

Social participation in health in Brazil and England: inclusion, representation and authority

Marian Barnes BA MA PhD* and Vera Schattan Coelho PhD†

*Professor of Social Policy, Health and Social Policy Research Centre, University of Brighton, Brighton, UK and †Coordinator of the Citizenship and Development Group – CEBRAP, São Paulo, Brazil

Correspondence

Marian Barnes
Professor of Social Policy
Health and Social Policy Research
Centre
University of Brighton
Falmer
Brighton BN1 9PH
UK
E-mail: marian.barnes@brighton.ac.uk

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Abstract

Aim This article offers a brief description and analysis of public participation in health in Brazil and England in order to highlight different motivators and tensions within an acceptance of participation as official policy.

Sources/methods The article draws on a range of research in both countries and an analysis of official documents relating to participation. It is based on collaboration between researchers deriving from broad programmes of work on public participation in which the authors are involved.

Argument There is a tension between different principles underpinning collective public involvement in health both within and between countries. Different aspirations or claims have been made about what such participation will achieve and there are trade-offs between design principles that have consequences for issues such as who takes part and thus also for what can be achieved. The democratic origins of public participation are more evident in the Brazilian situation than in England, but there are still questions about the inclusivity of the practices through which this is achieved. The English picture is both more diverse and dynamic, but formal decision-making power of participatory forums is less than in Brazil. Whilst social justice claims for participation have been made in both countries, there is as yet limited evidence that these have been realized.

Social participation in health in Brazil and England

Greater public participation in policy-making is evident in countries of the global North and South. Health services and policy-making are the focus of such participation in many countries where political systems and cultures, demography and the balance between state, private and

NGO action on health is hugely varied. This paper draws on collaboration between researchers in England and Brazil to offer a comparative analysis of the way in which collective participation in health policy-making has developed and the different principles and purposes on which this is built. We identify four purposes that are evident to different degrees at different times and in each country: (i) deepening

the democratic features of the decision-making process; (ii) amplifying the recognition of the needs of those who have been marginalized and excluded; (iii) promoting more equitable access to health services; and (iv) making better decisions. There is recognition in the UK that there is value in learning from public participation methods developed in Brazil, in particular those relating to participatory budgeting.¹ One aim of this article is to contribute to the possibility of further learning between North and South in relation to participation in health.

The public health systems in Brazil and England are very different but public participation is official policy in both countries. (We summarize the picture in Fig. 1.) In Brazil this has emerged out of a political movement to decentralize decision making and there are more than 5500 health councils involving over 100 000 citizen participants. In England the origins of public participation in health are more diverse, but much less closely related to democratic objectives. Rather the emphasis has been on service improvement and participants are recognized as 'patients' or 'members of the public' rather than as citizens. In both countries social movements, civil society organizations and health consumer groups face decisions about whether to work inside the system or to present

challenges from outside. The participatory spaces that have opened up in the two countries are not only of different types, they are shaped by different discourses of the relationships between public services and their publics, and by the configuration of civil society, social movement, identity-based groups and user groups with an interest in health issues.

In this article we highlight the different sources of legitimacy that underpin the design principles of participatory governance and focus on the debate about the possibilities and constraints offered by arrangements that assure different degrees of political authority to participatory arrangements.

Local knowledge, local representation as different sources of legitimacy

Supporters of participatory governance have argued that the reduction in the costs involved in the process of political mobilization would be guaranteed by decentralization and the opening up of local participatory bodies authorized to take substantive decisions.² From this perspective the cost of participation would be reduced as access to the decision-making process is made available to citizens without any need for expertise in the topic discussed – the 'ordinary

Public participation in health in England and Brazil compared

	Brazil	England
Origins	<ul style="list-style-type: none"> • Equitable access to healthcare • Social participation as a mode of governance • Social movement mobilisation 	<ul style="list-style-type: none"> • Government aspirations towards: service improvement, enhancing accountability, health improvement, creating more responsible/engaged citizens • Patient/user movement mobilisation
Mechanisms	Health councils at local, state and federal levels	From community health councils to patient and public involvement forums to local involvement networks. Foundation trust membership and boards
Focus	Deliberation, consultation, monitoring. Policy and finance.	Scrutiny, monitoring, accountability. Service delivery
Main principle for participation	Local representation, informed by local knowledge Right to participate.	Local knowledge – but also emphasis on 'ordinariness'. Local representation in foundation trusts. Duty to involve.

Figure 1 Public participation in health in England and Brazil compared.

people' that the National Health Service (NHS) seeks to engage.³ Nevertheless, the reality is far more complex as 'civil society' comes to be represented in a variety of ways: by individuals, nominated representatives from NGOs, elected representatives from neighbourhood associations, lay specialists, members of collective actors such as unions, and by activists from social movements.⁴ Different sources of legitimacy can be claimed deriving from election, recruitment or experiential knowledge. The design principles underpinning participatory governance derive from both local knowledge and local representation.

Local knowledge views engagement in governance as a process of creating understandings through deliberative relationships between citizens and officials. This results in better decision making because officials are able to understand more about the needs and preferences of the public, and to access lay or experiential knowledge to inform policy decisions. This underpins thinking about the significance of user (patient) in comparison with public involvement in England,⁵ an emphasis that is much less evident in the Brazilian context. The public are able to develop a greater sense of citizenship and inclusion through the recognition given to their knowledge and expertise.

Local representation positions civil society actors as decision makers on behalf of their constituencies. Engagement in governance is about 'representing' the views of particular local constituencies into the decision-making process, through formal mechanisms, and as a result legitimizing the decisions that are taken. Local representation enables the institution to make decisions that may be better informed through members speaking for constituencies, and are legitimated because of their presence.⁶

Stressing local knowledge may lower participation costs at the expense of legitimacy claims, while local representation may strengthen legitimacy at the expense of greater inclusion. We suggest participatory governance within the health systems of both countries involves negotiation and trade-offs between these principles.

Consultation or deliberation?

Collaborative or participatory governance brings public and private stakeholders in collective forums with public agencies to engage in discussions and decisions concerning public issues and policies.⁷ Early claims for participatory governance were that it would lower the costs of participation allowing the inclusion of a larger range of participants. These participants would make binding decisions through a more inclusive and democratic process which would encourage changes in the distribution of public funds, in policy implementation and the way agreements are reached. This in turn could contribute to the successful implementation of public policies and programmes.^{8,9}

More recent work has questioned the viability of putting these mechanisms into action, pointing out the asymmetries that shape relationships between the actors, as well as the excessive power of state actors in the participatory forums. Furthermore, they point out that special interest groups and party political groups can capture and manipulate these forums.¹⁰⁻¹²

Two different reactions were prompted by these findings. One calls for clear rules of representation and states the importance of assuring deliberation, that is to say, the decision-making powers over public policies of participatory forums. As Cornwall¹³ pointed out in this context the term 'deliberative' is being used with a different meaning to that used in writings on deliberative democracy in the United States and Europe: while Habermesian deliberation implies a search for communicative consensus, here the notion emphasizes binding decisions which may be reached without consensus. The other reaction is more concerned with inclusion than with representation and argues for more robust mechanisms of coordination between participatory forums and the legislative and executive branches. Whilst binding decisions should remain with elected politicians and public officials, such decisions should take into account recommendations from the participatory forums.

Our analysis suggests that public participation in practice demonstrates a working out of the balance between different principles, and that the accommodations that are reached are not static. Brazilian and English experiences prompt reflection on the extent to which it is possible to advance towards deliberation and collaborative governance, paying attention both to the importance of legitimacy and inclusiveness.

Brazil

Brazil has been seen as one of the world's most important laboratories of democratic innovation over the last decade.¹⁴ The 1988 Brazilian Constitution, which established the formal transition to democracy, sanctioned the decentralization of policy-making and established mechanisms for citizens to participate in the formulation, management and monitoring of social policies. Hundreds of thousands of interest groups worked throughout the country as the Constitution was being drafted and collected half a million signatures to demand the creation of participatory democratic mechanisms.¹⁵

From the end of the 1970s different studies began to be presented by researchers in the field of public health, managers of the public health system, users' associations and international agencies pointing to significant distortions in the distributive profile of the resources allocated in the area of health. Richer citizens and richer regions had much better access to public health services than the poorest.¹⁶ The 1988 Constitution defined health as a right of all citizens and a responsibility of the state, and established the Unified Health System (UHS), the Brazilian public health system – based on the principles of universality and equity of health-care provision.¹⁷ The UHS constitutes an innovative model for the nationwide provision of public health services and facilities, incorporating new forms of management aiming at the decentralization and democratization of Brazilian health policy.¹⁸

This legal foundation helped to promote the development of an extensive institutional framework for participation by civil society,

including management councils, public hearings and conferences. The central argument promoted at that time by those working for including social participation in the constitutional text was that it would guarantee the presence of users in the process of defining health policy and this would provide a counterbalance to the power that had been concentrated in the hands of the medical corporations and the state bureaucracy. From this perspective, the users' presence should contribute towards the reversal of distributive distortions.¹⁹ Participation in health policy-making was thus seen as a route to more just health outcomes.²⁰

The Basic Operational Norms (BONs), which regulate the UHS, make the transfer of resources within the health sector from the federal government (which manages 55% of the public health budget) to the states and municipalities, conditional upon the existence of the health councils. This legal disposition together with political circumstances described below led to the rapid institution of health councils throughout Brazil.

The emphasis given by the Workers Party (PT) upon social participation is clearly expressed in the way that its slogan 'the PT way of governing' was translated during the 1990s into support for the creation and participation in health councils and conferences. Another factor was the support of the Social Democratic Party (PSDB), which during part of the 1990s controlled the Ministry of Health, for the councils as bodies that could monitor the use of the resources transferred by the Ministry to the municipalities in order to counterbalance the power of corrupt local elites. Also important was the mobilization of social movements, such as the health movement and the indigenous people's movement, which supported the councils as mechanisms which could help them find a space for the recognition of needs linked to specific social and cultural conditions, and the implementation of flexible and appropriately designed programmes and services.

Between 1990 and 2000 more than 5000 health councils were established and approximately 100 000 citizens took part annually in their

activities. These participatory mechanisms are organized at all levels of government, from the local to state and federal level and provide fora in which civil society joins service providers and the government in defining public policies and overseeing their implementation. Thus, management councils enable citizens to have a voice in policy-making and provide a mechanism for greater downward accountability.²¹ The BONs confer deliberative, consultative and monitoring functions to the councils and they are authorized to solicit information from public and private entities to carry out any of these responsibilities.ⁱ

The functions carried out by the councils are important and diverse. Thus the process of selecting the councillors is also important. The regulations of the Brazilian Health Councils guarantee adequate representation of organized civil society, and the BONs establish that representation in these councils – municipal, state and federal – is based on a ‘parity principle’, which sanctions that the number of representatives of civil society must be equal to that of service providers, health professionals and government institutions added together.²²

This statement says little about how representatives will be chosen. For example, the municipal decree that formally constitutes the Municipal Health Council of the city of São Paulo defines that it consists of 32 effective and 32 substitute councillors. The government is represented by officials appointed by the Health Secretariat. In the case of users and service providers, the movements, associations and sectors define their candidates and an open meeting is held in which mandates are formalized. Elections are publicized and health system technicians monitor the appointment process.

ⁱThe Health Councils act as deliberative bodies about, for example, the formulation of public health strategies and the definition of directives to be observed in the elaboration of health plans and budget. The councils also act as consultative bodies, for example, in assisting the local or federal authority in the UHS planning process; or accompanying the scientific and technological process of development and incorporation in the area of health. And the councils act as monitoring bodies, when, for example, they follow the movement of the SUS financial resources in their area of activity or the performance of the accredited private sector in the health sector.

Similar procedures organize the representative basis of all health councils, at the municipal, the state or the national level.ⁱⁱ

This brief retrospective suggests that the Brazilian experience of participation in health can be identified as one of construction of collaborative governance: of a mechanism that engages stakeholders in collective decision making that aims to decide about health policy in order to ensure better access and better health. Broad powers were given to the councils and established legal requirements in the sense that the councillors represent civil society organizations and have effective decision-making channels about health policy.

However, a more careful analysis shows this prescription presupposes certain contradictory actions which have contributed towards reducing the councils’ potential to make resolutions. As pointed out in the introduction, much of the literature that supports participation argues that the poorest and most marginalized people would be encouraged to participate by reducing the costs involved in the process of political mobilization. From this perspective the cost of participation would be reduced as access to the decision-making process was made available to the citizens who only brought their own experience to the process. You just needed to be a citizen to participate in decisions.

This was not the path taken by the Brazilian councils. Here it was set out that it would be up to organized civil society to defend the interests of users and citizens with respect to the UHS. To make participation real many councils defined ‘quotas’ for the representation of different organized groups, such as the health movement, social movements, Unions, disabled people, indigenous peoples and others.ⁱⁱⁱ This resulted in

ⁱⁱA study of the civil society associations that are represented in these councils identified seven categories: community or philanthropic associations, participatory forums (e.g. representatives from the Participatory Budget or other councils), neighbourhood associations, social movements (e.g. the popular health movement), religious groups, civil rights groups and associations for disabled and/or chronically ill people.²

ⁱⁱⁱIn the Municipal Health Council there is a fixed number of seats reserved for each of these constituencies.

different types of representatives. Some have their presence in the councils justified by the politics of presence or the principle of local knowledge, which is based on the demand that the views of excluded groups are not simply taken into account; but that they are represented in politics by people who share their experience and identity. Other councillors have their presence justified as representatives who speak on behalf of local or particular constituencies without necessarily sharing their experience or identity – local representation.

As a result, different logics and priorities were superimposed. The strategy suggested by the ‘deepening democracy’ literature that recommends ‘opening the door’ to the worse off was replaced by the aim of guaranteeing the legitimacy of the representatives, even if this means higher costs of participation. The intention may have been to guarantee the inclusion of the worst off (through reserved seats) and the legitimacy of the councillors (through the notion of representatives of organized civil society). But in practice what is happening is reinforcement of the exclusion of the most marginalized, who in general are not as organized, and the production of weak forms of representation of organized civil society, as there are no clear mechanisms set out to regulate the relations between the representatives and the represented.^{23–25}

England

There is no equivalent clear democratic aspiration underpinning the development of collective public involvement in health policy-making in England. The NHS was founded as a national service, with delivery responsibilities at a local level, but no local democratic accountability. In spite of arguments that have been made from time to time, there has been a continuing reluctance to incorporate health services within the system of local government and the NHS has remained a highly centralized institution with a strong command structure influencing the way in which it is managed.

Like other public services the NHS has become subject to pressures to change its system

of governance and become more participative in the way in which issues are debated and decisions made. Across government in the UK aspirations for increased public and user participation in public policy and service provision have included: improving the quality and legitimacy of decisions in public bodies; improving the responsiveness of public services and outcomes for service users; reducing social exclusion through building individual and community capacity and skills; improving health and reducing health inequalities; and others.²⁶

These diverse aspirations and drivers for greater user and public participation have led to a dynamic and sometimes confusing picture of very different types of involvement within the NHS and within partnership based initiatives that include health objectives (e.g. New Deal for Communities).

Following the election of the first New Labour Government in 1997 the pace of policy action to secure greater involvement increased alongside substantial changes in the structure of the NHS and the relationship between the NHS and other agencies. Thus the establishment of Primary Care Groups as the bodies with main responsibility for health service commissioning at a local level was accompanied by a requirement for clear arrangements for public involvement. Initiatives designed to improve health and reduce health inequalities (such as Health Action Zones)²⁷ were also expected to deliver their objectives not only via partnership with other public, not for profit and private agencies, but also via ‘developing strategy and appropriate structures for involving the public on a continuing basis in partnerships for improving health and for monitoring services’.²⁸

The 2001 Health and Social Care Act placed a duty on all NHS organizations in England to involve patients and the public in planning services, proposals for changes to services and decisions affecting how services operate. A year later, Community Health Councils were abolished and a quasi independent national Commission for Patient and Public Involvement in Health (CPPIH) was established with local

branches that would be attached to every NHS Trust called Patient and Public Involvement Forums (PPI Forums). These forums comprised members appointed by regional offices of CPPIH. They were performance managed by CPPIH and had powers relating to access and inspection of health services, the right to receive information and to refer matters of concern to Local Authority Overview and Scrutiny Committees and other bodies with the power to scrutinize health services. These forums did not last long. In 2007 the Local Government and Public Involvement in Health Act abolished PPI forums and introduced a statutory duty to involve the public in health issues via the creation of Local Involvement Networks (LINKs). These are intended to be more inclusive networks of groups that will gather views and experiences of people not only on health services but also on social care services provided via local authorities. The emphasis is on service improvement and enhancing accountability rather than public involvement in policy-making and relies more on local knowledge – the expertise of those who use services than on principles of local representation. Local authorities are commissioning Third Sector organizations to co-ordinate these networks. For example, in Brighton the Brighton and Hove Community and Voluntary Sector Forum has been appointed to run the LINK. Unlike the centrally determined process and mechanism for establishing PPI Forums, the intention is that the nature of LINKs will be locally determined and no mandatory structure is proposed. The fluidity of the network model is emphasized and, whilst it is expected that local organizations appointed to run LINKs will need to ensure appropriate governance of LINKs and the Department of Health has issued guidance about this (see e.g. http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/DH_076366#_2), local LINKs will be able to choose which model structure they work with.

Another context for patient and public involvement in England is via the establishment of Foundation Trusts. The Foundation Trust

model was enacted in the Health and Social Care Act 2003 and the first wave of Trusts became operational in 2004. One purpose of this model was to enhance the local accountability of NHS services and provide an alternative to centralized ministerial control. Foundation Trusts have greater freedom than other services to develop their own governance arrangements, decide how to generate and use assets, to change services to suit local needs and to offer rewards and incentives to staff. Local people can become members of the Trust, have the right to elect representatives on the Board of Governors and through this role are argued to have an influence on its policies and services. Membership is the result of self-selection. This process was originally intended to give some sense of a Foundation Trust being ‘owned’ by its members and Government had originally conceived that ownership would be along a limited liability model, with members being liable for a £1 contribution in the event that the Trust became insolvent. This proposal was not implemented, and thus membership imposes no obligations on individuals. Members are divided into three constituencies: the public, patients and staff. Whilst the Foundation Trust model offers a clear example of the *principle* of local representation, in *practice* early experiences have questioned the robustness of the accountability of representatives as well as of their real power to shape policy. In practice, independence from government rather than robust participatory governance appears to be the major driver of the Trust model.

The dual identities of ‘patient’ and ‘member of the public’ are acknowledged in the various ways in which potential participants are targeted for involvement within the NHS. Official participation discourses identify patients as users of NHS services whose voices should be listened to in order to ensure responsive services and as consumers whose expectations have been raised about the standards of care and treatment. Those experiencing long-term health problems are recognized as having considerable expertise in managing their own health problems and able to play an active role in determining the best form of care and treatment.²⁹ But patients are

also sufficiently concerned about the nature of services in general to want to take part in Patients Forums to inspect the work of NHS trusts and PCTs and possibly to be elected to a Trust Board to 'have a real say in the way their local NHS is run' (Ibid, para 5.3).³⁰

Citizens as taxpayers and as beneficiaries of publicly funded health care want to have their say about priorities and developments and 'citizens who have tended to be excluded by poverty, disability and ethnicity deserve particular support in this respect' (ibid, para 5.11).³¹ But because most experiments in participatory governance in the NHS have failed to secure the active engagement of many such disadvantaged people, the emphasis has been on attracting those whose 'ordinariness' and 'commonality with the "wider community"'³² can be seen to enable them to mediate between the health service experts and the local population.

Throughout the period in which patient and public participation has become official policy within the NHS, patients groups, user groups and social movements have also organized separately and sought to influence both policy and practice. These groups are both condition specific: mental health groups, groups involving people who live with cancer, those who have arthritis for example and other groups with a broader remit, such as the Long-term Medical Conditions Alliance. They are hugely varied in political stance, their preparedness to work with public officials or to take oppositional positions, their national or local focus, and in their size and resources, but it is rare for any to refuse to have anything to do with the opportunities that the official acceptance of patient and public participation have created to seek influence.³²

But for those that have accepted the apparent benefits of 'partnership' with the NHS there have also been costs. For example, the Nottingham Advocacy Group (NAG) was influential in building not only a local but national voice for mental health service users. Well before participatory governance became the norm in the NHS NAG was involved in decision making about commissioning as well as in individual and collective advocacy at the service level. But having

entered into contractual arrangements to provide advocacy service it became vulnerable when the local trust decided to place the contract elsewhere.³³ The recognition given to the local knowledge of mental health service users was vulnerable in the absence of a formal system that offers representation to health user groups within local systems of health governance. LINKs may be seen as a means of accessing the expert knowledge of those who live with disability or health problems, but they do not offer direct representation or presence to such people within decision-making bodies. A key difference between the situation in Brazil and England is that whilst there is a now a *duty* on health services to involve the public³⁴ in Brazil there is a *right* to representation.

Conclusion: learning from comparisons

The diversity of models and locations for participatory practices that is evident from this brief overview indicates the different purposes which can be advanced for enhancing public participation in health and the different principles that inform its development. Whilst these purposes and principles interact, they prioritize different aspects of the processes of identifying and engaging participants, designing the practices through which participation can be achieved, and making links between this and political, professional and bureaucratic decision-making processes. Comparing public participation in health in Brazil and England helps highlight these different purposes and the tensions between them.

The range of opportunities for participation in the Brazilian context is arguably more limited than in England, but the principles on which this is based are more clearly those of representation and accountability. None of the mechanisms for involvement in England give either public or patients the degree of decision-making power available to the Health Councils in Brazil. To that extent, and in spite of the recent statutory duty to involve the public, the enduring ambivalence about enhancing the local democratic accountability of the NHS remains and it is hard to see these developments as being driven

primarily by a wish to deepen democracy. Patient and public involvement in the governance of Foundation Trusts has reintroduced the idea of local accountability into a service that had a history of upward accountability to the Secretary of State. But such accountability is accompanied by little effective power, is based on self-selected membership and provides no real mechanisms to act as representatives.

In Brazil, whilst municipal councils do have explicit powers, the big player remains the federal government in the sense that the Ministry of Health both retains an important strategic induction role through the formulation and implementation of health programmes and the definition of financial regulatory mechanisms.

In both England and Brazil an often unacknowledged tension between participation based on principles of 'local knowledge' and 'local representation' means that the roles that participants are expected to play are not always clear and the confusion can be used to question the legitimacy of their contributions.

In both countries developments offer some evidence of recognition being given to service users, both in terms of the validity of their experiential knowledge in shaping both service design and treatment decisions, and more broadly that those subject to policy decisions should have some say in them. This is particularly important for groups, such as indigenous peoples or those who live with mental health problems, who have been stigmatized and excluded. But in practice their direct representation remains limited and insecure.

In spite of aspirations that more participatory modes of decision making would mean more equitable access and better health, there is limited evidence of more equitable outcomes being achieved. Overall there has been an improvement in health in England but health inequalities have slightly increased during the period in which public participation has become official policy. In Brazil there has been a reduction in inequalities in the inter-regional distribution of public health resources.³⁵ Coelho and Silva also found that the consumption of services was increasing at a greater rate in the poorest regions

of São Paulo between 2001 and 2007, as well as the fact that there has been a reduction in the disparity between the consumption of services across the city regions with the best and worst indices of income, education and health.³⁶ But more work is necessary to conclude whether the redistributive aspirations of public participation in health can be realized.

Both our work and other research highlight the dynamic and contested nature of public participation in health. It is not possible to assume that any particular model of participation will generate specific outcomes, not least because the tensions between inclusion, representation, legitimacy and authority are evident in very different settings and types of participation initiative. In Brazil the efforts to assure legitimacy ended up opening space to weak forms of accountability that may reinforce the exclusion of the worse off, whilst in England there has been little evidence that participation has really gone much beyond consultation. Both cases point out how delicate is the equilibrium that allows a source of representativeness – as knowledge – to become a source of legitimacy capable of supporting binding decisions. Such comparisons help to clarify the issues at stake and suggest that if 'the public' (in whatever guise) are to have a say in the final decisions, then we still need to ensure that more efforts are made to find an adequate balance between the role and responsibilities of participatory bodies and the mechanisms that exist to assure their legitimacy and accountability.

Conflict of interest

There is no conflict of interest.

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