus in Brazil, members of government may exercise similar alliance-building and mobilization tactics once in office that they once used as members of popular leftist parties and social movements. Many activists involved in the emergence of the Brazilian public health reform movement or the health councils had long associations with the wider democracy movement and struggles against the dictatorship.

Yet the cases also make it clear that novel tactical repertoires may be created to provide new idioms for motivating activism or holding together collective identity. Thus in the South African case the notion of almost ritualised transformation of a person from 'near death to new life' which comes about through anti-retroviral therapies has come to unite and motivate activists in arguing for expanded treatment availability. In the UK, personal testimony projected in parents meetings and in the media became an important tactic of the mobilization around MMR. Health issues with their direct life and death and emotional resonance do lend themselves to powerful uses of personal testimony, both as a way of creating solidarity and emotional identification, and as a means of generating public attention and support.

Our analysis of these cases underlines the importance of looking not just at the trajectories through which health citizenship moves across and between spaces, but also at what happens within these spaces. An image emerges of active citizens making creative and strategic use of different tactics both within institutionalised fora and in mobilizations outside them; but also the limits to such agency, often created by longer histories of repressive state relations, and the deeply imprinted effects on consciousness and capacity to act of societal forms of marginalisation.

Representation

A recurrent concern of those seeking to promote more participatory ways of involving citizens in health policy is the challenge of inclusion: how to ensure that a broad spectrum of potential users of health services are able to participate effectively in deliberations over health policy or in expressing needs and preferences. This raises a number of issues. Deliberate attempts to include representatives of different interest groups beg questions about how such representatives come forward, who they speak for, who they are seen as speaking for, and the extent to which they are indeed able to speak up, out and for others. Questions also arise about who participants are participating as: how they construct their own identities, and the meanings of their participation, when engaging in mobilizations as well as in formal participation spaces.

Vera Schattan Coelho's Brazilian study (2007) offers a number of important insights into aspects of institutional design that favour broader and more

inclusive representation of societal groups. Her study of health councils in the municipality of Sao Paulo demonstrates that particular institutional designs favouring more inclusive representation are also associated with a more equitable distribution of health resources. Coelho draws attention to the variety of potential interest groups who come to present themselves as potential participants. The emergence of these new opportunities to be represented bring into sharp relief questions about on what basis people come to speak for others, but also how they are 'heard' by those who invite their participation. Indeed, despite formal inclusion as representatives – whether through rules specifying certain kinds of representatives, as in Brazil, or through quota systems and reservations of seats for certain social groups, as in Bangladesh – those who become representatives may find themselves unable to stake their claims effectively, and participate more as individuals than those who carry the wishes and claims of the collectivity. The case from Bangladesh provides ample illustration of the deeply embedded nature of assumptions about women's identities and interests, as well as their effectiveness as participating citizens.

People's reasons for participating and the subjectivities that they bring into forms of engagement may not tally with the expectations of health policy makers seeking to 'consult' or 'involve' them. Citizens' self-representations of why they participate in these groups and what they get out of participating may differ from the images and assumptions often projected by intermediary organisations and activists. In north-eastern Brazil, health councillors participate for a variety of reasons, which include future employment opportunities with the municipal government, to ensure their organization receives subsidies or contracts, to make

friends, to go on trips and a host of non-material reasons that are bound up with sociality rather than health policy or politics. On the other hand, people may gain the opportunity for representation and voice through their particular illness-related identities. This becomes evident in the cases of mobilization around HIV and MMR where people are united and acquire opportunities to act on the basis of a common health predicament and set of diagnostic or treatment possibilities. Robins emphasises in the case of HIV infection in South Africa how health-related activism, strong illness identities and issues of access and adherence to treatment are shaping new subjectivities which may in turn spin out to wider process of empowerment and rights-claiming.

The cases highlight starkly the importance of representation in relation to health policy and services when people have strong illness-related needs for treatment or access to resources. Institutional designs that enable broad-based representation are crucial, not simply for democracy but also for health equity. However, the cases also highlight the fact that people participate and join movements not just on the basis of illness-related identities or narrow interests in shaping health policy, but also as people with other needs for daily sustenance, recognition, social connectedness and so on. Ultimately, what motivates people to engage with health policy as citizens may be their own or their families' immediate health-related predicaments or interest, but it may be a broader concern with health as a social good and as a citizenship right.

Framing

The question of how health issues are framed and how such framings both shape and can be renegotiated through processes of citizen engagement recurs throughout many of the case studies. The cases illustrate diverse framings of what constitutes health, of particular illnesses, of what and whose concerns are legitimate, and of the scope and remit of particular participation processes. They demonstrate intense contests over whether issues should be understood in biomedical or non-biomedical terms, and between competing biomedical versions, and related to these negotiations over which forms of expertise and evidence can make a valid contribution to addressing health problems in policy, whether official or non-official, professionalised or lay, technocratic or experiential. These contests are sharpened in the health field not just because of the life and death nature of access to treatment, but also because decisions need to be made about the allocation of finite and often scarce resources.

Mobilization processes often involve protracted clashes between alternative framings that do not reach straightforward resolution. For example in the case of the MMR vaccine in the UK, parents mobilized around their view that this had triggered a series of symptoms in their children, framing the problem in terms of individual vulnerability to vaccines and demands for treatment and further investigation of these specific causes. They met a counter-mobilization from government and scientific communities concerned with maintaining population-level vaccination programmes who framed the issue quite differently in terms of whether or not a link between MMR and autism could be determined at a population level. These two framings spoke past each other, leading to polarisation and non-resolution of the controversy.

The cases offer examples of diverse forms of engagement with (biomedical) science. Thus parental mobilization around MMR did not just dispute scientific claims that there was no link between MMR and autism, but sought to expose biases in the science producing claims of MMR safety, arguing that this was linked with political interests in mass-vaccination and commercial interests in selling vaccines. Parents contested mainstream epidemiological science through their own observations of what they believed to be MMR-caused disease in their children, forming alliances with supportive scientists who took a clinical perspective. TAC's mobilization around HIV / AIDS in South Africa was in part a response to Mbeki and the 'AIDS dissidents' attempt to acquire a cachet of scientific authority for their political claim that there was no viral cause of AIDS. TAC drew on mainstream understandings of virology and disease causation to argue for investment in anti-retroviral treatments.

We also see diverse forms of expertise at work. For instance, parental observation and experience of child health was central to mobilization around the MMR vaccine in the UK. However, the ways expertise itself is framed can be highly contested. In various countries, there have been long struggles to gain acceptance for alternatives to biomedical explanations and treatments for disease, with some attempts made to accommodate indigenous framings and treatment practices. As Shankland shows for the Brazilian Amazon, there are epistemological incommensurabilities in the ways in which knowledge of health and disease are framed in indigenous and biomedical terms that have implications for how

indigenous health interests are addressed by the state in its delivery of health services to indigenous people.

Emerging from these case studies are stories not only of people with particular health concerns, engaged in struggles for recognition of their concerns and access to appropriate prevention and treatment. Evident also are broader social and moral concerns with good health as a societal good, for which people are willing to participate and mobilize even in the absence of specific health-related interests. Health has become an arena in which broader social justice struggles can be fought; and the health committee, health councils and other forms of institutionalised participation often include people who have engaged in these wider struggles, and whose concerns with health extend to its crystallisation of broader social equity concerns.

Conclusion

By drawing together perspectives from literatures on institutionalised governance and participation in health, with those on mobilization, movements and activism, this article has highlighted how public and citizen engagement with health service issues involves moving across, between and combining a variety of spaces, adapting strategies and tactics to each. Strategic political opportunities and openings present a range of potential entry points for citizen engagement, and success may depend on inserting appropriate tactics into them at the right moment. The significance of citizens' agency and creativity comes through clearly. Yet at the same time, this is shaped and sometimes constrained

by more historically and culturally embedded styles, practices and possibilities, contextual relationships between society, states and international agencies. Health issues are about bodies but they are also about engaging with a body politic with far broader concerns and ramifications.

To understand how public and citizen involvement shapes health services, this article suggests, closer attention needs to be paid to issues of representation, framing and the politics of identity and knowledge. Bringing a focus on tactics and spaces to bear on these issues reveals how framings are strategically altered to fit with different openings and opportunities. As we have seen, framing processes can also act to exclude and delegitimize citizens' concerns – and to defuse active engagement. This is a tendency in all sectors, but one perhaps particularly pronounced in the health field because of its dominance by powerful biomedical understandings and associated professional hierarchies. All this attests to the fact that negotiating health citizenship is a highly politicised process. Conceptual frameworks that divide mobilization from orchestrated participation miss many dimensions of these politics, as do institutional design approaches that focus only on the creation of formal opportunities. The best institutional designs may fail to elicit effective engagement if there is no background mobilization to take up places in invited spaces, pressure those in authority and hold them to account. 'Effective' public engagement is as much about creating effective publics, who are able to engage, as it is about authorities being capable of responding effectively to their demands (Cornwall 2009).

What, however, are publics engaging in? In many policy fora, the cases suggest, there is far less substantive debate about issues of health and disease than about the effectiveness of mechanisms to ensure the effective functioning of health systems. Much of what constitutes 'citizen participation' in these spaces actually amounts to being told about pre-existing health plans and programmes, and at best being involved in monitoring implementation of these plans and programmes. Citizens are not being asked, by and large, to play any role in priority-setting or even in defining health problems as they view or experience them. Meanwhile, it is left to the lobbying of disease-focused interest groups to push for their own disease interests whether inside or outside such fora. Effectively this amounts to the black boxing of decision-making over what 'good health' means in particular settings and how priorities should be set and responded to, leaving to expert committees, the push of donors and philanthropists and lobbying by pharmaceutical companies, and the often unholy alliances they may form with patient support groups and doctors, to decide which illnesses matter, and how they should be treated. The definition and prioritisation of health issues is rarely up for deliberation by those who represent the public in health policy fora. Social and political disputes about health priorities frequently become reframed as technical disputes and redefined as 'too difficult' for citizens to fully grasp, and citizens' knowledge and evidence is thus cast aside as opinions, views or impressions, or even as ignorance. This leaves a vacuum and a consequent lack of accountability, which becomes particularly visible by drawing mobilization and invited participation into a common analytical field.

As this article has suggested, a more integrated approach reveals a range of themes common to all cases, even when at first sight they might seem to exemplify modes of engagement that are distinct. Thus, to different degrees and in different ways, all the cases illustrate trajectories of public and citizen engagement that move through different kinds of spaces. They all illustrate multiple, adaptive tactics and styles in making use of different spaces and opportunities. They all illustrate the importance of paying closer attention to the dynamics of representation – who is speaking for whom, how are they speaking and how they are heard, and what it means to be a representative or participant. And they all illustrate the importance of framing and the politics of knowledge, not just about the nature of health issues, but also in defining or circumscribing what is up for deliberation. By paying closer attention to the synergies between mobilization and invited participation, we gain greater insight into how people negotiate health citizenship and influence the institutions and decisions that affect such a fundamental dimension of their lives.

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