BEYOND CONSULTATIONS AND SURVEYS: ENHANCING PARTICIPATORY GOVERNANCE IN HEALTH SYSTEMS

By: Dheepa Rajan, Eva Brocard, Charlotte Poulussen, Kira Koch, Naomi Limaro Nathan, Katja Rohrer-Herold and Pascal Melihan-Chenin

Summary: Participatory governance means engaging with the population with the aim of making policies more responsive and implementable. The COVID-19 pandemic has, however, highlighted that much-needed reforms towards true participatory governance of the health system has not been adequately prioritised and resourced. In this article, we explore what is meant by participatory health governance and the key actors involved, before considering two examples of participatory spaces in France and Portugal. We suggest that not one but a variety of participatory spaces should be made available to ensure a broad range of voices get heard, including population groups whose views and experiences are often left behind.

Keywords: Health Democracy, Participatory Governance, Policy-making Processes, Public Engagement, Community Participation

Introduction

Health decision-makers have consistently acknowledged the need to take into account people’s needs and views to ensure responsive policies. Indeed, the principle of participation has been affirmed time and again in various health-related international declarations and resolutions, as well as within national constitutions and legal frameworks. Yet in practice, neither the current discourse on pandemic preparedness nor the global attention paid to universal health coverage have adequately prioritised and resourced the much-needed reforms towards true participatory governance of the health system.

Part of the challenge is clarifying what participatory governance actually means in practice. What kind of participatory spaces are needed for governments to engage effectively with people? Who are ‘people’? What about engagement with crucial health stakeholders who can make or break health reform, such as health professionals and pharmaceutical manufacturers? How can government–people engagement be meaningful yet policy-relevant?
In this article, we aim to address these questions by providing an overview of what ‘people’ means in the context of participatory policy making. We then chronicle two examples of participatory spaces in Europe, before suggesting the use of not one single but a variety of such spaces to ensure that the broadest range of voices get heard – this includes both the stakeholders without whom the health system could not adequately function, as well as population groups whose views and experiences are often left behind.

**Participatory governance and people: who should participate?**

*What do we mean by ‘people’?*

A more comprehensive and serious approach to inclusive health governance essentially means engaging with the population with the aim of making policies more responsive and implementable. Making policies implementable will certainly involve increasing acceptance by those who have an obvious stake in the health system (health professionals, private sector, patient associations, etc.) as well as its feasibility based on on-the-ground realities. But making them more responsive means addressing the broader public at large, including those who may need preventive and promotive care more than anything else, and hence are not (yet) frequent users of curative health services. Both implementability and responsiveness need to be addressed – and doing so will mean creating and sustaining spaces where both affected and unaffected parties, as well as the partisan public can express their views and provide expertise (see Figure 1).

‘People’ are in reality a blend of different – and sometimes overlapping – mini publics, with the caveat that each person or group can be defined differently based on the aim of the participatory space and the specific role participants are given.

A patient living with diabetes would clearly be an affected party in a consultation process on chronic disease policy but would play the role of a lay person if the dialogue were on adolescent sexual health. A person or group’s role within a participatory space is thus contingent on a well-defined topic and the configuration of the space itself.

Of course, people and groups are multifaceted. The lay and partisan public can be seen as a spectrum where some groups will not neatly fit into a single category. For example, community groups may consist of a mix of affected and unaffected parties. Many participants may have more than one personal and professional identity. The categorisation can be seen as an orientation to help reflect on who should be participating, and whose views are needed for a particular policy question. Ultimately, the aim is to strike the right balance of participants, and avoid a dominance of one public type’s perspectives over the other – depending on the policy question, of course, since some policy objectives may demand a certain preponderance of views.

The partisan public already enjoys considerable influence on policies

The ‘partisan public’ is the group often subsumed under the term ‘health stakeholder’ and represents those with a vested interest in health system decisions. They thus usually have long-standing relationships with policy makers and traditionally already hold a certain level of influence on how the health system is shaped, although this will vary by stakeholder type and country. In general, governments are accustomed to engaging with the partisan public, and thus tend to be more effective in interacting with this group in a policy-relevant way.

The ‘partisan public’ is fairly heterogeneous as it can comprise of interest

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**Figure 1:** A schematic view of the 3 types of ‘publics’

<table>
<thead>
<tr>
<th>‘Unaffected’ Public</th>
<th>‘Affected’ Public</th>
<th>‘Partisan’ Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>assumed to be unfamiliar with the issues</td>
<td>those with relevant personal experience, e.g. of illness</td>
<td>those with a special partisan interest, technical expertise or professional identity</td>
</tr>
<tr>
<td>– lay citizen</td>
<td>– service user</td>
<td>– civil society organisations</td>
</tr>
<tr>
<td>– ordinary people</td>
<td>– patient</td>
<td>– professional associations</td>
</tr>
<tr>
<td></td>
<td>– consumer</td>
<td>– advocates</td>
</tr>
</tbody>
</table>

Source: Adapted from [1]
groups, advocates, non-governmental organisations representing an issue or population sub-group, and professional associations among others. The policy-maker’s aim of engaging with this group is grounded in the reality of policy implementability, i.e. the acute need for buy-in from, for example, medical associations, without whom policy decisions may simply not work.

The partisan public may be better funded or better organised than the other two publics, hence they may have a more dominant voice in the policy-making process than the others. This might be acceptable or not; it heavily depends on the participatory process objectives and the topic of discussion. For example, if the process objective is to address health worker burnout during the COVID-19 crisis, obviously a focused and repeated engagement with health professional associations is needed to find a policy solution which works. On the other hand, externally-funded interest groups may have vested interests which are particular to a small group in society, their dominant voice may need to be equalised with other voices.

**A concerted effort is needed to bring in the voices of the unaffected and affected public**

Governments tend to struggle more in their engagement with the lay (‘unaffected’) and affected public. With the former, many policy questions tend to be subject to one-way engagement modalities such as surveys or online questionnaires, while systematic investment in bidirectional interaction remains limited. Engagement with the affected public, especially patient associations, is recognised as significant in many places (see next section) but is often tokenistic and undervalued when it comes to uptake into policies.

A targeted, additional effort is thus needed to effectively listen to the voices of the lay and affected public, and especially to channel their input into a policy discourse. This is also because government-led, more institutionalised structures have the tendency to reinforce existing societal hierarchies and power.

In the health sector, this translates into those who already have access to decision-makers and already have influence on health policies (i.e. the partisan public) consolidating their views within a policy dialogue. Specific strategies such as those mentioned in the following section’s country illustrations are required to counter-balance these tendencies and give adequate weight to the experiential evidence (see Box 1) the unaffected and affected publics are able to bring to policy discussions.

**Using different participatory spaces to address different publics: illustrations from Europe**

**National Health Conference, France**

The National Health Conference (Conférence Nationale de Santé – CNS) can be seen as an expression of what is termed ‘health democracy’ in France. The notion of health democracy became more widespread in policy circles during the HIV/AIDS crisis beginning in the 1980s and the accompanying civil society activism which led to a greater influence on health policy making (see Box 2). The term later became enshrined in the 2002 ‘Kouchner Law’ which affirmed the right to health in concrete terms, laying out specific patient rights with redress mechanisms.

It is within this context that the CNS was created in 1996. The French CNS is a consultative body, consisting of 97 independent members, representing a wide range of health stakeholders (partisan public and affected public). Members are drawn from patient associations, health sector trade unions, social protection funds, regional health authorities, and regional consultative bodies for health, in addition to preventive care professionals, researchers, health service providers, and medical products providers. Despite the common practice of governments appointing consultative body chairpersons, the French CNS has retained a democratic quality by electing candidates to this office from its membership. Until 2019, the chairperson post was held by a patient association representative, rather than a health professional or medical expert.

A Secretariat within the Ministry of Solidarity and Health (MoH)’s General Directorate for Healthcare Services notably supports the CNS’s day-to-day operations and dissemination of Conference results.

France’s CNS is embedded in the Public Health Code, lending it a solid legal framework to formulate non-binding opinions to feed into national health strategies, to monitor and report annually on the state of patients’ rights, and to organise public debates on relevant health issues. The mandate to organise and stimulate public debates on health matters allows the French CNS to reach out to the ‘unaffected public’ and bring lay voices into policy dialogue. For example, in 2017, the French CNS facilitated a public debate on the use of digital health tools and apps, the results of which formed the basis of an official CNS Opinion which was validated in 2018 by the National Commission for Public Debate.

As in many countries, the beginning of the COVID-19 pandemic was characterised by a default governance mode which was not inclusive. In France too, the CNS and its regional equivalent were not consulted in

**Box 1: Experiential expertise**

Experiential knowledge refers to the real-life experiences that people have as service users or community members, for example, when accessing health services in a facility, or dealing with the inability to quarantine at home. In contrast to experts or health professionals who are required to make judgments, ostensibly objectively, based on facts or specialised knowledge, lay people or patients are supposed to bring in more practical evidence based on their lived experience, or, in other words, a non-expert view. This ‘expertise’ is and should be more recognised among stakeholders as a source of legitimacy within a participatory space.
pandemic decision-making, despite a long-standing CNS recommendation laying out the modalities to consult the population during a health crisis. The French CNS thus issued a resolution in April 2020, calling upon the government to make use of existing participatory governance mechanisms for COVID-19 policy making, especially when deciding on far-reaching public health response measures (curfews, lockdowns, vaccination strategies). In December 2020, CNS and public pressure led to the first MoH consultation with the CNS on the effects of the pandemic on overall patient care and health services. More recently, the Conference adopted a resolution on health inequities, representing one of the loudest institutional voices urging the French government to address inequities inherent to its COVID-19 vaccination strategy. The CNS was also a key player in policy debates on mandatory COVID-19 vaccination for health workers.

In October 2021, the Minister of Health announced a review of French health democracy, i.e., an evaluation of the CNS and other consultative bodies, in view of operational recommendations for their future. One key issue to be studied will be the link between organised civil society in the consultative bodies and direct consultation of the population, thereby affirming the need to reach out to all types of publics in a systematised way to ensure participatory policy making.

National Health Council, Portugal

The National Health Council (Conselho Nacional de Saúde – CNS) was formed in 2017 in Portugal as a government advisory body mandated by the Basic Health Law of 1990. The Portuguese CNS’s mandate is to establish an alliance across the whole of society to ensure a common vision for the future of the health system. The Portuguese CNS operationalises its mandate by consulting broadly with stakeholders and the public to feed into health policymaking processes, with the ultimate aim of promoting government transparency and accountability.

Membership consists of civil society organisations (6 fixed seats), professional associations (7 seats), trade union and private sector entities (5 seats), regional government representatives, and academics appointed by government, (together 10) – hence a broad mix of the partisan public with some affected public, similar to France’s CNS membership. With the president and vice-president, the Portuguese CNS consists of 30 members in total, each with equal voting rights. The president and vice-president positions are both nominated by the Council of Ministers after proposal by the Minister of Health, while the 6 civil society representatives are elected by Parliament. The civil society member selection process has been called into question for its government dominance and is currently under review.

Like its French correlate, the Portuguese CNS was set up with the explicit mandate of ensuring an inclusive debate on priority health matters which feed into official recommendations for policy. Besides its regular member deliberations, the Portuguese CNS reaches out to the lay public (unaffected public) by convening working groups to feed into public debate. This lay public engagement is still in its infancy, with a recent review recommending more pro-active outreach to this group, as it is precisely those working group deliberations aimed at public interaction which has proven useful to influence COVID-19 decision making.

In 2020, working group discussions on the pandemic’s impact on vulnerable communities provided valuable grassroots insights for government COVID-19 policies. The relatively new existence of Portugal’s CNS thus demonstrated that trusted access to civil society and communities is crucial during crisis situations, and can be effectively offered

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Box 2: The French HIV/AIDS movement & the role of civil society in influencing policy priorities

The HIV/AIDS epidemic in 1980s France was fertile ground for a movement led by civil society organisations (CSO) representing the beginnings of a prominent and vocal civil society landscape in the French health sector. Spurred on by the growing number of victims, the lack of available treatments, stigmatisation, and the slow adoption of adequate government policy measures, CSOs took on a prominent role in educating and mobilising the public. By doing so, they brought much-needed attention to patient rights, demanding clear action from policy makers.

As public authorities struggled to curb transmission, they gradually recognised the need to partner with civil society in the battle against HIV/AIDS, particularly in the field of prevention and risk communication. CSOs progressively gained trust and respect in policy making circles, leading to their own increasing expertise and subsequent influence in HIV/AIDS policy development. For example, CSOs were instrumental in the formulation of an anti-discrimination law based on health status and disability. They were also behind the policy decision to extend access to post-exposure treatment to anyone who feared they may have been exposed. Until that point, post-exposure prophylaxis had been reserved for health workers in the context of an occupational accident involving blood products.

By the end of the 1990s, HIV/AIDS CSOs and French policy makers were working in a collaborative modus operandi to reform the epidemic surveillance system. The reform led to a national system of compulsory declaration by health professional staff of all new HIV-positive cases.

Today, studies show that France’s response to the HIV/AIDS epidemic has delivered positive outcomes. The number of new HIV infections has broadly stabilised, with people diagnosed with HIV immediately placed on anti-retroviral therapy. The French HIV/AIDS community thus benefited enormously from the fruitful government-civil society collaboration in policy formulation and implementation.

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when mechanisms for participatory governance are already institutionalised and have previously been invested in.

Conclusion
In this article, two examples of institutionalised participatory governance mechanisms are elaborated on to demonstrate ways in which governments can target the different types of publics to foster a true ‘health democracy’. It is important to note here that CNS in France and CNS in Portugal do not represent the only government platforms to engage with the public, communities, and civil society. A comprehensive approach to health democracy must inevitably include a plethora of participatory spaces – such as public hearings, citizen juries, focus group discussions, and others – as each space may target a different type of public with its unique mandate and objective. A key message of this article is that policymakers should generally be aware of the different kinds of publics when designing a coherent approach to participatory governance, and clearly recognise the existing influence the partisan public already has on the health sector. This is not to say that the influence is not legitimate, yet the partisan public’s legitimate say in health policies should not be seen as the beginning and end of health democracy. Instead, a true ‘health democracy’ must also give countervailing weight to the voices of those affected by such health policies and those to whom the health system also belongs – the ‘unaffected public’, as well as part of the ‘affected public’ whose voices may not be heard through institutional mechanisms.

Given policy makers’ health system performance objectives of improving equity and overall health outcomes, the point of participatory governance is to lift the voices of population groups where health outcomes are worse, and understand more clearly which policies need to be put in places to address those groups’ health system challenges. For this, a resolute emphasis must be placed on consulting not only those with a more evident stake in health system operations, but also those who will bear the brunt of any operational decisions.

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