Voice, agency, empowerment - handbook on social participation for universal health coverage

World Health Organization

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Foreword

Universal health coverage (UHC) is at the heart of WHO's mission to promote health, keep the world safe, and serve the vulnerable, with the ambition of extending the benefits of UHC to an additional one billion people.

UHC implies access to quality health services for everyone – the rich and the poor, the healthy and the sick, the young and the old – without fear of facing financial hardship. The COVID-19 pandemic has demonstrated that societies are only as well-protected as their most vulnerable members; but equally that engaged, educated and empowered communities are one of the best defences against health threats.

The road to UHC thus runs through a strong, bold, and unwavering government engagement with communities, especially the most vulnerable. At the heart of that engagement is a participatory space for health that allows for meaningful dialogue and debate, and serves to amplify the voices of those to whom the health system belongs – its users.

In essence, it is about a social contract for UHC – a social contract based on true dialogue between those who control resources and those who lack resources; between those who provide access to health services and those that seek access to those services; between those who make decisions and those affected by decisions.

The Handbook offers countries a valuable tool for creating, sustaining, and strengthening social participation. It provides practical guidance for policy-makers to navigate the challenges of convening hard-to-reach population groups, of brokering dialogue when views are polarized, of addressing socially inherent power imbalances which hinder frank discussion – in short, this handbook addresses the challenging but critical 'how-to' of regular and systematic government engagement with the population, with communities, and with civil society.

I hope countries use this handbook to start new conversations, to deepen existing conversations, and to invest in the most valuable commodity in health: trust.

Dr Tedros Adhanom Ghebreyesus
Director-General
World Health Organization

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Chapter 1

Participation: a core instrument for voice, agency and empowerment

DHEEPA RAJAN
KIRA KOCH
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Handbook on Social Participation
for Universal Health Coverage

1.1 Rationale for social participation

Universal health coverage (UHC) is about ensuring that all people receive necessary health services without having to suffer financial hardship to do so (1). Reaching the noble goal of UHC involves strengthening health systems to perform in service of people's health. Global and national UHC efforts over the last decade have been keenly focused on health financing and service delivery. While those components are essential, good health system governance, or lack thereof, can make or break UHC reforms. The global health community therefore needs to recognize the criticality of putting attention and resources to strengthening health governance at country level, in parallel to making inroads in other health systems areas, to craft a health system co-owned by the population, communities, and civil society underpinned by UHC.

One crucial but challenging aspect of strengthening governance is systematically bringing in people's voice into policy- and decision-making. Indeed, the protracted Coronavirus pandemic throws an additional, glaring light on the need for social participation as foundational to fostering trust in government and public institutions (2), an element seen as key to the success of the Covid-19 response (3, 4). Trust can be fostered by more robust, regular, and institutionalized dialogue between governments and their population (5), when people feel that their governments listen to their interests and consider their perspectives. For people's views to be aired and heard requires an environment where people feel **empowered** to speak their **voice**; doing so gives populations **agency** over their own health and lives, a key step in fulfilling the human right to health.

The social participation gap during the Covid-19 crisis

The Covid-19 outbreak has intensified the need for health policies which are responsive and adapted to people's lived realities; otherwise, adherence to policy measures can be wanting and practical implementation riddled with challenges (6). Social participation mechanisms' very objective is to bridge the gap between policy-maker perspectives, and experiences and needs in communities (7) – a gap which is growing dangerously larger with the current lack of societal consensus on where exactly the equilibrium lies between protecting the Covid-vulnerable, impairing livelihoods, and impacting on the basic freedoms of populations (8).

Bridging that gap will require bringing in a people's perspective on health which clearly goes beyond the biomedical-technical one which dominate in government-expert circles (9). This implies a shift in government modus operandi and professional paradigms as they must "reconcile the operational logic of technical knowledge with community values and ways of working" (10). The cost of not doing so is population incomprehension regarding virus containment measures, with emergency response policies and communication disconnected with people's living conditions.

In this handbook, we aim to demonstrate to policy-makers that the remedy for the communication and responsiveness between those who make policies and those who are a target of policies is not a daunting task, and is in practice feasible and necessary: that remedy is investment in creating, strengthening, and institutionalizing social participation mechanisms. We also employ the term 'participatory spaces' to designate such mechanisms, an example list of which is provided in section 5 along with detailed descriptions.

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1.2 Rationale and concept of this handbook

The Ad Hoc Task Team on WHO-Civil Society Engagement's December 2018 report recommends that "WHO update its policies, guidance, and processes to encourage… Member States to more regularly, broadly, and meaningfully consult [civil society organizations]" (11). In addition, the 2019 Political Declaration on UHC was signed off by the United Nations' 192 Member States with several clauses underlining the need to govern in a participatory manner, one example being: "we… recognize that people's engagement… and the inclusion of all relevant stakeholders is one of the core components of health system governance, … contributing to the achievement of universal health coverage for all…" (12).

Yet bringing in people's voice into health policy- and decision-making is complex in practice, despite the simplicity in theory. This handbook thus aims to provide the most up-to-date best-practice synthesis of theory and practice, with a particular focus on the perspective of government policy-makers. Our target audience has been purposefully chosen due to **(1)** WHO's core mandate as a Member State-led organization as well as **(2)** advice from the Handbook´s external advisory group, the Social Participation Technical Network[1] that social participation capacity-building initiatives aimed at policy-makers are where the need and the gap acutely lies (13). Indeed, chapter 4 of this handbook on social participation capacities addresses the challenges linked to government cadres being principally trained in medico-technical matters by laying out the specific skills required to bring people of all walks of life together to engage in meaningful and policy-relevant dialogue (14-18).

As we address policy-makers in this handbook to work through the practicalities of putting in place participatory processes, we focus on three main modalities which may be slightly theoretical but provide a basic framework for research and data analysis: platforms for direct population engagement, engagement mechanisms at community level, and engagement with civil society organizations (CSOs). The three modalities are not mutually exclusive and in practice, large overlaps attest to a certain fluidity and multidimensionality in people's roles. For example, in India, the "communitization" pillar of the National Rural Health Mission (see Box 1.4) created the Accredited Social Health Activist (ASHA) cadre to act as a relay between communities and the health system. In communities where civil society organizations had established operations, they were able to boost ASHAs' role and more effectively amplify community voice (19). This example underscores that community and civil society engagement mechanisms are interdependent, as is exemplified in the overlapping spaces between the engagement modality circles in figure 1.

Next in figure 1, the question of context comes in as policy-makers wish to engage with their populations with a certain objective or policy question in mind. In this handbook, we focus on the policy-making context of steering a health system towards UHC, the debates and decisions of which are largely conducted on the national stage, with some exceptions[2].

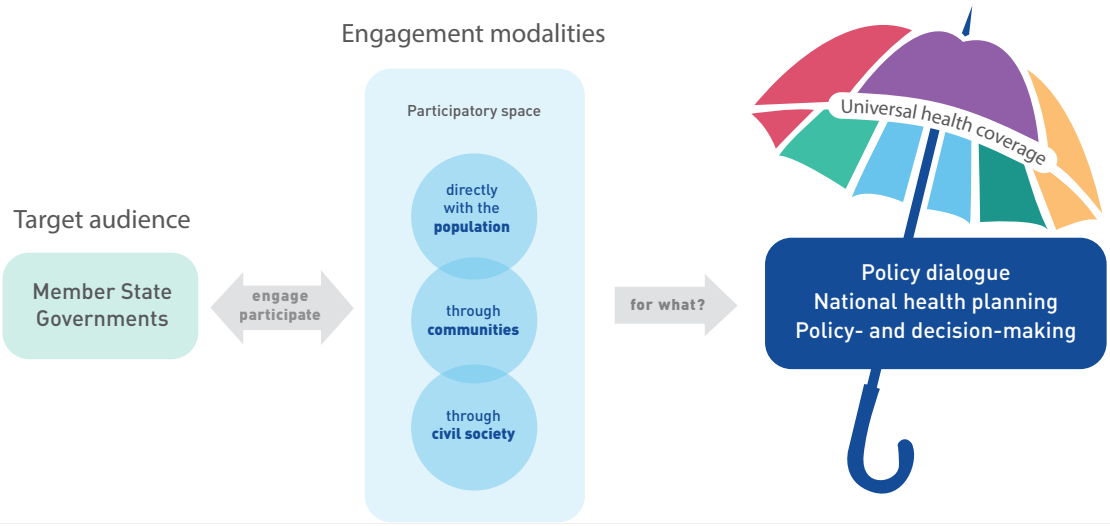
1 The Social Participation Technical Network is an external advisory group to the handbook with approximately 40 members split fairly equally between civil society members, Member State government cadres, and academia/international organizations.

2 In some countries, health sector decision-making may be largely conducted at sub-national level (examples: Nigeria, India).

Policy dialogue on UHC-related topics such as a nation's health financing strategy or health sector plan should reflect population, community, and civil society voice, without which it can be easily rendered irrelevant and/or unimplementable [20].

The handbook specifically focuses on bringing in the voices of people, either directly, through communities, or through civil society organizations, into policy-making for health. It does not address the specific complexities involved in government formally engaging with private sector entities and their interests. That being said, private sector entities may be organized into an umbrella civil society organization and take part in participatory spaces – issues to consider when dealing with special interests or more powerful interest groups within these spaces are discussed in and are integral to this handbook.

Figure 1.1: the Handbook concept



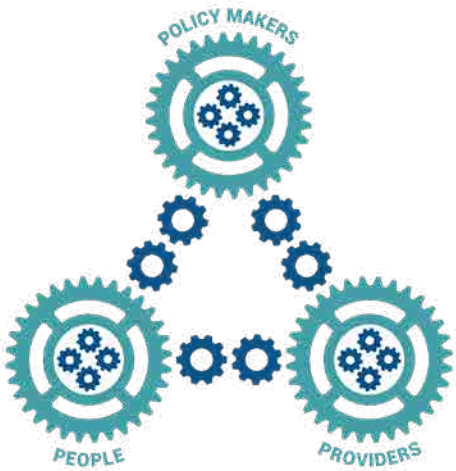
1.3 Placing social participation within health system governance and decision-making

A sub-function of health system governance is 'stakeholder voice' (21), i.e., ensuring that the stakeholder views, experiences, and needs are listened to and considered in decision-making processes. The stakeholder voice sub-function highlights the importance of various groups in society interacting with each other, and with decision-makers, to inform more responsive policies. This interaction is also at the heart of the World Development Report 2004 governance triangle (22) (see Figure 1.2) which shines a particular light on the stakeholder groups of policy-makers, people, and providers.

In this handbook, we specifically examine the interaction with policy-makers, predominantly between the 'people' and 'policy-maker' gears of the triangle. The third gear, health providers, is one of the most important and powerful stakeholder groups in health, depicted as a separate triangle vertex. The interaction between providers and policy-makers within the context of the social participation paradigm is characterized by the reality that a health system cannot function without health providers. Hence, policy-makers must acknowledge and value the weight of provider interests and perspectives, while at the same time ensuring an adequate counter-balance to their voice and interests from other population groups as duty-bearers for the right to health for the population as a whole. It is a delicate balance to strike which entails specific skills and institutions to be built, a topic we address head-on in this handbook.

The interaction between people and providers predominantly takes place within the health system function of service delivery where people, at least in theory, exercise their market power through their provider preferences. Of course, where little choice of provider exists, the power lies more in the provider sphere. As laid out in more detail in chapter 5, the objectives for participatory processes in health are varied but we focus here (see Section 1.2) on the objective of policy influence and anchoring people's voice in health sector decision-making. Hence, this handbook handles two sides of the triangle explicitly by laying out best practices in navigating the power relations that shape the people-policy-maker line. The provider-people line is often the subject of patient empowerment initiatives within vertical health programmes, and is not the explicit focus of this handbook.

Figure 1.2: The health system governance triangle (23)



1.4 Participation: levelling out power imbalances as an underlying handbook theme

A fundamental premise of this handbook, bolstered by findings from primary and secondary data analyses, is that a participatory space is essentially shaped by power relations.

A participatory space does not exist in a vacuum outside of society. Culturally and socially underpinned hierarchies and established channels of influence are brought into the participatory space, willingly or unwillingly. They must be acknowledged, analyzed, and counter-balanced as far as possible within the remit of achieving the objectives of the participatory process. For policy-makers, this can go a long way towards reaching the desired objective of more responsive policies which are accepted and implemented on the ground – hence, the counterbalancing measures to level out the playing field of the participatory space ultimately offers a win-win for all sides. An analysis of power and what it means for participation is thus elabo- rated upon in detail in chapter 2.

The complexity of managing a participatory space boils down to capably crafting its format and design to equalize to the maximum extent possible power imbalances which may hinder frank and worthwhile discussion. One pivotal aspect of participatory space design is how rep- resentatives are selected and derive legitimacy; an in-depth reflection on representativeness is provided in chapter 3. The capacities which are necessary to design, steer, and take part in a participatory process are reflected on in Chapter 4 – here, we not only dissect necessary capacities for government cadres themselves but also delve into what they can do to ensure that capacities are built and supported for populations, communities, and civil society.

A central theme in chapter 4 revolves around how increased capacities lift the power and influence of those who have less of it (often lay citizens and civil society) while bringing a mindful comprehension to those in positions of power (often government, but also potent inter- est groups) that humbly listening to diverse voices can help bring about more sustainable policy solutions.

The very notion of acknowledging, if not addressing, an imbalance of power and influence, and its consequences for a collective debate, inherently means that all actors take on different, perhaps more uncomfortable and less habitual, roles within the participatory space than they might outside of it. It is and must be a learning process for all sides, one which bears fruit when viewed and invested in as a longer- term course of action which does not always provide obviously visible policy gains in the short term. Yet they can, further down the line, by fostering trust in health system institutions, and a culture of dialogue, listening, and worka- ble solutions (24-26). Arriving at such solutions, with effective policy uptake of participatory process results, is examined in chapter 5.

Levelling out the playing field in terms of power and influence is also at the heart of frameworks which provide a legal basis for participatory activities in health. In chapter 6, we discuss how designing such frameworks with the power balance lens in mind can significantly contribute to more meaningful engagement of all stakeholders with each other. Finally, in chapter 7, we address the issue of maintaining the motivation for participation over time, and ensuring that it becomes institutionalized as a modus operandi of the health sector.

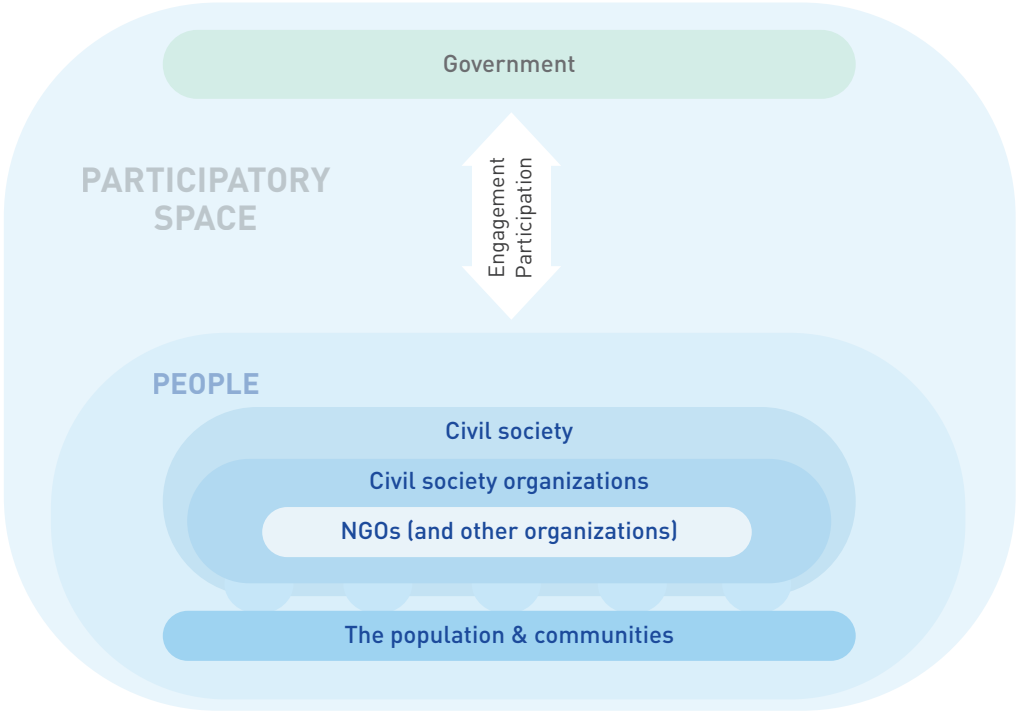
1.5 Handbook terminology

The central and most widely used participation-related terms from the English-language health literature (see Box 1.1) are captured in figure 3, with the exception of 'social participation' which is employed somewhat less frequently in English[4]. For purposes of this handbook, and emerging from our primary data analysis, however, the term 'social participation' seems to be the most encompassing term for any form of participation. We thus purposefully take the term as a title for the handbook and thus, figure 3 to signify what happens within the participatory space circle. The prefix 'social' alludes to individuals, populations, and communities but can also be associated with civil society. By bringing 'social' and 'participation' together, the nature of participation is given a level of specificity which would be absent by using the word 'participation' alone. The action nouns in figure 3, 'engagement' and 'participation', describe what government and civil society actors are doing. 'Participation' has a connotation of people doing the active participating. Government on the other hand is actively doing the 'engaging' to ensure that people 'participate'.

One of the central tenets of the social participation concept in figure 3 includes civil society, which usually aims at promoting democratic values and principles, with the implicit notion of working toward a common social good. Civil society, when organized and expressed as an entity, are civil society organizations (CSOs). For purposes of the handbook, the general population and communities are seen as part of civil society, without being necessarily a CSO (unless explicitly being organized into one). Thus, everyone who is part of civil society and not acting on behalf of the government is depicted as belonging to the designation 'people', regardless of how they are organized or not, regardless of identity or affiliation. Within the health sector, CSOs encompass all different types of organizations and associations who express their belief in participatory principles, human rights and social justice by serving and representing high health need population groups.

4 The list is not exhaustive; more terms and definitions can be found in the *Background paper for the Handbook on Social Participation for Universal Health Coverage, Definitions of terms related to social participation: a descriptive overview.*

Figure 1.3: **Social participation** as we employ the term in this handbook



Box 1.1

Common participation-related terminology used in health

An overview of common participation-related terminology seen in the literature is provided here, with a focus on their use in different health sector contexts. The objective is not to provide normative definitions for social participation-related terms. Rather, we seek to understand how these terms are commonly used in the health literature in order to align with them accordingly in this handbook. In other words, we wish to broadly use the same terminology and jargon which is most common among global, national, and local health policy makers, and civil society who are active in health advocacy and policy-making. The aim is additionally to ensure their common comprehension by readers.

The principal characteristics of each term is described in the following pages with the aim of clarifying their multifaceted nature and diverse use.

Terms related to organizational groupings

Civil Society

The literature refers to the term civil society as individuals or groups of individuals who associate together based on shared interests, goals, needs and functions (28-31). The over-arching theme for these goals or functions as seen in the literature could be summarized as democratic values or principles, such as the protection of citizens' rights, encouragement of free association and the idea of government being responsive to population needs (32).

The reviewed documents generally define civil society as lying outside the family sphere, referring to it as an autonomous space between the household and the state (28-30, 33, 34). Civil society is considered non-profit and therefore independent from the market; in this respect, it is often called the third sector, separating it from both the state and the market. This perspective underlines the independence of civil society from the public and private for-profit sectors (35, 36).

In addition, the literature commonly links the term civil society with the words "organized" and "organic" networks or groups, ranging from informal to formal associations (37, 38), as well as "voluntary" (34, 39-41).

However, the characteristics and societal role of civil society depend on the context and the country in which it operates, especially the contextual factor of the state's general disposition towards it. Depending on the functioning of the state, civil society can work in support of the state, complementing government development efforts, countermanding bad governments, or fill in gaps in case of failure of the state (41). The state can view and treat civil society as a trusted entity which is legally protected or view it with suspicion, and in the extreme but not entirely uncommon case, as an outright threat to be mistrusted (42).

Civil Society Organization

Civil Society Organizations (CSO) are the actual entities representing civil society, the "real locus of civil society and where it happens" (34).

The characteristics as seen in the literature include non-state, not-for-profit, voluntary, uncoerced, and self-governing (30, 33, 34, 36). The overarching goal of CSOs appears to be to promote democratic principles, often with an emphasis on human rights and social justice (43, 44).

A range of different groups and groupings are labelled as CSOs in the literature: international non-governmental organizations (INGOs), non-governmental organizations (NGOs), regional and national advocacy groups, service delivery organizations, community-based

organizations (CBOs). Examples are youth-led coalitions, professional associations, faith-based groups and service providers, indigenous groups, charitable organizations, research and academic institutions, commercial and professional associations and more (44-47).

Shanklin and others describe a variety of roles that CSOs can play, such as knowledge generation, priority issues advocacy, public service monitoring, policy input and guidance, implementation, support of vulnerable and hard-to-reach populations (11, 37). CSOs can also contest governments in some instances and this may or may not be linked to an explicit or implicit affiliation with the government (48). A term that is often used when describing the role of CSOs is "accountability", as their purpose and goal is often to hold the government accountable towards the population.

A debate about whom CSOs represent, linked to who funds and potentially influences them, is still ongoing in academic and practitioner circles. A general understanding of CSOs seems to be that they are, and should be, autonomous and self-governing at the very least. Some reports, however, question whether CSOs in certain contexts primarily represent the interest of donors from whom they receive funding, rather than the people they are supposed to serve (49).

There seems to be an overlapping grey zone between civil society organizations, the state, the for-profit private sector, and households. Pollard and Court highlight that identifying clear lines of separation between these sectors can be problematic (50). Many CSOs have complex and multifaceted relationships with the various other sectors and may be dependent on them not only for financial backing, but also political status and other kinds of resources which may be necessary to fulfil their objectives. Therefore, in attempting to find a common definition or understanding of CSOs, their mission and objectives as well as how and by whom they are being funded and governed may be the most relevant features (51).

Non-governmental organization

The definition of non-governmental organizations (NGOs) is not clear cut, as it is either used interchangeably with CSOs (34, 52) or as a subgroup of CSOs (37, 39, 46). It also seems to be used interchangeably with non-profit organizations; however, Paul demands a clear distinction between non-profit organizations, which could include institutions such as museums or universities with little advocacy work, and NGOs, which according to him always have an advocacy mission (53).

Yachkaschi as well as Kanyinga seem to see the difference between the term CSO and NGO in the fact that the latter are more formalized, at least in the African context (39, 42). In addition, there appears to be an understanding in some lower-income country contexts that NGOs receive funding from international/ foreign donors, making them dependent on their agenda (54). In China, the establishment of NGOs is under state control. This not only gives a formal connotation but also affects their mission, structure and activities, as well as funding; these "government-organized nongovernment organizations" do not receive foreign financial support (55).

Community

The term community can broadly be described as a group of individuals that have something in common; this can be merely the place where they live, but it can also be race, ethnicity, age, occupation, a shared interest or affinity (such as religion and faith) or other common bonds, such as health need or disadvantage (56-59). These different characteristics indicate that an individual can be a member by choice – when joining an association voluntarily or by virtue of their characteristics, such as age, ethnicity or residence (60). Connotations that are linked to the term of community include bonds, trust, social cohesion and relationships (61).

Community-based organizations, community organizations

Greer et al. [34] list different types of community organizations (which they use interchangeably with community-based organizations):

faith-based community organizations; Identity-based community organizations; Local community organizations; Social community organizations; Health condition-related community organizations (patient groups, support groups). Community-based organizations are more grassroots and local in their action, and therefore may not have the sophisticated structures and networks needed to raise and maintain resources. Overall, community-based organizations play an important role in initiating collective citizen action and influencing the development of a thriving civil society [54].

Terms related to modalities of engagement

Citizen participation

The term citizen participation seems to be used particularly in countries which are on their way to increased democracy, where citizen participation is the next step after citizen movements where the latter's purpose is principally to challenge the status quo and make way for reform [48, 62]. There may be a slight connotation of confrontation [63], thereby distinguishing it from community participation (see below).

Public consultation

Public consultation is the process of gathering information from the public, initiated by policy-makers in the context of the handbook [45, 64]. The main objective of public consultation is gathering information, with an insinuation that this is for policy purposes if the initiator is the government. Public consultations are often described as a mainstay of democracy since listening and responding to the public's voice and concerns is at the heart of democratic ideals [45, 65].

Participation, public participation

Participation is often used in relation to democratic ideals as well as empowerment [63]. Public participation in (health) policy is viewed as a process by which the government actively seeks out the public's views and inputs with regard to a decision or a way of civil society to influence the political agenda [66]. According to Abelson and Eyles and Abelson and Gauvin, participation can range from being passive in nature, where inputs are sought, to a more active involvement of citizens in decision-making [66, 67]. The main objective of participation for civil society seems to be to hold the government accountable for their obligations towards the population, while for governments the objective is to increase stakeholders' ownerships and to improve responsiveness and uptake of policies [45, 64, 67]. Another important aspect of participation as highlighted in the literature is the focus on marginalized and minority groups, as it allows the population that has been excluded from political processes to be included in planning, research and action in the health sector [63]. Participation therefore often also has a component of empowerment, as it weighs the input from members of the public equally with expert inputs [63].

Public engagement

Rowe et al. use public engagement as an overarching term for the full spectrum of the ways in which a government can involve civil society in policy-making. This can be one-way public communication to convey information from the government to the public; it can be a public consultation with the mere purpose of gathering information from the public; or finally, the involvement can include more active participation in decision-making (see the sections of each term for more detail) [64]. It is therefore the directional flow of information that distinguishes the forms of public communication from public consultation and public participation. Catt and Murphy pose the question as to who should be consulted – the

general public or a particular community, who represents each particular group's perspective and interests and how should the representatives be chosen (65). This question applies to all processes where input from civil society is sought.

Community engagement, community participation

The literature describes community engagement broadly as involving communities in decision making and planning (59, 68). Examples include needs assessment, community development, planning, design, development, delivery and evaluation (58). Some authors go a step further by using the terms collaboration, partnership and power sharing (60, 69). According to Williams (68), community engagement has become synonymous with legitimate governance. The WHO makes a clear difference between community engagement and community mobilization and considers community engagement as the process of developing relationships, which then allow for working together (57). While most of the sources use the two terms community engagement and community participation interchangeably, some authors, such as Paul (47), distinguish between engagement as being initiated by the government or policy-maker, and participation which is initiated by the beneficiary or client group with a view of enhancing their well-being. Similarly, Robertson and Minkler (70) describe community participation as groups identifying their needs and establishing mechanisms to meet these needs.

Overall, community engagement is seen positively as a powerful tool for bringing about improvements in the public services (60).

Deliberativeness, deliberative process

There appears to be a close link between participation and deliberation, where deliberation, or deliberativeness, refers to the provision of balanced, factual information or, as Blacksher puts it, "democratic talk" aiming at a fair process that yields public decisions, which all will view as legitimate (63). The aim of participation in health is often to engage different population groups in planning or research. By contrast, deliberative processes aim at creating conditions for reasoned dialogue, i.e. a participant in a deliberative process may come in with a certain viewpoint but the discussion may modify that viewpoint to include aspects of feasibility of implementation, the acknowledgement of opposition from other groups, and/or an understanding that the best possible solution for all may not be equal to the best possible solution for oneself. The assumption is that this type of dialogue can lead to well-considered judgements about health issues (63). Abelson et al. specify that the information provided includes diverse perspectives to provide the opportunity to discuss a wide spectrum of viewpoints to challenge competing moral claims (71).

The terms deliberativeness, deliberative process and public deliberation are used more often in documented processes of public deliberation in health which have been initiated by researchers (71).

In health care, deliberation has been used in developing policy guidance or recommendations; priority setting; provision of guidance on ethical or value-based dilemmas; assessing risks and determining who should have decision-making authority (72).

Social participation

Social participation may be the most encompassing term of any form of participation, which, at the same time, does not seem to be widely used in the literature reviewed. According to Chan (55), social participation means that social actors group their collective potential to achieve a collective good. Boje in contrast uses the term more broadly for social activities in everyday life, ranging from labour market involvement, family matters, community networks to advocating for democratic rights, indicating that it can refer to informal relations as well as active or passive membership in formal organizations (73).

1.6 Participatory spaces: a summary overview

A participatory space is one where people come together physically or virtually to interact with one another. Various modalities, techniques, instruments, and methods – often subsumed under the term 'mechanisms' in this handbook - are used by organizers of such spaces to foster communication and debate within the space (64, 66, 74-76). As Rowe and Frewe note "involvement as widely understood... can take many forms, in many different situations..., with many different types of participants, requirements, and aims..., for which different mechanisms may be required to maximize the effectiveness..." (64).

This section's non-exhaustive overview of participatory spaces aims to ensure that handbook readers understand the most common constellations of participation. Methods used for purely communicating information to and receiving feedback from a population group, without allowing a back-and-forth between participants and/or between organizers and participants (such as surveys, polls, interviews, radio and TV emissions etc.) are not included here.

The focus of this handbook is on government-led or steered participatory spaces. The aim is to gather people together to deliberate on a policy question or challenge, ultimately to feed into national health planning and policy processes. Policy-maker-organizers must therefore carefully reflect on which mechanisms adequately foster meaningful and sustainable dialogue within the context of their participatory space, while achieving its stated policy objectives.

A caveat which merits special emphasis is that there is no single-best participatory mechanism available; all have their context and content-dependent advantages and disadvantages but also mechanism-inherent pros and cons. As always, due consideration must be given to the needs of the policy question and the envisaged participant profiles. Therefore, employing a mix of mechanisms to balance out the cons of each single one allows for a more balanced result. It also helps to better triangulate and validate findings and ensure good representativeness (see Chapter 3). Indeed, many of the country examples examined in this book employ several mechanisms in a longer-term process: for example, the National Health Assembly in Thailand, the Societal Dialogue for Health in Tunisia, the Etats généraux de la Bioéthique in France.

The participatory space labels given below mask their varied usage by different professions and practitioners. The functional equivalence of similar terms are often difficult to categorize, and uncertain and/or contradictory nomenclature having led to dissimilar terms being described using the same term, or essentially similar terms being described using different terms. In addition, not all of these mechanisms are independent from each other; some might be a stand-alone process for enabling engagement while other may include other mechanisms completely or partly (64).

Countries also have differing histories and traditions. In one setting, the widely used term in francophone countries *états généraux de la santé* can refer to a population dialogue with large population samples. In another setting in francophone Africa, the same term is used for convening a consultation which resembles a consultative workshop or meeting (74). This xample further highlights the importance of recognizing the terminology employed in different languages.

This section attempts to distill down the various terminologies into a brief overview of the different types of participatory spaces commonly used in health. At the very least, we hope this overview puts handbook readers on the same understanding of terms used in this volume.

In-person, open-for-all forums

The first broad set of mechanisms refers to **in-person, open-for-all forums** set up to reach the maximum number of lay people as possible. These participatory spaces are often termed **'citizen assemblies', 'citizen forums', 'public hearings', 'open-mic events', 'town-hall meetings', etc.** In francophone countries, the term **'états généraux de la santé'** (EGS) is commonly used. Sometimes, the above-mentioned terms express the overall participatory approach to seek societal input, sometimes it refers to a specific mechanisms used within one approach.

In essence, such mechanisms aim to capture the views, needs and expectations of a large cross-section of the population. The emphasis is on the large sample size, aiming to capture diverse and divergent views from many different segments of a population. Typically, these events are open for everyone to take part in. Interested participants convene in a physical place such as a conference centre, hotel, classroom etc. Due to its in-person nature, these spaces are limited to people living in the same geographical area. Information about the open-to-all events are disseminated as widely as possible in simple not-technical language; attendance depends on motivating people to attend and give input (74).

As elaborated upon in detail in this handbook, how far a specific participatory mechanism fosters meaningful interaction and dialogue is ultimately shaped by many factors, including its format and design as well as overall capacity-building elements available to prepare and strengthen the participatory space.

Apart from face-to-face dialogue spaces, participatory space organizers can take advantage of digital technologies through mediums such as **websites and social media platforms**. Digital mediums help disseminate information to a wider public while also encouraging different users to interact with each other. The main advantage is the possibility to reach out to an even wider public than physical face-to-face events would allow, enabling users to contribute from the convenience of their homes or smartphones as per their personal schedules. Downsides of social media include limited access to digital technologies by lower-income groups and senior citizens, as well as the anonymous nature of some inputs (75). Digial media alone is usually insufficient for a comprehensive and meaningful participatory approach, yet can play a key role in reaching out to youth and time-poor working professionals in a well-reflected mix of mechanisms which forms a participatory space.

Consultative methods with attendance by invitation

A second set of mechanisms encompasses **consultative methods**, examples being consultative meetings, policy dialogues, stakeholder consultations, and focus groups. Contrary to large-scale engagement mechanisms,

consultative methods refer to an open forum for exchange albeit with a smaller and closed, usually invited numbers of representatives of population groups and technical experts. The purpose is equally to inform decision-making processes, foster participation and buy-in from key stakeholder groups.

Consultative meetings, policy dialogue, and **stakeholder consultations** convene various stakeholder groups who bring in a certain expertise and/or a set of experiences in a particular area. Invited participants are requested to weigh in with their opinions and assessment on a specific policy question. Participants should be carefully selected to ensure adequate representativeness across different groups, such as professional associations, patient groups, civil society, district health authorities, interest groups, etc. In an aid-dependent setting, development partners are often present to provide input in addition to government experts. Due to the smaller group size, discussions can go more into depth on a technical issue, in comparison with large groups encompassing a large cross-section of the population (74).

Focus groups are a well-established method in qualitative research. Here, a relatively homogenous group of six-12 people convene who share similar backgrounds and experiences, differentiating it from general stakeholder consultations where the point is to have different types of people present representing a variety of views, expertise, and experiences. Focus groups offer the opportunity for homogenous groups to discuss a topic freely and interactively, which they might not feel comfortable to do otherwise. It allows for in-depth discussions and exploration of divergent viewpoints, judgments as well as behavioral insights and beliefs. They are also very useful to elicit information on tangible and intangible changes resulting from an initiative. The moderator uses general guidelines and protocol to help facilitate the discussion while note-takers record comments and observations which are jointly reviewed after the focus group session. Generally, several sessions are held on the same topic (64, 74, 75).

Deliberative engagement methods

Besides consultative methods, there is a wealth of so-called **deliberative engagement methods**. They also consist of a small group of carefully selected participants but with a heavy emphasis on preparing participants with information and evidence once selected, and providing sufficient time to reflect on and 'deliberate' on the issues at hand. Examples are citizen panels, citizen juries, planning cells, consensus conferences, deliberative polling, scenario workshops etc.

Citizen panels (e.g. health panels) are characterized by a facilitated group setting with around 12-20 people. Citizen panels may be given a longer mandate – several months or a year – to deliberate on various topics at different points in time. Many panels can also operate in parallel, each deliberating on a different topic, with the possibility of rotating membership to give more people the chance to take part. Citizen panels can act as a 'sounding boards' for governing authorities on key policy questions, while offering a way to build long-term relationships (64, 66, 75, 77).

Citizens' juries are composed of a similar group size, usually around 12-20 people, who are randomly selected to become jury

members. They receive detailed preparatory information and hear expert and/or witness evidence in order to then deliberate a matter amongst themselves at length to reach a recommendation. This mechanism can work well when prepared thoroughly with competent facilitation, with organizers sincere in their aim of providing a well-rounded information base representing all viewpoints. It can also promote consensus building and a 'common good' perspective on societal objectives for health, allowing the development of collective views to complement individual ones (64, 66, 75, 78). In France and Tunisia, citizen juries were used as complementary mechanisms to open-mic hearings. A similar mechanism are **consensus conferences**, developed in Denmark, where a citizen panel of 10-16 people formulate questions for an expert panel to respond to in a conference format. This dialogue between experts and citizens is open to the public and the media. Similar in design are **planning cells**, a concept developed in Germany where deliberations take place with 25 people divided up into cells of five people. Facilitated discussions between experts and citizens take place between and within the different five-person cells (64, 66, 75).

Deliberative polls, also called **deliberative opinion polls**, which are based on traditional opinion polls methods, include additional deliberative elements, attempting to model what the public would think if it had a better opportunity to debate on a topic. Polling samples may differ from 50 to 500+ citizens. Selected participants are polled twice, pre and post deliberations. In between, participants are given the chance to deliberate, and experts present evidence and/or are on stand-by for deliberats to answer questions. It offers a structured way to aggregate participant opinions at two different time points (64, 66, 75).

Another mechanism is a **scenario workshop**. Workshop participants obtain prior to the workshop a set of different scenarios, i.e. short overviews of a possible course of actions or events, which are then jointly discussed during the workshop. Unlike the above mechanisms, this group of around 30 participants mix decision-makers, experts and citizens into one debate. If done well and regularly, this can foster dialogue, collaboration and planning activities for future health decision making (66, 75).

All of these mechanisms emphasize the deliberative nature to elicit informed opinions from lay people and others about a specific health issue. Deliberative engagement modalities offer the opportunity to examine a topic in depth in a safe, non-intimidating environment, and can introduce new perspectives and innovative solutions while challenging prevailing habits (e.g. societal views on bioethical questions).

Formalized mechanisms with fixed seats for populations, communities, and/or civil society

The following participatory mechanisms are more institutionalized and may have a legal framework behind it: **Health Council, Health committees, district committees, citizen advisory boards, representation on steering groups** (for example, health sector coordination committees, Country Coordination Mechanisms of the Global Fund for HIV, tuberculosis, and malaria, etc.) **and review boards.**

Besides one-off events or mechanisms used at specific points in time as part of a

mixed-method participatory process, population engagement can also be sought through a set of more conventional, formalized or institutionalized mechanisms, i.e. patient health councils, health committees, hospital boards, steering committee etc. The commonality of these mechanisms is that certain seats are reserved for population, community and/or civil society representatives.

Health Councils, prominently used in Brazil and Portugal, are permanent political-institutional structures linked to the administrative system of a country. They can exist at various administrative levels, and are related to a policy area, for example, health. A law provides a foundation for the council's existence, and determines its nature, membership composition, as well as the objectives and the parameters of its structure and its functioning (75). The Portuguese Health Council, for example, is the government advisory body, with the objective of strengthening "citizen's power" in the National Health Service (79). Six out of 30 seats are fixed for civil society and patient associations.

Health committees, or **district health committees** are usually seen as the intermediary between the community and district health authorities and/or the health facility. The composition may vary, ranging from community members, health personnel, community health workers and local government representatives. The same applies for the degree of empowerment and its functionality; usually, the committee is involved in identifying locally adapted solutions in the provision of health services (74, 75).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1.7 Handbook case studies

The process of handbook development included primary data collection in nine countries under the guidance of the SPTN. The social participation experience of these nine countries are referred to repeatedly throughout the handbook, more so than to other country examples. A brief summary of each of the case studies' focus areas and main findings are thus provided in the following boxes for readers' ease of reference.

The case study descriptions offer useful insight into the diversity of experiences moulded by different country and micro-level contexts and needs. Clearly, no one-size-fits-all approach exists for participatory spaces, yet definite themes emerge which are dissected in detail throughout this handbook and reflected on in subsequent chapters.

Box 1.2

Burkina Faso (17)

Description of participatory space studied

Government-civil society dialogue spaces for the development of the National Health Financing Strategy for Universal Health Coverage (SNFS-CSU in its French acronym) were: SNFS-CSU drafting committee, SNFS-CSU health financing thematic committee and the steering committee.

The drafting and thematic committees organized consultative meetings with civil society groups while the steering committee had civil society representatives as core members.

Multiple dialogue options between government and civil society, other sectors, and external development partners were built into the Strategy development process with the aim of increasing population ownership and facilitating subsequent implementation of the Strategy. A multi-stakeholder steering committee, chaired by the Ministry of Health, consisted of representatives of civil society, the private sector, other ministries and international partners. Its task was to coordinate the development process with different stakeholders and ensure a high-quality Strategy.

Study objectives

To understand and draw lessons on the role of civil society organizations during the development of a national policy, i.e. the SNFS-CSU, and evaluate their contribution. The specific objectives were to assess how far the participatory spaces available to civil society were effective in amplifying their voice in the SNFS-CSU.

Main findings

Equitable access to health care is a major challenge in Burkina Faso. Thus, the adoption of the SNFS-CSU was seen as a key step towards UHC. The Strategy development process kicked off in February 2015 with a strategic orientation workshop, followed by several meetings of the drafting committee and the health financing thematic commission. A draft SNFS-CSU was presented to the steering committee in May 2017 and was finalized in November 2018.

The main case study analysis results were:

- SNFS-CSU development coincided with a countrywide political democratization process which facilitated CSOs' increasing involvement in the political transformation of the country. Their role as active

stakeholders in policy-making processes thus enjoyed higher recognition in this context.

- In the health sector, where the role of CSOs was historically limited to service delivery activities, this led to CSOs starting to advocate more strongly for better social protection with universal health insurance, including payment exemption schemes for the most vulnerable.
- Civil society organizations, however, faced multiple strategic as well as practical challenges in contributing meaningfully to the SNFS-CSU:
  - The strategy development process was less of a political undertaking and had more of a specialized technical focus, which kept the process in the hands of technical ministerial experts.
  - Lay civil society representatives without this specific technical capacity were thus unable to meaningfully engage in technical discussions.
  - Stakeholder interviews underlined a perceived lack of civil society expertise and (technical) capacities.
  - Technical skills as well as the ability to communicate within a hierarchical context were highlighted as the main criteria by the Ministry of Health for selecting civil society representatives to take part in SNFS-CSU discussions.
- It was felt across the board that civil society is more of an operational actor whose contribution would be more relevant in the implementation phase rather than in the design phase.
- Logistical challenges for civil society participation were numerous: meetings were held in different parts of the country, with high transaction and travel costs for civil society representatives; meetings were convened last minute; invitations and other relevant documentation were not shared within reasonable timeframes; dialogue and consultation spaces were dominated by government stakeholders, both in numbers and in hierarchical positioning and speaking time, etc.
- However, Burkinabe civil society is growing and umbrella organizations like the permanent secretariat of non-governmental organizations in Burkina Faso (SPONG) and the National CSO Council (CNOSC) were founded to coordinate and strengthen civil society engagement and to amplify the communication channels between policy-makers and civil society.

Box 1.3

France (14)

Description of participatory space studied

This study examined the culture of 'health democracy' and social participation in France. Several participatory spaces at different administrative government levels were studied, including:

1) In 2018, a large-scale participatory approach, called 'Etats généraux de la bioéthique' (EGB), was used to obtain society's inputs as a basis for formulating an official recommen-dation for the revision of the Bioethics Law (56).

The EGB objective: obtain broad-based input on nine topics of bioethical relevance with the orienting question through¬out the participatory process being: what kind of world do we want for tomorrow?

The participatory spaces used were:
(i) 271 regional discussion events open to the general public: Around 21 000 participants took part in various event formats at different points in time across the country.
(ii) Online consultation via web site (57).
(iii) 154 civil society hearings.
(iv) Citizen jury: 22 citizens aged 18 and over were selected to provide anonymous feedback on the bioethics consultation process and methodology, and to deliberate on two topics in depth.

2) Regional Health Agency Supervisory Board is a formal advisory body of Regional Health Authorities (RHA) which includes civil society representatives. The RHAs were created with the explicit aim of creating responsive local health policies which contain population, community, and civil society input.

3) National Health Conference: As an advisory body under the Minister of Health, it aims to bring together different health system stakeholders, with a special emphasis on users, professionals and the public.

Study objectives

- To understand how the different social participation mechanisms within the culture of 'health democracy' work in France, with its unique historical background and participatory space genesis.
- To assess the extent to which population, community, and civil society voice is amplified through the various participatory spaces in place.

Main findings

- Spurred by the 2002 'Kouchner Law' affirming patient rights, the last two decades has seen a slow cultural change in government health institutions towards an understanding of social participation as necessary for health sector development.
- However, despite many inroads made, specialist experts, government cadres, and health professionals still dominate decision-making in a technocratic system that still must make more space for people's voice and experiential knowledge.
- The movement towards regionalisation of public policies in health has contributed to bringing health decision-making closer to communities.
- Health professional groups enjoy huge influence in decision-making and this power base is difficult to call into question
- Stakeholders from all sides recognized. the importance of the legal framework and budget accorded to a newly-formed national-level patient association platform (UNAASS in its French acronym). It was seen as a key tool to amplify patient voice in health decision-making.
- Overall, the EGB was perceived as a huge success. Reasons which were repeatedly given for this are:
  - The mixed-method approach of the EGBs which helped reach out to a wide array of French residents.
  - Health is an accessible subject which affects and mobilizes all types of people from all generations.
- One important drawback for the EGB where more effort should be focused on next time is ensuring better representation of marginalized and vulnerable groups.

Box 1.4

India (19)

Description of participatory space(s) studied

All of the platforms created or strengthened through the 'communitization' pillar of the National Rural Health Mission (NRHM). Examples are: ASHA/Village Health Worker programme, Hospital Management Committees (Rogi Kalyaan Samitis), community and local self-governance bodies strengthened with access to untied funds, Village Health Sanitation and Nutrition Committee, Community-based monitoring processes.

Study objectives

- To (retrospectively) examine the scope of community participation, the platforms, systems, and structures for facilitating community participation, the influencing factors, the impact of participation, the successes, and the areas for improvement of community participation in NRHM.
- To assess the context specific factors that have contributed to and hindered the effectiveness of social participation in advancing the commitment to Universal Health Coverage.

The National Rural Health Mission was identified as the object of study because it was one of the most comprehensive health programmes in the country, it boasted an explicit pillar called 'communitization', and emphasized community ownership and systematic engagement with civil society as part of its mandate.

Main findings

- The intent of 'communitization' and social participation at the state, district, and local levels in the NRHM marked a significant shift towards achieving community engagement and participation in the Indian health system. Spaces and structures for participation were made available through the mission, and people used these platforms to participate. However, the effectiveness of these platforms was limited by leadership, political intent and capacities. They functioned effectively in cases where these factors were enabling.
- While the NRHM provided platforms for social participation, these platforms were largely limited to service delivery, and decision-making to a smaller extent. Therefore, the scope of incorporation of community voices in planning, governance, and feedback was more limited.
- Social participation in vertical programmes such as the NRHM does not always lead to mainstreaming and integration of this philosophy and approach into the wider health system.

Box 1.5

The Islamic Republic of Iran (80)

Description of participatory space(s) studied

Civil society networks, call centres, Health Houses, People's Participation Houses, local/regional/national health assemblies

Study objectives

This review of participatory governance in in the Islamic Republic of Iran took place in 2017 and 2018 within the context of implementation of the 2014 Health Transformation Plan (HTP). A specific emphasis in the HTP was placed on social affairs, giving rise to the need for this study's objective: to gain more insight into which participatory platforms in health work well and which work less well and why.

Main findings

- The creation and maintenance of the Deputy Ministry for Social Affairs within the Ministry of Health is a crucial factor in the current enabling environment for participation.
- Formal citizen participation in health sector programmes initially focused heavily on programme support and implementation, rather than having volunteers give input into evaluation or decision-making. This has begun to change.
- Civil society networks, call centres, and local/regional/national health assemblies are some of the platforms which are currently being supported and encouraged by the Iranian government. Taken together, they demonstrate an increasing recognition of the value of participatory governance in health programming and decision-making.
- The valued mediator role of civil society fills a vacuum in the health space between the people and government/service providers.
- However, mandates are blurred between the different types of civil society organizations in in the Islamic Republic of Iran, bringing with it a certain level of duplication and fragmentation.
- The National Health Assembly mechanism is potentially a huge opportunity to de-fragment the approach to participation in in the Islamic Republic of Iran, bringing together the various uncoordinated formal, semi-formal, and informal structures working towards improving the population's health.
- A more formal legal framework may be needed to ensure that participation becomes part of the fabric of the health sector's modus operandi.

Box 1.6

Madagascar (81)

Description of participatory space(s) studied

- District health committees which included district health authorities, health professionals, and community health workers.
- The community health worker cadre was seen as a key relay between communities and district health authorities.
- District-level workshops supported by an international NGO brought together district health authorities, community health workers, and community members.

Study objectives

To assess how and to what extent communities were able to influence district-level and national policy making processes, including challenges and obstacles for meaningful community engagement.

The study focused on a community health system strengthening approach undertaken by the international NGO Action Contre La Faim (ACF) in two Malgèsh districts between 2016 and 2019. This approach built on the district health committee structure and sought to strengthen its capacities with training programmes, consultative workshops, and technical support for community health workers.

Main findings

- The sociocultural and economic back ground of community members was a determining factor for the degree to which they were able to engage in participation exercises.
- Thus, the major obstacles identified for meaningful community engagement were largely related to sociocultural power-imbalances:
  - Asymmetrical power relations rooted in historical inequities (e.g. social and traditional hierarchies) and a (perceived) lack of community capacity (e.g. language skills, technical knowledge) strongly impacted on the ability of communities to enter into dialogue with policy-makers.
  - Established norms of engagement confined public community input to technical matters. Within the community, personal experience with the health system was not deemed appropriate to be raised and considered during planning and decision-making processes.
  - A general sense of mistrust in elites and fear of repercussions from decision-making levels prevented community members from raising difficult topics, e.g. corruption.

- Concept of representation through formalized health committees was not fully taken onboard by participants and thus limited the role of the committees as mediators between communities and decision-making levels.

- Efforts by the international NGO to strengthen participation capacities clearly showed that it is possible to diminish power imbalances. Fruits of those efforts include:
  - Increased recognition of the rel evance of community input to national planning originated through the process itself.
  - Adjusted format and design features supported the creation of a level playing field between stakeholders (e.g. use of local language, convenient meeting venue for community members, no direct exposure to hierarchies).

Box 1.7

Mexico (82)

Participatory space description

A non-exhaustive list of formal and informal mechanisms of engagement between government officials, and civil society and community groups, on sexual & reproductive health matters are:

- interinstitutional reproductive health group;
- national and sub-national groups for the prevention of adolescent pregnancy;
- annual family planning evaluation meetings in Oaxaca;
- regular civil society-government meetings
- regular 'feedback meetings';
- informational meetings at the Chamber of Deputies' Gender Equity Commission.

These include participatory spaces at both federal and state government levels. The specific objectives of the different spaces vary slightly, they may be to obtain information, discuss research findings, formulate policy implications, a combination of these, or many other possibilities.

Study objectives

This case study examined civil society advocacy in Mexico for improved budget accountability within the National Programme for Youth Sexual and Reproductive Health (SRH). The specific objective was to understand how the roles and capacities of CSOs in monitoring the programme SRH budget led to significant and positive changes in budget execution levels and budget transparency.

Main findings

A coalition of several civil society and community groups claimed and engaged in various participatory spaces with federal and state health authorities to advocate for more effective SRH fund allocations within the SRH Programme. The SRH programme's principal aim was to reduce teenage pregnancy in several highly affected states; its initial phase ran from 2013-2016, during which time this specific advocacy was undertaken.

- Adolescent SRH was recognized as a priority in the public agenda which opened up policy and budget dialogue opportunities. Government cadres seemed to be generally willing to listen to CSOs yet willingness to collaborate varied greatly, depended on administrative level and micro-environment.
- Lack of a culture of transparency first provoked resistance from government officials, in particular state-level finance personnel, when CSOs requested budget

monitoring information but this hesitancy was largely overcome by dialogue and demonstration of a win-win situation.

- A wide variety of organizations came together in this coalition, each with its own strength complementing the other's. The full array of necessary skills and capacities required to make the advocacy successful was thus present:
  - research and analysis capacities, in par ticular in budget tracking, to derive technically sound evidence in SRH and budget monitoring;
  - a strong link in communities combined with a perceived legitimacy to generate information and speak on behalf of community needs;
  - advocacy work based on research findings to various target audiences by adopting language to better convey messaging and policy outcomes.
- The coalition's claiming of and engagement in participatory spaces enabled national policy changes with a direct impact on programme implementation effectiveness:
  - Programme budget modalities, including a schedule of fund transfer, is made public as soon as it is signed by federal and state entities.
  - A new mandate limiting the no. of months it should take for federal-to-state fund transfer came into effect.
  - State authorities are notified of fund transfer from the federal government as soon as it takes place.
  - State government are obliged to report to federal government on the use of the funds.
  - A long overdue update of government criteria for purchasing goods and services was undertaken after recognition of it limiting the ability of state governments to execute the budget.
- The Freedom of Information (FOI) Act was pivotal in that it ensured a right to access budget information which could be claimed. Any requests falling under the FOI Act is managed by an independent institutions whose mandate is to ensure the realization of rights.
- The above-mentioned successes are remarkable but more headway still needs to be made regarding transparency and budget accountability in Mexico. For example, results from government budget tracking tools are still not publicly available despite repeated CSO requests.

Box 1.8

Portugal [16]

Description of participatory space studied

The Portuguese National Health Council (NHC) began operations in 2017, almost 25 years after its legal framework, the Basic Health Law, was passed. It is a government advisory body independent from the Ministry of Health with the mandate to increase transparency and accountability by bringing in user voices to shaping National Health Service operations.

It consists of 30 members who possess equal voting rights, six of which are reserved for civil society organizations; the rest of the members represent professional associations, regional health authorities, and academia. The Council is chaired by a President and a Vice-President, both nominated by the Minister of Health.

The National Health Council is the only Portuguese national social participation mechanism in health planning and policy-making. It is tasked with providing non-binding recommendations on health policy matters to the Ministry of Health and the Parliament. Council members deliberate and develop recommendations either through plenary meetings or in specialized commissions. The Council can issue recommendations and opinions either on its own initiative or upon request of the Government, on four main policy areas: the governance and implementation of government health programmes, the state of health in Portugal, the National Health Plan, and health research and innovation.

The Council issues an annual report on the overall health status of the Portuguese population, including recommendations for the Ministry of Health to address bottlenecks and challenges. The Council is expected to disseminate its analyses widely in the interest of promoting public debate about key health issues.

Study objectives

- To assess the role of the National Health Council as a mechanism for civil society engagement in national health planning and policy-making in Portugal; more specifically, to evaluate:
  - the ability of the NHC to amplify civil society voices, especially of marginalized population groups, in national health policy-making;
  - the challenges for equitable civil society contributions within the working arrangement of the NHC.

Main findings

- In terms of overall societal impact, the NHC was broadly perceived as pivotal for widening the participatory space and institutionalizing public participation in health policy-making. Its pluralistic membership was positively valued for its recommendations encompassing the views and expertise of a variety of stakeholder groups.
- Amplifying civil society voice was identified as a persistent challenge. Even though the NHC leadership attempts to level out power imbalances by increasing the visibility of civil society representatives during debates and within the working groups, civil society representatives are proportionally underrepresented and in the minority position when the council has to vote on decisions. Civil society members pointed out that experts and government cadres tended to share views and perspectives and thus voted similarly on issues.
- Civil society organizations account for six of the 30 members, which many felt limited their actual representativity of the Portuguese population´s pluralistic interests.
- Civil society representatives lack human and financial resources to compete with the strong role of other actors within the Council.
- Some stakeholders felt that the independence of the NHC needs further reflection, as its President and Vice-President are nominated by the government and civil society representatives are appointed by the Parliament. Additionally, the Council´s budget is allocated by the Ministry of Health.
- Given that the Council was only recently established, policy uptake of its recommendations could not be assessed within this case study.

Box 1.9

Thailand (15)

Description of participatory space studied

National Health Assembly (NHA)

The NHA's foundation is the concept of the 'triangle that moves the mountain', the vertices of the triangle representing government technocrats, policy-makers and politicians (referred to often as the 'government sector'); civil society, communities, and the population ('people's sector'); and academia, think tanks, and research institutions ('knowledge sector'). The core principle of the NHA is to bring together the three groups represented by the triangle corners to combine top–down and bottom–up approaches to achieve progress and reform.

The NHA passes resolutions each year in December on the principle of consensus yet they are not binding for policy-makers. The one-year NHA preparatory process is managed by the National Health Commission Office (NHCO) and includes the selection of resolution topics from submissions which any Thai citizen can make. They must, however, fulfill one key criteria: that all three triangle groups have been consulted -- ideally all three sides should co-design the resolution application. The triangular approach thus aims to create synergy through the constant interaction and exposure between the three different groups within the structured environment of the NHA process and its clear objectives.

The NHA Organizing Committee (NHAOC) then works closely with the initiators of the selected resolution topics to help fine-tune the specific subject matter which the NHA will debate on. The NHAOC also encourages a widening of the base of stakeholders who jointly formulate the resolution's objective, while simultaneously engaging in dissemination activities and hearings to ensure that lay citizens and other affected parties can provide input.

A large effort is expended by the 90+ staff body of the NHCO to work with civil society organizations, community groups, and provincial health authorities to build capacity for engagement with the NHA and other participatory spaces offered within the Thai health sector.

Study objectives

- To contribute to the Thai national reflection process on what works well and less well after nine years of the NHA (2007-2016).
- Draw lessons on the complexities and chal lenges of setting up and maintaining a social participation mechanism from one which is widely seen as a best-practice example.

Main findings

Firstly, all stakeholders across the board acknowledged that the NHA is an extremely useful platform for bringing together a wide and inclusive range of stakeholders to discuss complex health challenges on a regular basis. It is recognized as a national public good. It has proved particularly beneficial to civil society and community groups, as its very existence has motivated and empowered them to more meaningfully engage with the health policy-making process. Part of this success can be attributed to the attention accorded to the process by the NHCO rather than to the three-day event itself. This has allowed the NHA to steadily improve in quality over the nine year period reviewed for the case study (2007-2016).

It is important to put this success into perspective. Much of the NHA's longevity and progress can be attributed to its firm entrenchment into a much broader reform movement which began in the 1990s and culminated in the 2007 National Health Act which gave legal birth to the NHA. A few key personalities in pivotal positions in government and civil society supported the reform movement, championed the value of participation, and advocated for the NHA's institutionalization. The National Health Act achieved this, and with it came a solid anchoring in the legal architecture of the country, and thus, a sustainable long-term perspective.

Yet challenges remain. Thorough follow-up and implementation of resolutions, and their integration into health policies and decisions, remains a key challenge. The NHA Resolution Follow-up Committee is a step in the right direction in this regard, and their ultimate objective should be to embed the NHA process within internal government policy-making processes.

Representativity of constituencies is also a challenge. Increased capacity and coordination skills are necessary within constituencies to select the right representatives, with high-capacity constituencies able to select participants who represent the full spectrum of a constituency's views but the lower-capacity ones still need more support.

Finally, there remain some population groups who still do not participate enough in the NHA. A more thorough analysis of who is not participating is needed, with targeted outreach and adapted techniques to bring in the voices of non-participating groups.

Box 1.9

Tunisia (18, 83)

Description of participatory space studied

The Societal Dialogue for Health (SDH) programme created the following participatory spaces for exchange between the population, communities, civil society, health professionals, and government:

- Citizen's Meetings on Health
  Usually organized at a regional level, these meetings were by invitation and sought 'societal' input on specific health topics. Preparatory material were put together by experts and the Technical Committee beforehand. Especially civil society opinions and views were sought on precise, more technical questions.
- Open mic sessions
  These meetings aimed at hearing from all parts of society and touched up more general, overarching health topics such as what the future health system should ideally look like.
- Focus groups
  Focus groups were set up with communities who were not participating in other participatory spaces. Marginalized and vulnerable groups were thus targeted in these small-group, homogenously constituted sessions.
- Citizen's jury
  Approximately 100 people were selected by lottery from each of the governorates to form a "citizens' jury" with the task of pronouncing a verdict on specific questions linked to specific themes
- National Health Conference
  A large participant list including citizen jury members, associations, NGOs, trade unions, parliamentarians, and many other come together here to validate policies and decisions.

Study objectives

- To assess how far population, community, and civil society voice was brought into health policy-making through the Societal Dialogue for Health mechanism.
- To understand what worked well and less well in order to draw lessons learned for future SDH operations.

Main findings

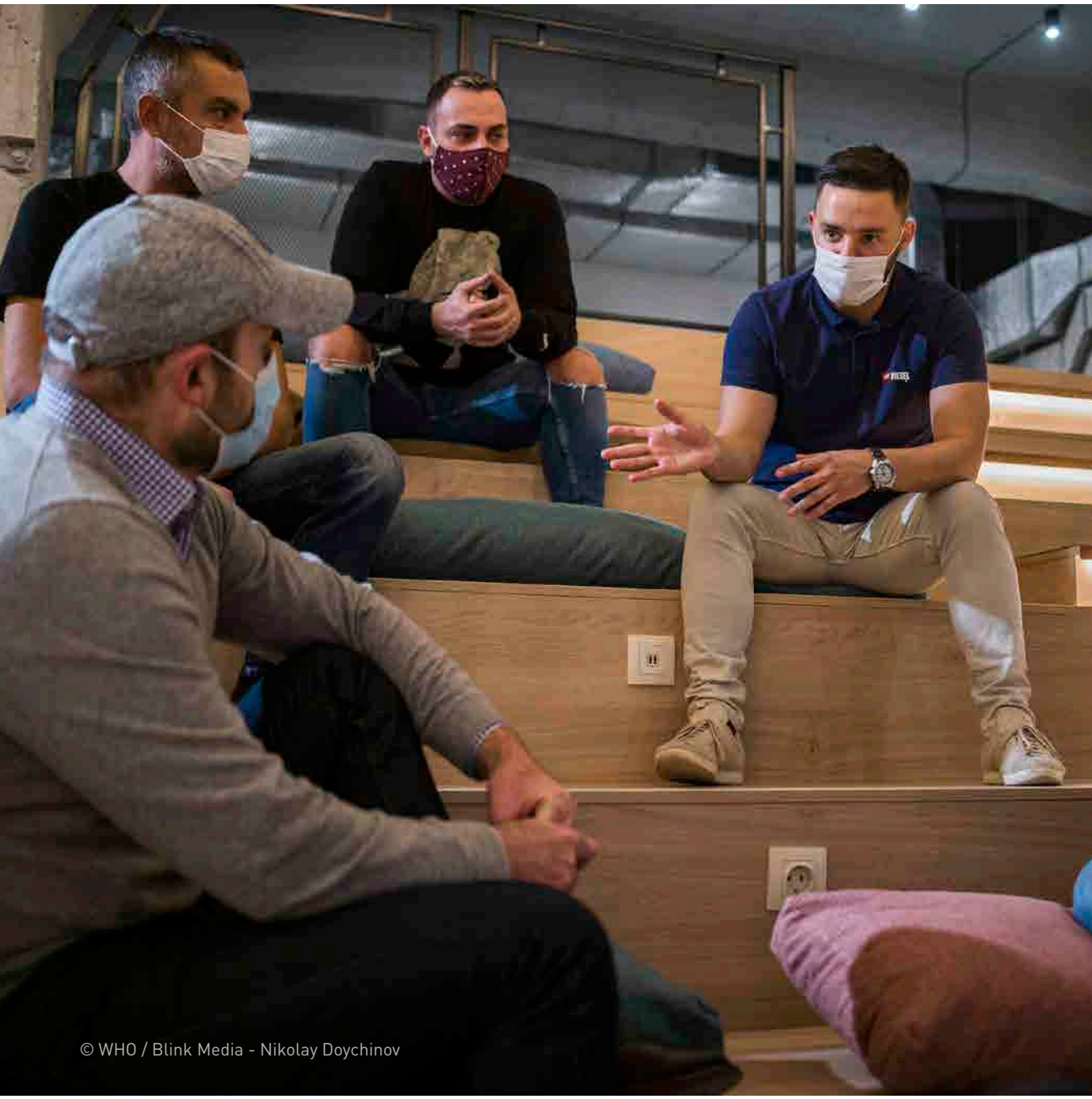
Following the 2011 Arab Spring revolution and considerable popular pressure, a funda¬mental reorientation of the health sector was needed. The Societal Dialogue for Health was launched in 2012 with great emphasis placed on the word "societal"

in order to highlight that the entirety of society's actors should have a say in how their health system is shaped (70). It is not a government institution per se and is largely run by civil society but has strong links to the Citizen Participation Unit of the Ministry of Health.

The SDH is run by a Steering Committee which includes civil society and high-level government representatives. Several working groups are coordinated by a Technical Committee which is also composed of civil society as well as mid-level technical Ministry cadres and WHO; their objective is to organize and prepare the different SDH events.

The main findings of this case study were as follows:

- Key success factors were the high-level political support as well as the availability of a core group of highly motivated and available citizens and experts to volunteer their time and knowledge.
- Flexible technical support of development partners provided not only catalytic funding but also technical expertise for running the different events.
- A key challenge was the fluctuation of Ministry of Health interest and involvement of key government technical cadres. This was overcome through painstaking and persistent advocacy and targeted outreach to government officials when windows of opportunity arose.
- Maintaining citizen interest to participate was another challenge. Periodic consultation meetings on the process itself, rather than only on content, seemed to help keep citizen interest in the SDH.
- Tensions between citizens and health professionals has been difficult from the very beginning. Separating the two groups for distinct discussions has helped but further dialogue techniques need to be reflected on and refined to enable more exchange between these groups.
- The next phase of the Societal Dialogue for Health should focus on ensuring better representation of a wider array of Tunisian society, reflect on anchoring the SDH process in a legal framework, build institutional links to decision- and policy-making, and develop a strategy to keep citizens and communities motivated to continue their involvement in the SDH.



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1.7 Conclusion

Social participation and participatory governance must be at the heart of countries' health system strengthening efforts as they tread the path towards UHC. This implies setting up, maintaining, and managing participatory spaces where people from all walks of society come together with experts and government cadres and anyone else relevant for the topic of discussion. Facilitating such a discussion in a policy-relevant way with the right group of people is challenging and complex. Investment in government and people's capacities to engage in such a space must therefore go hand in hand with its set-up and operationalization.

In this chapter, the handbook concept is introduced, including a brief summary overview of key definitions and a description of the main participatory spaces referred to in this handbook. The handbook's key underlying premise is then elaborated upon, i.e. that power relations which exist in society naturally carry over into a participatory space, and can even get consolidated within if countervailing power is not accorded to those with less of it. This can be done by thoughtful reflection of a participatory space's format and design, besides many other ways which are laid out in the following chapters of this handbook. The fruits of those efforts is more meaningful engagement of stakeholders with each other, which can be more effectively channeled towards relevant policy solutions.

References

1 World Health Organization (WHO). The World Health Report 2010: Health Systems Financing: the Path to Universal Coverage. Geneva: World Health Organization (WHO); 2010.

2 Cook FL, Jacobs LR, Kim D. Trusting what you know: Information, knowledge, and confidence in Social Security. The Journal of Politics. 2010;72(2):397-412.

3 Organisation for Economic Co-operation and Development (OECD). Transparency, communication and trust: the role of public communication in responding to the wave of disinformation about the new coronavirus: Organ- isation for Economic Co-operation and Development (OECD); 2020 [Available from: https://www.oecd.org/ coronavirus/policy-responses/transparency-communi- cation-and-trust-bef7ad6e/].

4 Marston C, Renedo A, Miles S. Community participation is crucial in a pandemic. The Lancet. 2020;395(10238):1676-8.

5 Bispo Júnior JP, Morais MB. Community participation in the fight against COVID-19: between utilitarianism and social justice. Cadernos de Saude Publica. 2020;36:e00151620.

6 Ryan NE, El Ayadi AM. A call for a gender-responsive, intersectional approach to address COVID-19. Global Public Health. 2020;15(9):1404-12.

7 Cornwall A, Gaventa J. Bridging the gap: citizenship, participation and accountability. Participation and Governance. 2002;8(23):1.

8 Irfan A, Arora A, Jackson C, Valencia C. Inclusive policy-making tools: a COVID-19 pandemic case study. Journal of Science Policy & Governance. 2020;17(1).

9 World Health Organization (WHO). Multisectoral preparedness coordination framework: best practices, case studies and key elements of advancing multisectoral coordination for health emergency preparedness and health security. Geneva: World Health Organization (WHO); 2020. Report No.: 9240006230.

10 Mosquera M, Zapata Y, Lee K, Arango C, Varela A. Strengthening user participation through health sector reform in Colombia: a study of institutional change and social representation. Health Policy and Planning. 2001;16(suppl_2):52-60.

11 Ad Hoc Task Team on WHO-Civil Society Engagement. Together for the triple billion: a new era of partnership between WHO and civil society. Geneva: World Health Organization (WHO); 2018.

12 United Nations (UN). Political Declaration of the High-level Meeting on Universal Health Coverage: "Universal health coverage: moving together to build a healthier world". United Nations (UN); 2019.

13 World Health Organization (WHO). Face-to-Face Meeting to support the development of the Handbook on Social Participation for UHC: meeting report. Geneva: World Health Organization (WHO); 2019.

14 World Health Organization (WHO), SciencesPo. France case study report: La démocratie de santé en France. Unpublished work. French.

15 Rajan D, Mathurapote N, Putthasri W, Posayanonda T, Pinprateep P, de Courcelles S, et al. The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016). World Health Organization (WHO); 2017.

16 Alves I. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work.

17 Zongo S. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French.

18 World Health Organization (WHO). 'Tunisia case study' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2018-2019. French.

19 Swasti Health Catalyst. Community Participation in the National Rural Health Mission (NRHM). Unpublished work.

20 Schmets G, Rajan D, Kadandale S, eds. Strategizing national health in the 21st century: a handbook. Geneva: World Health Organization (WHO); 2016.

21 World Health Organization (WHO), European Observatory on Health Systems and Policy. Health system performance assessment: working towards a common understanding. World Health Organization (WHO), European Observatory on Health Systems and Policy; 2021 (forthcoming).

22 The World Bank. World development report 2004: making services work for poor people. Washington DC: The World Bank; 2003.

23 Bigdeli M, Rouffy B, Lane BD, Schmets G, Soucat A. Health systems governance: the missing links. BMJ Global Health. 2020;5(8):e002533.

24 Gregory J, Hartz-Karp J, Watson R. Using deliberative techniques to engage the community in policy development. Australia and New Zealand Health Policy. 2008;5:16-.

25 Pagatpatan CP, Ward PR. Understanding the factors that make public participation effective in health policy and planning: a realist synthesis. Australian Journal of Primary Health. 2018;23(6):516-30.

26 van de Bovenkamp HM, Trappenburg MJ. Reconsidering patient participation in guideline development. Health Care Analysis. 2009;17(3):198-216.

27 Petit D, Zanamwe M, Rajan D. Background paper for Handbook on Social Participation for Universal Health Coverage: Definitions of terms related to social participation: a descriptive overview. Geneva: World Health Organization (WHO); Forthcoming.

28 Department for International Development. Government of the United Kingdom; [Available from: https://www.gov.uk/government/organisations/department-for-international-development].

29 World Health Organization (WHO). Social determinants: Civil society: World Health Organization (WHO); [Available from: https://www.who.int/social_determinants/themes/civilsociety/en/].

30 United Nations Children's Fund (UNICEF). [Available from: https://www.unicef.org/].

31 Overseas Development Institute (ODI). [Available from: https://www.odi.org/].

32 Liverani A. Civil society and social capital in North Africa. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

33 Kickbusch I. Citizens' rights and community mobilization. In: Figueras J, McKee M, Cain J, Lessof S, editors. Health systems in transition: learning from experience. Copenhagen: European Observatory on Health Systems and Policies; 2004.

34 Greer SL, Wismar M, Pastorino G, Kosinska M. Civil society and health: contributions and potential. Copenhagen: European Observatory on Health Systems and Policies; 2017.

35 Hein W, Bartsch S, Kohlmorgen L, Wogart JP. Conclusion: global health governance and the fight against HIV/AIDS in a post-Westphalian world. Global Health Governance and the Fight Against HIV/AIDS: Springer; 2007. p. 226-40.

36 United Nations (UN). Civil Society: United Nations (UN); [Available from: https://www.un.org/en/sections/resources-different-audiences/civil-society/].

37 Shanklin D, Tan J. A literature review: civil society engagement to strengthen national health systems to end preventable child and maternal death. Maternal and Child Survival Program. 2016.

38 VanDyck CK. Concept and definition of civil society sustain- ability. Washington: Center for Strategic & International Studies (CSIS); 2017.

39 Kanyinga K. Civil society and social capital in East Africa. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

40 Milani Filho MAF, Ribeiro Viana MS. Civil society and social capital in Brazil. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

41 Lyons M, Nowland-Foreman G. Civil society and social capital in Australia and New Zealand. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

42 Yachkaschi S. Civil society and social capital in Central and Southern Africa. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

43 Park T-K, Chang-Soon H. Civil society and social capital in Korea. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

44 Advisory Group on Civil Society and Aid Effectiveness. Civil society and aid effectiveness - synthesis of findings and recommendations. EC/UN Partnership on Gender Equality for Development and Peace; 2008.

45 Rodrigo D, Amo PA. Background document on public consultation. Organization for Economic Cooperation and Development (OECD); 2006.

46 The Commonwealth Foundation. Civil society engagement strategy. 2015.

47 Paul S. Community participation in development projects. Washington: World Bank; 1987.

48 Tsujinaka Y. Civil society and social capital in Japan. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

49 European Commission (EC). Civil Society: European Commission (EC); 2016 [Available from: https://ec.europa.eu/neighbourhood-enlargement/policy/policy-highlights/civil-society_en].

50 Pollard A, Court J. How civil society organisations use evidence to influence policy processes: a literature review, working paper 249. 2005.

51 Amburn B. An NGO by any other name...: Foreign Policy; 2009 [Available from: https://foreignpolicy.com/2009/11/17/an-ngo-by-any-other-name/].

52 Mohanty R. Civil society and NGOs. The Indian Journal of Political Science. 2002:213-32.

53 Paul JA, editor. NGOs and global policy-making. Global Policy Forum; 2000; New York: United Nations (UN).

54 Toogood-Luehrs K. Civil society and social capital in Central Asia. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

55 Chan K-M. Civil society and social capital in China. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

56 MacQueen KM, McLellan E, Metzger DS, Kegeles S, Strauss RP, Scotti R, et al. What is community? An evidence-based definition for participatory public health. American Journal of Public Health. 2001;91(12):1929-38.

57 World Health Organization (WHO). 7th Global Conference on Health Promotion: Track 1: Community empowerment [Available from: https://www.who.int/teams/health-promotion/enhanced-wellbeing/seventh-global-conference/community-empowerment].

58 National Institute for Health Care Excellence (NICE). Community engagement: improving health and wellbeing and reducing health inequalities. London: National Institute for Health and Care Excellence (NICE); 2016.

59 O'Mara-Eves A, Brunton G, McDaid G, Oliver S, Kavanagh J, Jamal F, et al. Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. Public Health Research. 2013;1(4).

60 McCloskey DJ, McDonald MA, Cook J. Community engagement: definitions and organizing concepts from the literature. 2013.

61 Mills S, Waite C. From Big Society to Shared Society? Geographies of social cohesion and encounter in the UK's National Citizen Service. Geografiska Annaler: Series B, Human Geography. 2018;100(2):131-48.

62 Natal A, Cadena-Roa J, Gordon S. Civil Society and Social Capital in Mexico and Central America. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

63 Blacksher E. Participatory and deliberative practices in health: meanings, distinctions, and implications for health equity. Journal of Public Deliberation. 2013;9(1):6.

64 Rowe G, Frewer LJ. A typology of public engagement mechanisms. Science, Technology, & Human Values. 2005;30(2):251-90.

65 Catt H, Murphy M. What voice for the people? Categorising methods of public consultation. Australian Journal of Political Science. 2003;38(3):407-21.

66 Abelson J, Gauvin F-P. Engaging citizens: one route to health care accountability: Citeseer; 2004.

67 Abelson J, Eyles J. Public participation and citizen governance in the Canadian health system. In: Forest P-G, Marchildon GP, McIntosh T, editors. The Roman Papers: Volume II: Changing health care in Canada. Toronto, Buffalo, London: University of Toronto Press; 2002.

68 Williams JJ. The politics of social change and the transition to democratic governance: community participation in post-apartheid South Africa. In: Pretorius J, editor. African Politics: Beyond the Third Wave of Democratisation. Cape Town: Juta; 2008.

69 Fawcett SB, Paine-Andrews A, Francisco VT, Schultz JA, Richter KP, Lewis RK, et al. Using empowerment theory in collaborative partnerships for community health and development. American Journal of Community Psychology. 1995;23(5):677-97.

70 Robertson A, Minkler M. New health promotion movement: a critical examination. Health Education Quarterly. 1994;21(3):295-312.

71 Abelson J, Blacksher EA, Li KK, Boesveld SE, Goold SD. Public deliberation in health policy and bioethics: mapping an emerging, interdisciplinary field. Journal of Public Deliberation. 2013;9(1).

72 Siegel JE, Heeringa JW, Carman KL. Public deliberation in decisions about health research. AMA Journal of Ethics. 2013;15(1):56-64.

73 Boje TP. Civil society and social capital in the European tradition. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. London: Springer Science; 2010.

74 Rohrer K, Rajan D. Chapter 2: Population consultation on needs and expectations. In: Schmets G, Rajan D, Kadandale S, editors. Strategizing national health in the 21st century: a handbook. Geneva: World Health Organization (WHO); 2016.

75 Participedia. Methods: Participedia; [Available from: https://participedia.net/search?selectedCategory=method].

76 Renedo A, Marston C. Spaces for citizen involvement in healthcare: an ethnographic study. Sociology. 2015;49(3):488-504.

77 Abelson J, Eyles J, McLeod CB, Collins P, McMullan C, Forest P-G. Does deliberation make a difference? Results from a citizens panel study of health goals priority setting. Health Policy. 2003;66(1):95-106.

78 Street J, Duszynski K, Krawczyk S, Braunack-Mayer A. The use of citizens' juries in health policy decision-making: a systematic review. Social Science & Medicine. 2014;109:1-9.

79 Serviço Nacional de Saúde. Conselho Nacional de Saúde [Available from: https://www.sns.gov.pt/entidades-de-saude/conselho-nacional-de-saude/].

80 Rajan D, Hadi Ayazi M, Moradi-Lakeh M, Rosami-Gooran N, Rahbari M, Damari B, et al. Chapter 4: Public voice and participatory governance in the health sector: status quo and way forward. In: Hsu J, Majdzadeh R, Harirchi I, Soucat A, editors. Health System Transformation in the Islamic Republic of Iran: an assessment of key health financing and governance issues. Geneva: World Health Organization (WHO); 2020.

81 Petit D. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

82 Colectivo Meta (COMETA). Case study on civil society involvement in policy processes in Mexico. Unpublished work.

83 Ben Mesmia H, editor. The Tunisian Societal Dialogue for health policies, strategies and national plans. WHO Information Network for Epidemics (EPI-WIN) Webinar; 2020; Online

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Chapter 2

An enabling environment for participation

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Handbook on Social Participation
for Universal Health Coverage

2.1 Introduction

Participatory processes are embedded within a country's social, political, and economic landscapes; these thus shape and define the prevailing ideas about participation and consequently influence its effectiveness (2-7). Contextual realities form the environment which shapes people´s attitudes towards participation as well as their abilities to participate (2). This chapter elaborates on these very contextual realities, with the basic premise that they are founded on power relations, be they political, economic and/or social in nature. The undeniable role of power relations in shaping contextual realities *(environment)*, and by extension, social participation efforts, is therefore scrutinized in the following pages. Specific policy-maker and civil society stakeholder actions which can make the environment more enabling, allowing social participation efforts to flourish, are subsequently laid out. These actions are at the centre of this chapter for two reasons. Firstly, because policy-makers, through their inherent power positions, have the ability to influence social participation processes to an uneven extent when compared with other social participation stakeholders. Generating ways to share this influence with other stakeholders is one of government actors´ major challenges in regard to creating an enabling environment for participation.

Secondly, civil society and community stakeholders also have options at their disposal to stimulate an enabling environment and government actors should be not only be aware of it but also actively support it.

> **“Power can also be understood as 'latent' and expressed as 'influence' in decision-making. From this perspective, there are no powerless individuals, but only people who are yet to become conscious about, and activate, their hidden power in order to exercise influence.”**
>
> Flores & Hernandez (1)

2.2 Objectives of this chapter

This chapter elaborates on the notion of a participatory space (see Chapter 1) where participants who are less powerful are empowered, to the maximum extent possible, to express their views and experiences without fear of reprisal or undue consequences. This is essentially what constitutes an enabling environment for more equal social participation. It signifies a humbling of voices who are usually more influential. In the following sections and throughout this book, we aim to demonstrate why this is needed, and how it is ultimately beneficial for *all* participants, *especially* those who are used to wielding significant influence such as policy-makers and government cadres. In the end, an enabling environment acts as a great catalyser for the participatory exercise to achieve its aims and expectations, however varied they might be.

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2.3 Enabling environment: conceptual clarification

Power dynamics end up creating unequal conditions for (social) participation because they

(a) pose structural barriers to participation for some parts of the population while

(b) (sometimes inadvertently) increasing access to decision-making structures for other parts of the population.

In order to understand those power dynamics, power must be defined, especially with relevance to the health and policy-making context.

What is power?

Power can be a controversial term with multiple perceptions and inherent facets. This is precisely why a clarification is needed for purposes of social participation and for this handbook.

First of all, this chapter does not claim to fully address the theoretical foundations of the concept of power. The main goal here is to consider the practical applications of the notion of power which are relevant to the idea of more equal social participation. In this vein, power can be understood as "an ability to achieve a wanted end in a social context, with or without the consent of others" [8]. Power thus relates to the ability to control and influence the use of resources – be it human, financial, intellectual (i.e. knowledge), or material – needed to achieve that "wanted end".

A pertinent aspect of power is its dynamic character. It can manifest within different social, economic, and political relations at any time, both between individuals and between groups within local health administrative levels, between local and national levels, and within the national level [9, 10]. It is pervasive because power underpins the conscious and sub-conscious principles which define the prevailing rules of society. A logical consequence is that they form society's policy choices.

A participatory space, when viewed through the lens of power, is essentially a political and societal process. Seen this way, power is thus the driver behind of who is included and who is excluded [11].

Power, in relation to social participation, is not only limited to formal power, i.e. manifested explicitly through formal (political) institutions. Informal types of power are implicitly, and sometimes subtly, also manifested in relationships between individuals or groups of individuals (11). Power imbalances are thus not always obvious nor conscious. An overt manifestation can be social status and socially hierarchical titles, while a covert manifestation might entail certain assumptions and prevailing beliefs regarding the abilities and characteristics of individuals and/or communities. However, both formal and informal power imbalances reinforce each other and usually lead to an uneven dialogue between stakeholders (10, 12).

Power and health policy-making

Power frames health policies in multiple ways, beginning with who is allowed at the policy-making table to how the negotiations take place between stakeholders on resource distribution and priority setting (13).

Power imbalances exacerbate (social, economic, and political) inequalities, even more so when it interacts with other vulnerability characteristics such as gender, religion, class, ethnicity, etc. (14). Health needs and experiences are greatly coloured by these characteristics (14) but vulnerable groups' inherent position of power inferiority means that their health needs are often not at the centre of health policy dialogue. Ultimately, power thus determines which health system challenges are addressed and prioritized (15). In the long run, misuse or abuse of power can therefore be understood as a key factor of poor health system performance (16).

Designing participatory spaces which counter the underlying reasons for unequal participation is a complex challenge because formal and informal power is exercised concurrently and incessantly by multiple actors at multiple layers of the health system (and beyond), sometimes deliberately (but not necessarily), and each with a differing rationale (12). Thus, participatory processes whose objective is to influence policy-making and priority-setting must contend with different types and peculiarities of influence and power.

2.4 An enabling environment: key issues to reflect on

This handbook aims to convince readers that conscious and visible efforts to level out the playing field within a participatory space is the single most effective contribution policy-makers can make towards an enabling environment for participation. Those efforts must acknowledge and take into account the following issues:

Power imbalances exist at both the macro and micro levels of society

Power imbalances can be found not just between different population groups (e.g. rich vs poor) but also within groups, often called intra-community inequalities (17). For example, even within the lower socio-economic strata of society or within a certain minority ethnic group, men usually still hold more influence than women (15). These power-related micro-dynamics shape all levels of society and impact heavily on participatory space interactions.

Vicious cycle: barriers to participation linked to power asymmetry exacerbate the imbalance even further

Many barriers to participation exist for the powerless and less powerful in society – these are explored in-depth throughout this handbook as exemplified in tables 1 and 2. An example of such a barrier are the costs of participation – direct costs linked to transportation and child care, for example, as well as opportunity costs from not attending work. These costs obviously increase in relation to the intensity of participation and are at the same time relative to people´s socioeconomic situations (18). Thus, the burden of social participation on socially and economically disadvantaged population groups is comparatively higher. This poses a major barrier to engage in a participatory space, aggravating the pre-existing societal power imbalance by ceding their place to groups which are already privileged or already influential to dominate a policy discussion (2, 3). Decision-makers must be keenly aware of this reality when moulding a participatory mechanism relevant for health policy.

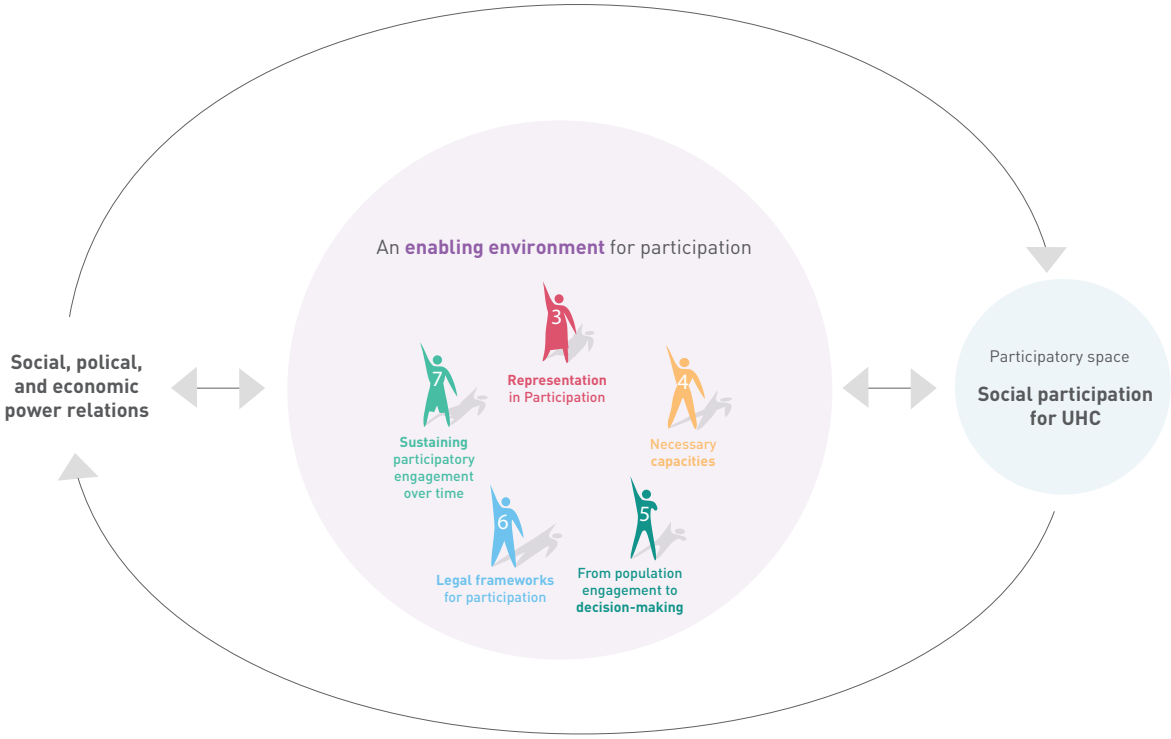
A participatory space can be a potent tool to minimize power asymmetries

As mentioned previously, meaningful, policy-relevant dialogue and exchange can only truly happen when visible and genuine efforts are made to devise a level playing field for participation. Indeed, some scholars even define participation as such, i.e. the "equalization of power relations in decision-making processes" (19). Thus, actions geared at bringing in people's voice into health decisions are in and of themselves a key means to reducing power imbalances. Having those with less power input and co-craft health policy can

fundamentally reshape power dynamics based on a participatory space's very notion of inclusion and fairness (20).

Hence, power and participation relate to each other in two directions (see Figure 2.1). The existing power imbalance can render a participatory space less meaningful and effective, but increasing the activity within that space with sincere intentions can tip the balance of power towards a more even power equilibrium. This then becomes a virtuous cycle because a more level playing field within the participatory space enhances meaningful dialogue and debate. This can increase the legitimacy of results derived from that space, thereby more sustainably influencing policies which empower and lend agency to groups with traditionally less voice and power.

Figure 2.1: Power and participation influence each other



Therefore, the principal means to attain the objectives which a policy-maker sets out for a participatory space is to create an environment where power imbalances ingrained in a country's political, social, and economic circumstances are evened out as much as possible. Chapters 3 – 7 in this handbook lay out which steps to take to do this, focusing on the key issues facing decision-makers when managing a participatory process. We specifically call attention to each chapter's link to an enabling environment in the next section.

An enabling environment for participation: format & design and capacities

Action by policy-makers is needed to address structural and other barriers for participation which exacerbate power asymmetries. While the details of those actions are the subject of the following five chapters, we summarize salient points specifically linked to creating an enabling environment in the ensuing two tables. The first focuses on actions linked to the **format and design** of the participatory space, including preparatory activities, which policy-makers can undertake to contribute to an enabling environment. The 2nd table examines the policy-maker **capacities** needed to ensure an enabling environment for participation.

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The format and design of a participatory space

can contribute significantly to reducing power imbalances and facilitating an enabling environment for participation. Format and design of the entire process is alluded to here, starting with the preparatory phase moving into the actual discussions within the participatory space, as well as follow up activities. The following tables will thus highlight what actions are most relevant to contribute to a level playing field and what government actors can do to ensure that power imbalances can be minimized as much as possible.

Format and design actions which contribute to a level playing field

Make human and financial resources available for (independent) participation

Chapter

Why is this important?

Involving the population, communities, and civil society in policy, planning, and decision- making requires adequate and available resources (21). The most prominent type of resources are human and financial resources, as well as time (22). Those who participate less generally are less well-off in terms of all types of resources.

To-dos

- Resources might be subject to political power struggles if allocated to participation exercises (23), especially if they are institutionalized participation mechanisms which have formal status
- However, a lack of logistic and financial support might challenge the (success) of the participation exercise (2) as it might be limited to those who have the means to participate.
- Participation is a process that will unfold over time and thus resources need to be long-term and reliable throughout the process (22).
- Government actors might need to find ways to support civil society in building (human) capacities and ensure financial flexibility (24), without compromising the independence and transparency of the process itself.
- Costs of the public participation processes should be clearly seen in relation to the benefitsin implementation (21), which might not be visible instantly and a temporary outweigh of costs might need to be accepted.

Be transparent about the participatory space

Chapter

Why is this important?

Transparency regarding objectives, participant selection, roles and responsibilities, format & design, and governance of the participatory space allows for equal levels of insight by all stakeholders, facilitating a more level playing field. Transparency also allows participatory space organizers to be held accountable for their commitments (18).

To-dos

- People need to know what their role is and how their contribution is going to be used (25). All stakeholders, the powerful and less powerful, should be given clear information on each participant's role as it legitimizes the roles and the representatives taking them on.
- The transparency principle includes an explanation of tools and techniques (26) and receiving feedback on information provided, i.e. addressing concerns of participants (27).
- One specific aspect of transparency is the provision of feedback to participants. Documenting and communicating how participants´ input was used and how it was considered for policy-making is also essential to increasing accountability (21, 29, 38).

Use a broad range of diverse dialogue techniques which are adapted to the different population groups

Chapter

Why is this important?

Different techniques can complement each other and cancel out each other's drawbacks. When used competently, dialogue techniques can be an effective means to strategically amplify people's voice in participatory spaces.

To-dos

- Techniques and tools should be adapted to the level of empowerment of the participants in the process (26). Examples include facilitation techniques which focus on bringing in views of those who speak up less, seating positions, location of the dialogue, small homogenous groups to make participants feel safe to speak up, translation facilities, etc.
- The mix of various techniques and tools needs to consider the time and resource requirements that might be necessary for participants to invest (30). Thus, tools and techniques might need to provide a balance between breaths and depths, depending on the availability and capacities of participants (21).
- The most relevant aspect for choice of tools and techniques is that they are able to include all participants in an equal, or even equitable, way to protect the process from any form of exclusion (21).

Provide opportunities for regular interactions within a participatory space

Chapter

Why is this important?

Increasing the opportunity to listen to each other helps cement an understanding of diverse views and builds trust and respect.

To-dos

- Invest heavily in participatory spaces and the capacities needed to sustain them over time
- Provide more frequent opportunity for interaction and reflection -- the more interaction there is between participants, especially between those with opposing views and backgrounds, the more likely it is that different groups will come to understand each other, whether or not they agree

Provide easy access to information and knowledge

Chapter

3
4

Why is this important?

Participants need to be provided with all necessary information and background to fully participate in the process (26). Knowledge and access to information is a source of power. Government stakeholders and experts generally have knowledge and information but the population, communities, and civil society do not always. Providing in-depth and accessible information is one means to balancing out the playing field.

To-dos

- Participants need to feel confident throughout the process, regardless of their socioeconomic background (30). One way to feel confident is to be well-prepared through access to relevant information and expert knowledge.
- Access to information and evidence in a timely manner allows opinions and interests to evolve and prepares the ground for fruitful debate (3).
- Well-prepared participants who feel that they are able to meaningfully contribute may feel empowered and are then able to contribute further to the empowerment of their communities (31).

Constantly cross-check who is NOT participating

Chapter

3
4
5
7

Why is this important?

The population, communities, and civil society might be constrained through various political and financial challenges. It is therefore crucial to closely monitor who is facing such constraints and therefore not participating in order to adequately fulfil participatory space objectives.

To-dos

- It is a challenge to understand who is (not) at the table and why (not). It requires willingness to recognise who represents whom and to what extent marginalized and vulnerable groups feel addressed by a participatory process.
- Participatory space organizers should look beyond formalized or institutionalized civil society partners to more informal groupings and local community groups to assess who is not present.

Provide post-dialogue feedback to those who have participated

Chapter

3
4
5
7

Why is this important?

Adequate feedback instruments and communication channels foster accountability (29).

To-dos

- Providing feedback on how participatory space results were used is a motivator for participation
- Demonstrating how participatory space results were useful increases the system-wide integration and buy-in of multiple stakeholders (26, 32-34). This can have positive effects on the implementation of policies (29).

Conduct regular evaluations of a participatory space to inform subsequent processes and to build evidence on what works well and less well

Chapter

7

Why is this important?

Public participation is a multistep process and not a one-time activity (35). One of these steps should be the evaluation of the entire participation process, including the preparatory phase, so that subsequent initiatives can benefit from the preceding ones. Evaluations should lead to an improvement of the process; this facilitates institutionalization of a mechanism which gives voice to the population.

To-dos

- Evaluation should focus on the process itself as well as on achieving its stated objectives.
- Evaluate what works, for whom, in what circumstances, by analysing the engagement processes, mechanisms and tools (36, 37).
- Evaluating the impact of a process which may take some time to reach policy goals is extremely difficult (37, 38); nevertheless, it should be undertaken, and all caveats underlined, as it can support policy- and decision-makers to inform subsequent participation processes (37) and make the case for participation among sceptics.

Table 2.1: Format and design actions which contribute to a level playing field

Capacities of government actors to level out the playing field

Policy-makers are naturally part and parcel of the web of informal and formal power relations. They must first be acknowledged and understood in order to learn how to actively promote a culture of participation. Democratic values and principles applied to the participatory space can catalyse and support government capacities. We highlight these and other selected cardinal government capacities for creation of a more equal social participation process – more information can be found in chapters 3-7.

Capacities needed to ensure a level playing field

Governments need to acknowledge that democratic principles and values are the foundations of a participatory space

Chapter

Why is this important?

Participation is intrinsically linked to basic democratic values of equality and social justice and relies on free and equal citizens (3, 21, 24). From a rights-based perspective, participation can be seen as a human right in itself that is essential for the achievement of other rights, for example, access to health care (2, 6). A participatory space for health, especially one where visible efforts are being made to equalize the balance of power, is thus a microcosm where democratic principles provide a foundation, whether or not such principles are adhered to in a country's overall politics.

To-dos

- Practicing the idea of more equalized citizenship involves giving people options to approach governments, independent of any government-led participatory exercise (1, 29). The openness to listen is signaled by such an approach to those whom decision-makers do not normally come in contact with – such as laypeople or civil society – thereby subscribing to the notion of health democracy.
- Democratic principles of listening to people, at least within the health space, includes acknowledging voices heard through demonstrations, protests, strikes, petitions, and campaigns via Internet. Taking unsolicited public engagement seriously can help to overcome social and politicalpower barriers (1, 5, 39). At the very least, acknowledging the messages that the population, communities, and civil society put across to decision-makers via such means is needed to increase the level of trust between population and government.
- In order to institutionalize participation mechanisms in health, and with it an anchoring of democratic principles in the modus operandi of the health (and perhaps other) sectors, legislation which enables participation is advantageous (21).
  The right to participate might already be enshrined in the country's constitution and can be leveraged as an endorsement throughout the exercise.

Understand and address social barriers to participation

Chapter

Why is this important?

Participation of marginalized population groups is determined by their "ability to participate".
However, in this context "ability" is a multifaceted concept that includes capacities, resources, as well as physical and social access. Thus, low socioeconomic status based on structural and economic inequalities may result in low access to institutional structures, including participatory processes (3, 18).

To-dos

- Even if economic and social empowerment cannot be the sole responsibility of the health sector, let alone through a limited participation exercise, it needs to be acknowledged as a structural factor that requires long-term investments (3, 40).
- Empowering marginalized population groups as individuals and as communities means embedding the recognition of barriers into the formulation of the participatory space objectives, format & design, putting a heavy emphasis on capacity-building, etc.
- Education, awareness-raising and information are further elements to promote empowerment and challenge social and power structures (1, 3, 40).

Maintain and communicate political commitment and genuine willingness to listen to people

Chapter

Why is this important?

Political commitment is decisive for effective participation (21, 30). From a participation perspective, the concept of commitment can be defined as the "willingness of politicians and public participation organizers to take action to achieve public participation" (21). However, the lack of political will is intrinsically linked to an inequitable distribution of power, money and resources, which makes it difficult for neglected groups' health system challenges to be of concern to those who have access to power structures. This is a vicious cycle which "keeps the marginalized marginalized" (20).

To-dos

- Political will and commitment need to be maintained and communicated even if impact and effectiveness of participation are not directly visible or equally interpreted by stakeholders.
- Getting communication right is a capacity which needs to be invested in.
- Communication channels between government and civil society should be are open and constantly broadened.

Provide post-dialogue feedback to those who have participated

Chapter

Why is this important?

Trust in the process and in the actors involved is essential for people, especially vulnerable and marginalized groups, to engage in a participatory space and express their views. A trustful relationship between civil society and governments allows for power relationships to change which can break down social barriers: passive (non-) receivers of care become active and informed citizens (civic empowerment) who participate in improving their health outcomes (6).

To-dos

- Participation can be leveraged to increase trust as it enables individuals to become a part of a collective effort (6).
- Stakeholders need to be taken seriously and treated with respect (2). This is foundational for trust.
- The strengthened partnerships that arise through regular interaction within a participatory space fosters relationships between policy-makers and people and thus positively impacts on the beliefs and opinions people have about the government (6).
- Participation can increase the accountability of decisions (6, 21, 23, 33), which also contributes to a relationship of trust.

Capacity to formulate a clear purpose for the participatory space

Chapter

Why is this important?

Transparently and competently formulating a clear purpose and goal for a participatory space is essential for effective public engagement (25, 26).

To-dos

- A lucidly nuanced objective statement is the basis for transparent communication. It can influence power relations and enable new political and social dynamics by lending a clear role and responsibility to those who generally have less say in decision-making (41). This competency needs to be prioritized among government cadres and supported by senior management.

Capacity to translate experiential evidence into information which is relevant for policy

Chapter

Why is this important?

Participation of marginalized population groups is determined by their "ability to participate".
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To-dos

- Even if economic and social empowerment cannot be the sole responsibility of the health sector, let alone through a limited participation exercise, it needs to be acknowledged as a structural factor that requires long-term investments (3, 40).
- Empowering marginalized population groups as individuals and as communities means embedding the recognition of barriers into the formulation of the participatory space objectives, format & design, putting a heavy emphasis on capacity-building, etc.
- Education, awareness-raising and information are further elements to promote empowerment and challenge social and power structures (1, 3, 40).

Capacity to formulate a clear purpose for the participatory space

Chapter

Why is this important?

Overcoming imbalanced power relationships which negatively impact on participation is a tall order as it represents a fundamental paradigm shift which can only happen slowly. It starts by fostering an institutional understanding and an organizational culture which comprehends and values social participation (28).

To-dos

- There is often a cultural resistance to participation within Ministries of Health (29) which should be examined and reflected on. It might be useful to dissect why civil society is often seen as an abstract construct unrightfully claiming power (42) instead of a potential partner for decision-making. This initial step can be helpful in devising strategies to overcome the cultural resistance.
- Governments can seek interaction with civil society stakeholders to increase their own exposure and learn from those interactions (3, 43). Experience demon- strates that more face time between stakeholders with each other increases not only understanding for each other's perspectives but also speedens the learning curve for all actors on the 'how' of participation. The old saying 'practice makes perfect' is relevant here!
- Accepting, tolerating, and listening to different types of people respectfully speaking their minds, even when their views are completely different or opposing to established ideas, can contribute to an (institutional) culture where people's views are valued. This needs to be practiced, trained, and learned by government cadres as well as the more powerful and influential in society.
- Governments who do not immediately have the capacity to manage a participatory space effectively can explore the advantages of a mediating body. Such an independent body can arbitrate the public discourse in order to reflect and systematize demands articulated by civil society as well as arguments articulated by government actors. One advantage of a mediating body is that it could potentially increase the legitimacy and quality of the participation process as it can translate information that is gathered through public consultations into actual policy priorities that can be taken-up by governments (21). Missing technical expertise and a lack of capability to define policy objectives from civil society could be thus mitigated. Additionally, a mediating body could act as an independent facilitator that can ensure impartiality as well as transparency for the participation exercise (30).

Table 2.2: Capacities needed to ensure a level playing field

5. Conclusion

This chapter focusses on conceptualizing power and stipulating its relevance for social participation. Power is manifested through formal and informal political, socioeconomic, and traditional hierarchies that create unequal conditions within societies. Thus, power dynamics determines how level the playing field is, thereby greatly influencing the effectiveness and quality of social participation.

To create an enabling environment for participation, governments need to understand and acknowledge the role power plays within social participation and ensure measures are put in place to reduce and ultimately diminish this imbalance of power. Two main areas which governments can focus on to address power asymmetries, and foster meaningful contributions from traditionally less powerful and disadvantaged population groups are:

- the format and design of a participatory space needs to counterbalance power disparities between participants;
- government capacities to understand and tackle formal and informal power relations need to be built.

This chapter serves as a connector between the participatory spaces (as outlined in chapter 1) and the following five chapters (chapters 3 to 7) by showing how a participatory space can be shaped to support meaningful engagement of stakeholders with each other by minimizing, as far as feasible, power asymmetries. By unfolding the relevance of power for an enabling environment, the chapter demonstrates the transformative potential that is embedded in social participation as it challenges societal conventions of whose voice should be heard, who should have agency over their own health and who should be empowered to meaningfully contribute to policy-making.

In summary, power imbalances need to be recognized as key obstacles to an equal interaction between stakeholders and thus, constant attention and political commitment are necessary to eliminate these obstacles and thereby create an enabling environment for participation.

References

1 Flores W, Hernández A. Accountability for health equity: galvanising a movement for universal health coverage. IDS Bulletin. 2018;49(2).

2 Williams JJ. The politics of social change and the transition to democratic governance: community participation in post-apartheid South Africa. 2008.

3 Abelson J, Blacksher EA, Li KK, Boesveld SE, Goold SD. Public deliberation in health policy and bioethics: mapping an emerging, interdisciplinary field. Journal of Public Deliberation. 2013;9(1).

4 Coelho VSP. What did we learn about citizen involvement in the health policy process: lessons from Brazil. Journal of Public Deliberation. 2013;9(1).

5 Matos AR, Serapioni M. The challenge of citizens' participation in health systems in Southern Europe: a literature review. Cadernos de Saude Publica. 2017;33(1):e00066716.

6 Meier BM, Pardue C, London L. Implementing community participation through legislative reform: a study of the policy framework for community participation in the Western Cape province of South Africa. BMC International Health and Human Rights. 2012;12(1):15.

7 Ruano AL. The role of social participation in municipal-level health systems: the case of Palencia, Guatemala. Umeå, Sweden: Umeå University; 2012.

8 Vermeulen S. Power tools for participatory learning and action. Participatory Learning and Action. 2005;53(1):9-14.

9 Mwisongo A, Nabyonga-Orem J, Yao T, Dovlo D. The role of power in health policy dialogues: lessons from African countries. BMC Health Services Research. 2016;16(4):213.

10 Global Health 50/50. The Global Health 50/50 Report 2020: Power, privilege and priorities. London, UK; 2020.

11 Eyben R, Harris C, Pettit J. Introduction: exploring power for change. 2006.

12 Lehmann U, Gilson L. Actor interfaces and practices of power in a community health worker programme: a South African study of unintended policy outcomes. Health Policy and Planning. 2013;28(4):358-66.

13 Sriram V, Topp SM, Schaaf M, Mishra A, Flores W, Rajasulochana SR, et al. 10 best resources on power in health policy and systems in low-and middle-income countries. Health Policy and Planning. 2018;33(4):611-21.

14 Hankivsky O. Intersectionality 101. The Institute for Intersectionality Research & Policy, SFU. 2014:1-34.

15 Benatar S. Politics, power, poverty and global health: systems and frames. International Journal of Health Policy and Management. 2016;5(10):599.

16 Sheikh K. Analyzing power in health systems: the case of medical dominance in India. BMC Proceedings. 2012;6(5):1-2.

17 Scott K, George AS, Harvey SA, Mondal S, Patel G, Sheikh K. Negotiating power relations, gender equality, and collective agency: are village health committees transformative social spaces in northern India? International Journal for Equity in Health. 2017;16(1):84.

18 Snow ME, Tweedie K, Pederson A. Heard and valued: the development of a model to meaningfully engage marginalized populations in health services planning. BMC Health Services Research. 2018;18(1):1-13.

19 Badou KR, Baldi V, Carpentier N. "Participation is a corrective of imbalances in power relations." An interview with Nico Carpentier. ESSACHESS–Journal for Communication Studies. 2018;11(1 (21)):5-25.

20 Friedman EA, Gostin LO. From local adaptation to activism and global solidarity: framing a research and innovation agenda towards true health equity. International Journal for Equity in Health. 2017;16(1):1-4.

21 Pagatpatan CP, Ward PR. Understanding the factors that make public participation effective in health policy and planning: a realist synthesis. Aust J Prim Health. 2017;23(6):516-30.

22 Gobermann-Hill R, Horwood J, Calnan M. Citizens' juries in planning research priorities: process, engagement and outcome. Health Expectations. 2008;11(3):272-81.

23 Frankish CJ, Kwan B, Ratner PA, Higgins JW, Larsen C. Challenges of citizen participation in regional health authorities. Social Science & Medicine. 2002;54(10):1471-80.

24 Ciconello A. Social participation as a democracy-consolidating process in Brazil. From poverty to power: How active citizens and effective states can change the world. 2008:207-17.

25 Kolasa K, Hermanowski T, Borek E. Importance of public participation in decision-making process in healthcare system illustarted with an example of the development of American and Polish scope of health benefit basket. Przegl Epidemiol. 2013;67(4):661-754.

26 Degeling C, Carter SM, Rychetnik L. Which public and why deliberate? A scoping review of public deliberation in public health and health policy research. Social Science & Medicine. 2015;131:114-21.

27 Campbell B, Tabiri-Essuman J, Gallo H, Verdiel V, Mandava L, Azhar MA, et al. Public consultation changes guidance on the use of health-care interventions. An observational study. Health Expectations. 2017;20(2):361-8.

28 Molster C, Maxwell S, Youngs L, Potts A, Kyne G, Hope F, et al. An Australian approach to the policy translation of deliberated citizen perspectives on biobanking. Public Health Genomics. 2012;15(2):82-91.

29 Woodford MR, Preston S. Strengthening citizen participation in public policy-making: A Canadian perspective. Parliamentary Affairs. 2013;66(2):345-63.

30 Gregory J, Hartz-Karp J, Watson R. Using deliberative techniques to engage the community in policy development. Australia and New Zealand Health Policy. 2008.

31 Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. The BMJ. 2002;325(7375):1263.

32 Guttman N, Shalev C, Kaplan G, Abulafia A, BinÐ Nun G, Goffer R, et al. What should be given a priority–costly medications for relatively few people or inexpensive ones for many? The Health Parliament public consultation initiative in Israel. Health Expectations. 2008;11(2):177-88.

33 Serapioni M, Duxbury N. Citizens' participation in the Italian health-care system: the experience of the Mixed Advisory Committees. Health Expectations. 2014;17(4):488-99.

34 Siddiqui FR. Annotated bibliography on participatory consultations to help aid the inclusion of marginalized perspectives in setting policy agendas. International Journal for Equity in Health. 2014;13(1):124.

35 Thurston WE, MacKean G, Vollman A, Casebeer A, Weber M, Maloff B, et al. Public participation in regional health Policy: a theoretical framework. Health policy. 2005;73(3):237-52.

36 Abelson J, Gauvin F-P. Assessing the impacts of public participation: concepts, evidence and policy implications. Centre for Health Economics and Policy Analysis (CHEPA), McMaster University, Hamilton, Canada, Centre for Health Economics and Policy Analysis Working Paper Series. 2008.

37 Mockford C, Staniszewska S, Griffiths F, Herron-Marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. International Journal for Quality In Health Care. 2012;24(1):28-38.

38 Conklin A, Morris Z, Nolte E. What is the evidence base for public involvement in health-care policy?: results of a systematic scoping review. Health Expectations. 2015;18(2):153-65.

39 Rohrer K, Rajan D. Population consultation on needs and expectations. In: Schmets G, Rajan D, Kadandale S, editors. Strategizing National Health in the 21st Century: a Handbook. Geneva: World Health Organization; 2016.

40 Kapiriri L, Norheim OF, Heggenhougen K. Public participation in health planning and priority setting at the district level in Uganda. Health Policy and Planning. 2003;18(2):205-13.

41 Maxwell J, Rosell S, Forest P-G. Giving citizens a voice in healthcare policy in Canada. The BMJ (Clinical research ed). 2003;326(7397):1031-3.

42 Mexico case study interviewee #1. Case study on civil society involvement in policy processes in Mexico. Unpublished work. Spanish.

43 Martin GP, Carter P, Dent M. Major health service transformation and the public voice: conflict, challenge or complicity? J Health Serv Res Policy. 2018;23(1):28-35.

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Chapter 3

Representation in participation

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Handbook on Social Participation
for Universal Health Coverage

3.1 Introduction

One of the most oft-cited concerns of stakeholders in participatory governance and social participation efforts is the (perceived) representativeness of those who contribute (1-8). The issue of representation is closely linked to the issue of legitimacy and credibility, the widely-held notion being that if those who are part of a participatory process are representative of whom they are supposed to represent (often the 'public'), then they are also considered legitimate. More importantly, the *results* of the participatory process are then also seen as legitimate.

The concept of representation is often not explicitly reflected on in many participatory processes yet it remains very present in both the participation literature and primary data collected for this handbook (9-16). Policymakers and organizers of participatory spaces struggle with the issue and "have no clear formula for assessing representativeness" (17). Some stakeholders propound an ideal of consulting a cross-section of the population at large, embodying so-called *statistical representation* (see Box 3.1). Yet in practice, this is administratively complex and costly, often rendering it unfeasible (18). Furthermore, as we will examine in this chapter, such an approach may not be useful in terms of the health policy question at hand.

What is representation, then, and what makes it useful in terms of participation which feeds into health sector policy-making? Boiled down to its essence, representation is 'acting on behalf of' someone, i.e. making them effectively present via a vicarious intermediary (6) because of the reality that not everyone can be invited. The idea is to ensure the same, or similar, expression of diversity (social or otherwise) through the participant group as exists within society, despite the smaller scale (19).

The pertinent question then becomes: *which expression of diversity is desirable?* Diversity in socio-economic class, in geographic residence, in the possible range of viewpoints on a specific topic, in ethnicity, in experience with the issue at hand... or a mix of these? It increasingly becomes clear that the answer depends heavily on the policy question or objective of the participatory process; adequately reflecting on and specifying this is critical to targeting the 'right' public who are considered legitimate to speak for themselves or on behalf of a constituency[1], and/or gain certain skills to do so during processes which are set up in a way that allows them to contribute in terms of a common good.

Representativeness for population engagement mechanisms is about getting the 'right' public with regards to the policy question at hand. The policy question needs to be precisely and clearly formulated and communicated in order to build a participation selection strategy on it.

1 A constituency refers to a particular group of people in society who are likely to support a person or an idea.

This leads us to the crux of this chapter and the conceptualization of representation which is most relevant for government-led participatory processes for national health planning and policy-making:

1. A well-reflected selection process can bring in participant diversity based on criteria which are adapted to the policy question at hand. This is based on inherent attributes of participants, their position and experiences in society, and/or their knowledge and exposure to pertinent issues.

2. The format and design of the participatory process can lend legitimacy and credibility to participants to represent a constituency (for example, the general public, a certain community, a patient group, etc.). This may be through their own personal experience, their expertise, or through their direct connections to the constituency. Legitimacy can thus be *acquired* through exchange and discussion when the format is thought through well and conducted sincerely.

The first point undergirds the importance for policy-makers to select participants based on the desired representativeness of a participant group or idea (9). The second point focuses on the representation role of individual participants, and how the participatory process itself can be instrumental in shaping that.

In addition, the representational role of individual participants and groups are recognized and bolstered by capacity-building initiatives. Government stakeholders also benefit from capacity strengthening, especially in terms of recognizing the benefits of participation for their own policy work as well as the practical 'how' of conducting participatory exercises and effectively undertaking 1. and 2. We discuss capacity needs in detail in section 6.

Box 3.1

Quantitative representation

(otherwise known as statistical representation or descriptive representation)

'Statistical representation' aims for a representative sample that reflects the characteristics of the total population (20); i.e. *'an exact portrait, in miniature, of the people at large'* (10). Random sampling is usually used as a method to select participants (5, 21).

The term 'statistical representation' is often used interchangeably with 'descriptive representation' (5, 21); the latter label emphasizes the use of demographic characteristics, such as age, ethnicity, education and income, to select representatives for a participatory process. The aim is the same: to ensure that the frequency of those characteristics in the participant groups reflects the frequency of occurrence in the population (22). Since the focus is on the frequency, or the quantitative distribution, of characteristics, Hainz et al. introduce the term *quantitative* representation (5, 21). The main advantage is that a quantitively representative sample of the public allows for a certain 'external validity' of results (23).

In this handbook, we employ the term 'quantitative representation' (as opposed to statistical, or descriptive, representation) and distinguish it from 'qualitative' representation (see Box 3.6).

3.2 Objectives of the chapter

This chapter thus aims to provoke the policy-maker to reflect on the central issues linked to

(a) selecting representatives and
(b) ensuring that the format and design of the participatory process lends participants the maximum level of legitimacy and credibility to represent the voice of the target public(s) of the participatory process.

The next section lays out the rationale for thinking through representation issues and explores the dilemma of representing so-called 'lay' people. We then go into the specifics of the selection process, the process format and design from the perspective of meaningful representation, and end with capacities which are necessary to fulfil representational roles.

Power imbalances affect the legitimacy of participants

The focus of this handbook is on government-led participatory spaces where it is imperative to acknowledge that governments (and in some settings, donors) have considerable power over how these spaces shape up, are used and are effective in actually giving voice to those who are affected by health policies (3). Acknowledging this reality also implies that the starting point of any such participatory space is imbalanced in terms of power and influence (11).

One source of power is clearly the legitimacy a participant may have, or be perceived to have, through their representativeness of a group, constituency or community. Some stakeholders may have their expertise (e.g. academics, health professionals) or governmental positions (e.g. Ministry of Health official) to legitimize their presence and contribution in participatory spaces. For lay participants or civil society organizations, it is usually not that straightforward. They often depend on representation of a group, community, or idea as their primary source of legitimacy, and thereby power and influence (24).

From the government perspective, one of the goals of a participatory space is to elicit and understand 'representative' views (25). Indeed, the reasons usually advanced by policy-makers as the rationale for social participation efforts emphasize the uniqueness of lay or civil society contributions as distinct from expert, professional, or government cadre input (20). This representative 'uniqueness' is what is sought after in its diversity.

Box 3.2

What or whom does a participant represent?

Policy-maker-organizers invite participants for dialogue within a participatory space in order to obtain diverse views representing:

- a constituency or community because the participant has regular interactions with those represented and/or has been selected by the constituency or community to be their representative;
- a constituency or community because organizers wish to hear an individual experience or view which they deem as potentially characteristic or typical for that constituency or community;
- an idea or perspective based on technical expertise.

Participants are therefore transformed into 'representatives' by virtue of the participatory process. Well-reflected participant selection as well as process format and design should lend legitimacy to the participants to *become* representatives; it should also render credibility to the participatory space as a forum to feed into decision-making.

Box 3.3

Participation & the balance of power

- Government-led participatory spaces are inherently imbalanced at the outset in terms of power and influence of actors.
- Organizers of participatory spaces often remain vague on details regarding whom they want to consult and why, leading to further power asymmetries and questioning of participant legitimacy.
- Transparency and explicitness about representation is needed to facilitate more equalized power relations for effective participatory outcomes.

However, those 'unique' contributions may not find a voice within a participatory space if policy-makers do not adequately account for pre-existing power imbalances among actors. One way to do so is to be explicit about representation, i.e. specify the expected representation or contribution (see Box 3.2) of each participant (for which the target public must be well-defined), and why each participant's presence is needed (for which the objective of the participatory process, event, or institutional set-up must be made clear). This explicitness lends legitimacy, and therefore power, to all representatives, especially to those who are lacking in it. It further facilitates buy-in from stakeholders whose interests and concerns can make or break successful implementation of health reforms (such as professionals and experts but also certain communities).

The credibility of a participatory space (also) hinges on legitimacy and representativeness

In practice, however, policy-makers often remain vague on whose views exactly should be solicited and what implications this might have for those who would be implementing policies such as communities or health staff on the ground (4, 11, 26, 27). As Martin asserts: *"staff [were expected to] recognize the legitimacy of participation, but [organizers] did not specify the terms of that legitimacy [which] reflects the frequent vagueness with which these broad policy intentions are translated into practice. Consequently, implementation becomes a matter of negotiation"* (11).

Credibility of the participatory space suffers when representation issues are not adequately thought through (18). The literature widely documents the problems associated with poorly designed representative selection: lack of transparency in selection criteria (6, 14, 16, 28), arbitrary selection of civil society representatives (29), and participation by the same familiar faces who are easily accessible and have resources (6, 30-33). The result is a further asymmetry of power and influence which can be mitigated with a more systematic approach to the selection process.

Another way this power asymmetry plays out is through the frequent use of representation (or lack thereof) as an argument to discard participation-based results during or after participatory processes. This may be due to a real concern for representativeness, but may

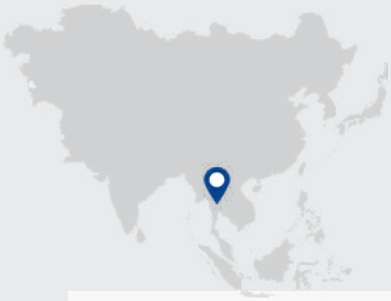
also be fueled by fear of losing control over the process, or losing (institutionalized) influence. Either way, the unease of government cadres and health professionals generated by the representation issue consistently proves to be a real challenge, leading to a potential negation of participation altogether (4, 11, 14, 26, 30, 34).

A vicious cycle can then ensue: if representativeness is not (seen to be) assured, the participatory space is not viewed as credible and it can be more easily abused and misused (11, 35). Tokenism[2] and the feeling of being manipulated are common complaints of civil society organizations, patient groups (2, 36), and the lay public (4, 5, 33), who are often in the minority (14, 16, 37, 38) in participatory processes, with government officials and managers sometimes conducting the exercise due to protocol or obligation (11, 33). This vicious cycle can be broken by devoting more attention to representation issues, making participant selection explicit and designing the process with legitimacy in mind (32) (see Box 3.4).

The risk of a low (perceived) level of civil society legitimacy is that more powerful interest groups, often the same high-capacity organizations, health professionals, experts, and/or lobby groups, crowd out the voices of those who are the main purported target of both the participatory space and health policy implementation efforts, potentially defeating the very objective of the exercise (1, 11, 24, 35).

The credibility of a participatory space is thus closely interlinked to legitimacy which brings us full circle back to representation and representativeness. Complicating an already complex topic is the fact that stakeholders have widely varying self-perceptions of one's own legitimacy and representativeness. In general, government stakeholders, experts, and health professionals tend to mainly question representativeness of lay people and civil society based on arguments of statistical representativeness and an elusive pursuit of 'experts in laity' (9, 11, 33). Members of the population, communities, and civil society often see their individual views and experiences as legitimate in and of themselves, worth bringing up and discussing in order to benefit the wider collective interest (9, 11, 39). Again, resolving this requires explicitness and transparency with regards to representation.

2 A 'tokenistic approach' in relation to participatory spaces is one where governments/organizers engage with the participants in order to fulfill legal requirements or satisfy a particular group of people, rather than conducting the exercise in the spirit of the law or policy. Engagement with population, communities, and civil society ends up remaining superficial and not always sincere, with government's/organizer's own interests predominating over the interest of society. Both a symptom and a cause of tokenism can be: civil society representatives are significantly underrepresented, organizers keep strict control of the rules of public engagement, i.e. the nature and level of public engagement fails to allow for meaningful public input (4).



Box 3.4

Constituency selection at **Thailand**'s National Health Assembly

The three broad constituencies (people's sector, knowledge sector, and government sector) for the National Health Assembly in Thailand are termed the 'triangle' constituencies based on the slogan that 'the triangle moves the mountain', i.e. all three forces must join together in order to bring about change.

The National Health Assembly (NHA) governance structure is thus tripartite, in that all three 'angles' must be represented equally. No one constituency has a privileged role in the NHA process when compared to another. The aim of representation within the NHA is to ensure complementarities of the varying perspectives of the three constituencies – the policy-maker view, the population's experiences, and the knowledge of those analyzing evidence. Unique to the NHA process is that every attempt is made to put all sides on an equal footing (through capacity-building, awareness raising work, etc., organized by the National Health Commission Office) with each other so they can each adequately fulfill their representational role and be complementary to each other. All constituencies at the NHA also have equal speaking rights.

Within the broad NHA triangle corners, the National Health Commission Office (NHCO) defines specific constituency groups with an assigned number of representatives, for example, 'civil society organizations working on HIV/AIDS, consumer protection or disabilities'. Each NHCO-defined constituency group organizes its own consultation process to select its representatives to raise their concerns at the NHA. Participants attend the NHA in their capacity as representatives of a NHCO-defined constituency group. Individuals wishing to take part in the NHA must thus first join a constituency group.

In general, the NHA is extremely diverse in its stakeholder base, with representation from government, think tanks, academia, civil society, communities, and private sector. The number of NHCO-defined constituency groups increases each year according to the resolution topics addressed at the annual NHA. No group is ever removed from the list; new groups are added each year as relevant. For example, at the NHA in 2016, there were 280 constituency groups, and the current NHA 13 accounts for around 350 constituency groups (32).

The representation conundrum: the 'ordinary' lay person does not really exist

The pursuit of laity by organizers of participatory spaces in health seems to be based on the appeal of consulting the 'common man' or 'common woman' who can provide 'ordinary' insights otherwise unavailable through other mechanisms (11). However, the 'common women' or 'common man' does not really exist in reality. Most people are not representative of a public in and of themselves, and no one person, or even a group of people, can necessarily represent the full spectrum of the public (24). In fact, some scholars assert that it is unfair to expect anyone to represent the public (40).

The dilemma is complicated by the mere act of participation itself – the more a person participates, the less 'lay' they become. The experience and exigencies of the participatory process can build confidence and skills (and this is often a stated objective), and thus create a more professionalized expert with the risk of then being branded as unrepresentative (26).

The conundrum continues when examining which lay people participate; experience shows a bias towards the elite in society, i.e. those who have time and resources, or a particular interest in the topic (11, 30). Yet, the latter group could be seen as having a potential conflict of interest, and therefore not very 'lay' (24).

Box 3.5

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 lack of running water at home, etc. In contrast to experts or health professionals who are requested to make judgments, ostensibly objectively, based on facts or specialized knowledge, lay people or patients are supposed to bring in a more subjective evidence based on their lived experience, or, in other words, a non-expert view (20). This 'expertise' is and should be more recognized among stakeholders as a source of legitimacy within a participatory space.

The boundaries are therefore fluid between lay, experiential, professional, and technical expertise (11), especially due to the increasing professionalization of civil society. This can lead to conflicting messages on participant selection. In one example from the UK, Martin describes leaflets used to enlist participants to a public forum which specifically calls for 'ordinary people' to apply but simultaneously extols the importance of *"knowledge or experience of a particular aspect of healthcare"* (5).

What is exactly the allure of having the ordinary person represented? It is effectively a question of (perceived) legitimacy lent by a participant selection which is random so as to provide a statistically representative sample

Box 3.6

Understanding the difference between quantitative and qualitative representation

- Quantitative representativeness is achieved if the frequency of prespecified characteristics within the (general) population is sufficiently represented within the participant sample. By creating a statistically quantitative sample of the population at large, often through random sampling, a certain level of 'external validity' of results can be achieved (23). The prespecified characteristics are usually demographic in nature, i.e. information that can be obtained through a population register, tend to be static (ethnicity, gender, etc.), and therefore easily verifiable in terms of their frequency within the population.

- Qualitative representativeness is achieved by guaranteeing the occurrence of prespecified characteristics within the sample even if these characteristics are not represented by the same frequency as in the general population. The underlying assumption is that these characteristics should be given more weight because they are relevant for the objective, or reason for selecting participants.

- Therefore, the aim with qualitative representation is to achieve a qualitative diversity of participants relevant to the participatory space objective instead of a quantitative proportionality often achieved by random sampling with access to population-level data (9, 21, 23, 26).

of the 'ordinary' population. Legitimacy is also given through an election with broad suffrage, the process of which boosts the authority of the elected person to perform a representation role through an explicit demonstration of population support by the ballot (5, 6).

Qualitative representation is more relevant for health sector population engagement mechanisms

As pointed out earlier, quantitative representation (i.e. consulting a proper cross-section of the population) and a general election process are administratively complex and costly (5, 18, 41, 42). Furthermore, the inherent failings of statistical or electoral representation are particularly relevant in terms of population input into health sector policy processes. Firstly, neither method guarantees that representatives mirror the population adequately in terms of characteristics relevant for health, which, besides the more widely available ones such as gender, ethnicity, or socio-economic status, also include health needs, user preferences, and health system experience (22, 37), which are not generally available in population registries. Also, elected representatives are not always representative of all voices (6) and are often contested by minority views or groups (24), the very target of policies aiming to improve health outcomes.

Secondly, inclusivity and 'leaving no one behind' is (should be) a key underlying principle of health policy-making with universal health coverage in mind. In general, the literature and case studies insinuate that *participant selection processes focusing on qualitative representativeness tend to be more successful in bringing in diverse voices* (11, 30, 43-45). Bringing in varied and marginalized voices means giving more weight to their views in relation to majority views, thereby abandoning the basic principle of quantitative representation. Bovenkamp et al. even caution that a collective voice is usually mobilized to protect the status quo (46). If real reform is desired in the health sector, individual voices should be particularly sought after as they usually stem from dissatisfaction and highlight system deficiencies.

Thirdly, many experts stress the distinction between (a) representing a population or population group through demographic characteristics and (b) bringing in a perspective of that population group, either by individual experience or through regular interaction and experience with it (25, 37). Strictly speaking, the full public is likely better represented as a whole through a quantitative representation approach. However, it is (b) which offers the most germane population, community, and civil society input in terms of health sector decision-making where policy options must address the needs and experiences of both individuals and populations.

Indeed, in addition to a more 'representative' *population* view, credible and useful input during participatory processes include personal experiences and perspectives as health system users, caregivers, family members, migrants, residents, citizens, etc. (9). This is expressed in the notion of 'experiential participation' where individual and shared encounters within the health domain is brought into public consultations and discussions (25, 37). Often, this experiential knowledge (box 5) is discredited as being unrepresentative, which some authors lament is due to professional-expert dominance in agenda-setting (11). However, as explored further in the next section, qualitative representativeness to bring in diverse views and experiences can strengthen the legitimacy of a participatory process, especially when the selection process is coherent with dialogue objectives (3).

Qualitative representation is thus more apt for health sector participatory objectives. However, this does not mean that quantitative representativeness is not useful in specific situations, especially when combined with selection criteria aimed at qualitative representativeness as well. The participatory process format and design are thus paramount; we elaborate on this further in section 5.

Box 3.7

Different terminologies and types of representation

Different terms are used to specify different types of representation, with definitions sometimes overlapping one another. Here, we aim to give readers a non-exhaustive overview of terms which are frequently employed in the literature and in practice.

For purposes of the handbook, however, we largely stick to two simple terms: qualitative and quantitative representation.

Formalistic - Electoral

Formalistic representation focuses on the institutional arrangements of representation, i.e. how representatives are formally authorized to act on behalf of others (17).
Electoral representation is an example of formalistic representation. Electoral mechanisms give representatives the mandate to represent the constituents' interests (6). Representatives are expected to be responsive and accountable to those being represented; they have the option to remove representatives or sanction them (17, 47). Representatives may or may not share constituent characteristics, and may or may not understand constituents' needs and preferences (5, 22).

Qualitative

Qualitative representation is achieved by guaranteeing the occurrence of prespecified characteristics (demographic ones but also characteristics such as viewpoints, experiences, but also other characteristics such as work location, relationship to a handicapped child, etc.) within the sample even if these characteristics are not represented by the same frequency as in the general population. The underlying assumption is that these characteristics are relevant for the objective, or reason for selecting participants, and hence are given more weight (21, 23).

Symbolic

Symbolic representation is related to the way in which representatives invoke meanings, attitudes, and beliefs in a symbolic way. A community leader is one such example, as he/she knows how to communicate locally, embodies meaning, and evokes common feelings and attitudes in those being represented. Symbolic representation is thus about the response elicited by the representative (17, 47).

Statistical

Statistical representation, descriptive representation, quantitative representation Statistical representation aims for a representative sample that reflects the characteristics of the total population (20); i.e. *"an exact portrait, in miniature, of the people at large"* (10). Demographic characteristics, such as age, ethnicity, education and income, are generally used as the standard type of information collected in population registries. The term 'descriptive representation' is used here as well (5, 21, 22).

Substantive

Substantive representation refers to representatives who take actions *on behalf of, and in the interest of those being represented* (17, 20, 47), regardless of whether or not the representative belongs to the same community or shares characteristics or background. Substantive representation is a typical role played by civil society and community organizations. The focus is on whose interests representatives pursue, not what the representatives are or look like (22).

Typical

Typical representation: an individual who is typical of others or who has similar characteristics or experiences is a 'typical' representative. For example, adults who have had allergies since childhood are seen to be typical of each other if the reference point is 'chronic allergy patient'. Emphasis is placed on the nature of the characteristic or experience. They do not represent a defined community per se. 'Typical' representatives' *personal, individual views* are then seen to be representative in and of themselves (20, 48).

3.4 Selecting participants: key issues to reflect on

A transparent and explicit selection process necessitates careful attention and reflection

As explored in chapter 1, the starting point in designing any participatory process is a clear objective and rationale, i.e. what is the precise reason for creating the participatory space(s), which question do organizers want answered by putting it in place?

Keeping that goal in mind, the target public or publics can and should be defined (see Figure 3.1) in a transparent and explicit manner. This is not a light task because those who are designated as 'the public' are given an inherent responsibility, power, and accountability by being defined as such (18). Especially when quantitative representation is not warranted, determining which people will represent which constituencies is certainly a central task of running participatory mechanisms (10).

For example, for large-scale population engagement mechanisms, the target public might mean the entire population of a country, region, or district. Yet not everyone is willing nor has the time, resources and capacities to participate. If participation is purely voluntary and reliant on people's interest, good will, and free time, the lay people who end up taking part through their own self-selection are usually middle class, educated, and/or retired... in the end, a small, selective group (4, 5, 20, 33, 46). This may be a good start; however, by comparing this group to the target public, i.e. the full population in this example, it is clear that many are being missed out. The next reflection process should focus on: what can be done to get input from and understand the views of those who are not participating?

Box 3.8

Critical selection process actions a policy-maker-organizer should sincerely reflect on:

- the objectives and desired outcome of the participatory space;
- which groups or individuals would respond to those objectives;
- where are there potential power imbalances and how can they be mitigated through participant selection.

The above question is one which can, on principle, be constantly posed at every stage of a participatory process to ensure that the full target public as defined by the participatory process objective is actually given a real opportunity to participate, ideally in an environment which truly enables all to participate (see Chapter 2).

Inadequate thought given to the representation issue can lead to further inequities as many participatory mechanisms may inadvertently reinforce societal hierarchies which may exclude women, minorities, marginalized groups, or others (15, 30). If only those who already have a certain degree of influence (e.g. interest groups and professionalized NGOs with resources and capacity) are present in spaces where participants' voice is given value, it is their already privileged interests which gets captured for health policy-making. These groups can have a place at the participatory table but not necessarily with a louder voice (depending on the policy question at hand and NGO structure).

Pro-active outreach to specific groups who may not be participating is often necessary, based on context (15, 31, 32). One Thai stakeholder expressed this sentiment by calling the National Health Assembly 'half-closed' (32), implying that some groups are left behind. Ensuring that those with community links, the marginalized or vulnerable are not among those groups is a decisive task of organizers of government-led participatory spaces.

Box 3.9

Selection process: to-dos:

- identify the target public(s) who correspond to the policy question;
- choose an appropriate mix of methods to select participants (more details in box 13);
- select participants in a transparent and explicit manner by clearly communicating roles, objectives and expectations;
- cross-check regularly during the participatory process whether the full target public as defined at the beginning is actually participating; if not, modify the selection strategy and reach out to those not participating.

Since there is no magical, single best participant selection method to use which is valid across all participatory mechanisms, a mixed method approach can help strike the best possible balance between the pros and cons of each method, and aid in having the 'right' (in terms of the policy objective) public participating. As explained in the following section, this could mean combining quantitative and qualitative approaches, or mixing open-to-all forums with focus groups for targeted, invited participants. Besides better matching policy objectives and the target public, a mixed-approach selection process may facilitate what Martin calls "representational authenticity" (5), that is, a jointly understood transparent, straightforward, clear representational role which is assumed and upheld by representatives.

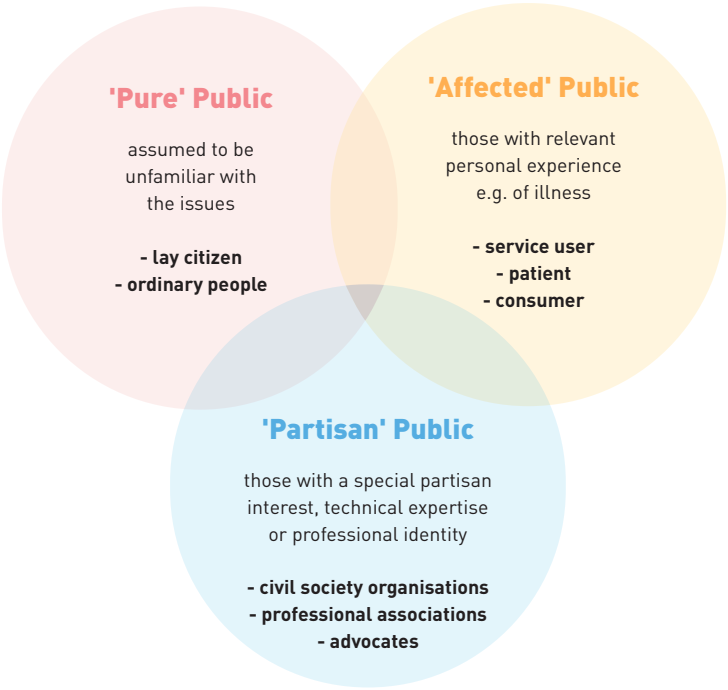
In summary, the participant selection process should support the aims of a government-led participatory space by using approaches best suited for the overall objective of obtaining feasible and practical policy options. This needs to be thought through and prepared well. Marrying the lay and experiential with the technical is needed; personal lay experience, community views, practitioner and expert knowledge must thus all be capitalized on through the thoughtful selection of representatives.

Understanding who the public is: different publics within society can assume varying roles in participatory spaces

The 'public' is in reality a blend of different mini-publics, with each person or group capable of being defined differently based on the role they are given and the objectives of participatory process. A patient living with diabetes would clearly be an *affected party* in a population consultation on diabetes but can potentially be seen as a *lay person* if the discussion is on a different topic such as youth sexual and reproductive health. Hence, the role given to a person or group in a participatory space depends on the topic at hand and the configuration of the space itself (33). In order to designate a role, however, a solid understanding of the different publics is helpful, while keeping in mind the caveat that the boundaries between the different categories are messy in practice, as exemplified by a hypothetical example of the diabetic patient, unbeknownst to organizers of the participatory space, who may have a pregnant teenager daughter and thus would not be an indifferent 'lay' person when discussing youth sexual and reproductive health.

Three basic constructions of the public are offered in the literature (18):

Figure 1: The three publics: a stylized schematic as a basis for understanding representation



As people and groups are multi-faceted, one can conceptualize the lay and partisan public as a spectrum where only a few participants will be squarely in one category or the other. Most will be placed somewhere in between; examining the characteristics of participants with this fluidity in mind during the selection process and design stage can help strike the most feasible balance in terms of avoiding 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. Nevertheless, using the structure of the three publics helps to better reflect on the different publics.

Box 3.10

Hazy boundaries between different participant roles

The blurry boundaries and potential contradictions between the different participant roles and identities are exemplified by Martin et al. They describe a theoretical participant of a population consultation who is both a taxpayer and service user (33).

Each role comes with different wants and expectations from service reforms. Those who use services more often may take on the role of a service user more, whereas younger, healthier participants may veer towards a taxpayer's perspective. In addition, there will be many in between who are able to take on both perspectives and may be best placed to give balanced input.

1. Lay public, often seen as the *pure* public

Citizens, the lay public, or ordinary people are those who are unfamiliar with the issue of discussion. The underlying idea is that an unaffected lay party should take part in a participatory space to reflect a more generic, unbiased societal interest (18). The lay public is targeted to contribute with more general public preferences and broad orienting goals that the population cares about such as universal health coverage (20). As pointed out earlier, this 'ordinary' person may not exist in reality or may be difficult to motivate to participate, precisely because he/she is unaffected. Nevertheless, it is important to keep the point of this public in mind in terms of selecting representatives for a participatory process: *to have a more unbiased, unaffected view on the topic*. For example, participants such as the diabetic member of the public mentioned above could be that person if the health sector topic does not concern him/her.

Especially because the same person or group or organization can take on different roles, organizers of participatory processes must be crystal clear as to the objectives and outcomes of the process. It is the very basis for thinking through which stakeholders are needed for which roles and ensuring that they are duly informed as such, while simultaneously accepting that the delineation between different roles may not be sharp.

2. The *affected* public

Alternative terms used for this group are consumers, patients, service users, etc. Depending on the discussion topic within the participatory space, the affected public could also be caregivers, family members, or community members living in a certain location (9). This group is thus directly defined by the participatory process objectives and expected outcomes. For example, if the topic of debate is air pollution's effects on health, all city dwellers may be the affected public vis à vis rural residents. If the topic is accessible care for the handicapped, disabled people and their caregivers may be the affected public. The notion here is that the 'affected' are those who live the reality of the issue at hand on a regular basis. Their experiential knowledge is what is sought since the lay public, as unaffected parties, do not possess this.

3. Organized groups, or the *partisan* public

This group is the most heterogenous as it can comprise of interest groups, advocates, non-governmental organizations representing an issue or population sub-group, a community organization, etc. The confines of this group against the affected public are not always clear as organized groups can be a cluster of affected individuals. Nevertheless, the main point here is for organizers of participatory spaces to reflect on the aim of bringing in representatives from this public in relation to the policy question at hand. That aim may be the reality that without interest group participation or buy-in, implementation may be difficult. It may be that certain communities are hard to reach but their voice can be more easily heard through a community-based organization intermediary. It may be because an NGO is respected within a certain health field and is involved in health service delivery. Depending on the context, a myriad of reasons can be given as a rationale to invite certain groups.

The partisan public may be better funded or better organized than the other two publics, hence they may have a more dominant voice 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 gather views of marginalized communities (e.g. elderly, migrants, LGBTQ) to improve health system responsiveness to these groups, then the selection process can ensure that those community representatives are present in large numbers and allowed predominance. On the other hand, externally-funded interest groups may have vested interests which are particular to a small group in society (49); their dominant voice may need to be equalized with other voices.

Some authors use the term 'sectional' interests when referring to this public, the notion being that a 'section' of society, or their interests, is represented in an organized way (20). Since the sectional, or partisan, public is a conglomeration of vastly different types of groupings, their mandate, funding, and vested interests should be examined closely and made transparent, in addition to their expected role in the process. The representativeness and legitimacy of the partisan public is especially vulnerable to be put in question if conflicts of interests and expected roles are not clear (46).

As a reminder, the objective of any selection process is to ensure that the voices which need to be heard in terms of the policy question are present and given a real chance to be heard. Part of this objective can also be fulfilled by the format and design of the participatory space but the selection strategy is also influential in this regard (9). Striving at all times to ensure a level playing field within the participatory space means being hyper-conscious of potential power imbalances and dominant voices, and mitigating them where needed, or purposefully not doing so if necessary. In order to 'purposefully' do anything, participatory process objectives must be lucid to both the organizers and all stakeholders.

Finally, since people are not unidimensional in reality, they can of course take on unexpected perspectives. An Italian study noted that the associations, or partisan public, in their health district Mixed Advisory Committees, were indeed able to take on a citizen-wide perspective, rather than sticking to a narrower patient-only view, the group they represented (37). This can also be reinforced through careful design of the participatory process, as explored in the following section. However, the message here is: *there is no need to strive for perfection in a qualitative selection process as people do not always behave as expected.*

Box 3.11

Conflicts of interest

Blurry boundaries between participant roles (see Box 3.10) can also mean that potential conflicts of interests may be unclear or easily glossed over. It is thus all the more important for organizers of participatory spaces to specifically look into any possible conflicts of interests, ensure that relevant ones are made transparent, and be prepared to deal with the consequences.

Careful examination of participant backgrounds may be needed in some contexts where people or organizations claim to represent a group or idea but may have another agenda altogether. While participatory space organizers should demonstrate transparency by being clear about objectives and expected roles, participants should be expected to disclose any motives which could contradict participatory space objectives.

Enhancing the lay and affected public's voice: the reality of volunteer participation

Volunteers are the backbone of population, civil society, and community participation. Unlike government cadres or academics who are usually paid for their time (as working hours) in setting up or contributing to a participatory space, civil society participation more often than not involves volunteers who are taking time and resources out of their normal day job or duties to participate.

As a first step, this needs to be recognized (and appreciated), including the consequences this may have on representativeness. Relying too much on volunteers can skew participant groups towards those who have time and means, for example, the privileged or the retired (4). Excessive volunteer reliance tends to exclude the poor, the working class (whose opportunity cost of participating is high), single parents (who are time-poor), minority groups (lack of motivation or understanding), etc. Also, due to time, and other constraints, volunteers who do participate may have limited capacities to fulfil their representational role adequately (37).

Relying on volunteers also gives undue space for professionalized civil society and academia who can afford to participate and have high capacities (14, 30, 33). Again, most of those associations have a clear and important role to play in participatory spaces but the balance of participation should not be tipped entirely in their favour. A high proportion of participants being professionalized civil society may raise concerns about representation and legitimacy – whether that is true or not depends heavily on the aims and objectives of the participatory space.

Volunteers are hard to come by, keep motivated, and retain. In the Italian Emilia-Romagna region's Mixed Advisory Committees for health, civil society organizations struggle to send representatives due to the paucity of available volunteers (37). Similarly, Bovenkamp et al. laments with regards to participatory spaces for health in the Netherlands: *"[T]here are too many opportunities for participation and many organizations simply cannot cope with this demand"* (36). A Portuguese Health Council representative emphasized in an interview that participation included not only the time at meetings and debates but also preparation time to feel technically competent so as to ultimately be considered a legitimate representative. On top of that, hidden costs such as transport and unpaid days off work need to be factored in, leaving many organizations struggling to fill volunteer positions (50). In Tunisia, the Societal Dialogue for Health relies heavily on a core group of volunteers who reported lagging motivation due to high population expectations and the challenges of obtaining results within the complexities and realities of government policy-making (51).

Paying, or covering the costs for, volunteers may be a solution but is not always feasible or desirable due to a number of reasons (see Chapter 7). In terms of representation, organizers must be aware of the skew caused by over-reliance on volunteers, and design a participatory space with counter-balancing measures.

Box 3.12

France's governmental advisory council on bioethics and its participatory approach to revise the bioethics law

The Consultative National Committee on Bioethics (CCNE in its French acronym) in France has the mandate to lead the drafting of a Bioethics Law every seven years. In 2018, the CCNE employed a large-scale participatory approach, called 'Etats généraux de la bioéthique', to obtain society's inputs as a basis for formulating its official recommendation (52).

Policy objective: obtain broad-based input on nine topics of bioethical relevance (defined by the CCNE). The orienting question throughout the participatory process was: What kind of world do we want for tomorrow?

Target population: the lay public (for a more unaffected, neutral view), the affected public (to understand the realities confronting people whose lives are affected by the Bioethics Law), the partisan public (hearing the voice of the numerous civil society organizations advocating for a certain group or viewpoint on specific topics).

Participatory spaces used:
(i) **271 regional discussion events open to the general public**: Around 21 000 participants took part in various event formats at different points in time across the country. The spirit of openness characterized the CCNE approach towards these events. Information about each of the open-for-all exchanges was disseminated as widely as possible, aiming to reach a broad base of French residents. Adolescents and young adults were subject to targeted outreach with roughly one third of the events held at high schools and universities.

Debates on the topic of artificial intelligence and robotics saw a higher turnout of young people. Otherwise participants tended to be older and of higher educational background. Notably, many well-resourced NGOs and lobby groups were very vocal and tended to dominate the discussion.

The self-selection strategy thus helped hear the voice of a particular sub-section of the population but not necessarily the marginalized, vulnerable, ethnic minorities nor adults with young families.

(ii) **Online consultation via web site** (53): CCNE leveraged its online platform to disseminate in-depth information to a wide audience as well as to gather further inputs. Nearly 30 000 people provided online input into the nine main consultation topics. Again, many civil society groups used the platform to advocate for their stances. Many members of the lay and affected public also contributed. Some groups may have not used the online possibility as much as others, particularly the elderly or those who are less at ease with digital technologies.

(iii) **154 hearings for the partisan public**: In 2018, the CCNE employed a large-scale participatory approach, called 'Etats Généraux de la Bioéthique', to obtain a statement of interest for an exclusive hearing with the CCNE. The response saw 88 health service user associations/interest groups, 36 think tanks/professional associations (scientific or medical), nine philosophical/religious groups, three private sector entities and 18 other organizations submitting such a statement. A hearing was then conducted by CCNE staff with the different organizations to understand in more depth their experiences and perspectives.

(iv) **Citizen jury**: 22 citizens aged 18 and over were selected to provide anonymous feedback on the bioethics consultation process and methodology, and to deliberate on two topics in depth. A market research institute was tasked to select participants who reflect the diversity of the French population in terms of gender, age, socio-professional category and place of residence.

Random sampling of volunteers from lists used for similar studies helped preselect potential citizen jury candidates. The pre-selected people were then requested to fill out a questionnaire which helped exclude the partisan public (people working for associations, trade unions, political parties etc.) who were already well represented through other events. More lay public representation was thus brought in to complement information gathered through previous exchanges. Citizen jury participants appreciated the safe space to express themselves freely; in particular, it was noted that young people were more vocal and active within the small-group citizen jury deliberations compared to the mass free-for-all events.

Overall, the Etats Généraux de la Bioéthique received a significant number of contributions, the fruits of a solid communication effort by the CCNE and a high level of population interest in bioethical topics. The partisan pubic seems to have given the most input which is not surprising given their organization skills and partisan interest in the topic. They may have crowded out other voices, such as the lay and affected public, in some spaces. It remains unclear how far, and how, the lay and affected public contributed in some of the larger consultation events as participant profile information was not collected. Both the partisan and the affected public seemed to have participated more actively in the online forums where experiential knowledge was shared.

The citizen jury process proved to be an excellent forum to obtain the lay public's views. An extra effort may be necessary the next time around (in seven years) to reach minority groups who face multiple barriers to access information as well as the participatory spaces themselves. Adults with young children might also have been left out due to time and other constraints (54, 55).

An additional effort is sorely needed to reach out to marginalized groups

The primary and secondary data analyzed for this handbook are clear on one point: despite all the grand efforts and sophisticated selection techniques used by the most mature participatory processes, marginalized and vulnerable groups still get left behind (30, 32, 46). A study shedding light on well-intentioned State Health Councils in Brazil emphasizes this message which is not unusual in institutionalized participatory mechanisms: *"Users with physical and mental disabilities, prisoners, and, in general, low-income segments of the population are insufficiently represented in [Health Councils]. Young people (both men and women) are scarcely represented, as are the various ethnic minorities"* (6).

Government-led, more institutionalized structures have the strong tendency to reinforce existing societal structures and power (29, 56). Without an additional effort to counterbalance these tendencies, those hierarchies and privileges can play out in participatory spaces. As laid out at the beginning of this chapter, the starting point of a participatory space led by government is inherently imbalanced as government, and its allies, tend to be the most influential. It is for this very reason that the constant attempt to create a level playing field should be made; one way to do this is to regularly review who is not at the table and find ways to reach out to those groups. *Not* doing so could lead to a false sense of inclusiveness where the views of some publics are actually actively eliminated from a process that conceals that reality (33).

Many strategies can be used to ensure participation of hard-to-reach groups. Long-term strategies include specific and targeted capacity-building efforts (see Chapter 4) to enable them to participate eye-to-eye with other groups. Short-term efforts include homogenous focus groups like in Tunisia where they may feel more comfortable amongst 'equals' (57), physically going to where such groups are located to listen to them in their own environment, and/or seeking them out in their workplace or during their day-to-day activities in order to overcome the barrier of being unable to take time off other duties.

Combining selection methods has the most advantages for government-led participatory spaces

Each system of selection comes with inherent plus and minus points (see Box 3.13). Carson and Hartz-Karp thus make the case for a mixed-methods approach: *"the weaknesses of one [can] be overcome by the strengths of another"* (43). Combining techniques also allows for a targeted and separate approach to selecting participants from each of the publics, as necessary, depending on the policy question. Ensuring the presence of different relevant public types goes back to the notion that each of the 'publics' have something distinct to add to a discussion – experts or health professionals as partisan publics are required for different reasons than the lay public in a participatory space (20).

In addition to thinking through participant recruitment from the different publics, an adapted approach might be additionally needed as discussed above for hard-to-reach groups. This cannot be repeated enough. Also, organizers must always reflect on how best to create a level playing field through participant selection and ensure that those who tend to crowd out other voices in civic spaces are counterbalanced (see Section 3.5) (58). Finally, no selection strategy will obtain perfect results as each system of selection can, and most likely will, be manipulated. However, the best possible and most feasible result can be obtained with due reflection to the representation issue.

Box 13 summarizes key selection methods within the qualitative representation paradigm.

Box 3.13

Selecting, recruiting, and reaching out to participants

We present here a non-exhaustive list of potential ways to select or reach out to participants with the aim of qualitative representation. Combining methods usually allows for a more targeted match between the final participant group and the participatory process objectives. That being said, it is important to keep in mind that every selection strategy is vulnerable to manipulation. *Therefore, the most important feature of any strategy is transparency of process, clarity of roles and objectives linked to the selection strategy, and adequate (collective) reflection on the pros and cons of each method.*

1. Self-selection among a constituency or community group or NGO coalition

Self-selection among a constituency can occur through various means, for example, by vote, appointment, or consensus. The self-selection method which works best varies by context or group or experience/expertise needed. The key question to ask is whether the group has the adequate capacity to self-select, and if not, building capacity to do so should be a priority (see Box 3.4). Capacity-building should focus on making the group aware of the different issues around self-selection, potential pitfalls, and adequate measures to remedy them.

Voting within a constituency can help bolster legitimacy of the selected representative, especially in participatory spaces where powerful people and groups exert influence. In Madagascar, for example, the design of the community health worker programme called for a community vote to select the community member for the job. Instead, many community health workers were appointed, either by the village chief or the health centre management. Stakeholder interviews evinced many doubts from different groups as to the real representativeness of the community health workers going back to the lack of a community vote (15). In India, district-level stakeholders reported more meaningful participation by community health workers who were chosen from within the community, usually by community vote (13).

Challenges with self-selection within a group can be that those selected tend to have the time and resources to participate, thereby over-representing the more privileged in society (4, 6, 46). In (most) societies where class structures and hierarchies are culturally ingrained, self-selection by appointment may reinforce them, with those locally in power choosing representatives who may understand and represent the majority but not the minority. For example, in many Asian countries, seniority as a form of hierarchy leads to few younger faces as heads of self-selected groups.

When the self-selection is within an NGO platform or coalition, all of the inherent challenges linked to volunteerism is valid, as well as the risk of having the larger, stronger, and better funded NGOs selected by very virtue of their ability to influence decisions internally.

2. Self-selection via an open-to-all public forum

Public forums and open-to-all accessible hearings can be a good way to get lay input from people who would not participate otherwise. Much of it depends on how well the information about the forum is disseminated and who is targeted for each specific hearing. Public forums can be a particularly good method in geographically remote locations to reach out to those who may not be able to come to more central places (59). However, the timing and the volunteer nature of participation in such forums may skew participant profiles towards those who have time and resources, including interest groups, unless specific outreach efforts are undertaken to motivate other groups to participate (11). In any case, this method is a good one to signal openness and the willingness to listen, and its drawbacks can be compensated by combining it with other approaches.

3. Self-selection via an online consultation

An online consultation has the appeal of being theoretically accessible to anyone at any time. Especially those who mainly have time constraints may be more prone to respond to an online consultation. However, experience does show that online consultations may be more carefully responded to by interest groups and the partisan public (60). In addition, the digital divide and digital inequality play out here, favouring again those who are generally more educated and privileged in society (61). Here again, all of the drawbacks of self-selection come into play, unless a regular monitoring of respondent profiles is undertaken to then compensate by reaching out to specific unresponsive target groups.

4. Appointment/Nomination by government authorities, parliamentarians etc.

Government bodies often select participants through appointment or nomination, usually for institutionalized participatory spaces. Nominations by high-level politicians underline government commitments but may also be prone to criticism of a tokenistic approach if only those people in favor of governmental political standpoints are invited. It also tends to keep the power and authority firmly in government hands. Many of these drawbacks can be at least partially mitigated by an explicit and transparent selection process, with criteria announced from the beginning.

In Portugal, the President and Vice President of the Health Council are appointed by the Council of Ministers, following a nomination by the Minister of Health. The four civil society representatives of the Health Council are appointed by the parliament. Health Council members have raised concerns about the independence of the Council since the appointment system is susceptible to political parties bringing in people with similar political leanings. Members of the Health Council have also drawn attention to the civil society appointment process mainly bringing in well-organized, better resourced CSOs who enjoy established working relations with parliament, to the detriment of smaller community-based or grassroots groups with less access to government circles (16).

5. Purposive stratification of random samples

Purposive stratification can be done where it is possible to obtain or have access to population registers with relevant information on each registered person for stratification, i.e. information on ethnicity, gender, residence, etc. (44). The challenge here for participatory processes in health is that health-specific criteria would be the most relevant to stratify by but this information is generally not available. However, purposive stratification along available criteria such as gender, age, residence, housing type, income level. can be done to target the lay public, while the affected public can be invited separately through other methods.

6. Popular election by government authorities, parliamentarians etc.

In some specific cases, popular elections for health-specific participation representatives may be undertaken. Here, everyone who would vote in a general election for a political representative would be allowed to vote for a health-specific representative. The advantage this has is the legitimacy gained through a popular vote as an act of authorization; disadvantages include the usual challenge of ensuring minority groups and views are represented.

In Quebec, various forms of social participation efforts have been tested in health, including popular election, specifically for local-level Health and Social Service Centres. This system which was in place from 2003 until 2014 is as follows: out of the 16-17 members of a Centre's Board of Directors, four seats were reserved for lay residents who were elected by the general public either when the local authority held an election anyway or by any other election held in the region (62, 63).

For more information on the participatory mechanisms and approaches, please see Chapter 1 for an overview on participatory spaces.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3.5 Format and design of the participatory process: key issues to reflect on

Apart from the selection strategy to find the 'right' representatives, the design and format of the participatory process influence the ability of participants to effectively engage in a representative way during deliberations (9, 64). In this section, we address process format and design elements which influence the extent to which the process itself is able to lend legitimacy to representatives, or at the very least, support participants' representative role.

Transparency and clearly formulating roles provide participants the legitimacy to be at the table and justify their contributions

A high level of transparency throughout the process from selecting representatives to clearly formulating roles, objectives and expectations is essential to lend participants the legitimacy to be at the table and justify their contributions in front of others. This point cannot be overstated as the success and sustainability of the participatory space hinges on it.

How participants are selected often remains a black box though which can fuel unnecessary mistrust or scepticism. Organizers often do not disclose selection strategies, nor monitor intended or actual representation to improve selection strategies (27). Part of the reason may be the lack of priority, and therefore time and resources, accorded to the participatory space in general. Transparency requires organizing and communicating information in audience-adapted formats, it requires an investment in making information available. Partly it may be linked to the struggle many government cadres have with the 'how' of setting up a participatory process, the tendency to underestimate the work load it requires vis à vis policy deadlines, and a lack of awareness of the criticality of ensuring transparency. Or, the lack of disclosure can be linked to the political economy of health in a country (11). Either way, as a result, the legitimacy of participants, usually those with whom interests are not shared, is questioned, or the whole process is criticized in its entirety (4, 11, 26).

Besides the selection process, the literature repeatedly reports that the roles of representatives are not always clearly articulated, and the reason for their input is not always obvious (4, 26, 37). The lack of explicit terms of reference and the resulting ambiguity in participant function lead to confusion around tasks and concerns around representativeness. Degeling et al.'s scoping review of over 60 participatory processes revealed that *"although the questions asked in these studies were clear and well-reasoned, the overall purpose of many of the studies was ambiguous, the roles performed by the publics ill-defined, and the reasons for the choice of public not explained"* (18). Moreover, the fact that multiple publics exist who can deploy various roles with potential conflicting interests was often ignored. Furthermore, as Nathan noted in the Australian context, less than a third of health staff was able to confirm that they understood the role of community representatives on health service committees and knew how to work with them in an open manner. This led to doubts with regard to representativeness of their community representatives (26).

Explicitly stating representative roles provides a starting point for negotiating and adapting those roles as per community needs. A positive example of this is noted in Canada where *"public members (..) questioned the credibility of their contribution in certain aspects of their task and negotiated the boundaries of their role to ensure its coherence with their specific expertise"* (9). In Tunisia, the post-revolution Societal Dialogue Health programme raised many hopes which were later dashed, partly due to a lack of clarity in what the initiative could realistically achieve in the short term, and what exactly representative roles were within those objectives (65).

Box 3.14

Format and design good practices

which lend legitimacy to participants and to the participatory space itself:

- transparent selection process;
- clear articulation of representational roles, expectations, and objectives linked to the social participation initiative;
- varied engagement mechanisms using a mixed methodology approach, matched as far as possible to the objectives of the process;
- balanced, factual information made available to all participants in a timely manner;
- skilled facilitation which supports equalizing power asymmetries during participatory events;
- fair consideration given to all inputs;
- balanced engagement of all participants, with special emphasis given to those whose voices are generally less heard;
- follow-up and feedback provided to participants after process completion.

Preparing participants with balanced, factual information

Preparation should include the provision of balanced factual information, packaged in an accessible and simple format, to be able to understand the issues at hand from different perspectives.

The preparation of lay people, community groups and civil society is a critical prerequisite for an effective participatory process (18, 49). Through the provision of balanced factual information prior to, and in some instances, during the event, participants have the possibility to gain a good understanding of the topic and make informed judgments based on the latest available evidence, thereby legitimately taking on their representation role (9, 44, 66).

To ensure an unpartisan process and procedural soundness, the literature stresses the importance of the availability of 'neutral' information, i.e. a compendium of, or access to, information demonstrating the various viewpoints on a particular topic so that participants can reason and form their decisions. The aim is to reduce any bias as far as possible of one solution over another. Balancing the level of technical details without overwhelming non-technical participants is challenging, and requires skilled organizers and moderators. Preparing information in different formats (reports, briefs, infographics, video clips) can further compensate topical complexities (32, 67).

Importantly, information should be provided to participants with sufficient time ahead of the event. In Tunisia, several citizen jury stakeholders expressed frustration at the last-minute sharing of technical preparatory material which they were supposed to pronounce an opinion on. Street et al.'s scoping review also found that very few studies specifically emphasized the objective of a timely, balanced presentation of the evidence (44). The lack of timely access to information has the risks of participants feeling as if their input is tokenistic.

Especially lay participants positively value the availability of a wide range of experts 'on call' to ask questions and listen to in-depth explanations (66). In the case of Canada's public involvement initiatives through Health and Social Service Centres, a one-day preparation format was chosen where background information from different viewpoints was provided to participants, and time taken to clarify issues prior to the deliberation. The aim was to not only make participants feel more comfortable and confident to speak up and ask questions in a non-threatening environment but, in this particular case, also to foster a more 'public' perspective and expertise. The participants' sense of credibility which is thereby built and their ability to contribute to discussions with a serious grasp of the issues lends legitimacy to their role as representatives (9). The latter point is critical for organizers of participatory processes to comprehend as it essentially means that it lies partly in their hands whether participants are seen as, and are, legitimate representatives sitting at the decision-making table.

Ensuring a safe space for representatives to express themselves freely

The goal of any participatory space is, among other things, to listen to people's views and experiences. Once efforts are made to ensure representative participants, they should all be made to feel equally comfortable (as far as feasibly possible) to speak up. Any misgivings or lack of trust in the process may lead to silence on the part of some, with comparatively loud voices on the part of others, leading to less representative input into the policy question. Certainly, some people by nature speak up less than others; the point here is to ensure that the reason people are not doing so is not that they do not feel safe to express their views.

A 'safe' space is a somewhat intangible concept. It entails the subtle impression that one's contribution is not valued, and a fear of repercussions for expressing views within societal and hierarchical structures. The feeling that contributions are less valued can come from many sources - for example, when assumptions are taken for granted and accepted when they come from more powerful bodies (health professionals, experts), and subtly dismissed when it is derived elsewhere. Regarding repercussions, a case in point comes from the community health workers in Madagascar who were invited to district health planning workshops together with their direct supervisors in charge of running the health facility. One participant stated that they did not feel comfortable to speak out of fear of backlash for criticizing common practices such as informal payments. The consultations also

took place in a fancy hotel which put community representatives out of their comfort zone, and certainly not feeling 'safe' to speak (15).

The quality of leadership and the culture of participation which is fostered by example from upper management can be instrumental in gaining trust in the safe space that should be the participatory process, however diverse and controversial their experiences. Participatory exchanges should therefore follow a format favouring a listening mode on the part of organizers, experts and more influential groups. Those who traditionally do not speak up as much due to societal hierarchies or weaker capacities should be given extra space, time, and opportunity within the participatory process, or be consulted additionally and/or separately in environments where they may feel freer to speak up.

Box 3.15

What do we mean by a 'safe' space?

A safe space is one where power relations are as equal as possible, where visible efforts have been made by those with power to equalize terms so that the input of traditionally less powerful participants (often lay people, community members and civil society) is given equal consideration and value, at least within the space where it is given (9).

More fundamentally, a safe space allows participants to adequately play their representative role, and express opinions freely, without the fear of being ridiculed nor fear of repercussions within societal structures.

Experts need to be briefed beforehand to understand their role as either a supportive one to enable population and civil society to make informed choices (see following sub-section on the importance of facilitation), or as an interest group which has its say but whose inputs need to be balanced out by less powerful voices. Careful preparation is needed to ensure that these roles do not get confused, by both the experts themselves as well as organizers of participatory spaces. When the process format and design are not thought through well enough, the default position of experts is often one representing their own interest group. Indeed, French stakeholders repeatedly mentioned that health sector experts, notably health professional bodies, are more involved in directly influencing decisions rather than being made available for citizens and communities to question, learn, and draw information from (12). In Tunisia's Societal Dialogue for Health, tensions between lay representatives and health professionals came to the fore and hindered fruitful discussions around health system reform. The solution was to separate out the two groups and give them each a dedicated (safe) space to speak freely amongst themselves and contribute to solutions (68).

Hence, in processes organized and led by government or experts, decisions such as who participates (selection process), who has how much speaking time, and what kinds of arguments and propositions are allowed prominence (format and design) form the core of balancing out participant power relations to enable a space where participants can safely take on their representative role. Besides adhering to participation as a principle, the

rationale for the required effort to level off the playing field is that it has the best chance to lead to the most rational, feasible solutions with buy-in from all relevant stakeholders (23).

The paramount importance of competent facilitation

Across the literature and country case studies, the importance of a neutral facilitator emerged as a key factor in balancing out power differences and lending legitimacy to representatives, especially the less powerful (9, 42). In France, key informants noted differences in facilitator quality at different bioethics consultation events (see Box 3.12), and the visible impact this had on whether all voices were equally valued and given legitimacy (30). In Madagascar, facilitation in French rather than Malagasy contributed to reduced participatory engagement by communities, thereby negating their representative role (15).

Facilitator-moderators can basically influence many key format and design decisions such as seating plans, ground rules with participants (e.g. Chatham House rules), and agenda flow during sessions. Skilled facilitators have various moderation techniques at their disposal to actively seek out the participation of marginalized groups or minority views (for example, *"I would be interested in hearing from someone with the opposite opinion"*), thereby offering a safe opportunity to express dissent with powerful participants (9).

In a Canadian trial health priority-setting dialogue space, a specialist in group processes was brought in to concentrate on levelling out power differences. Having a specialist moderator who had specific experience with group dynamics was evaluated as critical for meaningful representation and deliberation in this study (9).

In Thailand, facilitation skill is the principal expertise sought when selecting chairpersons of the resolution drafting group and of many deliberative committees. Over a decade of experience with the Thai National Health Assembly has taught organizers that a chairperson's moderating ability greatly affects the quantity and quality of contributions between the three big constituency groups (lay people, affected publics & civil society, academia, as well as policy-makers). Beyond moderating ability, the perceived standing of the chairperson within the three groups was acknowledged to promote or hinder trust in the process (45).

Box 3.16

Facilitation as a tool to help level the playing field

Adequate investment and organizer reflection accorded to moderating skills and competencies can reap benefits for the quality of representation and the legitimacy accorded to participants and the process.

This can be done by:

- outsourcing moderation to professionals specialized in group processes;
- selecting facilitators with technical expertise that also possess skills to counter balance power relations;
- building moderation capacity within government health institutions as a long-term in-house asset.

Parity of constituency groups and participant rotation

In the context of formalized or institutionalized participatory mechanisms, i.e. patient health councils, health committees, hospital boards, steering committees, etc., seats reserved for civil society representatives or the lay public raises questions regarding the adequate number of seats needed to be fair, ensure legitimate representation, and ultimately to influence decisions-making.

Too few civil society seats for such institutions elicit concerns of 'tick the box' exercises and participants facing criticisms of representativeness (11). When the balance is tipped too strongly towards civil society representation, an insufficient link to decision-makers and policy-making may be the result (see Chapter 5). There is clearly no magic number nor ideal percentage split in terms of the balance between the different types of representatives, yet too often such decision mechanisms heavily favour government or experts in terms of numbers, risking a real negation of the representative role of civil society or lay persons, and exacerbating the power imbalance which is usually the starting point of such spaces (12).

In Burkina Faso, civil society representatives expressed disappointment at the composition of the technical committees formed to deliberate on the National Health Financing Strategy; state officials largely outnumbered civil society groups. One civil society advocate commented on the repercussions for effective representation: *"there is... under-representation. We are not asking for equality, but we have to make sure that if you really invite civil society to something, it is because you believe that it can contribute something"* (69). He further continued: *"... often civil society is in a minority in these bodies to such an extent that if you defend a position... where it is the principle of consensus first, immediately... governmental [interests] can oppose..."* (69).

In the Portuguese Health Council, six out of 30 seats are fixed by law for users' representatives. Key informants from patient organizations voiced concern that this leads to an imbalance of power which may have negative consequences when discussing more contentious issues (16). In Thailand, participation as a principle is ensconced in the 2007 National Health Act, operationalized through the stipulation that the three constituencies of people's, knowledge and government sector, dubbed the 'triangle', should be equally represented as far as possible on a number of public health decision-making bodies as well as in National Health Assembly (NHA) working groups. The National Health Assembly Organizing Committee composition also mirrors the triangle principle as the distribution of seats between constituencies usually reaches parity (32).

Another principle linked to the notion of legitimate representation is participant rotation. This point is key in terms of the power balance and the level playing field that a participatory space should always strive to achieve. The Thai NHA operates on the convention that no constituency which has been included in the past will be removed; however, every year, depending on resolution topics and health sector needs, new groups are always added. Doing so ensures that the original mix of constituencies and representatives do not hold onto power excessively, and are forced to contend with new, relevant actors. At the same time, those who are motivated to participate, and continue contributing, are still welcome to do so; their learning and institutional memory are not lost and are instead capitalized on (32). In Portugal, the occupants of the fixed civil society seats are appointed by parliament and rotate after a fixed four-year term, ceding their places to other players who can also legitimately contribute (16). The risk of 'elite capture' exists if term limits are not set or if the group composition in a participatory space remains the same for too long a period.


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3.6. Capacity aspects to consider which are pertinent for representation in participation

People's capacities

Capacities of the population, communities, and civil society influence their ability to legitimately represent their constituency, as laid out in detail in chapter 4 of the handbook. In this section, we touch specifically upon capacity aspects for participatory process representatives which can support or validate their representational role in order to have, and/or be perceived to have, a maximum level of legitimacy in participatory spaces.

(a) Capacity to speak on behalf of a larger constituency, i.e. to represent 'collective views'

During participatory processes, participants may be requested to speak on behalf of a larger constituency (e.g. the general public, a community, a patient group) and therefore represent 'collective views' (5, 9, 11). This is not to say that participants should necessarily represent a constituency at all (70, 71); for example, people may be selected based on their individual experiences and civil society organizations may be selected based on their specific expertise (see Box 3.4).

However, where such a constituency representative is sought, it is important to demonstrate that they know their constituency and, armed with that knowledge, convey common positions (5). By moving away from *individual* experiences to collective views, individual representatives of a constituency gain legitimacy as a representative of the group. Other participants, including government cadres and experts, are then more likely to consider contributions as valuable and valid (9). The significance of the perception of validity by those who generally have more power and influence is a gradual levelling of the playing field that is the participatory space.

Yet, speaking on behalf of a larger constituency requires a certain skill set which some participants may be lacking (72), as expressed by one participant during a public involvement event to reconfigure the English National Health Service, *"there's nothing worse than somebody just talking about their own experience or the experience of their neighbour next door endlessly"* (33). Instead, as a Thai focus group participant rightly says, *"these representatives must bring the opinion of the group that they are representing, not just their own opinion"* (32). Ideally, participants should combine personal experiences with experiences from other group members to put the issue into a broader health context. This pre-supposes an understanding of the health system beyond one's own interactions as well as a certain level of technical know-how (discussed further below). Taking diverse perspectives into account also demands a high-level of reflectivity from the representative, a process through which a certain level of 'public expertise' is developed,

partly by deliberately distancing oneself from one's own experience through critical analysis (5, 9). Capacity-building initiatives, organized by government or others, can impart and support reflexive thinking, alongside efforts to increase stakeholders' technical understanding of the health system.

Awareness raising and capacity-building initiatives should also focus on helping participants better understand their representational role and the expectations linked to it, as expressed by a Thai civil society representative: *"We do not join as an individual but on behalf of the network. And we have already discussed the issue to be presented. For me, I am from the network of Paed-rew, Sustainable City Assembly"* (73). Participants, whether lay people or civil society or community organizations, must learn, practice, and understand the importance of reaching out and interacting within a constituency in order to aptly convey their sectional interests on the one hand (see Box 3.2), while simultaneously linking it as far as possible to societal (public) interests as well – a delicate balancing act (20). Abuse of a representative role to push through a personal, or a narrow sectional, viewpoint can be assuaged through capacity-building measures which can be used as a vehicle to communicate information on how participatory processes work, including the expected roles of each participant or group.

In the end, organizers of participatory spaces must acknowledge that capacities among representatives differ greatly and not everyone will be able to understand, articulate, and form meaningful judgments at the same level (18). Lay or civil society inputs may come in forms that are not always sophisticated. In addition, it is important to remember that not every participant is invited to represent collective views, as some participants may be invited to present their own views or an idea for which they are advocating.

Box 3.17

The capacity to reach out to communities: country illustrations

Reaching out to communities, and being responsive to and supported by them, is crucial for legitimacy in the eyes of both the communities themselves as well as policy-makers and health professionals. In many settings, civil society plays an able middle-man/-woman role in seeking out and listening to community members who may neither have the time nor the skills to claim their rights, and transferring their needs and concerns to decision-makers.

Some CSOs are borne out of the community and have a naturally grounded interaction with community members. Others must gain the trust of communities through regular exchanges with them to fulfill the role as their delegate. The capacity to do so is crucial as community-based group's legitimacy and value-add as a member of the partisan public is to represent the communities' interests.

In **Mexico**, a civil society key informant underlined the significant impact of the resources invested in advocacy staff in a few selected provinces. Initial reservations from management were strong, stemming from the civil society organization's core mandate lying in health service delivery, not advocacy. However, the advantage soon became apparent in that more adapted and useful data could be collected in real time on the ground. This community-level data could subsequently be analysed and presented to state and federal officials, who greatly valued the information for facilitating their own work. The consequence was a growing reputation, standing, and legitimacy of the CSO with policy-makers (34).

Similarly in **the Islamic Republic of Iran**, CSO territorial presence in both the capital Tehran and in provinces and districts allowed relationships to be built and maintained with both communities and patients as well as policy-makers (74). Relationships of trust are the foundation on which an understanding can be built as to the needs of the community. Trust often functions as a door-opener for decisive information on implementation issues (32). Much of the Societal Dialogue for Health's success in **Tunisia** was founded on its initial efforts to build trust in a mistrustful post-revolution period by reaching out to as many population groups across the country as possible. Large number of volunteers were given the task to engage with the population especially in the interior of the country, far away from the capital. The grassroots support won through those efforts allowed the Societal Dialogue to be seen as the voice of civil society which subsequently was also recognized by political leaders (31). In the case of **Burkina Faso**, a civil society alliance managed to be taken seriously by the interim government as the only legitimate voice of the population following previous unrest due to their close links to communities. Their legitimacy allowed them access to dialogue spaces with policy-makers where they were able to make the case for the adoption of the Universal Health Insurance Law (14).

Reaching out to communities can also happen through digital technologies, especially in contexts with limited funding. For example, in Burkina Faso, social media was used as a key communication platform to inform and interact with affected constituencies or the general interested public (69). Web sites were leveraged in many case studies as both a knowledge platforms as well as a medium for online consultations due to its fairly simple set-up and usage (16, 30, 31).

(b) The quality of representation can be augmented through technical capacity

Technical knowledge and the ability to generate and understand evidence is a mainstay of capacity needs for anyone entering into health-specific participatory spaces (9). The reason why it is especially relevant in terms of representation is that community or constituency representatives are confronted with the experiential evidence on the ground and must anchor it within broader health system challenges and goals when communicating and advocating with policy-makers. Put differently, representatives must represent community experiences, communicate them as evidence, and embed them into the dialogue with policy-makers. In essence, the latter two are highly technical tasks.

Yet, by very nature of being grassroots and practice-oriented, community organizations' and civic groups' forte is not necessarily to understand and analyse evidence. Smart organizations may recognize that they lack this capacity and bridge the gap by partnering with groups who do. The value of being close to the community with local evidence is potentiated by the capacity to analyse and repackage information into messages for policy-makers on behalf of the community, thereby fulfilling a key representational role.

The objective of (government-led) capacity-building in this domain is therefore to increase the technical know-how on health topics as well as related skills, such as reading and writing, internet literacy, language skills etc., the aim being to have civil society be on more of a level playing field with experts and government cadres. It is in government's interest to support such capacity-building efforts as it is the assimilation of academic, technocratic and experiential information which leads to decisions that have a higher impact on population health (5). From the government perspective, bringing these different types of intelligence together can be done through different means, for example, through the participant selection process as well as the participatory process design – but also through capacity-building efforts.

(c) Building capacity means that certain participants' perspectives will shift from that of the lay public to the partisan public

A caveat for policy-makers to keep in mind, and which will be a recurring warning throughout this book, is that possessing technical knowledge and skills can place lay members or volunteers into the 'extraordinary' category of participants due to their expertise and professionalization, potentially posing a problem of representativeness (4). Thanks to increased capacities, community groups, civil society organizations, or even members of the lay public can be more strategic in action and focus with a more targeted approach to participating in discussions and influencing policy-making. On the other hand, professionalization can mean that these agents no longer share the same typicality with their communities, once the decisive element of legitimacy as a representative. Certainly, professionalized civil society can still act to defend the interests of their constituency but it may be less grounded in an understanding of community health needs and more founded on technocratic evidence (46).

Organizers of participatory spaces simply need to be conscious of this issue and counterbalance it through the same means as mentioned above: participant selection, format & design, and capacity-building efforts. Some

civil society groups will also be aware of the risk and may counter-balance it themselves by following a more strategic approach to bringing up community voices.

Long-term capacity-building measures can aim to explore this issue with the population, communities, and civil society as a tool to making representative roles clearer. Basically, both high-capacity, professionalized civil society is needed, as well as civil society who is close to communities and can amplify their voice as middleman/-women. One organization or group can sometimes cover the two but more often than not, a group's forte will be on one side or the other. Capacity-building can assist in the recognition of that reality and encourage alliances which complement each other on these fronts.

(d) Funding sources can undermine the legitimacy of civil society groups to speak on behalf of their claimed constituency

Funding and resources can be a double-edged sword. It is consistently mentioned as a constraining factor for civil society and community groups to fulfil their representational role but at the same time, it can skew representation and accountability lines towards the priorities of those who fund rather than towards those of the communities served (2). It can also pull the participatory process itself towards topics with more funding as the accompanying loud voices draw their strength from resources rather than from the representative needs of the population. A case in point is described by Bovenkamp et al.'s study of Dutch patient organizations where those representing patients with high prevalence diseases had more funds than those representing less frequently occurring or neglected diseases (36). An even more dire funding situation can be observed for civil society groups advocating for broader, more cross-cutting issues such as patient rights, universal health coverage and social determinants of health.

A sticky point is when funding comes from groups with a potential conflict of interest, or, at the very least, vested interests in the outcome of the participatory dialogue. Funding coming from the private sector is seen particularly critically as their (real or perceived) profit-influenced interests can undermine the legitimacy of civil society organizations to speak on behalf of the community, their proclaimed constituency. In the realm of patient organizations, many came into being with funding from pharmaceutical companies as part of their 'disease awareness strategies', while others are set up by clinicians to support research fundraising (2); both of these objectives may not necessarily align neatly with community needs and interests. Another funding source which is viewed critically are donor agencies in aid-dependent settings where donor country public opinion and parliamentarian views, rather than the needs of recipient communities, influence CSO operations (75).

A Portuguese Health Council representative summarized the funding vs. representativeness predicament in which civil society often find themselves: *"When we look at the sources of funding for these associations, we see that the state does not invest, and so there is a dependence on the private sector... Now we have to recognise that, if we are tightening up and restricting the criteria [for state monies], ... we will increasingly force these associations to accept [external] funding and make themselves conditional to certain interest groups, which perhaps they otherwise... would not have to do"* (76). A Portuguese representative of a patient association platform acknowledged

their member organizations' financial support coming generally from lobbies linked to the pharmaceutical industry and *"of course this reduces their capacity for independent intervention"* (77). The representative mused further about civil society needing to guard against external vested interests: *"Therefore it [is] preferable… for the state to support [patient associations] financially, to preserve their independence, their autonomy"* (77). Civil society stakeholders in France emphasized this point as well, acknowledging that government subsidies and tax breaks allowed them to function adequately and independently (30). In Thailand, the Thai Health Promotion Fund, set up with sin tax monies, was instrumental in providing predictable funding for civil society groups without strings attached (32).

For governments and their allies organizing participatory spaces, it is cardinal for legitimacy of the participatory process (and therefore its results) to ensure that representatives who participate are as legitimate, and accepted as legitimate, as possible, in the eyes of all stakeholders. In terms of funding and funding sources, transparency is imperative. All potential conflicts of interest should be disclosed mandatorily, and potentially even subject to discussion within the participatory forum. Linked to this is transparency and good communication of the participant selection strategy based on each participant's expected representative role. Real conflicts of interest may lead to exclusion of certain groups from participatory spaces. Keeping them included may necessitate state-supported independent funding. In any case, the issue of civil society funding needs to be discussed at a more fundamental level among government circles if a country is serious about institutionalizing participatory governance mechanisms for health.

(e) Capacity to build alliances & networks

Across the case studies, the importance of building alliances between civil society-population-communities was underlined, not only to generate credible expertise but also to divide up the various tasks needed to represent collective interests in participatory processes, given limited resources. Boivin et al. also found that establishing alliances with other participants was beneficial for bringing up the constituency's viewpoints and ultimately influencing discussions (9). Moreover, coalition-building was also a factor positively valued by policy-makers in terms of representativeness and legitimacy.

Building alliance requires time and energy; it is not necessarily an easy task as involved parties with different institutional paradigms need to learn how to work in a mutually beneficial way. Yet, when done successfully, invested resources pay off. In Mexico, for example, the strength and influence of the civil society coalition to monitor budget execution for the national sexual and reproduction health programme was derived from the complementary skills each group brought into the alliance, ranging from expertise in maternal health to budget analysis to insights into community needs. Only through this combination of different skills, technical or otherwise, were they able to put the different pieces together to generate the evidence and assume a truly representative role that convinced policy-makers to revisit changes to their budget cycles (34).

In Burkina Faso, health policy-makers have increased the interaction with civil society due to an umbrella network structure which facilitates exchanges based on the topical policy issue. As a coalition, civil society is able

to more broadly cover the different population sub-groups and health needs, and thereby be more widely representative. The coalition secretariat has particularly invested in staff capacity to cover broad topical areas who are ready to 'jump in' if the respective technical CSO is unable to send its representative (14).

In Thailand's National Health Assembly, building alliances is strategically given due weight as a way of increasing reach and representativeness. The NHCO stipulates constituencies within which the different stakeholder groups must collaborate, reach out to communities, and come to the Assembly with a unified voice. The government's intent is to strengthen networks and interaction between technical experts, communities, and their own government cadres. Heavy investment in building capacities of the constituencies to enable operational networks is a key pillar of the National Health Assembly process (32).

Box 3.18

Take-home messages: government capacities

- Practice makes perfect – maintain and keep participatory spaces operational. Government exposure to population, community, and civil society interaction boosts skills and abilities.
- Set aside time and resources for team reflection on participant representativeness based on the policy objectives at hand.
- Invest in government capacities as a long-term endeavor, recognizing that skills take time to build gradually with increased practice and exposure.

Governments must recognize the need to thoroughly think through representativeness and legitimacy in a participatory space;

once recognized, robust technical and communication skills are needed to ensure that representativeness and legitimacy are assured

Despite a certain level of recognition that participatory governance is necessary and important, most government cadres struggle with the 'how' of social participation (see Chapter 1). One of the crucial areas where insufficient reflection takes places is the issue of representation; capacities need strengthening in this area. Not thinking through participant representativeness carries with in great risks as stakeholder perceptions of each other's legitimacy is the basis for valuing collective input. As mentioned at the beginning of this chapter, representativeness and legitimacy go hand in hand.

A lack of confidence and practice in conducting social participation exercises are often at the root of government perceptions that opening the door to civil society will result in a barrage of unmanageable complaints and, ultimately, an extra burden for ministerial staff. Investing in capacity-building and committing long-term to operationalizing participation mechanisms exposes government cadres to the art of selecting representatives, bringing their diverse views together and brokering solutions. The old adage 'practice makes perfect' is extremely relevant here.

A clear and thought-through participatory process is of immense importance. Ticking the box for the sake of 'doing' social participation is risky and paves the way for tokenistic approaches to (mis)use representatives as a 'legitimate' approval tool (35). An Indian civil society representative regretted that *"civil society is present but not always heard. They are invited because of the guidelines"* (78). Putting thought, emphasis, and resources into a solid selection process and process design is one key step towards having the 'right' people in the room as per policy objectives and preventing rubber-stamp participation.

Government capacity-building on ensuring representativeness is also needed to allay inherent tensions between different participants, and between government and non-state actors. Perceptions regarding representativeness and legitimacy are often at the heart of, or can exacerbate, inter-participant tensions. The discomfort of mid-level government cadres with non-state actors is often rooted in the participation task assigned to a government institution with no prior discussion nor training, nor a clear idea of participation goals, often following sweeping high-level politician commitments to the people. Martin et al. noted: *"[T]he weight of expectation … meant professional participants were alert to the need to demonstrably involve the public … but also created doubts about exactly what should and should not be exposed to public… input, reflecting tensions, … [which] manifested in the way public participants were recruited for the process"* (33).

Governments may consider contracting out the representative selection process to external parties

As iterated previously, representative selection to a participatory space is a key component of legitimacy of both the representative, and by extension, the process itself. For this reason, and in some contexts, giving this task to external experts who are perceived as independent may be an option. It does not necessarily have to be done for every event or step within a participatory process; yet, it might be adequate to do so for a single event. In France, for example, an external polling company undertook the participant selection only for the citizen jury (see Box 3.12). The company had access to lists of volunteers ready to participate, out of which a sample of 22 French citizens, aged 18 and over, reflecting the diversity of the French population in terms of gender, age, socio-professional category and place of residence, were selected. The aim was not to constitute a statistically representative sample of the population, but rather to qualitatively reflect the diversity of the French population. Random sampling from the volunteer list was used at first to pre-select potential candidates. A questionnaire was then sent to all randomly sampled candidates to gather more information about them. The second selection round aimed for both diversity and as much 'lay' character as possible (exclusion of people working for associations, trade unions, political parties etc.) (54).


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3.7 Conclusion

Representation is acknowledged as crucial in theory yet is regularly overlooked in practice in terms of the attention and reflection it receives when organizing participatory processes. Representation in government-led participatory spaces is about 'matching' representatives to a clearly formulated policy question, and once selected, lending them the maximum possible legitimacy through thoughtful format and design of the participatory space.

This chapter discusses how exactly this can and should be done, principally with the policy-maker viewpoint in mind. Firstly, a more nuanced understanding of representation is needed amongst policy-makers, but also other involved parties, in order to account for power imbalances among participants and different interests and vested interests.

Secondly, a fully transparent selection process is needed so that the selected participants themselves fully understand what their representational role is. Transparency is also critical to ensuring that participants understand each other's roles. One way in which legitimacy is gained is when others perceive, understand, and accept each other's roles.

Finally, the format and design of participatory processes heavily influence whether or not adequate representation is ensured. Well-reflected design features facilitate participants taking on their representational role; the participatory mechanism should offer a safe space where all contributions are valued fairly and as equally as possible.

In summary, representation is not to be taken lightly by organizers of a participatory space. Sufficient attention and resources should be paid to this important topic which can influence the success of deliberations.

References

1 Daykin N, Sanidas M, Tritter J, Rimmer J, Evans S. Developing user involvement in a UK cancer network: professionals' and users' perspectives. Critical public health. 2004;14(3):277-94.

2 Coulter A. Involving patients: representation or representativeness? National Center for Biotechnology Information. 2002;5(1):1.

3 Woodford MR, Preston S. Strengthening citizen participation in public policy-making: A Canadian perspective. Parliamentary Affairs. 2011;66(2):345-63.

4 O'Shea A, Chambers M, Boaz A. Whose voices? Patient and public involvement in clinical commissioning. Health Expectations. 2017;20(3):484-94.

5 Martin GP. 'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare. Sociology of health & illness. 2008;30(1):35-54.

6 Bispo Júnior JP, Gerschman S. The legitimacy of representation in forums with social participation: the case of the Bahia State Health Council, Brazil. Cadernos de saude publica. 2015;31(1):183-93.

7 Ansell C, Gash A. Collaborative governance in theory and practice. Journal of public administration research and theory. 2008;18(4):543-71.

8 Sörensen E. Democratic network governance. In: Ansell C, Torfing J, editors. Handbook on Theories of Governance: Edward Elgar Publishing; 2016.

9 Boivin A, Lehoux P, Burgers J, Grol R. What are the key ingredients for effective public involvement in health care improvement and policy decisions? A randomized trial process evaluation. Milbank Q. 2014;92(2):319-50.

10 Morone JA, Marmor TR. Representing consumer interests: the case of American health planning. Ethics. 1981;91(3):431-50.

11 Martin GP. Representativeness, legitimacy and power in public involvement in health-service management. Social science & medicine. 2008;67(11):1757-65.

12 World Health Organization (WHO), SciencesPo. France case study report: La démocratie de santé en France. Unpublished work. French.

13 Swasti Health Catalyst. Community Participation in the National Rural Health Mission (NRHM). Unpublished work.

14 Zongo S. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en oeuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French.

15 Petit D. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

16 Alves I. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work.

17 Baggott R, Jones KL. Representing whom? UK health consumer and patients' organizations in the policy process. Journal of bioethical inquiry. 2018;15(3):341-9.

18 Degeling C, Carter SM, Rychetnik L. Which public and why deliberate?–A scoping review of public deliberation in public health and health policy research. Social Science & Medicine. 2015;131:114-21.

19 Kohler-Koch B. Representation, representativeness, and accountability in EU-civil society relations. Efficient and democratic governance in a multi-level Europe; Mannheim: Social Science Open Access Repository; 2008. p. 1-21.

20 Fredriksson M, Tritter JQ. Disentangling patient and public involvement in healthcare decisions: why the difference matters. Sociology of health & illness. 2017;39(1):95-111.

21 Hainz T, Bossert S, Strech D. Collective agency and the concept of 'public' in public involvement: A practice-oriented analysis. BMC medical ethics. 2016;17(1):1.

22 Frankish CJ, Kwan B, Ratner PA, Higgins JW, Larsen C. Challenges of citizen participation in regional health authorities. Social Science & Medicine. 2002;54(10):1471-80.

23 Hainz T, Strech D. Which public to involve? More reflection on collective agency and sufficient representativeness is needed. The American Journal of Bioethics. 2014;14(6):31-3.

24 Contandriopoulos D, Denis J-L, Langley A. Defining the 'public' in a public healthcare system. Human Relations. 2004;57(12):1573-96.

25 Thurston WE, MacKean G, Vollman A, Casebeer A, Weber M, Maloff B, et al. Public participation in regional health policy: a theoretical framework. Health Policy. 2005;73(3):237-52.

26 Nathan S, Braithwaite J, Stephenson N. The scope and impact of community participation: The views of community representatives in an Australian health service. Journal of health organization and management. 2014;28(3):405-21.

27 Abelson J, Blacksher EA, Li KK, Boesveld SE, Goold SD. Public deliberation in health policy and bioethics: mapping an emerging, interdisciplinary field. Journal of Public Deliberation. 2013;9(1):5.

28 Gollust SE, Apse K, Fuller BP, Miller PS, Biesecker BB. Community involvement in developing policies for genetic testing: assessing the interests and experiences of individuals affected by genetic conditions. American Journal of Public Health. 2005;95(1):35-41.

29 Ramiro LS, Castillo FA, Tan-Torres T, Torres CE, Tayag JG, Talampas RG, et al. Community participation in local health boards in a decentralized setting: cases from the Philippines. Health policy and planning. 2001;16(suppl_2):61-9.

30 World Health Organization (WHO), SciencesPo. 'La démocratie santé en France' dataset. In: World Health Organization (WHO), SciencesPo, editors. Year of data collection: 2018. French.

31 World Health Organization (WHO). Tunisia case study dataset. In: World Health Organization (WHO), editor. Year of data collection: 2018-2019. French.

32 Rajan D, Mathurapote N, Putthasri W, Posayanonda T, Pinpratеep P, de Courcelles S, et al. The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016). World Health Organization; 2017.

33 Martin GP, Carter P, Dent M. Major health service transformation and the public voice: conflict, challenge or complicity? Journal of health services research & policy. 2018;23(1):28-35.

34 Colectivo Meta (COMETA). Case study on civil society involvement in policy processes in Mexico. Unpublished work.

35 Harrison S, Mort M. Which champions, which people? Public and user involvement in health care as a technology of legitimation. Social Policy & Administration. 1998;32(1):60-70.

36 Van de Bovenkamp HM, Trappenburg MJ, Grit KJ. Patient participation in collective healthcare decision making: the Dutch model. Health Expectations. 2010;13(1):73-85.

37 Serapioni M, Duxbury N. Citizens' participation in the Italian health-care system: the experience of the mixed advisory committees. Health Expectations. 2014;17(4):488-99.

38 Barnes M. Whose spaces? Contestations and negotiations in health and community regeneration fora in the UK. Spaces for change. 2007:240-59.

39 Ruano AL. The role of social participation in municipal-level health systems: the case of Palencia, Guatemala. Glob Health Action. 2013;6:20786.

40 Greer SL, Wismar M, Kosinska M. Chapter 1: What is civil society and what can it do for health? In: Greer SL, Wismar M, Pastorino G, Kosinska M, editors. Civil Society and Health. Copenhagen: World Health Organization (WHO); 2017.

41 Kuruvilla S. CSO Participation in Health, Research and Policy: A review of models, mechanisms and measures: Overseas Development Institute London; 2005.

42 Dryzek JS, Braithwaite V. On the prospects for democratic deliberation: values analysis applied to Australian politics. Political psychology. 2000;21(2):241-66.

43 Caron L, Hartz-Karp J. Adopting and combining deliberative designs: juries, polls and forums. In: Gastil J, Levine P, editors. The deliberative democracy handbook: strategies for effective civic engagement in the twenty-first century. Jossey-Bass: Wiley-Blackwell; 2005.

44 Street J, Duszynski K, Krawczyk S, Braunack-Mayer A. The use of citizens' juries in health policy decision-making: a systematic review. Social Science & Medicine. 2014;109:1-9.

45 Rajan D, Mathurapote N, Weerasak P, Posayanonda T, Pinprateep P, de Courcelles S, et al. Institutionalising participatory health governance: lessons from nine years of the National Health Assembly model in Thailand. BMJ Global Health. 2019.

46 van de Bovenkamp H, Vollaard H, Trappenburg M, Grit K. Voice and choice by delegation. Journal of Health Politics, Policy and Law. 2013;38(1):57-87.

47 Pitkin HF. The concept of representation. Berkeley and Los Angeles: University of California Press; 1967.

48 Crawford M, Rutter D, Thelwall S. User involvement in change management: a review of the literature. NCCSDO; 2003.

49 Abelson J, Forest PG, Eyles J, Smith P, Martin E, Gauvin FP. Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. Soc Sci Med. 2003;57(2):239-51.

50 Meier BM, Pardue C, London L. Implementing community participation through legislative reform: a study of the policy framework for community participation in the Western Cape province of South Africa. BMC International Health and Human Rights. 2012;12(1):15.

51 Tunisia case study interviewee #14. Case Study Tunisia. Unpublished work. French.

52 Comité Consultatif National d'Éthique (CCNE). Avis 129: Contribution du Comité consultatif national d'éthique à CCNE à la révision de la loi de bioéthique 2018-2019. Comité Consultatif National d'Ethique (CCNE); 2018. French.

53 États généraux de la bioéthique 2018. [Available from: https://etatsgenerauxdelabioethique.fr]. French.

54 Comité Consultatif National d'Éthique (CCNE). Rapport de synthèse du Comité consultatif national d'éthique; Opinions du Comité Citoyen. Comité Consultatif National d'Éthique (CCNE); 2018. French.

55 Comité Consultatif National d'Éthique (CCNE). Rapport d'activité 2017-2018. Comité Consultatif National d'Éthique (CCNE); 2018. French.

56 Nelson E, Bloom G, Shankland A. Accountability for Health Equity: Galvanising a Movement for Universal Health Coverage. IDS Bulletin. 2018;49(2).

57 Keane J. Civil Society, Definitions and Approaches. In: Anheier HK, Toepler S, editors. International Encyclopedia of Civil Society. New York, NY: Springer US; 2010. p. 461-4.

58 Gregory J, Watson R, Hartz-Karp J. Using deliberative techniques to engage the community in policy development. Australia and New Zealand Health Policy. 2008;5(1).

59 HUD Exchange. The eCon Planning Suite: Citizen Participation and Consultation Toolkit. HUD Exchange; 2014.

60 Participedia. Online Consultation on Higher Education in North Rhine-Westphalia, Germany: Participedia; [Available from: https://participedia.net/case/4161].

61 Participedia. Online Consultations: Participedia; [Available from: https://participedia.net/method/733].

62 Martin E, Pomey M, Forest P. The Reform of Regionalization in Quebec, The Introduction of Bill 25 Proposing the Transformation of Regional Boards Into Health and Social Services Agencies and the Implementation of Local Service Networks. 2006.

63 Bill 83 (2005, chapter 32): An Act to amend the Act respecting health services and social services and other legislative provisions, Québec Official Publisher (2005).

64 Schmidt VA. Democracy and legitimacy in the European Union revisited: Input, output and 'throughput'. Political Studies. 2013;61(1):2-22.

65 Tunisia case study interviewee #15. Case Study Tunisia. Unpublished work. French.

66 Guttman N, Shalev C, Kaplan G, Abulafia A, BinÐNun G, Goffer R, et al. What should be given a priority–costly medications for relatively few people or inexpensive ones for many? The Health Parliament public consultation initiative in Israel. Health Expectations. 2008;11(2):177-88.

67 Brücker G, Caniard E. États généraux de la santé: Une démarche innovante pour plus de démocratie. Actualité et dossier en santé publique. 1999;27.

68 Tunisia case study interviewee #6. Case Study Tunisia. Unpublished work. French.

69 Burkina Faso case study interviewee #4. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en oeuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French.

70 Renedo A, Marston C. Healthcare professionals' representations of 'patient and public involvement'and creation of 'public participant'identities: Implications for the development of inclusive and bottomÐup community participation initiatives. Journal of Community & Applied Social Psychology. 2011;21(3):268-80.

71 Renedo A, Komporozos-Athanasiou A, Marston C. Experience as evidence: the dialogic construction of health professional knowledge through patient involvement. Sociology. 2018;52(4):778-95.

72 Parkinson J. Hearing Voices: Negotiating Representation Claims in Public Deliberation. The British Journal of Politics and International Relations. 2004;6(3):370-88.

73 Thailand case study interviewee #1. The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016). 2017.

74 Rajan D, Hadi Ayazi M, Moradi-Lakeh M, Rosami-Gooran N, Rahbari M, Damari B, et al. Chapter 4: Public voice and participatory governance in the health sector: status quo and way forward. In: Hsu J, Majdzadeh R, Harirchi I, Soucat A, editors. Health System Transformation in the Islamic Republic of Iran: an assessment of key health financing and governance issues. Geneva: World Health Organization (WHO); 2020.

75 The World Bank. World Development Report 2004: Making Services Work for Poor People. World Bank and Oxford University Press; 2004.

76 Portugal case study interviewee #8. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work. Portuguese.

77 Portugal case study interviewee #2. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work. Portuguese.

78 India case study interviewee #7. Community Participation in the National Rural Health Mission (NRHM). Unpublished work.


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Chapter 4

Capacities for meaningful government engagement with the population, communities, and civil society

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Handbook on Social Participation
for Universal Health Coverage

4.1 Introduction

Social participation, as described and defined in chapter 1, requires all stakeholders in the participatory process to be able to adequately and fully exercise their roles. In order to do so, all stakeholders should be, as far as possible, on an equal footing with each other in terms of the skills and abilities needed to have influence on the participation-based discussions. The crux of this chapter therefore centres on how ensuring the neces sary capacities for government cadres as well as the population, communities and civil society, to engage meaningfully and systematically with each other can enable a level playing field.

No generally accepted definition of capacities for (social) participation exists; this might be due to the subjectivity of what is actually 'necessary' in terms of capacities. It might also be due to the individual nature of capacities required for each participation scenario which may be difficult to generalize. Or, it may be that practitioners are also generally less preoccupied by the conceptual perspective on capacities, given their needs for concrete implementation and its accompanying challenges (1).

Box 4.1

Capacities: Key points to understand

- In terms of social participation for health, ensuring necessary capacities for menaingful government engagement with the population, communities, and civil society is principally about ensuring a level playing field.
- The objective is to put all stakeholders on an equal footing with each other in terms of ability to have influence on the participation-based dialogue.

In this handbook, the aim is to clarify what is meant by 'necessary capacities' for social participation[1] with a decided focus on the government role of ensuring that as level a playing field as possible is achieved, where all stakeholders in the process are able to engage on an equal footing. We specifically emphasize the crucial role of governments for creating a level playing field due to their inherent and uncontested steering position in regard to political decision- and policy-making. Meaningful social participation implies that governments understand how to use the power vested in them to create this level playing field. An analysis of available evidence demonstrates that governments struggle with this role, and targeted capacity-building is direly needed in this area.

Undeniably, civil society also plays an important and decisive role in their own capacity-building and that of communities. However, this handbook specifically targets governments and government actors and thus emphasises their part in building and acknowledging civil society capacities to ensure that stakeholders involved in a participatory process, regardless of their affiliation, can equally and meaningfully engage in social participation.

Governments need not, and indeed do not, conduct and organize all capacity trainings, as explained further below. They may lead some training programmes of course; but they can also contract out and steer external institutions to do so, ensure an enabling environment for private capacity-building initiatives, and/or secure legislation facilitating civil society funding. These, and many other potential capacity-building roles and responsibilities of government are explored in this chapter, in addition to government's own capacity needs for themselves to meaningfully conduct and engage in social participation mechanisms.

1 Please note that each chapter will provide additional information on capacities specifically pertaining to the chapter topic.

4.2 Objectives of the chapter

Governments require specific capacities to understand the added value of engaging in social participation and to pro-actively work in collaboration with a full range of stakeholders in a way that is beneficial to their core business of policy-making. This chapter aims to shed light on these very capacity issues, in addition to laying out the key aspects for governments to consider for strengthening people´s capacities, i.e. capacities of the population, communties, and civil society to interact with governments on an equal level.

The following section of the chapter will contribute to closing the conceptual gap around social participation capacities and clarify what capacities for meaningful government engagement for social participation are. Based on literature reviews and case studies, a set of social participation capacities for both civil society and governments are identified and put into the context of this handbook. Subsequently, the chapter will focus on the key challenges in regard to social participation capacities and capacity-building. We conclude by presenting action-oriented key messages targeted to policy-makers on how best to overcome challenges in order to strengthen and build necessary capacities for meaningful government engagement with populations, communities, and civil society.

Box 4.2

Government vs. People´s capacities: theoretical concepts and reality

A note of caution regarding the idea of achieving a level playing field between "government" on the one hand and "the population, communities, and civil society" on the other hand: we do not imply that these are two opposites on either side of a spectrum of actors. We acknowledge that none of these groups are homogenous bodies. Especially 'civil society' can be quite heterogenous in many settings, inclusive of interest groups who may enjoy disproportionate influence. These terms only describe one quality of the two poles of actors, the lowest common denominator so to speak: one is either associated with the population/communities/civil society or is part of the government (in this context it would usually be the Ministry of Health but can also be other government health institutions). This bipolar scenario achieves the level of simplification required to examine the necessary capacities to ensure a more equal interaction between these two major types of actors. However, it certainly does not negate the need for other stakeholders' active presence in participatory processes.

4.3 Capacities for equal social participation: conceptual clarification

Empowerment is a crucial concept for capacity-building for social participation

For the objective of ensuring a level playing field, the concept of empowerment is critical, especially with regard to equal participation. Two main components of empowerment are advanced: civic and managerial empowerment, followed by a clarification of how they are linked to capacities for equal social participation. Based on these two aspects of empowerment, three dimensions of capacities (related to technical, recognition, and communication skills) deemed to be most relevant to action on capacity-building by government actors is elaborated upon (see Figure 4.1).

Box 4.3

Empowerment

- Empowerment is a social action process that creates in people, organisations, and communities a sense of confidence to take action towards collective goals.
- Empowerment enables the action of being a part of and/or influencing decisions which affect those who are empowered.
- Capacity-building within the remit of social participation in health can be seen as a process of empowerment.

Capacity-building within the remit of social participation in health can be seen as the process of empowerment since it relates to the development of knowledge, skills, commitment, structures, systems and leadership to enable health (2). This process is transformational and purposeful in empowering organizations and individuals to take action on their particular goals (3). Therefore, the aim of capacity-building in health is to impart practices, approaches, structures and/or values which create, sustain and enhance the abilities of practitioners and their organizations to address health issues (3).

Capacity-building activities and interventions for CSOs can be developed by multiple agencies, i.e. governmental and non-governmental, and at local, national, and international levels. Here, the focus is on capacity-building by national or sub-national governmental actors, either directly conducted, or contracted out and steered by them.

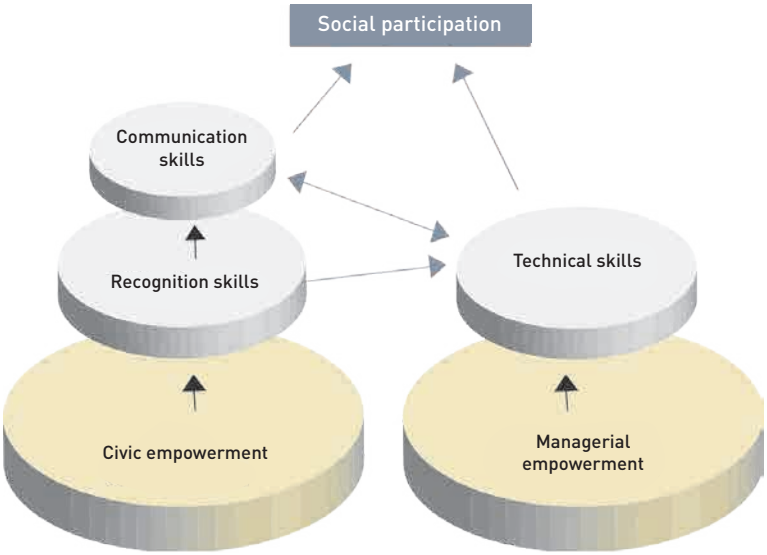

Figure 4.1: Capacity-building for social participation

Two components of empowerment: managerial and civic empowerment

Empowerment can be viewed as a "health-enhancing strategy to reduce disparities" (4), and can thus be defined as a social action process that creates in people, organisations, and communities a sense of confidence to take action towards collective goals such as increased community control, political efficacy, improved quality of life and social justice (5). Consequently, empowerment impacts on political, social, and cultural norms. It also supports individual and institutionalized forms of civil society to express their views, ideas, needs, and concerns.

The WHO Health Promotion Glossary frames empowerment in terms of the capacity "to devise strategies for involvement in decision-making, and [to] achieve political, social

Box 4.4

Two components of empowerment

- **Managerial empowerment:** gaining confidence and belief in oneself through enhancement of technical skills to engage on an equal footing with technical experts.
- **Civic empowerment:** gaining confidence and belief in oneself to address social needs by acquiring or enhancing the ability to claim social rights.

and cultural action to meet those needs" (2). The glossary further pinpoints the rationale for empowerment as a way for people to see a closer correspondence between their goals in life and a sense of how to achieve them, i.e., a relationship between their efforts and life outcomes (2).

The concepts of empowerment described above all point towards the action of being a part of or influencing decisions which affect those who are empowered.

In terms of the individual, this would entail capacities to understand their own health or that of their community or family; decision-making capabilities; and a belief (confidence) in their own autonomy (6).

In terms of the community, a group of empowered individuals have the confidence and belief in themselves to collectively gain control over and influence the health of their community (6).

In terms of an organization or institution, an empowered organizational leadership and staff have the technical skills which contribute to institutional confidence (from a society's perspective, this would translate into organizational respect and standing) to use their mission and mandate (bestowed, for example, by a legal framework, or by the community, or a board, etc.) to influence decisions within a sector of operation.

Two main components of empowerment crystallize out (see Box 4.3): managerial empowerment which is broadly based on the idea that technical skills need to be enhanced. The second component relates to civic empowerment, which refers to capacities that are needed to address social and community needs (see Figure 4.1).

Mirroring these two components of empowerment, governments hold a critical role in building and strengthening civil society´s managerial as well as civic capacities to systematically and meaningfully engage in social participation. Government capacity-building would be focused on (a) understanding the needs of civil society's managerial and civic capacity-building and ensuring that those needs are met, and (b) understanding their own capacity needs and acting on filling any capacity gaps.

Three dimensions of capacities that serve as enablers for equal interaction in social participation

A guiding question of this chapter is whether a set of skills can be articulated and are specific to social participation in terms of enabling equal involvement of civil society vis à vis other actors, notably government, but also more powerful interest groups, in national planning and policy-making. Acknowledging that capacities for social participation are highly context-dependent, we address the question by distinguishing three capacity dimensions based on their contribution to achieving a feasible equality between stakeholders (see Figure 4.1): technical, recognition, and communication skills. Expressed differently, these capacity dimensions are necessary for both government and the population, government and civil society for meaningful engagement with each other. In addition, governments can feasibly support civil society capacity-building in these areas to increase the chances of achieving a level playing field. Increasing capacities within these three dimensions would ensure that stakeholders are able to address varying political as well as technical challenges during participatory processes.

The different types, interpretations and qualities of the capacities presented next are exemplary – they are not meant to be exhaustive nor normative. The objective is rather to underscore the need for governments to take different dimensions of civil society and government capacities into consideration, especially with regard to how they impact on the equality of the social participation process.

Box 4.5

The three dimensions of capacities for meaningful government engagement with the population, communities, and civil society:

1) **Technical** skills
2) **Recognition** skills
3) **Communication** skills

4.4 Capacity dimension 1: Technical skills

I. Technical skills needed for the population, communities, and civil society to meaningfully engage in social participation

Managerial empowerment is the aim of technical capacity-building

Capacity-building activities to build technical skills aim at managerial empowerment, that is, at increasing the type of skills necessary to actively engage in participatory processes. "Skills" are a type of capacity related to knowledge or, in this case, technical understanding. Specific skills can support, or if lacking, impede, the type and quality of interaction between governments and the population, communities, and civil society. Technical skills to understand the topic, to form an opinion, and to make an informed choice on how to participate strongly influences the quality of the participation process and ultimately the ability for civil society to engage with government on as level a playing field as possible. Capacity-building processes should be targeted towards increasing technical skills to equip civil society to fully comprehend the issues at stake and enter into an equal discussion with governments and topical experts. This includes technical details of the subject at hand but also communication techniques, for example, in the area of advocacy, lobbying, awareness raising, and monitoring and evaluation (8). In Burkina Faso, the technical specialization of civil society representatives on health financing was perceived as one of the main factors of their success in advocating for vulnerable groups' service access as a core tenet of the health financing strategy (9).

A non-exhaustive overview of skills identified as relevant for social participation are described in this section. These skills emerged from the data analysed for this handbook as most salient for meaningful and systematic engagement with governments in participatory processes.

Technical knowledge of the topic at stake is especially relevant to hold one's own at the policy table (10), like in Mexico where civil society needed to learn how to analyse a health budget to be able to engage with the federal and state governments (11). Technical skills include not only technical knowledge of the topic at stake but also evidence generation and use. The Mexican example clearly demonstrates that civil society organizations needed specialized technical skills to understand and analyse evidence from health budgets in order to hold government accountable for timely budget transfers (12).

Language skills were repeatedly mentioned as a barrier to participation in Madagascar, where workshop participants felt they were less able to interact due to their lack of French (13-15). Internet literacy was relevant in Burkina Faso, where civil society organizations are increasingly well-connected through social media and even use the internet to stay connected to the government (16). Fundamental educational skills like reading and writing and the capacity to understand written texts were also relevant in the Madagascar case where rudimentary education was essential for community representatives to convey messages within a district community system strengthening programme (17).

The capacity to read and write can be viewed as integral to civic empowerment rather than managerial empowerment. Indeed, literacy is closely linked to socioeconomic determinants of health and thus strongly related to poverty and inequality reduction interventions (18, 19). However, from the standpoint of policymakers undertaking or organizing capacity-building initiatives, reading and writing is seen as a managerial empowerment issue (i.e. a technical skill) as it can be taught on a very technical level without much civic input per se.

II. Technical skills needed for governments to ensure a level playing field for meaningful social participation:

Government cadres require more technical skills on the 'how' of social participation

In general, the literature and international debate are fairly silent in regard to the capacities needed for governments to ensure that civil society can be on an equal footing during participatory processes. We attempt to begin clarifying and articulating some of these aspects in this handbook.

Technical skills to design and facilitate the process seem to be one of the key areas where government capacities need strengthening. Governments need to be able to choose the appropriate methods and tools for participation (20) as well as design appropriate processes (21), depending on the actors involved, the context and the content. It is essential for the processes and the methods to match the background, skills, and abilities of the stakeholders involved to ensure an equal footing.

A clear capacity deficit governments evince is the ability to take people's experiential testimonies and relate it technically to the subject at hand. Stakeholders in France involved in regional, routine participatory processes in health acknowledged that the personal experience of patients and health care users, i.e., experiential knowledge, were only theoretically considered equal to technical knowledge; in practice, it was not given its due weight in participatory discussions (22). A Dutch study found that the reason for the poor influence of patients' association input on clinical practice guideline development was their unequal starting position where their experiential knowledge was not seen as valuable and insightful as technician knowledge (23). These studies point to vital information remaining lost or unused in terms of feeding into potential solutions, partly due to decision-maker inability to process information in an unfamiliar format which is less formal and polished.

III. **Governments' role** in levelling out power imbalances due to a lack of technical skills for the population, communities, and civil society

Simplify jargon while simultaneously building civil society technical capacity to speak in jargon

Language and jargon are areas where civil society capacities need strengthening, and which can have considerable impact on enabling a more level playing field. Technical language and dialect differences can quickly and obviously reveal an imbalance of power, putting those who are less articulate at an immediate disadvantage.

Governments would do well to learn how to simplify their language when engaging with non-technicians in the interest of finding common ground. At the same time, governments can provide capacity training in technical areas, or set up (independent) funding mechanisms to do so. In Thailand, for example, the Thai Health Promotion Fund, financed by a sin tax on alcohol, funds civil society capacity-building; a more able and skilled civil society was then able to participate in the National Health Assembly with a more coherent voice (24). Civil society which is enabled to participate then does participate more; with more exposure and experience, more capacity is built, closing the virtuous cycle.

Box 4.6

Capacity-building tenets for managerial empowerment:

- technical topics need to be made relatable to people's lives;
- technical jargon should be avoided;
- technical details necessary for participating need to be provided and easily accessible;
- practical barriers to participation need to be addressed (access to internet, travel time, opportunity cost of participation);
- personal experience (experiential knowledge) should be valued (not just technical evidence).

Governments must make the effort to create, maintain, and expand the opportunity provided by participatory platforms as it empowers through its very use and existence.

Opportunities for learning-by-doing should not be underestimated in terms of capacity-building potential

Capacity-building happens during the very process of participation itself. Enabling environments which allow participation to happen play a significant role in allowing capacities to be built by virtue of the opportunity and practice of participating. As mentioned previously, participants at the National Health Assembly in Thailand reported that they began to understand technical topics as well as procedural aspects of participation the longer they were engaged with the Assembly. As one participant put it clearly: "Some people grew up [in] this place, from the assembly process" (25). Civil society representatives at the Portuguese Health Council noted their increasing technical professionalism due to the exposure offered by Health Council activities (26). These examples suggest that room should be given within participation processes for a learning-by-doing approach which can be accompanied by targeted capacity-building initiatives.


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4.5 Capacity dimension 2: Recognition skills

I. **Recognition skills needed for the population, communities, and civil society** to meaningfully engage in social participation

The need to recognize that participation is a possibility

The ability to recognize that participation in planning and policy-making processes is a possibility which can be beneficial to one's goals is a fundamental capacity for meaningful participatory engagement (7, 10, 27, 28). It is related to the individual´s capacity to understand one´s own abilities (7, 21, 29, 30) and be able to articulate the type of capacities which might be missing. In India and Madagascar, interviews showed that sometimes civil society and communities need to have a clear reason, or stimulus, to recognize how engaging in social participation mechanisms can be useful. In both cases, the need for improving local-level health services created an understanding for communities of why raising their voices through available social participation mechanisms could be advantageous (8, 17).

Perceiving and comprehending one's needs and those of the community

Recognition relates to the ability to be assertive and emphatic in regard to perceived needs and views. Thus, recognition includes aspects like being critically aware of what is happening in your environment (29), understanding the importance of public accountability (10), and perceiving what might be best for oneself/the community (6, 10, 27, 29). In Madagascar, many rural inhabitants with little access to health care were unaware that interactive workshops set up with the explicit aim of seeking their views was a mechanism which could be used for their own collective interest of improving the local health system (31). In Tunisia, on the other hand, social participation is seen by many civil society actors as a constitutional right, recognized within society, and claimed through the Societal Dialogue for Health mechanism (32).

II. Recognition skills needed for governments to ensure a level playing field for meaningful participation

Governments need to understand the value-add participation offers for policy-making

Building recognition skills essentially aims at civic empowerment. This requires governments to recognize and understand their own role during the participation process. Thus, capacities are needed for governments to understand the added value of participation and ensure that participation literacy for equal engagement is enhanced both in civil society and government institutions. In turn, governments who are serious about ensuring meaningful and sustainable social participation need to (a) be able to recognize participation as essential to health planning and policy making (27) and (b) be willing to create equitable spaces for participation grounded in government accountability to the population. This involves building a trustful environment for all engaged stakeholders (21) and truly understanding power relations and their impact on participatory processes (6, 21).

Recognizing power relations also forms the basis for skilfully including actors with differing views and backgrounds into a participation space, accounting for their differing interests yet brokering a solution nevertheless (33).

A more in-depth recognition of the beneficial nature of equal interaction with civil society is more sustainably fostered when governments come with a long-term outlook to their own capacity-building. The fear of "losing power" to others can be very real; it can take time and repeated exposure to participation experiences for governments to understand the long-term benefits of capacity-building which are strongly related to human development and socioeconomic change (34).

The need to acknowledge that experiential and expert knowledge are both extremely relevant for policy

Knowledge or technical information do not only derive from formal skills and expertise in technical areas but also from personal experience, the latter being just as relevant for policy. The Portuguese Health Council's civil society representatives expressed worry that their personal experience with a disease or a health issue, the very reason why they are part of the Health Council in the first place, was not recognized as valuable (26). This worry basically reflects a potential inability by government and experts to perceive the significance of experiential knowledge for what it is actually worth, reflecting on the need to build capacity for governments in that area.

Political will is necessary to ensure sustainable commitment to capacity-building

Political will and commitment by policy-makers is needed to maintain capacities and keep capacity-building on the radar, especially during times of change (29). Political will can be supported by government civil servants demonstrating benefits of the popular support for policies which have gone through a participatory process.

Capacity-building linked to recognition is especially needed for mid-level technical civil servants

Increasing the understanding and knowledge levels of government actors is critical not just at the highest political levels where the theoretical (political) gains of supporting participation may be easier, but also with mid-ranking technical cadres who are left with the concrete task of doing participation. In India, feudal societal elements which protected existing power structures at times blinded government civil servants to recognizing the added value of collaborating with civil society (35). A civil society representative from Burkina Faso pointed out that within governments, one actor might be enough to block entire processes (36). In Tunisia, some government officials saw the Societal Dialogue for Health as encroaching into their policy-making space; it was seen as a threat rather than complementary to their work (32). A positive example comes from Mexico where civil society-government collaboration was fruitful; one reason cited was that government actors from different levels saw advantages in engaging with civil society as they valued their up-to-date access to local information as a key component of their own programme monitoring (11).

Dialoguing internally within government circles to ensure internal buy-in should therefore be a core component of any government capacity-building strategy. Here again, patience is key as a mindset change is essentially envisaged which never happens quickly.

Box 4.7

"How can a participatory approach be useful for me in my policy work?": a question every government official should know the answer to

- Besides high-level officials who may more easily gain politically by supporting participation, all staff at lower levels need to understand the ideas and aims of social participation, especially mid-level cadres who hold budgets and influence policies.
- Resources and time need to be invested in efforts towards internal buy-in for participatory processes within government institutions.

III. **Governments'** role in levelling out power imbalances due to a lack of recognition skills in the population, communities, and civil society

Box 4.8

Governments can help level out power imbalances due to a lack of recognition skills in population, communities, and civil society: practical tips

- Convene selected and targeted homogenous groups to avoid hierarchy barriers (e.g. women-only forum; indigenous group-only discussion).
- Consult directly in people's familiar surroundings (schools, religious centres, health centres, community recreation centres, commune buildings, local cafés, sports centres, etc.) to avoid the daunting nature of official meeting environments (such as government buildings; spaces where formal clothing is the norm; settings where more formal language is usually expected).
- Use simple language without jargon or technical terms.
- Use facilitators who speak the local language or dialect – depending on the setting, even official translation services might end up 'officializing' the event and hindering frank expression of community thoughts.

Recognition is the most fundamental dimension of capacities for equal interaction, but the most difficult to build as it implies addressing cultural context and hierarchy

For both civil society and government actors, the most fundamental of capacities needed for interaction on an equal level is the ability to understand (recognize) one's own role in participation processes. In Madagascar, even though the health centres were built within the communities, and the management structures were embedded within the communities, many community members did not understand that they could strategically and practically influence these health centres (37, 38). In fact, an attempt at influencing health centre planning was at times seen as negative if it involved a complaint to or about the health centres. The sociocultural aspects of how to behave in which situations can impede recognition and lead to low community engagement (see Section 4.7). Thus, an understanding of concepts of accountability and ownership need to be gradually introduced through capacity-building and planning processes, as was the case in Madagascar, and translated to the living conditions of the population (17).

In India, it took some time at the beginning for ASHAs to understand their roles and responsibilities, including the broad scope of work

Box 4.9

Building recognition capacity in **Madagascar**

In Madagascar, strong hierarchies and social fragmentation was cited by many local stakeholders as a barrier to participation in general. A strong need was perceived to build basic civic capacities for social participation, especially for those living in remote areas, with lower education levels.

One vehicle to do so was through various programmes run by international NGOs targeting community-based health planning and monitoring. Action Against Hunger (ACF in its French acronym) is one such NGO who runs district-level programmes to promote community input into local health system decision-making. The aim is to confer more agency to people and communities over their own health by providing a platform to lend their voice to shaping a more responsive health system. That platform is offered in a workshop format, where community health workers, community members, health centre staff and management are convened together by ACF to enter into a facilitated discussion on local health needs, challenges, and possible solutions.

While these workshops were clearly appreciated for their opportunity for bottom-up planning, they also exposed the deep-seated cultural deferral to those in positions of power along with the very real difficulties for community members to keep up with technical discussions due to language barriers and limited medico-technical knowledge. Compounding this was the underlying lack of a basic recognition of their own rights and possibilities for influence, leading to a mediocre quality of community engagement in workshops.

The community-based, bottom-up health planning process is clearly an important opportunity to strengthen and empower local communities in Madagascar. Strengthening the recognition capacities of stakeholders, that is, catalysing an understanding of the added value of one's own input and being aware of the possibilities to contribute in one's own or in the community interest, should be the starting point in this process (17).

and mandate they had; doing so (recognition) enhanced their leadership roles within the health system, and facilitated communication skills within and beyond their communities. The introduction of the ASHAs had even further repercussions on recognition as they played a key role in mobilising other community members to formulate their views and needs as demands (39). Capacity-building in this dimension is hence extremely important but at the same time very difficult since recognition is rooted in a basic understanding of democratic principles and the value of a human being to society (40). Addressing these issues through the health sector only will have a narrower impact unless simultaneously intervening in education and poverty alleviation.

In many cases, addressing broad socio-cultural issues outside the remit of the health sector will only be minimally possible. In such cases, governments can still focus on analyzing and understanding those sociocultural barriers to recognition and create safe spaces for participation where they are addressed: for example, by convening women separately where their status is lower than men's; or going into poorer communities to hear their views in their own familiar environment rather than convening them in an official government building which might be daunting; by using the local language or dialect in meetings, etc. These spaces help communities to recognize and voice their needs and expectations.

Investing time in understanding the hierarchies, becoming conscious of their consequences in terms of participation, and cautiously addressing barriers which stem from them are certainly within the realm of what a government body managing a participatory process should do, but where, admittedly, the skills, training, and support to do so are lacking in many countries.

Box 4.10

India: ASHAs and the recognition capacity

A key mechanism to implement a strategy of community participation under the National Rural Health Mission was, among others, the establishment of the Accredited Social Health Activist (ASHA) Village Health Worker Programme. ASHAs are female community health workers that are selected by the community and tasked with linking the community to the health system.

The ASHAs receive an intense training programme mostly focused on technical, programmatic capacity-building but many are also sent to courses in leadership and communication. The basic leadership training helped increase confidence, counterbalancing in some ways the lower social position often ascribed to women, and thereby impacting on the recognition dimension of capacities.

ASHAs were selected locally and were embedded in community life, playing a significant role in improving awareness in health matters, health seeking behaviour, access to services and entitlements. Thus, ASHAs stimulated a process within the communities that generally increased recognition and awareness in regard to health services, quality of care, and right to health. ASHAs also played a key role in creating an understanding within communities that they do indeed have a right to demand services.

The ASHA capacity-building experience confirms that recognition is one of the most fundamental dimensions of capacities, is closely intertwined with overall community empowerment through the civic empowerment of women which had trickle-down effects on the entire community (8).

4.6 Capacity dimension 3: Communication skills

I. **Communication skills needed for the population, communities, and civil society** to meaningfully engage in social participation

Honing communication skills improves the quality of interaction with a more formal audience

The capacity to interact and communicate with other stakeholders and especially governments is crucial for meaningful engagement in social participation processes. Thus, these abilities are related to transforming perceived inequities into well-formulated arguments and justification for actions (21, 29, 33).

Speaking in front of an audience or in public is a key component of this capacity dimension as exemplified by the Madagascar case where community representatives were summoned for workshops and felt inadequate to speak up (37, 41), or by the Portugal case where Health Council Members from civil society reported apprehension at speaking in front of a formal and very hierarchical expert audience for the first time (42). Thus, speaking in public also has an empowerment dimension linked to recognition.

The capacity to listen (25) is also a core aspect of the ability to communicate and exchange information. Accepting contrary views in debates, taking responsibilities and adapting communication for different audiences are communication capacities that are closely related to the recognition and technical skills needed to support the formulation of arguments.

Clear and good communication facilitate coalition-building. Partnerships were a pivotal element in the Mexico case where the strategic use of networks led to civil society successfully advocating for increased budget transparency (43). In Burkina Faso as well, a civil society coalition was able to amplify civil society voice in the development of the free health care policy for pregnant women & under-five children (44). In Thailand, civil society is forced to partner with each other in the National Health Assembly's constituency format which requires solid communication and related coordination skills (24).

A recent analysis of health governance in the Islamic Republic of Iran demonstrates the significance of communication not only for the exchange between organized civil society and governments but also between civil society and communities. The said analysis found that civil society held a key mediating role in the Islamic Republic of Iran, communicating effectively with communities, and then re-packaging their information and formulating arguments to the government (45).

This aspect of engaging with constituencies as a form of communication capacity was also present in other case studies. The Tunisian Societal Dialogue for Health, as a voice of civil society, ensured outreach to the interior of the country to ensure the involvement even of remote communities (32). Similarly, in Mexico, the networks formed to increase pressure for budget transparency included local communities, without whom local implementation evidence would not have been gained (11). On the one hand, communication capacity with communities and lay people is crucial to grasp local issues; on the other hand, a different kind of communication ability is necessary to ensure that those local issues get heard in higher-level policy discussions.

Civil society interaction with media

Interacting with media and specifically channelling information through media is also a relevant part of communication capacity, as it can be challenging for both civil society and governments (see Section 4.6). Stakeholder interviews in Burkina Faso cautioned that the use of media and the interaction with the press needed to be handled with care because it can potentially jeopardize established relationships of trust between governments and civil society (46). In Tunisia, the Societal Dialogue for Health partnered with media to ensure that the population understood the genuine nature of the large-scale consultations in its initial phase. Media messaging was a part of a broader communications strategy to build trust with the population in the post-revolution context (32).

While communication skills are crucial, capacities deriving from all three dimensions need to be bundled to properly interact with media representatives to potentially use media as a mouthpiece and advocacy tool to ensure that relevant information is transparent and public (see Box 4.13).

Box 4.11

Interacting with media in **Tunisia** during the Societal Dialogue for Health (phase 1)

During a time of political transformation (Arab Spring, 2011/12), the *Societal dialogue for Health* in Tunisia was born as an independent organ created as a partnership between civil society and government, largely due to a grassroots civil society movement demanding more participation in health. It became a platform for the Tunisian people to express their views and ideas. *The Societal Dialogue* also sought to reaffirm citizen rights of participation by capturing people´s needs and opinions on health matters.

Realizing the criticality of population trust for the success of the *Societal Dialogue*, active collaboration with media was leveraged to channel information and messages on participation to the population. The goal was to allay scepticism that consultations would be tokenistic (as they had often been in the past) and reassure the population of the intent of the participatory process.

The *Societal Dialogue*'s partnership with the media centred on transparency and information sharing on the proceedings and functioning of the participatory events it organized. It included the coverage of the *Societal Dialogue* Technical Committee meetings, radio programmes, and newspaper articles – all aiming to increase confidence in the accountability of the *Societal Dialogue* to the population.

The media was thus part of a broader communication strategy to convey messages and restore democratic beliefs. The *Societal Dialogue* conducted training workshops for media to ensure that correct information was conveyed to the population. The workshops also served as forums for media to ask questions and clarify major issues which the public was seen to want information on. The civil society organizations which founded the *Societal Dialogue* initiative were at the forefront of partnering with media, evincing their strength and high capacity to carry the *Societal Dialogue* initiative forward (32).

II. Communication skills needed for governments to ensure a level playing field for meaningful participation

Governments need more deftly use different communication channels to listen, engage and provide feedback

The capacity to "listen" is just as relevant for governments as it is for communities and civil society. It is related to governments' ability to find and use different (communication) channels to hear and understand attempts by the population, communities, and civil society to express needs (10, 29, 47). Linked to this is the ability of government actors to translate and communicate abstract health system topics and concepts into relatable and concrete real-life issues (21). Governments thus require capacities not only to "hear" messages in colloquial language and distil from it what is relevant for policy, but also to convey messages back in simpler language to different audiences through participatory platforms in order to steer discussion and debate towards feasible policy options (48).

This leads us to another relevant communication-related skill set needed to ably manage a full participatory process: the capacity to provide and disseminate feedback and results after the process is over (21). Feeling at ease with online tools to interact with the population, communities, and civil society, and being able to negotiate in an adapted way with different stakeholder groups are further communication skills needed amongst government cadres.

Box 4.12

Individual vs organizational civil society capacities

The skills and abilities described above are equally valid and necessary for individuals, less formalized civil society groups (for example, community initiatives or unregistered civic groups), as well as for organizations.

However, certain capacities might be especially relevant for (formal, semi-formal) civil society organizations, such as the ability to formulate its mission, strategic targets and motivate individuals and organizations to participate in the achievement of these targets. In addition, the capacity to translate local health concerns into advocacy activities may be more relevant for organizations vis à vis individuals. Administrative capacities, mainly related to organizational functioning and financing, are necessary to stay viable and strategic. In the Islamic Republic of Iran, for example, cumbersome bureaucratic procedures for civil society registration meant that stronger and well-connected civil society groups were the ones who managed to become formalized (45). Indian stakeholder interviews highlighted that administrative tasks overwhelm civil society organizations' existing capacities at times, leaving a perception of poor credibility with risks of not being invited to engage in social participation forums (39).

Participatory process preparation: provision of timely and adapted technical background information is crucial

Government capacity to simplify technical nuances and perceive technical issues from the population and lay person perspective is especially important in preparing background information for participatory processes. Simplifying complex issues while still keeping a relevant nuance is not an easy task, and may require several rounds of testing and piloting to ensure the right messaging for the right target audience. In the end, it is an investment in time and resources which often gets de-prioritized in favour of programmatic activities which is seen to have more direct impact on health sector results. However, the investment can bear fruit as seen during France's 1999 large-scale population consultations, the Etats Généraux de la Santé. Government organizers at central and regional level put a special emphasis on ensuring that everybody wishing to participate in the consultation had all the necessary information at hand, packaged in easily accessible language, to ensure full understanding of the topic of consultation (48, 49). It was one of the many reasons for the large numbers of people which the consultations managed to attract to participate in the various participatory events.

As always, an additional emphasis and reflection is needed to ensure that the most vulnerable population groups, i.e. those who tend to have the most difficulties in understanding technical details, are sought out and given additional support for technical capacity building.

Box 4.13

Communication skills are at the heart of the interaction between civil society and government actors

- The quality and impact of interaction depends on civil society´s capacity to express their views and on government actors' capacities to listen.
- For both civil society and governments, media can be a mutually beneficial medium to communicate with constituencies.
- Communication skills are partly built through practice – creating & maintaining participatory spaces keeps a channel of communication open.

Governments need to engage more smartly with media

Government investment in communication abilities is also necessary to work constructively with the media to ensure the type of participation which is desired. In France, the 2018 national bioethics consultation involved a communication strategy which targeted media appearances by the head of the organizing government body to inform the public about the opportunity to participate (22).

III. **Governments' role** in levelling out a lack of communication skills for the population, communities, and civil society

Creating spaces for participation

Social participation heavily depends on civil society's ability to communicate, meaning their ability to formulate arguments and influence public debate. Consequently, social participation also depends on governments´ ability to actively increase the space for participation to give the population, communities, and civil society the opportunity to communicate.

The catch-22 situation is that, unfortunately, the poorer the existing civil society capacities are in regard to communication and interaction, the more the government needs to compensate for it by creating those interaction and communication channels. Reaching out actively to "receive" and "hear" civil society´s arguments and debates is one way of compensating. Essentially, offering adequate participation spaces, for example, through targeted meetings to hear from civil society, fixed seats on boards and councils, institutionalizing community-level consultations during policy processes, etc, is one of the most important efforts a government can make. The exposure these spaces offer allow for learning-by-doing capacity-building, besides deepening an understanding of differing viewpoints, whether agreement is found or not. The capacities which are built by repeatedly interacting with each other are on both the government and civil society side.

A case in point is Thailand where the 10-year-old National Health Assembly process obliges stakeholders from all sides, including government and civil society, to confront other viewpoints, and think through their own position and communicate them to those who may think differently. The platform is offered to stakeholders every year in December with the rest of the year taken for in-depth preparation through several working group meetings where civil society takes part. The repeated exposure has helped to increase capacities on all sides, and is acknowledged by all stakeholder groups to have been a key vehicle to improving communication between those with differing views (50).

Some aspects of communication (e.g. formulating arguments, negotiating) can be learned through structured training but those training efforts are more effective when the socioeconomic barriers (e.g. communicating with hierarchies) relating back to recognition are recognized themselves by those organizing the capacity-building, and taken into account. Ideally, this would entail measures to address those barriers; at the very least, the barriers should be adequately considered when designing capacity-building exercises.

	Capacity dimension I: technical skills	Capacity dimension II: recognition skills	Capacity dimension III: communication skills
The population, communities, and civil society	‣ Language skills ‣ Technical knowledge of the topic ‣ Evidence generation and use ‣ Internet literacy ‣ Educational skills ‣ Understand written texts	‣ Recognize that participation can be beneficial ‣ Understand one's own abilities ‣ Articulate the type of capacities missing ‣ Be assertive, confident, and critically aware ‣ Liability and accountability ‣ Confident about what might be best for oneself/the community	‣ Transforming perceived inequities into well-formulated arguments ‣ Speaking in front of an audience ‣ Accepting contrary views in debates ‣ Taking responsibility ‣ Adapting communication to audience ‣ Strategic use of networks ‣ Engaging with the population ‣ Interacting with media
The government	‣ Design and facilitate the process ‣ Actively increase the space for equitable civil society participation	‣ Understand the added value of participation ‣ Understand how equal engagement can be mutually beneficial ‣ Recognize participation as essential to health planning and policy making ‣ Willing to create equitable spaces for participation ‣ Long-term outlook	‣ The capacity to 'listen' ‣ Provide and disseminate feedback post-consultation ‣ Use of online tools ‣ Ability to negotiate

Table 1: Capacity dimensions in practice

As discussed, the three capacity dimensions are interconnected and capacity-building in one dimension will have positive effects on all capacity dimensions (see Figure 4.1). However, the table below shows these interlinkages and highlights concrete examples of how capacity-building is a cross-cutting exercise.

Examples of cross-cutting aspects (non-exhaustive)	Capacity Dimension I Technical Skills	Capacity Dimension II Recognition Skills	Capacity Dimension III Communication Skills
The use of language: Participation processes depend on the ability of the involved actors to communicate with each other. The way language is used throughout the process needs to be actively shaped in a way that language does not pose a barrier to participation but that it enriches participation. Knowing and understanding how to deliberately use language is a core capacity for all actors involved.	**For the population, communities, and civil society:** to understand / speak the technical language, or "jargon", of the participatory space in order to more effectively interact and understand the technical topic of deliberation. **For the government:** to take messages conveyed in colloquial language and distil from it what is relevant for technical health policy.	**For the population, communities, and civil society:** to understand the importance of being adequately equipped and skilled to speak up in front of an audience, to understand the need to communicate differently with different types of actors. **For the government:** to recognize how a lack of understanding of technical terms might prevent participants from actively engaging in processes.	**For the population, communities, and civil society:** to be able to speak in front of an audience using language which everyone in the participatory space understands. **For the government:** to use language during interactions which matches the language skills of participants, for example, by conveying technical information in simpler words.
Importance of experiential knowledge: Topical discussions within a participatory space are often shaped by technical inputs and research-based evidence. However, testimonies of lived experiences, or experiential knowledge, must also be recognized as crucial information to be incorporated into technical discussions.	**For the population, communities, and civil society:** to contribute to discussions by introducing experiential knowledge with an understanding of how it is relevant technically to the topic of discussion. **For the government:** to be able to take people's experiential testimonies and relate it technically to the subject at hand.	**For the population, communities, and civil society:** to recognize that experiential knowledge is a valuable contribution to the discussion and be confident in conveying experiential messages. **For the government:** to recognize experiential knowledge as a valuable input to the participation process and subsequently give it its due value in policy-making.	**For the population, communities, and civil society:** to be able to form arguments that are based on experiential knowledge. **For the government:** to be able to enter into a technical discussion that might be based on experiential knowledge and convey messages that relate experiential knowledge to technical expertise and thus actively increase communication channels for "experiential experts".
"Learning by doing": an intrinsic element of sustainable capacity-building. Participatory spaces offer the possibility to "practice" participation, i.e. understand each other better through increased exposure to one another, develop & fine-tune a basic set of skills relevant for participation. Providing more possibilities to interact is one of the most effective capacity-building strategies.	**For the population, communities, and civil society:** Exposure to factual discussions will increase technical skills. **For the government:** to know how to deliberately create and maintain spaces where learning by doing for all involved actors is possible.	**For the population, communities, and civil society:** Exposure to participation processes will increase recognition by civil society that participation is an option and is useful for community aims. **For the government:** Exposure to participation processes will increase recognition by governments that participation is beneficial for their policy objectives.	**For all:** Understand and encourage the importance of opening and maintaining participation channels to serve as opportunities for constantly improving communication skills.

Table 2: Example of cross-cutting aspects

* Arrows indicate the interdependencies between the different capacities. Increases in one capacity will impact on other capacities.


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4.7 Social participation capacities in practice: key issues to reflect on

I. Challenges

Since stakeholder capacity is such a determining factor for the success and sustainability of a participatory process, challenges and potential hindering factors for strengthening and using capacities need to be considered. Different types of challenges stemming from contextual as well as social, cultural, and economic determinants are elaborated upon below.

Socioeconomic status can impede participation in capacity-building activities

As alluded to previously, civic empowerment, or the lack thereof, is closely linked to low socio-economic status, making it a hindering factor for participation (29). The socioeconomic context also determines the success of capacity-building efforts that would be necessary to instill civic empowerment in communities. Organizers of participatory spaces, and capacity-building efforts linked to them, need to be conscious of and acknowledge these limits, understand how to manoeuvre within them but at the same time challenge the paradigms where feasible.

On that note, we delineate two principal capacity-building challenges where awareness and sensitivity is needed, borne out of low socioeconomic status:

(a) Inability to invest time or resources in participatory or capacity-building activities

The capacity to invest time and money and to accept trade-offs that need to be accounted for are relative to the socioeconomic situation of the individual or the organization participating (21). Costs include transportation, child care, opportunity costs for not attending work, etc. and need to be covered in order to enable participation. In the end, it is the participants and organizations themselves who bear those costs if they are not covered otherwise. The Portuguese Health Council's civil society representatives do not receive financial compensation for their participation; it is reported as a clear barrier for participation (51). The consequences are the inability to have truly equal participation between governments, civil society, and in the case of Portugal, private sector (51). A stakeholder from Burkina Faso (52) echoed the same point by pinpointing the lack of finances and human resource capacity as one of the main hindering factors for civil society's meaningful participation in policy processes. Those who are participating as part of their (paid) day job (government) have the luxury of preparing adequately and being up-to-date on the knowledge and positioning of stakeholders, giving them an edge over the others on top of the advantage and position of power they already have.

The resource-strapped conditions within which many civil society organizations operate often leads to those working for the CSOs having volunteer status and paying out of their own personal pockets to cover expenses

Therefore, to ensure a level playing field, governments need to acknowledge and potentially account for financial and time investments that might be necessary for all stakeholders to participate equally.

linked to participation. Interruptions in activities are also a likely consequence of a lack of funding. This can skew participation to those who have the time and/or finances at their disposal, as was seen in large-scale public consultations in France (22) or in community engagement mechanisms in Madagascar (31). The relative time and financial investments necessary to take part in the participation process are usually higher on the civil society side than on other stakeholders' side.

(b) Sociocultural hierarchies impeding on the use of capacities and capacity-building

Recognizing one´s own ability and being able to speak up is also determined by the sociocultural idea of hierarchies and the norms determining how to deal with those hierarchies. In Madagascar, a general fear of negative repercussions (e.g. difficulty in getting treatment in health facility) through people "higher up in the system" and a socio-cultural respect of hierarchies impeded on community´s ability to express themselves (31).

Similar experiences were reported in regard to the ability to enter into dialogue. Stakeholder interviews in Madagascar, Mexico, Burkina Faso, and Thailand repeatedly demonstrated that when trying to overcome hierarchies and other sociocultural barriers for the sake of equal social participation, the ability to communicate (as defined above) is vital (31, 43, 53). In these cases, civil society organizations who took great care to formulate and position arguments for their engagement which was not seen as 'confrontative' or 'complaining' found greater success.

Hierarchical structures in government institutions mirror society's hierarchies, where civil society in general is already placed lower down the rung. Achieving a level playing field in such situations definitely needs a good dose of government good will, as pointed out by Mexican stakeholders who acknowledged the general openness of most government entities working with budget advocates to interact with civil society (12, 54).

> **“Capacity development starts from the principle that people are best empowered to realize their full potential when the means of development are sustainable – home-grown, long-term, and generated and managed collectively by those who stand to benefit.”**
>
> United Nations Development Programme (34)

Capacity-building requires sustainable funding because it is a long-term process

Building and strengthening capacities for social participation is very resource intense (55, 56). Of course, some capacity-building interventions are more costly than others, depending on the setting, the format and the context (55). But without a doubt, funding is enabling when present and hindering when not in terms of sustainable capacity-building efforts.

Sustainable and predictable funding allows capacities to be built up slowly and in an adapted way over time. The patience required for capacity-building activities to show results is difficult to impossible with short timelines and funding windows. Many of the complex governance- and health-related capacities which are needed for effective social participation are not developed through one-off workshops or through short exposure to the issues at hand. Instead, it requires a long-term support of individuals, communities, and/or organizations to foster an in-depth understanding, a skill set which has had the opportunity to try and test, and, most importantly, a sense of self-esteem and confidence to truly enable participation. None of this happens overnight, and is jeopardized if interrupted due to a halt in funding or change in political commitment to capacity-building for participation (57).

A case in point is the long process for India's (female) community health workers, or Accredited Social Health Activists (ASHAs), to overcome a technical knowledge gap and a lack of confidence. Interviews with ASHAs confirmed that sustained and long-term training opportunities, including communication and leadership skills, empowered the women to be more confident in their daily encounters with cultural and social hierarchies. However, it proved to be a time-intense process as the ASHAs' confidence led to a re-adjustment of their place in village society. The accompanying (slow) change in cultural environment allowed the women to be more accepted within their communities but it implied a long community learning phase which is easily disrupted if longer-term commitment to participation and capacity-building is absent (38).

The ASHA example from India demonstrates how long-term commitment to capacity-building efforts for participation can strengthen recognition and communication skills.

Available resources for capacity-building thus influences both the quality and quantity of capacity-building as well as the resulting capacities which are brought into a participatory process.

Capacity-building needs to meet people´s expectations

Capacity-building's success depends on how far the new skills, competencies, and knowledge enter the daily lives of individuals and are relevant to people´s needs and ideas (10). For example, when combined with measures to improve education levels and alleviate poverty overall, people are more likely to accept and invest time in these activities (6).

Ownership of capacity-building activities and initiatives, even if promoted by government actors, should be endogenous to those organizations (or individuals or communities) that benefit from the training or development (19, 34). In practice, this entails capacity builders and those who guide and organize capacity-building to be sensitive to the level and type of change which is feasible and acceptable for the population. A Portuguese stakeholder pointed out within the Health Council context that civil society should have a role in their own training programmes because they are best positioned to know what their capacity needs are (26).

The Indian government's National Rural Health Mission took exactly this approach and tasked civil society organisations already established within communities to take on capacity-building activities of local participation platforms (8).

Capacity-building has limits

Capacities can be strengthened and built only to a certain extent. The political culture of the country itself has a strong influence on the design and ideas of capacity-building activities (see Chapter 2). Additionally, the prevailing political paradigms and leadership approaches are not just factors enabling a conducive environment. They can also be factors strongly limiting social participation (19). Taking this further, limits to capacity-building for social participation might be rooted in the political and constitutional construct of the country itself. Thus, the ability to exercise full and free participation is related to the democratic self-conception of the country.

II. Overcoming challenges to capacity-building

The challenges discussed above serve as a basis to reflect on the following lessons learned that could support governments to strengthen their meaningful and systematic engagement in capacity-building activities for social participation. Key issues to consider to potentially overcome various capacity-building challenges are categorized into the three capacity dimensions (technical, recognition, and communication skills).

Capacity dimensions are dependent on each other and on contextual factors; hence, capacity-building needs to consider the full spectrum of capacity needs

Capacity-building for social participation necessitates a holistic approach, as the three capacity dimensions (technical, recognition, and communication skills) depend on each other and on a multitude of contextual factors, as described earlier.

Governments can support the population, communities, and civil society in:	Governments need capacity-building to ensure that they:
▸ understanding that they can play a role and take on responsibilities in planning and policy-making (recognition skills);	▸ realize the need and added value of social participation, and understand what it is, as well as what it is not (recognition skills);
▸ using that role effectively by communicating needs upwards to policy-makers as well as downwards by gathering and coordinating community voices;	▸ are able to bring together and listen to different stakeholders, including those with differing views and vested interests, in order to broker a common solution to health system challenges (communication skills);
▸ improving their technical knowledge to fully engage in discussions pertaining to the process at hand (technical skills) (58).	▸ have not only the health-related technical skills but also those needed for governance and steering the sector (technical skills).

Table 3: The specific role of governments in capacity-building for meaningful social participation

Box 4.14

Capacity-building needs to:

- consider all three dimensions of capacities;
- be linked to socioeconomic improvements;
- take people´s realities into account.

The interdependence of the different capacities means that a long-term, socioeconomic context-specific investment is required as some of the capacities only bear fruit over time. Adapting to the socioeconomic context means potentially using local structures and addressing general literacy issues, both of which take time. The time factor implies keeping people motivated to participate in capacity-building exercises which might be easier if a benefit is tangible for their own lives; addressing less complicated 'quick win' issues might help maintain community interest in capacity-building, thereby increasing sustainability (21).

Partnerships and networks within civil society can support capacity-building

Effective partnerships and networks within civil society (potentially even internationally) should not be underestimated, and governments have a key role to play in providing conducive grounds for them. For example, Mexican civil society representatives acknowledged that the so-called 'feedback meetings' with federal government staff to discuss civil society's budget analysis offered an opportunity to consolidate a budget advocacy coalition which brought in a variety of skills and abilities (for example, budget analysis, familiarity with communities, dialogue with policy-makers) channelled for a common purpose. The different coalition partners complemented each other and potentiated each other's' capacities while simultaneously learning from each other (12).

In Thailand, the National Health Assembly system incentivizes in many ways the collaboration, dialogue, and coordination between civil society organizations but also between civil society and communities and academia. Firstly, any resolution proposal is rejected if consultation has not taken place first between the different types of stakeholders. Secondly, once a proposal is accepted and seed funding given to form a working group around the proposal topic, those coalitions with a unified and coordinated voice have a better chance at a working group seat. Thirdly, targeted capacity-building is provided to weaker constituency groups to help coordination efforts between organizations working on similar topics (24).

The Thailand example demonstrates clearly that it is in government's interest to strengthen civil society. Dialogue with a strong, professionalized civil society is more straight-forward, and can lead more easily to concrete policy options with win-wins for both sides (59). In Burkina Faso, two civil society health platforms SPONG (includes international NGOs as well as local ones) and the CNOSC (locally based civil society) are used by government as first points of contact to dialogue with non-state actors. On the one hand, it is easier for government to deal with one or two main civil society partners than with several fragmented voices; on the other hand, SPONG and CNOSC amplify each single civil society group's voice with the legitimacy of numbers behind it. In addition, civil society coalitions offer platforms for cross-learning due to the different technical skills and expertise brought in by each group. For example, the SPONG facilitated joint learning and capacity-sharing during the development of the Burkinabe free health care policy for pregnant women and under-five children, making them a valuable partner for the MoH in different stages of strategy development (44).

Box 4.15

Le Secrétariat Permanent des Organisations Non Gouvernemental (SPONG): The permanent secretariat of non-governmental organizations in Burkina Faso

The SPONG was created in 1974 on the initiative of several NGOs. Today, it has more than 200 member organizations. It is the only collective of national and international NGOs as well as development associations in Burkina Faso. SPONG coordinates the participation of NGOs in development-related activities and ensures that their voices are taken into account in public policies. SPONG also coordinates communication for Burkinabe civil society in general. One of its objectives is to promote the involvement and participation of civil society in monitoring and influencing public policies.

The SPONG enables civil society organizations to bundle their capacities and technical knowledge and work in collaboration with other organizations to strengthen civil society´s impact (44).

Le Conseil National des Organisations de la Société Civile du Burkina Faso (CNOSC): The Burkinabé National CSO Council

The CNOSC was legally founded in 2011 to ensure effective civil society representation in formalized participatory spaces and to enable systematic communication amongst CSOs for a more unified and coordinated voice in these spaces. It is headed at the national level by a National Coordination Office, with representation in the 13 regions of Burkina Faso.

While SPONG brings together both national and international non-state actors and works within the international development space, it defers to the CNOSC for domestic issues. The CNOSC consists of national organizations only, with a focus on those issues which national civil society prioritize.

Both mechanisms act as advocacy bodies for civil society actors to participate in public debate. As umbrella organizations, they have acquired legitimacy over the years to interact with state authorities as well as with donors and international cooperation agencies (44).

(Formal) partnerships between government and civil society can facilitate long-term capacity-building

Effective partnerships and relations between civil society and government are a crucial element in social participation as they become part of each other's organizational cultures. Capacity-building depends to a great extent on the willingness of both governments and civil society to maintain these relationships for the benefit of social participation.

Reliable long-term relationships between governments and civil society for capacity-building might be the only way to really ensure sustainability related to recognition which is fundamental for equal social participation (39). In Mexico, key informants confirmed that increasing capacity to undertake budget transparency was also related to the fact that civil society organizations had a long-term, trusted working relationship with state health authorities which went beyond formal meetings (11, 12, 60). In the Islamic Republic of Iran, the nascent National Health Assembly is seen as an opportunity to build a long-term, more regular working relationship between civil society and government institutions (45).

The caveat is to ensure that partnerships between government and civil society for capacity-building are not misused or misunderstood as an attempt to influence civil society´s ideas and views.

Box 4.16

Effective government-civil society partnerships

Effective partnerships between government and the population, communities, and civil society as well as among and within the population, communities, and civil society are crucial for sustainable capacity-building.

- Incentivizing intra-civil society coordination in the design of participatory platforms can simplify government-civil society interaction whilst amplifying population voice with a unified front. Capacity-building initiatives can profit from this.
- Long-term government-civil society partnerships can facilitate increased interaction between the two sides which, in turn, helps build capacity.

Overcoming the funding challenge

From the perspective of ensuring a level playing field between governments and civil society for social participation, governments additionally need to actively address the issue of funding.

In France, capacity-building was enabled over the course of two decades through sustainable and predictable funding through government subsidies (49). Similarly, Thailand provides regular funding for civil society capacity building through the Thai Health Promotion Fund (24). In India, training ASHAs to take on leadership roles within the health system was seen as a priority investment from the government and thus substantially funded through the National Rural Health Mission. Multiple key informants saw the significant government investment in training ASHAs as a key reason for their high functionality in many communities (8).

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4.8 Conclusion

This chapter focuses on how governments can support populations, communities, and civil society in ensuring managerial as well as civic empowerment, manifested in three dimensions of capacities (technical, recognition, and communication skills) so that government and the population, communities, and civil society can enter the participation process on as equal a footing as possible. These three capacity dimensions are conceptually relevant when designing capacity-building activities as they mutually depend on each other.

Firstly, a fundamental constraint for participation is the lack of technical skills of the population, communities, and civil society to fully comprehend the issues and topics at stake and enter into an equal discussion with governments. On the government side, technical skills to run and facilitate participatory processes need capacity strengthening as many government cadres struggle with the complexities of brokering a feasible policy agreement between the various viewpoints and stakeholder types.

Technical skills are essential for manifesting a strong vision and clear targets for engagement – it is therefore in the interest of all stakeholders, especially government, to invest in capacity-building of technical skills for themselves and for the population, communities, and civil society to ensure that they are knowledgeable and informed to fully enter the discussion.

The second dimensions, recognition, is acknowledged as the most difficult to build as it is strongly linked to social, cultural, economic, and political conditions. Communication, as a third fundamental dimension of capacities, is based on recognition and is linked to a great extent on the skills of governments to create and maintain spaces for participation.

Besides investing in and supporting civil society capacity-building initiatives, government capacity needs in social participation require special attention. Most government health institutions are well endowed with medico-technical skill sets but often lack adequate capacities to listen, convene, and communicate – the very basics needed for meaningful social participation.

References

1 Morgan P. The concept of capacity. European Centre for Development Policy Management. 2006:1-19.

2 Smith BJ, Tang KC, Nutbeam D. WHO health promotion glossary: new terms. Health Promotion International. 2006;21(4):340-5.

3 Bergeron K, Abdi S, DeCorby K, Mensah G, Rempel B, Manson H. Theories, models and frameworks used in capacity building interventions relevant to Publich Health: a systematic review. BMC Public Health. 2017;17(1):914.

4 Wallerstein N. Empowerment to reduce health disparities. Scandinavian Journal of Public Health. 2002;30(59_suppl):72-7.

5 Hawe P, Shiell A. Social capital and health promotion: a review. Social Science & Medicine. 2000;51(6):871-85.

6 Kapiriri L, Norheim OF, Heggenhougen K. Public participation in health planning and priority setting at the district level in Uganda. Health Policy and Planning. 2003;18(2):205-13.

7 Cantelli F. Deux conceptions de l'empowerment. Politique et Sociétés. 2013;32(1):63-87.

8 Swasti Health Catalyst. Community Participation in the National Rural Health Mission (NRHM). Unpublished work.

9 Burkina Faso case study interviewee #1. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire au Burkina Faso. Unpublished work. French

10 Frankish CJ, Kwan B, Ratner PA, Higgins JW, Larsen C. Challenges of citizen participation in regional health authorities. Social Science & Medicine. 2002;54(10):1471-80.

11 Mexico case study interviewee #1. Case study on civil society involvement in policy processes in Mexico. Unpublished work. Spanish.

12 Mexico case study interviewee #4. Case study on civil society involvement in policy processes in Mexico. Unpublished work. Spanish.

13 Madagascar case study interviewee #22. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

14 Madagascar case study interviewee #28. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

15 Madagascar case study interviewee #11. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

16 Burkina Faso case study interviewee #4. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire au Burkina Faso. Unpublished work. French.

17 Petit D. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

18 United Nations Educational Scientific and Cultural Organization (UNESCO). Literacy: United Nations Educational, Scientific and Cultural Organization (UNESCO); 2018 [Available from: https://en.unesco.org/themes/literacy].

19 Organization for Economic Cooperation and Development (OECD). challenge of capacity development. Working towards good practice. Organization for Economic Cooperation and Development (OECD); 2006.

20 Rowe G, Frewer LJ. Evaluating public-participation exercises: a research agenda. Science, Technology, & Human Values. 2004;29(4):512-56.

21 Snow ME, Tweedie K, Pederson A. Heard and valued: the development of a model to meaningfully engage marginalized populations in health services planning. BMC Health Services Research. 2018;18(1):181.

22 World Health Organization (WHO), SciencesPo. 'La démocratie santé en France' dataset. In: World Health Organization (WHO), SciencesPo, editors. Year of data collection: 2018. French.

23 Van de Bovenkamp HM, Trappenburg MJ, Grit KJ. Patient participation in collective healthcare decision making: the Dutch model. Health Expectations. 2010;13(1):73-85.

24 Rajan D, Mathurapote N, Putthasri W, Posayanonda T, Pinprateep P, de Courcelles S, et al. The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016). World Health Organization (WHO); 2017.

25 Thailand case study interviewee #7. The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016). 2017.

26 Portugal case study interviewee #3. The Portuguese Health Council Case Study – A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work. Portuguese.

27 Kaufman J, Liu Y, Fang J. Improving reproductive health in rural China through participatory planning. Global Public Health. 2012;7(8):856-68.

28 Anderson JM. Empowering patients: issues and strategies. Social Science & Medicine. 1996;43(5):697-705.

29 Genard J-L. De la capacité, de la compétence, de l'empowerment, repenser l'anthropologie de la participation. Politique et Sociétés. 2013;32(1):43-62.

30 Kilewo EG, Frumence G. Factors that hinder community participation in developing and implementing comprehensive council health plans in Manyoni District, Tanzania. Global Health Action. 2015;8:26461.

31 World Health Organization (WHO). 'Madagascar case study: Étude de cas sur les mécanismes d'engagement de la communauté' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2019. French.

32 World Health Organization (WHO). 'Tunisia case study' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2018-2019. French.

33 D'Agostino TA, Atkinson TM, Latella LE, Rogers M, Morrissey D, DeRosa AP, et al. Promoting patient participation in healthcare interactions through communication skills training: a systematic review. Patient education and counseling. 2017;100(7):1247-57.

34 Wignaraja K. Capacity development: a UNDP primer. United Nations Development Programme (UNDP); 2009.

35 India case study interviewee #3. Community Participation in the National Rural Health Mission (NRHM). Unpublished work.

36 Burkina Faso case study interviewee #13. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French.

37 Madagascar case study interviewee #34. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

38 Madagascar case study interviewee #27. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

39 Swasti Health Catalyst. 'Community Participation in the National Rural Health Mission (NRHM)' dataset. In: Swasti Health Catalyst, editor. Year of data collection: 2019.

40 Cantelli F, Garon F, Schiffino N. Participation et pouvoirs: pour une lecture renouvelée. Politique et Sociétés. 2013;32(1):3-19.

41 Madagascar case study interviewee #21. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

42 Portugal case study interviewee #1. The Portuguese Health Council Case Study - A mechanism for Civil Society Organization's engagement in national health planning and policy-making in Portugal. Unpublished work. Portuguese.

43 Colectivo Meta (COMETA). 'Case study on civil society involvement in policy processes in Mexico' dataset. In: Colectivo Meta (COMETA), editor. Year of data collection: 2019. Spanish.

44 Zongo S. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French.

45 Rajan D, Hadi Ayazi M, Moradi-Lakeh M, Rosami-Gooran N, Rahbari M, Damari B, et al. Chapter 4: Public voice and participatory governance in the health sector: status quo and way forward. In: Hsu J, Majdzadeh R, Harirchi I, Soucat A, editors. Health System Transformation in the Islamic Republic of Iran: an assessment of key health financing and governance issues. Geneva: World Health Organization (WHO); 2020.

46 Burkina Faso case study interviewee #3. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French

47 Butler JRA, Wise RM, Skewes TD, Bohensky EL, Peterson N, Suadnya W, et al. Integrating top-down and bottom-up adaptation planning to build adaptive capacity: a structured learning approach. Coastal Management. 2015;43(4):346-64.

48 Rohrer K, Rajan D. Population consultation on needs and expectations. In: Schmets G, Rajan D, Kadandale S, editors. Strategizing National Health in the 21st Century: a Handbook. Geneva: World Health Organization (WHO); 2016.

49 World Health Organization (WHO), SciencesPo. La démocratie santé en France. Unpublished work. French.

50 World Health Organization (WHO). 'The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016)' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2017.

51 Alves I. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work.

52 Burkina Faso case study interviewee #14. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French.

53 World Health Organization (WHO). 'Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2019. French.

54 Mexico case study interviewee #5. Case study on civil society involvement in policy processes in Mexico. Unpublished work. Spanish.

55 DeCorby-Watson K, Mensah G, Bergeron K, Abdi S, Rempel B, Manson H. Effectiveness of capacity building interventions relevant to public health practice: a systematic review. BMC Public Health. 2018;18(1):684.

56 Miles S, Renedo A, Marston C. 'Slow co-production' for deeper patient involvement in health care. The Journal of Health Design. 2018;3(1).

57 Simmons A, Reynolds RC, Swinburn B. Defining community capacity building: is it possible? Preventive Medicine. 2011;52(3-4):193-9.

58 Báscolo EP, Yavich N, Denis J-L. Analysis of the enablers of capacities to produce primary health care-based reforms in Latin America: a multiple case study. Family Practice. 2016;33(3):207-18.

59 Thurston WE, MacKean G, Vollman A, Casebeer A, Weber M, Maloff B, et al. Public participation in regional health policy: a theoretical framework. Health Policy. 2005;73(3):237-52.

60 Mexico case study interviewee #2. Case study on civil society involvement in policy processes in Mexico. Unpublished work. Spanish.

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Chapter 5

From population engagement to decision-making

DHEEPA RAJAN

Handbook on Social Participation
for Universal Health Coverage

5.1 Introduction

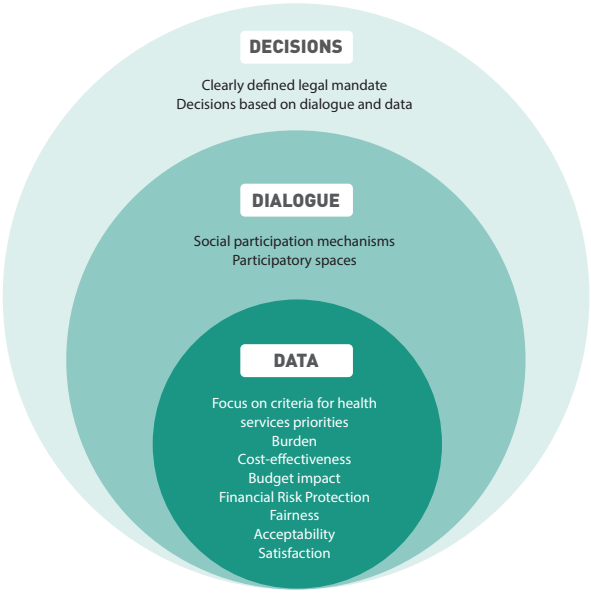
One goal of social participation in health is to influence health policy-making; this is the focus of this handbook and thus the principal entry point for the question this chapter attempts to answer: how, and by whom, are decisions taken once participatory processes (public consultations, population engagement mechanisms, deliberative processes) have taken place? How far do results and insights from participatory processes in health translate into policy decisions? What are the issues governments should think through to increase uptake into decision-making?

This is not to say that other social participation objectives besides policy influence are not relevant nor desired. As discussed in this chapter, the end point of a participatory process is subject to different perspectives and depends very much on the expected result of a participatory space. Yet here we focus on the goal of policy uptake, given that the handbook target audience is the policy-maker, and the organizer of participatory spaces is thus assumed to be connected to government and a public sector objective.

Since this handbook examines social participation as a vital element of policy- and decision-making, we take a closer look at a stylized health sector decision-making process to understand where social participation fits in. Figure 1 shows the '3Ds', i.e. Data, Dialogue, and Decisions (1), a schematic first published to explain how decisions should ideally be taken within a national health planning process (2). The smallest ball, 'data', is essentially about the evidence which needs to be generated and analyzed as a basis for decision-making. This evidence generation element should include not only research-based, more classical scientific evidence, but also experiential, implementation evidence, i.e. quantitative and qualitative studies and other, varied forms of documentation (case studies, reports, etc.) (3). The next component is 'dialogue', where the available information and evidence is taken into consideration by a wide range of people and stakeholders and debated from different perspectives, experiences, and angles. The final component, 'decision' is when the data and dialogue pieces feed into decisions and policies. These three procedural elements need not happen in any particular order and they may, in reality, happen in parallel.

In this chapter, we zoom in on the 'dialogue' element, particularly for purposes of policy- and decision-making, i.e. we address the link between the last 2Ds, 'dialogue' and 'decision'.

Figure 1: 3D approach: data, dialogue, decisions.



5.2 Objectives of the chapter

This chapter aims to provoke the policy-/decision-maker reader to reflect on the central issues linked to ensuring that results emanating from a participatory process in health leads to real policy decisions.

The next section lays out the key concepts, which is followed by an in-depth look at the central issues for policy-makers to think through. Practical country illustrations help drive home key messages. We then draw attention to two critical cross-cutting topics for a policy-maker which have practical implications when managing a participatory process: the process format & design as well as the necessary capacities needed by stakeholders to ensure decision-maker uptake. Dos and don'ts and practical tables are scattered throughout the chapter.

5.3 Population engagement & decision-making: conceptual clarification

The "deliberation-to-policy gap", or the disconnect between a participatory process and decisions

The currently available literature reports heavily on the process of participatory governance mechanisms; what happens once the process is over, and how the input is used and analysed is unclear (4-8). However, the process itself, that is, its format and design, may be partly responsible for the extent to which process results are taken up for decision-making, as explored further in this chapter.

What is clear from the literature, however, is that a 'deliberation-to-policy gap' exists (see Box 5.1) (9, 10), and that the link between participation input and decision-making cannot be assumed (4). Unfortunately, little guidance and documentation is available on the subject (11), which may be a reflection of the fact that the step of incorporating participation results into policy is fairly intransparent. Indeed, the impact on policy is often described as the most contentious issue of deliberation (12).

Box 5.1

The origins of the term 'deliberation-to-policy gap'

The term *deliberation-to-policy* gap originated within the area of biomedicine and biotechnology; it was used by Doherty and Hawkins (22) to describe a lack of practical translation of participatory deliberation results into human tissue biobank policy-making. The researchers analyzed a 2009 public deliberation exercise on the use of a biolibrary (a network of biobanks) in Canada. Bringing in population voice into the biolibrary's activities was seen as a means to address the ethical concerns of biobank use. Doherty and Hawkins' analyses concluded that despite multiple public engagements, the practical translation of participatory input into biotechnology policies remained limited. They emphasize that *"the link from public engagement to policy relevance is not automatic"* (22).

The authors posit that the lack of policy uptake despite numerous debates within participatory spaces goes back to the lack of clear objective and output definition for the participatory space, underlining policy-makers' struggle with the 'how' of participation.

Molster et al. (9) also employ the term *deliberation-to-policy gap* to describe the practical and theoretical shortcomings of a 2008 West Australia citizens' forum set up to formulate biobank use recommendations. They too lament the limited policy uptake of the forum's recommendations and link it to the ambiguous framing of the participatory space.

In 2014, Lander et al. conducted a systematic review of *"public involvement activities"* (described as activities related to information & communication as well as consultation, participation and deliberation) in biomedical research and innovation initiated by academic institutions (23). They came to a similar conclusion, stating that the *deliberation-to-policy gap* is particularly acute for academia's public involvement activities, leading to little policy uptake (but numerous journal publications).

This deliberation-to-policy gap is further exemplified by the lack of formal links between many participatory mechanisms and an accountable enforcing authority (13-15) (see Section 5.4). Sometimes the formal links are with a decision-maker but not the one directly responsible for the topic of deliberation. For example, the results of a 2008 Israeli Health Parliament experiment led to concrete recommendations by the Ministry of Health (MoH) -- but the Ministry was not the government body with a mandate to make decisions on the topic of deliberation. In the end, the government institution which was linked to the deliberation topic ignored the Health Parliament's recommendations, making the Health Parliament experiment a one-off exercise (10).

From local-level community mobilization efforts in Madagascar, the Islamic Republic of Iran, and India to sophisticated, institutionalized population engagement mechanisms like Thailand's National Health Assembly or Tunisia's Societal Dialogue for Health, we note policy follow-up challenges (16-20). In essence, ensuring uptake of participatory process input into policies seems to require an additional concerted effort and collective reflection on how to ensure it.

Interestingly, there seems to be a disconnect between the perception of how far public input influences policies and the reality of its influence. A review of UK National Health Service patient and public involvement initiatives revealed the lucid perception of all stakeholders that patients and the public influence policy greatly; however, no documented information could corroborate how this was actually the case (21).

Translation into policy is not always the priority in participatory governance processes

This chapter is focused on how to ensure more participation-based results uptake into policies; however, it is important to understand that this is not always the principle objective of every participatory process in health. Indeed, many authors advance a value-driven argument that participation is a value in and of itself, an intrinsic goal. A strong principle filters through both the literature and case studies that people who are affected by a certain policy should have their say to lend process legitimacy, and empower citizens along the way (7, 14, 24, 25). The emphasis here is on the process itself and empowerment, whether or not people's input is subsequently directly linked to policy.

People themselves seem to share this view at times as evinced by the Israeli Health Parliament participants who were emphatic that they did not need a guarantee of policy influence but felt that the process was most important (12). A Dutch study observed that patient associations' involvement in clinical practice guideline development did not necessarily modify nor improve the guidelines but that that may not be the point (7). Degeling et al. even advance the argument that, as long as the participatory governance mechanism is squarely embedded in a larger political process, then *"exerting influence on policy is not really [the] issue... but rather [it is] recognising the value, role and limitations of the evidence produced [by the participatory process]"* (26). If policy uptake is not the principal objective of participatory processes in the health sector,

then the pertinent question to be asked is: what is?

There seems to be little consensus on the answer, as evinced by a plethora of public participation effectiveness studies which use differing assessment end points (27). The 'effectiveness' of participation is defined very differently across the social science community, and often linked to process-related outputs rather than policy decisions (11). The confusion around the end point for participatory processes is partly linked to the ambiguity of objective and lack of rationale which plague such undertakings (see Chapters 1 and 3) (28, 29). In addition, concepts and indicators to examine participation outcomes are not well developed nor specified, besides being used inconsistently. Clearly, different perspectives mean different end points for participation, and which stakeholder is defining the end point makes all the difference.

From the perspective of the policy-maker stakeholder, we contend that policy uptake is not necessarily the priority nor goal of every single step of the participatory process, but can indeed be an objective of public participation in general. This reflection assumes that participation is, indeed, a process with several steps and events, each using different methodologies adjusted to different event-related objectives which may or may not be policy change. Indeed, public consultation in 'multiple stages' can be seen as a solution to various problems faced when policy translation is premature and the pressure is high to show participation effectiveness. Such problems include detracting from the expression of non-mainstream views and offering solutions without sufficient dialogue and trust (11).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5.4 Policy uptake of participatory space results: key issues to reflect on

This section highlights the principal factors which seem to tip the balance towards more rather than less participation uptake into decisions.

A culture of participation increases the likelihood of public participation input translating into policy

It may be unsurprising that an institutional culture which views participation as necessary and mutually beneficial takes participatory input more seriously during decision-making (26, 28, 30, 31). An institutional culture which embraces innovation is more open to the change which comes about when listening to others and taking their views into account (9). In some countries, the tendency and outlook of the government in place has a significant influence on how far interaction is fostered with the population, either through institutionalized mechanisms or otherwise (20). In addition, support from senior management is also key to making concrete policy changes based on participatory process inputs, and is a reflection of the organizational culture (32).

Such a culture does not happen overnight and is cultivated by increased exposure to participatory processes. Attitudes seem to change to become more favourable to participation-based decisions with more interaction between different stakeholders, albeit slowly and over time (25, 33, 34). An attitude shift does not necessarily happen at the beginning, and can even be antithetical at first (15, 17). However, with multiple opportunities to interact, exchange, agree and disagree, an understanding of other viewpoints and mutual respect is developed (15, 16, 35). This points to a need for a long-term commitment to participation and participatory processes for health decision-making.

Long-term relationships can foster a culture of participation built on trust and also act as a factor of policy- and decision-making influence. Participants who are exposed to each other more regularly are more able to forge a shared identity which enables individual interests and a collective perspective to co-exist while crafting solutions (5). Long-term relationship-building is encouraged by a serial and regular schedule of participatory events as well as by combining participation techniques with different target groups so that people have the opportunity to hear varied viewpoints. For example, a review of several citizen juries' policy influence found that the jury time period

Box 5.2

How can a culture of participation be fostered?

It can be fostered through:

- increased exposure for all stakeholders to participatory processes;
- regularity in participatory exchanges;
- a combination of methodologies with the aim of hearing varied viewpoints;
- long-term commitment to participation;
- long-term relationships between stakeholders;
- a format & design which encourages stakeholders to understand the collective interest perspective;
- transparency of deliberations, with feedback provided, and/or minutes of meetings made available.

of one-two days is much too short to enable constructive dialogue and long-term relationships which enable decision-making (14). We explore format & design of participatory processes in more detail in section 5.

Political will and decision-maker commitment increase the integration of public voice into policies

Policy-maker will and commitment can be make-or-break factors in policy uptake of participation-based input. In the Islamic Republic of Iran, civic space was clearly opened up by more liberal governments (36) and ultimately led to the Health Transformation Plan which gives participation a central place in the country's health reform process (20, 37). In Thailand, high-level political support for the reform movement from which the National Health Assembly (NHA) was borne paved the way to today's culture of participation in its health sector. Even within the current NHA process, stakeholders with different institutional identities reported that NHA resolution implementation depended heavily on the political will of those who had the power to implement (38). Pagatpatan et al. (2018) sum it up clearly:

> **"Success of public participation initiatives relies heavily on... political leaders' commitment and authority. As such, building genuine political commitment is so important in achieving... public influence on policy decisions."**
>
> Pagatpatan et al. (5)

The same message is echoed in an experience from Australia recounting a particularly committed Minister who championed the use of deliberative techniques for decision-making. Not surprisingly, she adopted a large majority of the recommendations that came out of those participatory processes while at the same time pointing out that those decisions ultimately came under her responsibility (39).

This anecdote exemplifies that, in practice, political will and commitment are closely intertwined with decision-maker authority and capacity. In addition, the degree to which the decision-maker is willing to endorse and legitimize the participatory process, and thereby take responsibility for its results, has a profound impact on whether policies are inclusive of those results. We break down these three aspects further below.

(a) Decision-maker authority: the need for support from both high political levels and mid-level cadres

Many of the studies reviewed described participatory processes initiated by research institutions or civil society with government officials invited into the process at different stages, sometimes early on in the planning stage, and sometimes later down the line. Even where there was general support from the policy-maker(s) in question, the processes were not directly under the decision-maker's authority, making it more difficult and less likely that results were used for policy purposes.

That being said, the simple fact of government initiation of a participatory process for a policy question does not guarantee policy uptake. The level of government authority seems to play a critical role, both in terms of high-level government commitment *as well as* ownership by decision-makers within Ministries and government institutions who hold budgets and influence policy content (often Director-level administrators, mid-level government cadres and/or career civil servants (40)). For example, in Thailand, the Prime Minister (or his/her Deputy) is the chairperson of the National Health Commission, the governing body for the National Health Assembly (NHA) which brings together Thai citizens of all walks of society to discuss health-related issues (41). However, department directors and budget holders from the MoH are less present in the NHA process, signalling a certain scepticism regarding the NHA's utility value, and contributing to a mediocre level of NHA resolution implementation (15). The need for high political levels (Prime Minister of Thailand) to support participatory governance platforms is evident but the actual practical decision-makers need to be on board as well. This point is also underlined in Tunisia's Societal Dialogue for Health which is also plagued with the challenge of policy uptake despite Ministerial and Prime Ministerial commitment due to scepticism within Ministry ranks (17). Papers examining the British National Institute for Clinical Excellence (NICE)'s inclusion of patient and public voices in decision-making demonstrate that both NICE leadership as well as its rank-and-file managers were given the mandate and necessary training to apply population engagement mechanisms into their work, thereby successfully integrating people's input into their policies and decisions (6, 42-45).

Box 5.3

Political will & policy uptake of participation

- High-level support is needed as well as mid-level Ministerial hierarchy, i.e. those who hold budgets and lead policy development.
- Participatory processes need to be linked to the specific government entity who has decision-making authority on the topic under consultation.
- High-level policy-makers may be more willing to endorse participation-based input if they are perceived as being representative of people and/or population groups.

Another issue alluded to with the Israeli Health Parliament example previously is the need to link the participatory process to the correct decision-making entity who has jurisdiction over the topic at hand and has the authority to act on the results (46). A case in point is expressed by a Portuguese Member of Parliament with regards to reports from their Health Council (see Box 5.4): *"We try…to do something about some of the recommendations. Some of them… do not fall within the competence of the Parliament. The Parliament legislates and supervises. Some of the recommendations… are more within the purview of those who ha[ve] the capacity or the power to execute, and therefore they [should be] addressed to the government"* (47).

Box 5.4

National Health Council, **Portugal**, established in 2017: high hopes for policy influence

The Portuguese Basic Health Law mandated the National Health Council as an independent government advisory body (48, 49) to "ensure citizens' participation in the [formulation] of health policies and [to] promote a culture of transparency and accountability to society" (50).

The Council consists of 30 members with equal voting rights. Members include professional associations, regional government representatives, universities, and six seats reserved for civil society organizations.

The Council aims to influence health policies by bringing the voices of its diverse members together into one institution and by issuing publicly accessible statements and recommendations on topics formulated on its own initiative or by government or parliament request. One of its main tasks is to put together an annual report on the state of health in Portugal which is presented to the Minister of Health and the Parliament (51).

The Council's aim of capturing citizen voice is thus manifested through the fixed civil society seats. The Council deliberates through periodic plenary meetings which all members attend or through working groups (so-called specialized commissions) called on specific subjects.

The Council is currently in its infancy, and many stakeholders have expressed high hopes for the Council´s influence on health policy. Many also underlined its growing visibility in Portuguese society and hope that it will increase the impact of its recommendations on decision-making through bottom-up support. It is seen by members and the public as a valuable mechanism to institutionalize social participation in health and to increase decision-makers' understanding of its importance for policy-making (51).

(b) Decision-maker capacity: a specific skill set is needed to link participatory results to policies

Please refer to the cross-cutting section *'Capacity aspects to consider which are pertinent for decision-making influence'* further below.

(c) Decision-maker commitment to endorse and legitimize the participatory process

In essence, government commitment to endorse a process is about taking responsibility for both the process and its results (5). This commitment is often heavily determined by the soundness of the participatory process, its format and design. We reflect further on the latter two elements in the cross-cutting section of this chapter: 'Format and design of participatory process which can increase uptake of results by policy-makers' below.

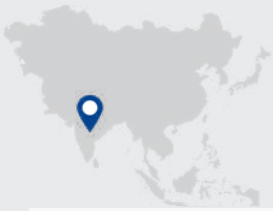
In addition, in many settings, the overall political will can influence the commitment levels of the individual decision-maker to make the added effort to endorse a participatory process and its results. In the Islamic Republic of Iran, stakeholders from government, civil society, and academia all acknowledged that when the highest levels of government were advocating for more social participation, more attention was paid to participatory input and use (20). This likely had to do with like-minded officials being appointed to middle management government posts and government entities working more regularly with community volunteers as their modus operandi, thereby confronted more often with the added value of experiential evidence to their policy work (20).

Governance vs. service delivery approach to participation: it matters for policy uptake

One can distinguish between two different approaches of decision-makers to participation and participatory processes in health: one which has the primary objective of improving health service delivery, increasing health facility utilization rates, and augmenting service quality; and one which has the principal purpose of ensuring good governance of the health sector, which focuses more on listening and capturing people's voice to establish an accountable and responsive health system. Naturally, the two approaches overlap in practice as much of the population's voice which will be captured pertaining to health will be closely linked to health service availability and quality (largely service delivery matters). Nevertheless, the mindset with which participatory processes are organized by governments seems to make a tangible difference with regards to how far people's voice are taken up in health policies. The 'service delivery' approach tends to be more focused on bringing information to communities and people and incentivizing and convincing them to use curative and preventive health services. A quintessential example would be a vaccination campaign whose aim is primarily to work with communities to ensure high immunization coverage. Once the campaign is finished, and vaccine coverage levels are up, the objectives for collaboration with communities have been reached (until the next one starts again). Information tends to flow one-way from decision-makers to communities. The 'governance' approach on the other hand has the

explicit interest of having a two-way flow of communication, with the flow from people to health authorities being of particular interest.

For example, in a recent study of the "communitization" pillar of the National Rural Health Mission (NRHM) in India (see Box 5.5), it was clear that many of the stakeholders involved in implementing the Mission programmes approached their interaction with communities with service delivery targets and programme implementation in mind. As one former Indian government official described it, the aims of social participation in the NRHM "would be raising awareness, getting access, ensuring that the services are being delivered the way they should be" (52). This sentiment was common among key informants of the study. One of them defined the community as those "who access health services and public health facilities" (53). This definition is compelling as it highlights the perceived role of the community under NRHM as beneficiaries of services rather than those whose health rights must be fulfilled and needs met (19, 54).



Box 5.5

The governance vs service delivery approach: National Rural Health Mission's (NRHM) communitization pillar, India

NRHM design

The National Rural Health Mission (NRHM) was introduced in 2005 to improve access to quality health care for the rural population, with a focus on the most vulnerable (it has since been blended in with the current National Health Mission). One of the key components of the NRHM framework was 'communitization'. This community engagement pillar created interlinked participation platforms, forums, systems and structures across national, state and local levels (19).

A national level advisory group (Advisory Group on Community Action) was set up to design and support community-based planning and monitoring through existing government and community structures. At local level, *Accredited Social Health Activists* (ASHAs) were created as a community health worker cadre to be selected by communities and link them to the health system, and vice versa. ASHAs are the backbone of the communitization pillar and are conceived as the primary vehicle through which community access to services is increased.

The NRHM communitization pillar also created the *Village Health & Sanitation Nutrition Committee* (VHSNC) as a platform for village-level planning and management. The VHSNC design blended them with existing structures such as the Panchayat Raj institutions, expanding participation to ASHAs and other community members (55). The VHSNCs were intended to increase community autonomy with flexible, discretionary funding, although this often proved difficult to implement in practice (56).

Civil society organizations are given a pivotal role in NRHM design with grants for specific tasks, like capacity-building for local initiatives and the provision of community services (19).

NRHM on the ground

Although the language of many of the NRHM documents aim for increased community agency and government accountability through the communitization pillar, in practice much of the newly created or strengthened platforms and systems heavily focused on improving service delivery utilization at the local level. Listening to community voices with the primary goal of understanding community context and ensuring transparent policies (i.e. more of a governance approach to participation, although they are not mutually exclusive) was not necessarily the main concern of local implementers on the ground. ASHA training programmes centred on clinical care and programme management, as one local stakeholder noted: *"this training has not been able to include areas like patient-centred care, how to hold health facility accountable, understanding of how to participate in different advocacy forums and platforms"* (57).

Communities were predominantly viewed by key informants in interviews as *beneficiaries* of services rather rights-holding citizens. Communities themselves also engaged in participatory spaces based on this very self-understanding of their role, limiting the impact of their input on local government accountability (19).

Nevertheless, the NRHM´s vision to amplify community voice was widely viewed as a milestone given its outreach (56). The narrative for public health in India no longer ignores the need to incorporate the population, communities, and civil society into health system operations.

A case study from Madagascar examining community mobilization efforts in the health sector found that, in practice, the main role of the district-level body meant to work with the local population is mainly a technical, service delivery-oriented one. The Committee's main responsibilities as described by all study interviewees were to raise awareness, mobilize communities and detect diseases. This technical role suggests that communication between the community and health workers is mainly focused on transmitting messages from the district health centres to the community, such as the dates and locations of the next vaccination campaign, or information on how to access health centre services. Two-way communication between the District Health Committee and communities which might deepen understanding of the community's perspectives did not seem to be of concern (18).

The 'governance' approach was distinctly taken in France's recent Etats Généraux de la Bioéthique, a large-scale public consultation on topics of bioethical relevance. The explicit aim of the consultation was to hear the public's views for the sole purpose of revising the Bioethics Law. The emphasis on listening to the public with the objective of steering the sector on bioethical matters underlines the 'governance' approach to participation in this example (58). Here, the consultation results were taken up the Parliament into the 2019 Bioethics Law (see Box 5.6).

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Box 5.6

France's 2018 Etats Généraux de la Bioéthique and the 2019 Bioethics Law

The French term "democratie sanitaire" (health democracy) is used to denote a culture of participation as part of the health decision-making process, emphasizing the aim of ensuring people's voice as an intrinsic element of governance. Under this umbrella, the National Consultative Ethics Committee (CCNE in its French acronym) organized its latest "états généraux de bioéthique" (EGB) in 2018, a large-scale public engagement effort to hear from the population, communities, and civil society on matters of bioethical concern.

Sensitive issues such as assisted procreation, organ donation, and end-of-life care were discussed. Through the use of a broad range of tools - online consultations, regional discussions, stakeholder hearings, citizens' jury, etc., the CCNE sought to encourage public debate and gauge population views. The objective of consulting the population was clearly to listen rather than to deliver (health) messages or increase service coverage.

The CCNE is an advisory body embedded within the French public health system landscape, with 39 members, including civil society. Its principle mandate is to ensure input of "a broad panorama of society's opinions" into the revision of the Bioethics Law every seven years. The results of the 2018 EGB exercise were presented as official CCNE recommendations to the lower house of the French parliament (National Assembly), subjecting it to further parliamentary debate. The final Bioethics Law, include EGB input, passed in 2019.

The French EGB example elucidates how many favourable factors coming together can pave the way for participatory input to be taken up into policy: the governance approach to participation, i.e. the main objective for the participatory approach was to hear people's views; the mandate to influence policy rested with the participatory space manager, i.e. the CCNE; and a clear objective for the participatory process, i.e. the revision of the Bioethics Law (58).

Institutionalized government-initiated and/or -supported spaces for participation seem to have higher policy uptake

The concept of 'invited vs. claimed' (also called 'invited vs. invented') spaces is mentioned in the literature, with the former being spaces where government or those with decision-making power are doing the inviting (5, 59). The latter, 'claimed spaces', refer to spaces created by civil society or researchers which do not necessarily (but certainly can) influence policy. Inherent to this concept is the understanding that a policy link is more likely if those who are making policies are initiating the participatory process. Several studies highlight the critical role of public officials and state institutional support for the policy success of population engagement processes (11, 26). Many authors point to a lack of policy-maker initiation or support as the principal reason behind failed policy influence (12, 44, 60).

An example of an 'invited space' is the Health Council in Portugal (see box 4). It is an independent government body advising the Ministry of Health. Although it has only been in existence for two-three years and policy impact is still to be evaluated, the very fact that it is a public institution with a legal basis means that Ministry of Health and Parliament are obliged to consider its recommendations. As one Portuguese stakeholder put it: *"I think it can be effective. Because it has legitimacy and legitimacy is very important"* (61).

In the Islamic Republic of Iran, a unit within the Ministry of Health dedicated to NGO collaboration was created as part of the 2014 Health Transformation Plan. This unit can be seen as an 'invited space' where NGO input is actively sought after on specific topics by dedicated government staff to feed into health policy. Stakeholder interview data from a recent evaluation of participatory structures in the Islamic Republic of Iran demonstrated that the exchanges which happen in this space do indeed feed into government decision-making (20).

Another 'invited space' in the Islamic Republic of Iran is a call centre operated by the Ministry of Health where citizens can call in to give feedback on their health system experience and issues of concern. A specific follow-up committee at provincial level ensures that every valid issue is addressed and referred to a responsible entity for follow-up. The call centre data is systematically collected and analysed to feed into the MoH's day-to-day policy work (20).

That being said, 'claimed' spaces created by communities and civil society are just as critical for participatory culture and effectiveness, and are complementary to invited spaces. Both are needed and the two types of spaces are not always entirely discrete, with one sometimes influencing the other as membership overlaps. In some contexts, invited spaces face challenges of legitimacy in

Box 5.7

Examples of government-initiated spaces for participation

- Thailand's National Health Assembly
- France's Etats Généraux de la Bioéthique
- Portugal's Health Council
- Islamic Republic of Iran's call centre based within MoH

the eyes of communities (62). While acknowledging these limitations, and scrutinizing specifically the issue of policy uptake, the documented experience to date demonstrates that 'claimed' spaces end up taking a bumpier road to decision-making (17, 63, 64).

Legal frameworks can support public participation input taken up for health decision-making

In Thailand, the National Health Act 2007 "ensconced the idea of participatory national governance into the health landscape" (15) through the establishment of participation as a principle of health policy-making, be it through the National Health Assembly, public hearings, or seats for civil society and community groups on various health institution boards. Despite policy uptake challenges in some areas, it is generally acknowledged that health policies in Thailand have a fair share of public input represented in them. Some argue that a political mandate for public involvement in decision-making should be a pre-requisite for participatory processes, implying enforceable laws that help nudge policy-makers to engage with the population, communities, and civil society and use that input actively for decision-making (5).

Taking a peek outside the health sector, a review of participatory processes in the United States Forest Service recommends existing legislative frameworks to be modified to facilitate and incentivize collaboration and participation for decision-making (24). The legislation which existed provided a mandate for public participation and opened doors for participatory processes to happen in the first place. One could also argue in the U.S. case that a legal framework helped build up an institutional culture where participation is valued, thus creating fertile ground to go to the next level of the Forest Service *"[recently taking] the lead... in changing its management philosophy to be more holistic and inclusive"* (6, 24, 35).

In France, legal frameworks specify the guidelines for civil society organizations to get accredited and take part in hospital and local regional government policy-making bodies (for caveats and issues to think through with regards to legal frameworks, see Chapter 6). These frameworks were seen by French civil society stakeholders as crucial for transparency and policy-maker trust in accredited associations (65). In Tunisia, attempts to institutionalize meaningful population engagement in health sector decision-making is making headway but an increasingly loud chorus of stakeholder groups feel that the Societal Dialogue for Health now needs a legal framework (66).

Box 5.8

Legal frameworks and decision-making: key messages

- Legal frameworks can help nudge more participation-based input into decisions.
- Legal frameworks can help assure regularity of structured stakeholder exchanges – this is key for fostering a culture of participation which gives people the necessary exposure to each other to find common solutions -- which influences policy uptake.
- Legal framework can help give weaker stakeholders a more solid mandate to feed into policies.

As underlined by chapter 6 dedicated to legal frameworks, they by no means guarantee decision-maker uptake of participatory input, nor are they needed as a pre-requisite for active participation in the health sector. In Thailand, civil society and community groups thrived locally before the National Health Act was passed, and indeed, their advocacy based on years of participation experience was one of the main reasons why it did pass in the first place.

Decision-making transparency and feedback facilitate policy uptake

A recent qualitative synthesis noted that one of the mechanisms of political commitment which makes public participation more effective is the 'feedback loop' between policy-makers and participants of a deliberation exercise (5). This feedback loop serves to inform the public as to how their input was used (or not) internally by the organization leading on the deliberation exercise. An example is the You Said, We Did communication method in the UK's National Health Service which encouraged local health districts to provide feedback to its catchment area population on how its inputs, complaints, and suggestions were acted upon (67). For example, many districts published on their website both the actual feedback received and the accompanying decision and action taken (68-71). The act of transparent feedback meant that public input could not be ignored one way or the other.

The feedback loop is thus seen as critical for transparency and accountability of the process by several authors (31, 72, 73). There appears to be a correlation between policy-makers and public institutions who are committed to transparency as a principle and the care taken to use input from the public into policies and guidelines (13, 28, 29). In the Islamic Republic of Iran, for example, the Ministry of Health under a government supportive of social participation revamped an existing call centre set-up within Ministry premises for feedback and complaints from the public. The call centre, which had not been accorded high priority before, subsequently became highly functional with new investment in the call centre staff and training, and a process in place to evaluate complaints, refer them to the responsible body, and/or act on them within the Ministry's remit. Call centre data is analyzed regularly with a special committee in place at provincial level to act on more systemic bottlenecks. For example, the initial bulk of public feedback was related to informal payments made to health providers; this continued even after health insurance reimbursement rates were revised as part of the Health Transformation Plan (HTP) to secure adequate health provider income. Call centre information was a basis for further discussions between the government and health providers to ensure that HTP reforms were complied with. The deluge of phone calls, and the commitment to respond back to complaints deemed as valid, seems to have pushed the Iranian government to prioritize the informal payment issue and enforce recent reforms vis à vis the professional medical community (20).

The policy and decision link is easier if it aligns with decision-makers' views

It is probably not surprising that participatory process results which are in line with policy-maker views find their way into policies much more easily. An Australian study examining a citizen consultation on biobanking concluded that policy translation happened effortlessly partly because the deliberated citizen recommendations were largely similar to both draft guidelines and to the views of other local stakeholders (9).

In Mexico, a representative of a government health institution underlined the facility with which civil society and government could collaborate when they see eye to eye: *"there are organizations... that are interested in the welfare of the population and seek the same goal that we do. We like to work with these organizations because we can join efforts to achieve a common goal"* (63).

However, care must be taken in such situations to avoid the participatory process being perceived as simply a rubber stamp for pre-conceived decisions (73). We elaborate further on this in the next section.

A tokenistic approach does not lead to public input influencing policy (and is risky)

Those who come with experiential knowledge to a consultation process are often in a dependent position vis à vis professional-experts, with an inherent risk of instrumentalization of the former (see Chapter 3). One study from the Netherlands showed the low uptake of patient organizations' input into clinical guidelines; the authors lament the lower value given to experiential knowledge and the subsequent misuse of patients' presence on decision-making committees to 'tick the box' of 'consultation' (7). Other studies have observed the instrumentalization of patient and population input to legitimize decisions which would have been made anyway (13, 35). Obviously, tokenism does not allow for real public input into policy decisions.

The risks, however, are huge. Participatory governance mechanisms rely heavily on trust between the stakeholders involved as well as trust in the process. Barratt et al. describe a failed participatory process in a local English community where mistrust led to frustration on all sides, and the community feeling 'dismissed' in their views. As the authors highlight in conclusion, "trust is difficult to create and easy to lose; once lost, it is difficult to regain" (74). A genuine approach without pre-determined decisions is clearly best practice, without which subsequent engagement processes would be onerous, burdened by a trust deficit (75).

In Portugal, Health Council recommendations to date have been based on a fairly easily-won consensus. However, the one time a controversial topic was debated, civil society actors found themselves with a minority view with their six votes out of 30; the majority view went forward in the end. Discontent was expressed by a few stakeholders at being part of a decision which they did not necessarily agree with, which they had no chance at influencing due to their small vote numbers, but which was released as a recommendation 'endorsed' by civil society (49). It is early days for the Health Council as an institution but a risk definitely exists in general for governments to be perceived as abusing such participatory platforms to rubber stamp government will (76). An additional effort is therefore needed to ensure that the design and format of a participatory mechanism allows for meaningful population, community, and civil society input which has the chance of a more equal voice at the decision-making table.

Why is a tokenistic approach detrimental to participation?

"Trust is difficult to create and easy to lose; once lost, it is difficult to regain."

Barratt et al. (74)

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5.5 Format and design of participatory spaces: increasing results uptake by policy-makers

Format and design of the participatory process should match context and policy-related needs

The format and design of a participatory process is crucial for increasing the likelihood of policy uptake. Format and design aspects which emerge from the literature and primary data analysis as most relevant for policy uptake are (5, 15, 18, 21, 39, 73, 77):

(a) the representativeness (including the *perception* of representativeness) of the participants (see Chapter 3);
(b) the availability of expertise and information *to* form informed views to complement individual interest;
(c) framing linked to policy;
(d) regularity of exchanges (regular meetings);
(e) format favours civil society/population subgroup alliance-building.

Each participatory process design aspect is elaborated upon further below:

(a) Representation

Much of the mistrust, scepticism and criticism of participatory processes lies in the (perceived) lack of participant representativeness. As described in more detail in chapter 3, representativeness is essentially about (perceived) legitimacy which can be derived from representation of a particular group, experience, or idea (7, 9, 39, 78, 79). Representative legitimacy can be gained from the community itself, through the participation selection process, or developed during the participatory process through intelligent process format and design.

In Tunisia, a common belief expressed by stakeholders was that the Societal Dialogue consultations needed to be seen as representative of the people in order for policy-makers to use the results and take better decisions (17). A balanced and transparent selection process supporting participants' ability to take on a legitimate representational role – be it of a community, experience, or idea - is an important factor linked to policy uptake (78, 80).

Policy-makers should be aware of the multiple publics and groups within society and find ways to ensure inclusion of hard-to-reach groups who are usually not represented through the usual representatives (5). Strategies are needed to balance out constituencies such as lobby groups who can dominate civic space and crowd out other voices (39). Managing a participatory space where participant selection criteria and the process format are transparent and collectively reflected on goes a long way in facilitating policy-maker commitment to population engagement mechanisms.

Box 5.9

An extra effort is needed to reach out to vulnerable groups: an example from **Tunisia**

During Phase 1 (2012-2014) of Tunisia's Societal Dialogue for Health initiative just after the Arab Spring Revolution, the focus of activities was on capturing the breadth and depth of people's views and expectations for their health system. This was seen as a critical step in the path towards health sector reform. Many different participatory spaces were used, such as citizen juries, open-mic sessions, regional citizen meetings, etc. However, it was increasingly clear that the participant profiles of those sessions were predominantly male, with certain population groups either not attending at all or not speaking up if present.

The Societal Dialogue for Health Steering Committee thus decided to undertake a series of focus groups to reach out to vulnerable populations and those whose voices were not being heard. They were organized in several governorates, each focus group being homogenous and targeted. Examples include: patients living in remote areas; patients living in poor urban zones; single mothers; families living in impoverished regions; isolated senior citizens; families living in polluted industrial areas. Focus groups were often held in or near the communities themselves; the fruits of those efforts led to solid turnout, enabling an in-depth understanding of real challenges for some communities in interfacing with the health system.

The Societal Dialogue programme's outreach to an inclusive and broad group of stakeholders lent it legitimacy for being the voice of the many rather than the voice of a few. This helped maintain the Societal Dialogue's visibility with both the population and the government, leading to it withstanding the test of time despite multiple government changes as well as political and economic upheaval (17, 81).

(b) The availability of expertise and information to develop informed views

Making information available to participants in a timely manner adapted to both participants' knowledge levels and the policy objective is a specific communication skill which many government institutions must strengthen – this point is further elaborated upon in chapter 4, section 6. In Tunisia, several citizen jury stakeholders expressed frustration that information material was insufficient and provided very late on technical issues they were supposed to pronounce an opinion on (14). This led to some Inter-Regional Meeting outcomes to stay very general in the recommendations, rather that provide the depth and nuance which may be needed to translate them into policies (82-84).

In terms of expertise, the perception of neutrality in the evidence provided is crucial to ensuring buy-in from all sides. This entails allowing data and information analysed by a wide spectrum of experts and institutions to be presented to participants. Expertise at the disposal of participants when needed is seen as crucial to procedural soundness as is information provided at the right level of complexity (26, 81). All of this pre-supposes immense investment in preparing an unpartisan participatory process which brings with it the advantages of higher decision-maker commitment to using the results for policy.

Making expertise available at the right time by the right people and the right place is more easily said than done. Experts need to be briefed beforehand that their role is a supportive one to enable population and civil society to make informed choices; this is quite different from the role they have otherwise in participatory events to represent their expert or professional group. Indeed, French stakeholders repeatedly mentioned that health sector experts, notably health worker groups, are more involved in directly influencing decisions rather than explaining evidence for citizens and communities to question and draw information from (65).

(c) Framing linked to policy

Having all of the public's points of view represented and given a fair hearing is also about the framing of the deliberation and what it is supposed to culminate in. A framing linked clearly and specifically to a policy or policy question piques policy-makers' interest, commitment, and willingness to endorse results. The 'right public and the right policy question' is pivotal in securing and sustaining policy-maker focus (26) as it is at the core of a well-designed participatory process. A well-reflected and clearly formulated policy question helps steer the participatory space's format and design to ensure representativeness, which then boosts (perceived) legitimacy of both the participants and the space – this then augments policy-maker willingness to take participatory process results more seriously.

For a more detailed discourse on the framing of a participatory space, please see Chapters 1 and 3.

(d) Regularity of exchanges

Regular meetings and/or events to exchange and contribute to decisions allow participants to build a relationship of trust, or at the very least, come to an understanding of different (opposing) points of views. Increased stakeholder exposure to each other makes it more likely to find common ground which can lead

to solutions and concrete recommendations, thereby facilitating policy uptake.

Meetings can be used as a decision-making space like in Mexico where some state-level authorities interact regularly with civil society organizations to hear how programme implementation is progressing in communities and discuss how to jointly find solutions to bottlenecks (63). The opportunity to interact regularly allows for real-time monitoring as well as relationship-building, the latter of which is essential for more informal contacts as needed in between more formal meetings. Inadvertently, more face time between decision-makers and the population, or representatives of population groups, builds capacity of both sides by testing and trying different ways of collaborating and corresponding for decision-making which works in the local context.

The very fact of making time and space for regular events and meetings inherently gives priority to civil society, communities, and the population and their voices. A health centre director in Madagascar expressed it as such: *"We have monthly meetings. This is the time to know the needs of the community. And it is on the basis of these needs that the details of the plan for improving the health status of the population can be determined"* (85).

The more regular a meeting or event becomes, the more inclined it is to become institutionalized. A case in point is Thailand where the National Health Assembly began to be held regularly when a reform movement began in the late 1990s; eventually, the event became institutionalized in the National Health Act of 2007 (15).

(e) Format favours civil society/population sub-group alliance-building

A format which obliges different groups (civil society organizations working on similar topics, population groups affected by the same issue, academics researching the same subject, etc.) to coordinate with each other, form networks, and exchange regularly amongst themselves seems to lead to more feasible solutions and therefore favours decision-making. A coordinated voice with policy positions already reflected upon is easier for governments to engage with in terms of their concern: feasible policy solutions. In Thailand, a nine-year NHA evaluation found that the NHA platform, by providing a constructive space for civic engagement organized into constituencies, forced civil society and communities to better think through their ideas, anchor them in evidence, and coordinate and advocate more closely amongst themselves (15). The constituency concept brought together different groups with a stake on the same topic or with similar mandates, and required them to choose a representative to send to the NHA and have those representatives speak on behalf of the constituency. Of course, this may require targeted capacity-building efforts to accompany the constituency to ensure that this is done well. In Thailand, the National Health Commission Office invests much staff time and resources with outlying provinces and different constituencies to ensure adequate capacity.

In Mexico, one of the factors of success of a decade-long reproductive health budget advocacy effort on the part of civil society was the potentiation of capacities through CSO alliance-building (63). Many Mexican stakeholders interviewed acknowledged that the

fruit of the collective budget advocacy efforts could only have been done jointly. Each organization in the alliance came with different skills and knowledge which collectively complemented each other. For example, one CSO came with budget analysis skills and mentored the others in this realm; another CSO had a strong reputation for sexual and reproductive health expertise, and had experience collaborating with central government authorities; other groups were firmly anchored in their respective communities and knew what programme implementation looked like on the ground. Together, they were able to join forces over a multi-year period to advocate and bring about changes in the way budget transfers were undertaken between federal and state level in Mexico (63).

DOS	DON'TS
Do be open and transparent about participant selection	**Don't** let interest groups and lobbies crowd out other voices ⟶ **instead**, hold separate meetings or events with them and/or give the same speaking time to other stakeholders
Do analyze who is **not** participating & reach out specifically to those groups	**Don't** have short timelines for participants to read through and process information ⟶ **instead**, give participants sufficient time to understand the evidence and different viewpoints
Do prepare information in different formats for different levels of professionalization ⟶ lay citizens need information to be free of jargon, in local languages/dialects, and/or images	
Do consider having experts 'on call' for questions and explanations	
Do consider more regular meetings and events vs. one-off exercises	

Table 5.1: Format and design of participatory processes in terms of decision-making: dos and don'ts

Evidence as a facilitator for more reasoned discussions leading to feasible options

Participatory processes and civic spaces can be an important vehicle to bring together the available evidence on complex issues, together with population views and expectations on the same. Especially in health where issues and policies are complex, this can be powerful in terms of finding adequate solutions. The glue which brings the different pieces of the complex puzzle together is the evidence – it gives material for dialogue amongst stakeholders and at the same time moves the discussion from advocacy to practical feasibility.

Country case studies repeatedly show that evidence at the heart of stakeholder debate nudges civil society to work more closely with academia, form alliances when in-house evidence analysis capacity is weak, or build it themselves. In Thailand, government officials acknowledge that the NHA platform has given civil society the opportunity, incentive, and means to collaborate more closely with academia. One government cadre emphasized that *"[civil society] has become more mature. They don't go and complain anymore. They come with the evidence and knowledge"* (86). The evidence focus thus helped all Thai stakeholders, including government, to think through solutions to problems, rather than focusing solely on the problems themselves.

Dialogue and debate need material for discussion; hence, it is a virtuous cycle as more structured dialogue demands more evidence analysis. In Thailand, evidence is the crucial piece both at the NHA topic proposal stage as well as when solution options are debated on. When a topic proposal is accepted, the drafting group which includes civil society, government representatives, and academia, receives funds to concretize the issue at hand and anchor it more strongly in evidence. If the group is unable to establish sufficient evidence, or is unable to gather sufficient information to concretize the issue further, the proposal is tabled until the following NHA, thereby giving the group more time to collect the evidence. This system favours stakeholder groups who have already closely examined the evidence, are able to demonstrate a clear evidence base on their topic, and offer potential solutions. With civil society and the research community strongly encouraged to join forces under the NHA model, government institutions end up also following the firm emphasis on knowledge and evidence. Many government cadres have realized that evidence clearly help legitimize policies. In this way, the evidence orientation pushes for decisions to be made more easily.

This sentiment is echoed in the Portuguese context by a professional association representative who sits on the Health Council:

> **"If we make our way in what unites us together, then it is easier for us to find solutions in what separates us at the beginning... [the Health Council] structure... guarantees that participation has a common language, which is the evidence."**
>
> Portuguese professional association representative (87)

Consensus-based recommendations may lend itself better to policy translation

Consensus-based recommendations may find themselves more easily in policy decisions, the caveat being that certain conditions or process-related features must be in place to make consensus feasible (6, 88). The literature suggests that consensus is easier where there is an underlying common interest and an identifiable solution in sight (11). Some conditions for consensus which are mentioned are: clear & binding rules, agency leadership; facilitator-moderators who know how to manage conflict (89).

A facilitator and decision-maker from a Regional Health Authority in France referred to reaching a consensus as 'magic' which was necessary to facilitate decisions (65). He went even further in making his point by alluding to the idea that decisions simply follow naturally from consensus when the requisite effort is made to prepare the process well for the consensus to develop.

Consensus is thus fostered through a collaborative process which is perceived as meaningful and fruitful, and where longer-term relationships are built around a certain topic. A participatory process format which gives space to forge a shared identity, and which is allowed to grow over time through increased exposure to each other, is more likely to build a collective view to complement individual interests, thereby facilitating consensus (5). The key point here seems to be the opportunity to participate at several events over time and a regularity in participation throughout different types of events or stages in a process. Authors elucidate that even where consensus is unlikely, participants usually can agree at least on sub-topics when they are formulated in a clear and specific way (72).

A stakeholder from Portugal defined consensus as a form of compromise, insinuating that a consensus is a compromise where most participants may not get what they want but agree that the best possible solution has been achieved. *"When you don't get consensus,"* he asserted, *"you get compromise"* (90).

That being said, consensus is not always the objective and it may simply not be possible. The literature also points to majority-rule recommendations being more suited in some settings such as where interests differ, when participants are less closely tied, and where an easy solution is not foreseeable (for example, sensitive issues like euthanasia or abortion) (11). Further implementation research in the health sector is needed in the future to understand which specific health policy questions should be underpinned by which type of participatory decision-making.

Some topics lend themselves more easily to a tangible outcome to be held accountable for

In one literature review, the authors state that "intangible outcomes of public participation brought about by broadly defined issues promote the notion that nothing comes out of it". They cite the example of teenage pregnancy as a topic which has generated a more tangible public participation outcome in some countries than broad and more nebulous issues such as the economic determinants of health where a clear-cut solution may not readily exist (5). Another in-depth review study looking at results linked to participatory governance mechanisms found that the subject under discussion together with the context determines how far participation input is reflected in decisions (11).

Box 5.10

How to formulate a topic for a participatory space in view of policy uptake?

- Topics submitted to a participatory mechanism for debate should have a well-defined policy question with a tangible and clear objective ⟶ increases the likelihood of policy uptake.
- The participatory process recommendation should lead to concrete 'to-dos' for the policy-maker.

It seems that both broad strategic directions as well as specific and well-defined policy questions can be submitted to population consultations. The key feature seems to be a clear tangible objective and outcome of each stage of the population engagement mechanism, with the right public, preparation, and information provided for that clear, tangible objective and outcome to be realized.

In France, the Bioethics Law is seen as covering value-ridden topics and therefore need population input for seven-yearly law revisions. The topics are quite specific and the mandate given to population groups has the clear objective of feeding into an updated draft of the law (58). In Portugal, on the other hand, the Health Council recommendations have been rather broad in nature but seem to have oriented certain MoH policies and actions as expressed by one government cadre: *"the [Health Council] report was presented in December, we have already had changes in terms of advertising legislation [and]... unhealthy food around schools. We have already had changes to paternity leave... Therefore, I think that until now the reports of the council have left some seeds that have germinated. I think that the recommendations, not being binding, always go from a strategic and also a political position. And also, of some convenience of implementation, because some of them are a little more structural and broader"* (90).

5.6 Capacity aspects to consider which are pertinent for decision-making influence

Capacities of the population, communities, and civil society to engage in participatory processes in health greatly influences how far their input is taken up for policy decisions. Just as relevant are government capacities to conduct a well-reflected and purposeful process which enables participants to adequately take on their representative role, and feed into policy-making.

Chapter 4 goes in-depth into the necessary capacities for meaningful government engagement with the population, communities, and civil society. Here, we briefly highlight specific capacity aspects, for both the people's and government's side, which are relevant for decision-making influence; further details can be found in chapter 4.

People's capacities

(a) Funding and capacities influence each other... and both are critical for policy influence

Across the literature and case studies, funding was mentioned consistently as either a constraining factor for civil society and community groups to function as they should, or a factor influencing success if funding flows were sufficient. In Thailand, the Thai Health Promotion Fund, set up with sin tax monies, was instrumental in providing predictable funding for civil society groups and seen as crucial to building their capacities (15). In Mexico, on the other hand, stakeholders lamented the declining funding situation of the civil society alliance formed for joint budget advocacy efforts around reproductive health services, lauding their initial string of successes but warning of future prospects (77). In the Islamic Republic of Iran, NGOs were acknowledged to lack in resources; many stakeholders viewed the lack of funding as the root cause of CSOs unable to build capacity and professionalize, thereby risking their relevance and representativeness of the people they are supposed to serve (91).

Funding gaps means that organized civic groups are dependent on volunteers who have other day jobs and priorities (see Chapter 3, Section 3.4). Government stakeholders in Portugal noted that a big barrier to active civil society participation in the Health Council was taking time off work. Another stakeholder recounted the selection process for Health Council civil society representatives, regretting that many CSOs refrained from coming forward after hearing about the *"amount of meetings and work involved"* (86).

In essence, without a minimum level of longer-term funding, it is challenging, or in some instances, near impossible, for organized citizen groups to build and maintain the capacities needed to influence decision-making. Stakeholders in France highlighted this point, acknowledging that government subsidies and tax breaks allowed them to function adequately and build capacity in the health sector (65).

(b) Middleman/-woman role of civil society organizations is key for bringing community voices up to relevant formal structures

Civil society in many settings plays a significant role in capturing community voice and bringing up community concerns to the relevant formal structures. In the Islamic Republic of Iran, volunteers in the People's Participation House, a

Teheran municipality initiative, reported giving their phone numbers to local community members who ring them with their concerns. The volunteers spent much of their time writing letters and contacting local authorities such as the Provincial Working Group on Community Health and others, on behalf of their community (20). Although the Provincial Working Group, as betrayed by its full name, was set up with the sole purpose of working on the community's health, having community needs channelled in a consolidated and professionalized way through civil society organizations facilitated their work and decisions.

This example demonstrates the potential for decision-making influence of a person or organization ably acting as a mediator between the grassroots and policy-makers. The mediator (civil society) organization's influence hinges on having the networks, structures, and resources to stay connected to the grassroots so as to legitimately reflect their views and challenges (see Point (e)). The Islamic Republic of Iran example illustrates the merit of a well-organized civil society who understands government structures and knows how to relay and advocate for grassroots needs.

(c) Claimed spaces which become institutionalized enjoy legitimacy from both policy-makers and communities, creating a virtuous cycle which can influence policy

As mentioned previously, 'claimed' spaces created and claimed by communities and civil society are just as critical for participatory culture and effectiveness as are 'invited' spaces. Often, civil society-claimed spaces end up leading to more institutionalized and formalized structures which may not have come about without the bottom-up, grassroots pressure in the first place. A case in point is Tunisia where the Social Dialogue for Health was created within a window of opportunity which presented itself post-revolution when the public was keenly aware of its power and wanted a say in social issues (92). It can therefore be seen as an 'claimed' space which came about through grassroots pressure; indeed, the Societal Dialogue initiative is run by a Steering Committee independent of the Ministry of Health (although MoH staff are Steering Committee members). In nearly a decade since the Societal Dialogue's existence, it has been confronted with several new incoming governments who have attempted to eliminate it. The fact that no Minister of Health or Head of State has managed to do so is testimony to its grassroots support and several influential champions who have kept it afloat, thereby quasi-institutionalizing it (17).

The Societal Dialogue for Health would never have come about through government effort alone. Community groups who are able to seize opportunities to create claimed spaces also claim and gain legitimacy. In addition, they shape the very platforms where decisions can be made. In Mexico, budget advocacy groups devised the 'feedback meetings' with the Federal Ministry of Health as a 'claimed' platform where monitoring findings fed into decision-making (63). A Mexican civil society stakeholder affirmed: *"the government took [the opportunity] and adopted it… that space wouldn't be there if… [we] hadn't knocked on the door"* (93). This capacity is thus crucial for more participation uptake in policy decisions.

(d) Strategic, professional, and evidence-oriented civil society is better able to influence policies

A discourse in the literature draws attention to both the up- and downsides of civil society and community groups professionalizing (see Chapter 3, Sections 3.3, 3.4, and 3.6). The evident advantage is the ability to be strategic in action and focus in a targeted way on influencing policy.

However, professionalizing might mean losing the link and perspective of communities and lay people, although those characteristics need not be mutually exclusive. In India, civil society respondents from a National Rural Health Mission study lauded the advocacy capacity and strength of professional civil society in the country; at the same time, doubt was expressed as to how far they represent people's voice and even know how to capture them. Respondents also acknowledged that community groups may be skilled in mobilizing the community, but many are unable to *"translat[e] that into an advocacy ask... [it] is something that that they are not very good at, where their capacities need to be strengthened"* (53).

In any case, civil society which is strategic, professional, and evidence-oriented (both research and experiential evidence is meant here – see Chapter 3, Box 3.5) is better able to influence policies. The budget advocacy civil society coalition in Mexico had all of these distinct traits – they were strategic in targeting the right policy-makers at both state and federal level, their professionalism is reflected in their in-depth technical work analyzing budgets and reproductive health statistics, and the civil society coalition was organized into a coherent alliance where each organization took on a role where they were able to add value. The coalition subsequently had significant policy influence in that federal-to-state budget transfer modalities were made more transparent and modified as a result of its advocacy efforts (63). In Thailand, much of the capacity-building efforts undertaken by the National Health Commission Office is to help civil society and community groups provide input to National Health Assembly resolution drafts which draws on their experiential knowledge but packages that information to feed into more practical solutions (15).

"[Feedback meeting]... did not arise out of state necessity. It arose because we are an organized, evidence-oriented civil society... This sector... has created these spaces for dialogue."

Mexican civil society representative (93)

(e) Capacity to reach out to communities is at the core of legitimately representing grassroots voice –and drawing policy-makers' attention

The Mexican civil society coalition mentioned previously retained their capacity to reach out to communities by ensuring that community groups were part of the coalition and a core contributor to its budget advocacy work (77). Mexican stakeholders from both civil society and government

recognized that the budget advocacy efforts successfully leveraged the grassroots implementation information to complement the more technical analyses. The critical point here is that those who are truly able to listen to, understand, and channel community voice to policy-makers are highly valued for their input; this can give those civil society and community groups weight in the eyes of those who take decisions.

Much of the Societal Dialogue for Health's success in Tunisia was founded in its initial efforts to reach out to as many population groups as possible, however remote and reticent they were (92). This cultivated trust, a hard-won principle in the post-revolution years. The trust and grassroots support allowed the Societal Dialogue to be seen as the voice of civil society which subsequently gave them clout in government circles (17).

In France, especially government stakeholders commended civil society groups which used innovative approaches to reach out to their respective communities (65). In the Islamic Republic of Iran, government stakeholders acknowledged the need for community views by including them separately from civil society organizations in the 2017 local health assemblies (91). This basically points to the value given by decision-makers to those who can report on grassroots needs and voice. It also underlines the fact that technical capacity alone may not be sufficient; a link to communities may at times be even more valued as technical expertise is more easily accessible to government cadres anyway.


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(f) Capacity to build alliances

Almost all of the case studies conducted for this handbook demonstrate the significance of alliance-building by the population, communities, and civil society in influencing policies. In Thailand, stakeholders recognized that much of the National Health Assembly's influence came from its broad stakeholder base and the significantly strengthened community and civil society networks (15). In Mexico, as mentioned previously, the civil society coalition was strong because of the different skills each group brought into the alliance. Stakeholders also acknowledged the difficulty in collaborating, stressing the need for time and effort to learn how to work together in a mutually fruitful way (77). In the Islamic Republic of Iran, within the Health Transformation Plan's emphasis on participation, the MoH actively supported civil society and charities to connect more with each and form networks, realizing the added value for their own policy work (20). In Tunisia, existing CSOs, who had been restrained in their abilities to act under periods of dictatorship, used their impressive existing networks to rapidly launch an active and lively Societal Dialogue for Health; the networks were thus key to making the Societal Dialogue happen within the initial window of opportunity.

The capacity to build alliances also extends to (civil servant/career) government cadres as well, and can help insulate from high-level political personnel changes. In Mexico, the CSO alliance managed to successfully create allies in state government cadres; together, they were able to resolve problems vis à vis the federal government (63). French government stakeholders spoke highly of one specific CSO platform, emphasizing its characteristic of having wide and strong networks of communities and credible personalities, and noting that this characteristic gave them more weight in decision-making discussions (65). This platform also managed to form coalitions with local regional health bodies to co-shape decisions.

Government capacities

More guidance is needed for policy-makers on how to specifically translate participation-based input into policies

The capacity of policy-makers to steer, convene, deal with vested interests, manage diverging views, and broker consensus and solutions is not a given (a more in-depth analysis of stakeholder capacities can be found in chapter 4). Neither is the ability to create an open decision-making environment and to carefully weigh the value of different responses in a transparent way. None of these capabilities regularly feature in the skill set sought after by government health institutions where medico-technical expertise is prized. Campbell et al. highlight the need for more guidance and coaching for decision-makers on how to translate participation input into policy (43). They describe a review of UK's NICE's online public consultation process which feeds into NICE decisions (see Box 5.11). The study found that the large success rate of almost 75% of the decisions reviewed evincing some degree of public consultation input was due in part to the guidance given to NICE personnel on how to act upon participatory input (94).

Box 5.11

The UK's National Institute of Clinical Excellence (NICE)'s decisions & its public consultations

The Interventional Procedures (IP) programme at the National Institute for Health and Care Excellence (NICE) develops guidance on the effectiveness and safety of (new) interventional procedures for use in the UK health service (95). In addition to patient involvement in guideline development, draft guidance documents are published online for a four-week period for the general public to respond. These online consultations are publicized widely, including among stakeholder groups where input is particularly sought: academia, medical organizations, clinicians, and relevant patient associations (43).

Campbell et al.'s review of NICE's public consultation processes for 183 draft guidance documents found that in 75% of the final published versions, concrete changes had been made based on consultation inputs (40). The study authors came to the conclusion that the use of open public consultations with clear guiding instructions on how to handle the incoming responses were determining factors for the high uptake of consultation input into the finalized guidance documents.

Responses to the consultation can be up to 20 pages, submitted via the NICE website, email, fax, or post. A structure is provided for consultation responses but respondents are not required to stick to it in order for their input to be considered. NICE staff handling the consultation inputs are guided by transparent processes and detailed briefings on how to evaluate the responses. Study authors conclude that "[t]he detailed consideration given to each response can be time-consuming and challenging, but it is feasible and provides an increased level of confidence that published guidance has been open to scrutiny and comment by everyone who might be affected by it" (43).

The NICE example demonstrates how adequate guidance and coaching for decision-makers can strengthen the link between the inputs given by the public and health policies and recommendations.

A specific skill set is required for government cadres to enable policy uptake

The cost-effectiveness and priority-setting literature suggest that the policy uptake step should be done by an independent institution or separate (government or government-contracted) unit to interpret information and neutrally translate them into priorities for policy (5). This would clearly increase the influence of participatory process input into health policies as the mediating body would have exactly that in their terms of reference. This suggestion is likely a reflection of the need for a specific skill set to interpret public participation input and undertake translation into policies. These skills are often not present in government health institutions, risking the negation of the whole participatory process. One author aptly stresses the need for policy uptake capacities:

> **"Exercises in public involvement provide some of the raw material for policymakers. But information that is raw and that has to be swallowed whole... will probably be regurgitated by the policy process."**
>
> Tenbensel (4)

Other authors clarify that the mediating role can be taken on by "in-house staff or a full department specializing in public involvement" (31). Such a role would cover the task of bringing decision-makers and the public together to better understand and tailor the objectives of the population engagement exercise to a distinct policy question, while underpinning the process in a solid understanding of the context and local community.

The ability to understand the added value of population, community, and civil society input into policy work

Participatory input will not be taken up by governments if it is not in their interest to do so. Besides the obvious political economy challenges, governments might need more interaction with civil society and population groups through structured mechanisms to begin to understand how the information and feedback emanating from such exchanges can add value to their work. In Mexico, for example, state-level authorities were initially sceptical about the budget advocacy coalition's work. However, the civil society organizations insisted on meetings to feed back information from both federal level where they had a presence and community level. One civil society key informant recalled how "state-level civil servants became... allies" (93) when they began to realize what a rich and important source of implementation information civil society had. In France, some stakeholders regretted the paternalistic attitude of government cadres and the resulting lack of effectiveness in the health governance domain. At times, the paternalistic world view also led to siding with or caving into health professional (vested) interests to the detriment, according to some stakeholders, of civil society and population views (65).

A big deterrent to policy uptake of participation-based input is when government officials see the participatory process as competing rather than complementary. In Tunisia, many mid-level government cadres actively resisted the perceived encroachment of the Societal Dialogue for Health into their policy-making space, despite buy-in from the Office of the Minister (17). Much of this was based on resentment due to the unclarified link between the Societal Dialogue's planning input and the Ministry's health planning work at the time. Many Tunisian stakeholders lamented the poor ownership by government cadres of Societal Dialogue results which at times even deteriorated into ignoring them completely. This was a period when it was unclear whether the White Book's content would be validated by forming the basis of a new post-revolution health policy. In the end, the health policy did happen a few years later but Ministerial capacity might have been one of the reasons for its delay.

Weak Ministries and inflexible bureaucracies are often a deterrent to policy uptake

In Tunisia, high turnover of Ministers and Ministry-appointed focal points for the Societal Dialogue for Health definitely delayed decision-making. Stakeholders from the government and civil society side pointed to government institutions' pace of work grinding to a halt each time a new Minister came in (17). In the Islamic Republic of Iran, key informants mentioned the general lack of the necessary flexibility within government health institutions required for more community involvement. Indeed, even pro-participation officials were constrained by bureaucratic structures which did not always allow processes to change from the status quo (91).

In general, the weaker the governance capacity of a government in general, the more difficult it often is to find government officials reaching out to different population and stakeholder groups. Indeed, many weak ministries are simply struggling to manage their day-to-day processes. Further compounding the problem is the fact that many health institutions are staffed with biomedical-technical experts rather than those who may possess the soft skills needed to bring people together and facilitate difficult discussions.

5.7 Conclusion

In this chapter, we establish that a gap clearly exists between results and recommendations coming from participatory spaces and policy decisions ('deliberation-to-policy gap'). Key issues are laid out for a policy-maker (and others) to reflect on when engaging with populations, communities, and civil society actors through participatory mechanisms in order to ensure that this gap is closed.

Those key issues include the decided emphasis on political will as a catalyser for solid policy uptake of participation-based input. Political will can also provide fertile ground for a culture of participation to be built if it does not yet exist, which increases the likelihood of public participation input translating into policy. Linked to political will is the concept of government organizing, or having a large stake in, the participatory space ('invited' space) as an important factor for policy uptake.

Consensus-based recommendations tend to find themselves more often in real-world policies as there is buy-in from all sides. Evidence is shown to be a major facilitator for policy uptake, also for improving the chances for consensus, and piquing politician and policy-maker interest to engage more closely and therefore influencing political will.

It goes without saying that tokenistic participation solicited by government actors to 'tick a box' can lead to widespread mistrust in government processes in general. Trust is a critical capital needed for health governance in any country to work, hence tokenism carries with it inherent risks.

We differentiate between a governance and service delivery approach to participation even though the two overlap considerably. Especially with regard to policy uptake, the governance approach to participation is more fruitful as it is bidirectional, with input given by civil society and communities for purposes of being heard and ensuring a responsive health system, and government feeding back and listening to counter-responses. A service delivery approach, which may be needed for specific policy objectives, focuses more on the need to ensure comprehensive health coverage, tends to be one-way (the quintessential example being a vaccination campaign), and is more preoccupied with ensuring higher service utilization rates and good programme implementation. The two approaches are not necessarily mutually exclusive, and can complement each other.

The format & design of the participatory process can lay a solid foundation for increased policy uptake. Several examples are offered in this chapter which underline the need for both civil society and (especially) government capacities to ensure systematic policy uptake of participation-based results. Ultimately, a robust connection between participatory spaces and policy-making hinges on the overall enabling environment which influences all of the little details which make policy uptake likelier: capacities of different actors, their representativeness, participatory space design which lends legitimacy to actors, etc. All of these issues are elaborated upon thoroughly in previous chapters.

References

1 World Health Organization (WHO). From value for money to value-based health services: a twenty-first century shift. Geneva: World Health Organization (WHO); 2020.

2 Terwindt F, Rajan D, Soucat A. Priority-setting for national health policies, strategies and plans. In: Schmets G, Rajan D, Kadandale S, editors. Strategizing National Health in the 21st Century: A Handbook. Geneva: World Health Organization (WHO); 2016.

3 Rajan D, Koch K, Rohrer K, Bajnoczki C, Socha A, Voss M, et al. Governance of COVID-19 response: a call for more inclusive and transparent decision-making. BMJ Global Health. 2020.

4 Tenbensel T. Interpreting public input into priority-setting: the role of mediating institutions. Health Policy. 2002;62(2):173-94.

5 Pagatpatan CP, Ward PR. Understanding the factors that make public participation effective in health policy and planning: a realist synthesis. Aust J Prim Health. 2018;23(6):516-30.

6 Kitzhaber JA. Prioritising health services in an era of limits: the Oregon experience. BMJ. 1993;307(6900):373-7.

7 van de Bovenkamp HM, Trappenburg MJ. Reconsidering patient participation in guideline development. Health Care Analysis. 2009;17(3):198-216.

8 Coelho VSP. What did we learn about citizen involvement in the health policy process: lessons from Brazil. Journal of Public Deliberation. 2013;9(1).

9 Molster C, Maxwell S, Youngs L, Potts A, Kyne G, Hope F, et al. An Australian approach to the policy translation of deliberated citizen perspectives on biobanking. Public Health Genomics. 2012;15(2):82-91.

10 Blacksher E. Participatory and deliberative practices in health: meanings, distinctions, and implications for health equity. Journal of Public Deliberation. 2013;9(1):6.

11 Abelson J, Gauvin F-P. Assessing the impacts of public participation: Concepts, evidence and policy implications. Canadian Policy Research Networks Ottawa; 2006.

12 Guttman N, Shalev C, Kaplan G, Abulafia A, Bin-Nun G, Goffer R, et al. What should be given a priority–costly medications for relatively few people or inexpensive ones for many? The Health Parliament public consultation initiative in Israel. Health Expectations. 2008;11(2):177-88.

13 Degeling C, Carter SM, Rychetnik L. Which public and why deliberate?–A scoping review of public deliberation in public health and health policy research. Social Science & Medicine. 2015;131:114-21.

14 Street J, Duszynski K, Krawczyk S, Braunack-Mayer A. The use of citizens' juries in health policy decision-making: a systematic review. Social Science & Medicine. 2014;109:1-9.

15 Rajan D, Mathurapote N, Putthasri W, Posayanonda T, Pinprateep P, de Courcelles S, et al. The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016). World Health Organization (WHO); 2017.

16 Rajan D, Mathurapote N, Putthasri W, Posayanonda T, Pinprateep P, de Courcelles S, et al. Institutionalising participatory health governance: lessons from nine years of the National Health Assembly model in Thailand. BMJ global health. 2019;4(Suppl 7):e001769.

17 World Health Organization (WHO). 'Tunisia case study' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2018-2019. French.

18 Petit D. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

19 Swasti Health Catalyst. Community Participation in the National Rural Health Mission (NRHM). Unpublished work.

20 Rajan D, Hadi Ayazi M, Moradi-Lakeh M, Rosami-Gooran N, Rahbari M, Damari B, et al. Chapter 4: Public voice and participatory governance in the health sector: status quo and way forward. In: Hsu J, Majdzadeh R, Harirchi I, Soucat A, editors. Health System Transformation in the Islamic Republic of Iran: an assessment of key health financing and governance issues. Geneva: World Health Organization (WHO); 2020.

21 Mockford C, Staniszewska S, Griffiths F, Herron-Marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. Int J Qual Health Care. 2012;24(1):28-38.

22 O'Doherty KC, Hawkins A. Structuring public engagement for effective input in policy development on human tissue biobanking. Public Health Genomics. 2010;13(4):197-206.

23 Lander J, Hainz T, Hirschberg I, Strech D. Current practice of public involvement activities in biomedical research and innovation: a systematic qualitative review. PLoS One. 2014;9(12):e113274.

24 van Wersch A, Eccles M. Involvement of consumers in the development of evidence based clinical guidelines: practical experiences from the North of England evidence based guideline development programme. BMJ Quality & Safety. 2001;10(1):10-6.

25 Miles S, Renedo A, Marston C. 'Slow co-production' for deeper patient involvement in health care. The Journal of Health Design. 2018;3(1).

26 Degeling C, Rychetnik L, Street J, Thomas R, Carter SM. Influencing health policy through public deliberation: Lessons learned from two decades of Citizens'/community juries. Social Science & Medicine. 2017;179:166-71.

27 Conklin A, Morris Z, Nolte E. What is the evidence base for public involvement in health-care policy?: results of a systematic scoping review. Health Expect. 2015;18(2):153-65.

28 Renedo A, Marston C. Healthcare professionals' representations of 'patient and public involvement' and creation of 'public participant' identities: Implications for the development of inclusive and bottom-up community participation initiatives. Journal of Community & Applied Social Psychology. 2011;21(3):268-80.

29 Renedo A, Komporozos-Athanasiou A, Marston C. Experience as evidence: the dialogic construction of health professional knowledge through patient involvement. Sociology. 2018;52(4):778-95.

30 Renedo A, Marston CA, Spyridonidis D, Barlow J. Patient and public involvement in healthcare quality improvement: how organizations can help patients and professionals to collaborate. Public Management Review. 2015;17(1):17-34.

31 Li KK, Abelson J, Giacomini M, Contandriopoulos D. Conceptualizing the use of public involvement in health policy decision-making. Social Science & Medicine. 2015;138:14-21.

32 Kornberger M, Meyer RE, Brandtner C, Höllerer MA. When bureaucracy meets the crowd: Studying "open government" in the Vienna City Administration. Organization Studies. 2017;38(2):179-200.

33 Ruvalcaba-Gomez EA, Renteria C. Contrasting the perceptions about citizen participation between organized civil society and government with an open government approach: the case of the state of Jalisco, Mexico. 2019 Sixth International Conference on eDemocracy & eGovernment (ICEDEG) 2019 Apr 24 (pp. 39-46). IEEE.

34 Abelson J, Eyles J, McLeod CB, Collins P, McMullan C, Forest P-G. Does deliberation make a difference? Results from a citizens panel study of health goals priority setting. Health Policy. 2003;66(1):95-106.

35 Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. BMJ. 2002;325(7375):1263.

36 Mohebi M. The Formation of Civil Society in Modern Iran: Public Intellectuals and the State: Springer; 2016.

37 Braithwaite J, Mannion R, Matsuyama Y, Shekelle P, Whittaker S, Al-Adawi S. Health systems improvement across the globe: Success stories from 60 countries: CRC Press; 2017.

38 World Health Organization (WHO). 'The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016)' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2017.

39 Gregory J, Watson R, Hartz-Karp J. Using deliberative techniques to engage the community in policy development. Australia and New Zealand Health Policy. 2008;5(1).

40 Martin GP, Carter P, Dent M. Major health service transformation and the public voice: conflict, challenge or complicity? J Health Serv Res Policy. 2018;23(1):28-35.

41 Thailand National Health Commission Office (NHCO). Our structure: National Health Commission Office: Thailand; [Available from: https://en.nationalhealth.or.th/our-structure/].

42 Rawlins MD. Pharmacopolitics and deliberative democracy. Clinical Medicine. 2005;5(5):471-5.

43 Campbell B, Tabiri-Essuman J, Gallo H, Verdiel V, Mandava L, Azhar MA, et al. Public consultation changes guidance on the use of healthÐcare interventions. An observational study. Health Expectations. 2017;20(2):361-8.

44 Matos AR, Serapioni M. The challenge of citizens' participation in health systems in Southern Europe: a literature review. Cadernos de Saude Publica. 2017;33(1):e00066716.

45 Kapiriri L, Norheim OF, Heggenhougen K. Public participation in health planning and priority setting at the district level in Uganda. Health policy and planning. 2003;18(2):205-13.

46 Swamy R. Explorations in the concept of social accountability from theory to practice, and from practice to theory. India: Centre for Budget and Governance Accountability (CBGA); 2019.

47 Portugal case study interviewee #19. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work. Portuguese.

48 República Portuguesa. Lei Básica de Saúde, Lei n. 48/90. Assembleia da República, (1990). Portuguese.

49 World Health Organization (WHO). 'The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2019. Portuguese.

50 Ministry of Health Portugal. Henrique Barros appointed President of the National Health Council 2018 [Available from: http://www.cns.min-saude.pt/2018/12/17/henrique-barros-appointed-president-of-the-national-health-council/?lang=en].

51 Alves I. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work.

52 India case study interviewee #17. Community Participation in the National Rural Health Mission (NRHM). Unpublished work.

53 India case study interviewee #14. Community Participation in the National Rural Health Mission (NRHM). Unpublished work.

54 Gaitonde R. Divergences, Dissonances and Disconnects: Implementation of Community-based Accountability in India's National Rural Health Mission. Umea: Umea University; 2020.

55 Ved R, Sheikh K, George AS, Raman V. Village Health Sanitation and Nutrition Committees: reflections on strengthening community health governance at scale in India. BMJ Global Health. 2018;3(Suppl 3):e000681.

56 Swasti Health Catalyst. 'Community Participation in the National Rural Health Mission (NRHM)' dataset. In: Swasti Health Catalyst, editor. Year of data collection: 2019.

57 India case study interviewee #5. Community Participation in the National Rural Health Mission (NRHM). Unpublished work.

58 World Health Organization (WHO), SciencesPo. France case study report: La démocratie de santé en France. Unpublished work. French.

59 Gaventa J. Finding the spaces for change: a power analysis. IDS bulletin. 2006;37(6):23-33.

60 Iredale R, Longley M, Thomas C, Shaw A. What choices should we be able to make about designer babies? A Citizens' Jury of young people in South Wales. Health Expectations. 2006;9(3):207-17.

61 Portugal case study interviewee #5. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work. Portuguese.

62 Population Foundation of India (PFI). Community Action for Health: Experiences, Learnings and Challenges. 2016.

63 Colectivo Meta (COMETA). Case study on civil society involvement in policy processes in Mexico. Unpublished work.

64 Zongo S. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en oeuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French.

65 World Health Organization (WHO), SciencesPo. 'La démocratie santé en France' dataset. In: World Health Organization (WHO), SciencesPo, editors. Year of data collection: 2018. French.

66 World Health Organization (WHO) Tunisia country office. Phone communication. 2019. French.

67 National Health Service (NHS) England. Patient and public participation in commissioning health and care: statutory guidance for clinical commissioning groups and NHS England. 2017.

68 Hounslow Clinical Commissioning Group (CCG). You said, We did. [Available from: https://www.hounslowccg.nhs.uk/your-voice/you-said,-we-did.aspx].

69 Merton Clinical Commissioning Group (CCG). You said, We did. [Available from: http://www.mertonccg.nhs.uk/Get%20Involved/you-said-we-did/Pages/default.aspx].

References

70 City and Hackney Clinical Commissioning Group (CCG). You said, We did. [Available from: http://www.cityandhackneyccg.nhs.uk/about-us/you-said-we-did.htm].

71 Hambleton Richmondshire and Whitby Clinical Commissioning Group (CCG). You said, We did. [Available from: https://www.hambletonrichmondshireandwhitbyccg.nhs.uk/you-said-we-did].

72 Molster C, Maxwell S, Youngs L, Kyne G, Hope F, Dawkins H, et al. Blueprint for a deliberative public forum on biobanking policy: were theoretical principles achievable in practice? Health Expectations. 2013;16(2):211-24.

73 Kolasa K, Hermanowski T, Borek E. Importance of public participation in decision-making process in healthcare system illustarted with an example of the development of American and Polish scope of health benefit basket. Przegl Epidemiol. 2013;67(4):661-754.

74 Barratt H, Harrison DA, Raine R, Fulop NJ. Factors that influence the way local communities respond to consultation processes about major service change: a qualitative study. Health Policy. 2015;119(9):1210-7.

75 Department of the Prime Minister and Cabinet Australia. Best Practice Consultation. Guidance Note: Government of Australia; 2016.

76 Ward JK, Colgrove J, Verger P. Why France is making eight new vaccines mandatory. Vaccine. 2018;36(14):1801-3.

77 Colectivo Meta (COMETA). 'Case study on civil society involvement in policy processes in Mexico' dataset. In: Colectivo Meta (COMETA), editor. Year of data collection: 2019. Spanish.

78 Boivin A, Lehoux P, Burgers J, Grol R. What are the key ingredients for effective public involvement in health care improvement and policy decisions? A randomized trial process evaluation. Milbank Q. 2014;92(2):319-50.

79 Van de Bovenkamp HM, Trappenburg MJ, Grit KJ. Patient participation in collective healthcare decision making: the Dutch model. Health Expectations. 2010;13(1):73-85.

80 Morone JA, Marmor TR. Representing consumer interests: the case of American health planning. Ethics. 1981;91(3):431-50.

81 Rohrer K, Rajan D. Population consultation on needs and expectations. In: Schmets G, Rajan D, Kadandale S, editors. Strategizing national health in the 21st century: a handbook. Geneva: World Health Organization (WHO); 2016.

82 Habboubi F. Les rendez-Vous Régionaux de la santé: Deuxième Phase. Dialogue sociétal sur les politiques et les stratégies et les plans nationaux de santé. 2019 [Available from: http://www.hiwarsaha.tn/Fr/documentations_7_80_P2]. French.

83 Bouhafa Chtioui R. Dialogue sociétal sur les politiques, les stratégies et les plans nationaux de la santé (Phase II): Appui au comité technique pour l'élaboration du rapport des rencontres interrégionales - Perception de certaines options stratégiques. Dialogue sociétal sur les politiques et les stratégies et les plans nationaux de santé. 2019 [Available from: http://www.hiwarsaha.tn/upload/1566907557.pdf]. French.

84 Dialogue sociétal sur les politiques et les stratégies et les plans nationaux de santé. Les Rendez Vous Régionaux - Plan. Dialogue sociétal sur les politiques et les stratégies et les plans nationaux de santé. 2019 [Available from: http://www.hiwarsaha.tn/upload/1552579793.pdf]. French.

85 Madagascar case study interviewee #12. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

86 Thailand case study interviewee #3. The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016). 2017.

87 Portugal case study interviewee #11. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work. Portuguese..

88 Grant J, Sears NA, Born K, editors. Public engagement and the changing face of health system planning. Healthcare management forum; 2008: SAGE Publications Sage CA: Los Angeles, CA.

89 Bryner G. Cooperative instruments and policy making: assessing public participation in US environmental regulation. European Environment. 2001;11(1):49-60.

90 Portugal case study interviewee #14. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work. Portuguese.

91 World Health Organization (WHO). 'Chapter 4: Public voice and participatory governance in the health sector: status quo and way forward' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2018.

92 Universal Health Coverage Partnership. Health Reform by and for Tunisian Citizens. 2014 [Available from: https://uhcpartnership.net/health-reform-tunisia/].

93 Mexico case study interviewee #4. Case study on civil society involvement in policy processes in Mexico. Unpublished work. Spanish.

94 Siegel JE, Heeringa JW, Carman KL. Public deliberation in decisions about health research. AMA Journal of Ethics. 2013;15(1):56-64.

95 National Institute for Health Care Excellence (NICE). NICE guidance. [Available from: https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance].

Chapter 6

Legal frameworks for participation

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Handbook on Social Participation
for Universal Health Coverage

6.1 Introduction

All legally binding international human rights treaties recognize the essential role of participation in realizing fundamental human rights including the right to health (1, 2). Obligations of governments to implement the right to health at the national level were made clear in 2000 by the United Nations Committee on Economic, Social and Cultural Rights in their General Comment No. 14 (1). These include the obligation to give sufficient recognition to the right to health in the national political and legal system, preferably formalised in legislation and coupled with national health policies detailing how the right to health and participation will be realized in practice. This 'how' should include positive measures that enable and assist populations and communities to enjoy the right to health, including the creation and maintenance of participatory spaces and processes.

In practice, countries have taken very different approaches in terms of realizing the right to participation and health. This is linked to contextual factors and legal traditions but also the civil society and participatory culture in a country (see Chapter 2). The different country contexts reflect the full range of realities seen in terms of participatory processes on the ground and how far they are covered by a legal text or not.

This range goes from active, structured participatory activity undertaken by communities with tacit support from policy-makers to a strong legal framework for participation which may or may not be fully implemented. The former can be seen as fertile ground and an opportune moment to bring in legal protection to a prevailing participatory culture while the latter may have suffered from inadequate preparation of actors and capacities to give effect to the law. We address both of these issues, and other crucial caveats and risks, in section 6 of this chapter.

Laws can by design or by default also hinder participation. Here, we do not examine legal texts which have the stated intent of decreasing participation and/or disempowering certain population groups. We instead navigate laws whose intent is to foster participation but point out design features which can help overcome societal and other barriers to implementation which may at times feel impregnable. A fundamental tenet propounded here is thus that legal frameworks need to take the basic reality of unequal power relations into account. What this means in practice is elaborated upon in section 4.

6.2 Objectives of this chapter

This chapter provides an overview of the principal types of legal frameworks affecting participation. A series of key issues around participation legislation will be advanced for policy-makers to reflect on. We then highlight how solid preparation of, and building consensus for, the legal framework can go a long way to ensuring its implementation and fostering meaningful participation in the health sector. We also elaborate on the necessary detail which might be needed in a legal framework to ensure that it does actually legitimize population voice, rather than reinforce existing hierarchies that might hinder countries' implementation of right to health commitments and efforts towards universal health coverage.

Legitimizing population voice is basically a means for levelling the participatory playing field; by lending people legitimacy through the legal framework, both power and influence is granted to those who enter the playing field with considerably less leverage and resources vis à vis government and other actors in terms of policy-making.

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6.3 Legal frameworks for participation: conceptual clarification

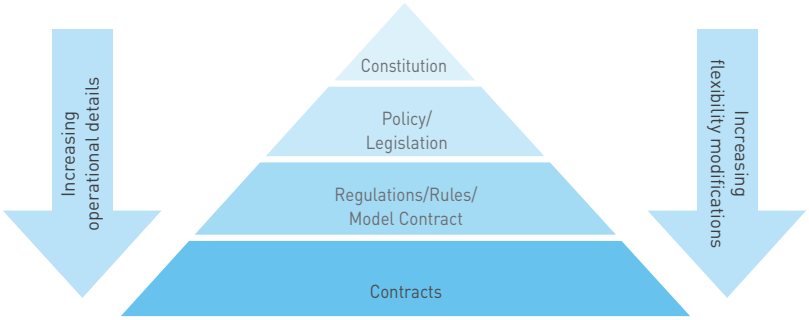

Figure 1: The legal framework pyramid (3)

Legal frameworks covering participation can be seen as a collection of legal instruments which complement each other, each document providing complementary information regarding the operationalization of the policy intention formalised in the law. Figure 1 depicts the legal framework pyramid beginning with the overarching instrument of the Constitution (in some countries, this may have another name such as 'Basic Law'), which outlines "the basic principles and laws of a nation... that determine the powers and duties of the government and guarantee certain rights to the people in it" (4). The overarching legal environment as per a country's Constitution including provisions for basic freedoms such as speech and press can be a significant determinant of how far people's voice is let into decision-making spaces.

Box 6.1

Legal framework: A definition

A legal framework is "a broad system of rules that governs and regulates decision making, agreements, laws, etc." (6).

The 2nd layer consists of legislation or policies, instruments which "have the force of authority by virtue of their promulgation by an official organ of a state" (5), usually a legislative body such as parliament. With regards to participation, this pyramid layer would include decentralization legislation, human rights laws, Health Acts and freedom of information legislation, amongst many other possibilities. Here, concrete rights and rules are laid out based on the principles of the constitution. The level of operational detail increases moving to the 3rd layer as granularity is generally given on issues such as responsibilities for rule enforcement and consequences of non-adherence to the law. The final layer is the actual contract between two parties where implementation is stipulated in further detail. Hence, moving down the pyramid means that increasing operational detail is stipulated while at the same time augmenting the flexibility with which modifications can be made. For example, a constitutional amendment (top layer) requires a huge effort to undertake vis à vis a rewording of a contract (bottom layer).

The transitions between the different layers are fluid and extremely context-dependent. The level of detail necessary at each layer depends heavily on the law in question, the history and

political economy of the constitution, and legal traditions of a country. In this chapter, we focus principally on the 2nd layer, legislation and policies, i.e. the instruments which are endorsed by a legislature. However, we acknowledge that in many contexts, the functions as elaborated upon in following sections may be part of the third layer instead of the second.

That being said, we focus now on the principle legal instruments which have a bearing on participation, the ones which the vast majority of health policy-makers are confronted with. They are not necessarily health- nor participation-specific but represent legislation which embody the spirit of bringing public policies closer to people and their expectations. Since participation is integral to that spirit, it may be referred to briefly or mentioned explicitly as a principle, means, and/or right which is necessary to give effect to the law.

Finally, we wish to emphasize that the 2nd layer of the pyramid pre-supposes the existence of the 1st primordial layer which is the constitutional framework of the country. This layer is fundamental to ensuring an enabling environment for population, community, and civil society input into health policies (see Chapter 2). Constitutionally guaranteed fundamental rights such as the freedom of expression, freedom of movement, and freedom of assembly greatly facilitate a culture of speaking up, contributing, and participating. This is not to say that participation cannot happen without certain guaranteed freedoms. Within health, numerous examples do exist of flourishing participatory activities in countries with great limitations on formal freedoms – but those activities then stand on shaky ground, and can be dismantled more easily, with no basis for populations to claim them back.

Decentralization legislation

Decentralization in the health sector can be seen as "the transfer of formal responsibility and power to make decisions regarding the management, production, distribution and/or financing of health services, usually from a smaller to a larger number of geographically or organizationally separate actors" (7). Across countries and regions, the documentation on decentralization efforts in the health sector demonstrates that this legislation can be a powerful creator of and contributor to a participatory space and culture.

Indeed, in many countries, the stated rationales for decentralization, whether captured categorically in the legal text or not, is bringing governing closer to the people through a structured platform placed locally to ensure population voice in policy-making. Even if participation may be less explicit in a decentralization law, its other common aims go hand in hand with participation: protecting minority rights and integrating heterogenous societies, for example, through territorial autonomy.

Nevertheless, most decentralization legislation explicitly mandates some form of participation, although the level of detail and the actual authority conferred varies greatly by context. For example, the South African Municipal Systems Amendment Act (2003) and the Municipal Structures Act (2000) state that "communities must contribute" to municipal decision-making, and that Municipal Councils "must consult" local committees (8). On the other hand, the Ugandan Local Government Act 1997 leaves practicalities more open to interpretation in the description of the local government executive committee functions:

"to serve as the communication channel between the Government, the district council and the people in the area" (9). Either way, the theory as expressed in most of these legal frameworks is that community participation and people's voice are expected to be amplified by a new decentralized administrative status quo in the country.

Right to health legislation

The right to health is not the same as the right to be healthy but rather it is the right to have access to all actions necessary to be healthy. The 1946 WHO Constitution was the first to formulate that very right (10), followed soon by numerous national constitutions. Potts further acknowledges that the right to health cannot be de-linked completely from other rights such as civil, political, economic, social, and cultural rights, a particularly relevant point in terms of the ease with which participatory activities can take place in countries (11).

The concept of the human right to health is inextricably linked to participation. The extensive human rights literature documenting international, national, and regional treaties all include the notion that in order to realize people's right to health, they must have a say in health (10). The WHO Constitution´s manifestation in national-level legal frameworks is decisive in that it, at least in theory, means that participation through institutionalized mechanisms to influence health policy-making can be claimed as integral to the right to health (1, 8, 11).

Many scholars go further and frame participation as not only inherent to the rights-based approach to health but as a human right in and of itself (12). Government as duty bearers for realizing the right to health thus have the obligation to put in place such participatory governance mechanisms and ensure their functionality for the population to express themselves on health matters (13). Indeed, the existence of such mechanisms is even viewed as a good proxy indicator for a government's commitment to a human rights-based approach to health systems.

Health Acts

A Health Act is used in many countries as an overarching legal instrument guiding and regulating government-led health services. Especially in health systems with a large share of public funding, the Health Act becomes the orienting legal framework laying out the underlying principles and mechanisms for protecting and promoting the population's health.

Participation and community involvement in health-related decision-making is an integral part of Health Acts in many countries, thereby providing the legal basis for participatory processes in the health sector. In Thailand, the National Health Act of 2007 was pivotal in kicking off a more institutionalized culture of participation, and anchoring into law many local-level participatory efforts which were already taking place, giving them not only a boost in terms of resources and visibility, but

also in terms of connecting those local efforts more systematically to national-level policy-making. Moreover, it founded the National Health Commission Office which is given a legal mandate to run a National Health Assembly every year (14).

South Africa's National Health Act (2003) created Health Committees at primary health care facilities (8), and the United Kingdom's commitment to public participation initiatives is enshrined in the Health and Social Care Act, the National Health Service (NHS) Constitution and the National Health Service Act 2006 (15). The level of detail varies in terms of stipulation of participatory activities across the different Acts, some pointing clearly to specific population groups or stakeholders who must be included and other frameworks leaving it more open.

Acts creating a public health service (UK, Greece (16)) often establish mechanisms which bring in local communities in decision-making; they are not always implemented in practice but the legal framework which does exist can be leveraged when the political window of opportunity arises.

Freedom of Information legislation

In many countries, Freedom of Information (FOI) legislation has been a key tool for population, communities, and civil society to access information relevant to the implementation of health policies in their communities. In Mexico, for example, FOI legislation allowed civil society to obtain basic information on health budget transfers between central and state governments, giving them the necessary evidence to put on the dialogue table with the government (17). FOI legislation therefore played a key role in the success of Mexican civil society creating 'claimed'[1] participatory spaces which opened up 'invited' spaces (see Chapter 5, Section 5.4).

Swamy, in her social accountability frameworks, emphasizes access to information as integral to "the right of the citizen to engage with the administration through public collective platforms" (18). As highlighted in chapter 3, information and knowledge are a source of power and legitimacy for experts, professionals, and government, besides the fact that without it, decisions cannot be rationally made. Allowing this same information and knowledge access to civil society facilitates the possibility of the latter being on a more level playing field with experts and facilitating true influence on decision-making within a participatory space (19, 20). The importance of FOI legislation for participation thus cannot be underestimated.

1 Claimed, or invented, spaces are those which are created by populations, communities, and/or civil society; invited spaces is a term used for government-led processes which other stakeholders are invited to

6.4 Legal frameworks: key issues to reflect on

Participation can and does take place even when legal frameworks do not exist

It is important to remind oneself that participatory activities take place in many settings formally or informally without a legal framework in place. Not having an underlying law or policy should not hinder a policy-maker from undertaking a participatory activity, and does not in practice. Countless examples exist where local initiatives, a favourable environment, and/or a specific policy question have led to the creation of participatory spaces which flourish in some places and struggle in others. They may take place formally, led by government health institutions, for a specific purpose such as national health policy development (21) or informally, through grassroots action and community initiatives (22).

An example of a formal initiative taking place without an underlying legal framework is the Societal Dialogue for Health in Tunisia which was borne out of the 2011 Arab Spring revolution (see Chapter 1) and is set up with a formal Steering Committee and Technical Committee, each involving both civil society and government representatives. The formalized nature of the Societal Dialogue for Health is also evinced by their drafting of the first post-revolution National Health Policy which was presented at the 2019 National Health Conference (23, 24).

In the community setting, Informal and quasi-formal participatory initiatives take place frequently as well. Numerous examples exist, from programme-led community participation mechanisms for malaria (25), HIV, tuberculosis (26), etc. to community-led water & sanitation provision (22), all of which take place without a formal legal basis but supported by local social and policy initiatives. Vibrant grassroots and quasi-formal participatory activities in health may be an indication that the time is ripe for a legal framework to formalize what is happening in practice already (see Section 6.6).

Legal frameworks do not guarantee participation per se as they constitute just one of several elements needed to ensure participation

For a variety of reasons, numerous legal frameworks exist which have not been implemented, within the area of participation and health (16), or otherwise. In South Africa, the National Health Act (2004) mandated primary health care facilities to consult health committees. However, provincial legislation must give effect to the Act's intentions, which has been slow to come, sometimes taking over a decade as in the Western Cape where legislation was passed in 2016. Still, even with provincial follow-up legislation, Health Committees are yet to be set up there (8). In Portugal, a 1990 Basic Health Law (27) mandating a National Health Council was only implemented in 2017 when a formal structure was created and access to funding granted (28).

Many factors are usually in play with regards to faulty implementation or non-implementation of a legal framework for participation (29). The reigning political and societal culture might

not view participation as a priority which may translate into a lack of real political commitment or lack of any grassroots pressure and demand for participation, or both.

Power structures which are entrenched in society and culture are hard to overcome, and a legal framework may not be enough (30). A series of papers from Guatemala, for example, demonstrate that poor and indigenous communities face huge hurdles when claiming equal voice in participatory spaces due to embedded power structures (22, 31). Several studies from Brazil also noted that laws mandating community participation for public service planning was in and of itself not sufficient to change the social hierarchy and racism entrenched in the social relations between professionals, health officials, and rural marginalized communities that use public services (32).

The lack of public demand for participation is also a result of low capacities linked to education levels and an internalized sense of disenfranchisement due to societal structures (see Chapter 4, Section 4.7). In Madagascar, for example, community members expressed their fear of speaking up unless they truly had no other choice. One community health worker explained, *"if... the 'important men' are there, [villagers] don't express themselves much. But if they are amongst themselves [in the community], they can be very vocal"* (33).

These underlying challenges and power imbalances need to first be acknowledged, then counter-balanced, which a legal framework alone may not be able to do – but it can be a very good start.

Box 6.2

Legally mandated participatory spaces in health: Examples

- District health committees
- Portugal's Health Council (17)
- Thailand's National Health Assembly (14)
- Brazil's Municipal Health Councils (32)
- Guatemala's legally mandated citizen participation in the monitoring & evaluation of public services (Urban and Rural Development Councils Act) (31)

Legally mandated spaces risk getting captured by the local elite

While all countries should aspire to create or strengthen institutionalized channels of participation in health, their formal character comes with specific challenges. Mechanisms which are formalized tend to be steered and influenced by those in formal positions, i.e. those who already wield influence and power (32). In fact, the literature and case study data indicate that marginalization can be easily exacerbated in legally mandated, 'invited' spaces unless targeted counterbalancing measures are put in place (8). Formalized spaces for participation thus risk becoming a reflection of society's power structures rather than acting as an equalizer to it. Swamy drives home this point in the Indian context by describing how bottom-up accountability and true social participation remains a

challenge because local elites can still impose their views within through caste, gender, and community-based norms to act in the name of people (18) (see Chapter 3).

In essence, then, legal mandates risk institutionalizing societal inequalities unless the legal framework recognizes and addresses those risks to counter-balance them (see Chapters 3 and 4 for counterbalancing measures). Several analyses of administrative decentralization efforts following the passage of decentralization laws (Tanzania, Uganda, Bangladesh, Indonesia, etc.) report extensively on elite capture of local power and rent-seeking behaviour simply shifting from central to decentralized levels (34-36). The common factor in all of these decentralization processes is the transfer of power from one authority (central government) to another (local government) with no safeguards ensured for power to be actually conferred to people and communities as well (37, 38). As Ramiro notes for the Philippines context, "mayors approved of devolution because it gave them more 'power' or 'control' over health services. But if control is seen as the most important dimension of devolution, rather than democratization, this is problematic for community participation" (38). The tall task, then, for those developing legal frameworks impacting on participatory processes is to take this reality into account.

> **"When we started our work, we had a technical and linear view of accountability. There was a new law mandating citizen participation in the monitoring and evaluation of public services, and our project focused on providing training to both service providers and the communities that use those services. Once trained, both groups of actors would engage in participatory planning, monitoring, and evaluation. In our first project, the intervention seemed straightforward... [We soon learned that] we [had] not take[n] into account that a law ordering the participation of communities in the planning of public services was not sufficient to change the social hierarchy, racism, and discrimination embedded in the social relations between professionals, health officials (all of them non-indigenous), and the rural indigenous communities that use public services."**
>
> Flores & Hernandez (31)

In general, it is still more advantageous to have a legal framework supporting participation than to not have it

Whether functional or not, having a participatory space or a right to participation laid down in a legal text protects the existence of a mechanism for people and communities to dialogue with the government on policy-relevant topics (12). Put differently, the existence of a legal framework covering participation gives populations the (theoretical) possibility to claim a right. In addition, even in settings where the legal framework is not implemented in practice, its very existence allows for smoother and more rapid operationalization of participatory spaces at a later date when the window of opportunity arises. A case in point here is the Health Council in Portugal, anchored in a decree-law in 1990 but only established in 2017, a full 27 years later. The legal texts which gave the Health Council its mandate in 2017 made explicit reference to the 1990 intention and acknowledged that it was not given effect earlier, thereby facilitating the path to its (delayed) set-up (39).

Where participation happens without an explicit legal basis, providing for one can formalize and legitimize existing mechanisms, thereby giving them a boost in policy priority, access to funding, and/or capacity-building initiatives. In Guatemala, for example, a decentralization law explicitly created community participation mechanisms, opening up a formal space within which to place some of the longstanding, well-functioning but informal community decision-making platforms. These community groups then had easier access to expertise and monies, allowing them to strengthen existing local services they were struggling to put in place (22, 40). In South Africa, many community health committees have remained informal while waiting for provincial legislation to give effect to the National Health Act (2003)'s intentions, leaving them with an unclear role, thus reducing their potential influence on local health policy and planning (12).

Box 6.3

Inclusion of marginalized groups needs careful consideration in legal framework design

- Recognize embedded and informal power structures within societies and communities to ensure that participation of marginalized groups is not hindered by the legal framework.
- Use legal framework design to re-set power imbalances which uphold the disproportionate influence of some groups over others.
- Stipulate roles and responsibilities clearly in legal frameworks to increase opportunities for marginalized communities to participate in decision-making.
- Create a legal environment (through the legal framework) that gives more weight to marginalized & vulnerable population groupspublic services (Urban and Rural Development Councils Act) (31).

6.5 Legal frameworks: conditions which favour an increase in participation

The devil is in the details: why careful design of the framework matters for participation

Legal frameworks have the potential to greatly facilitate meaningful engagement in participatory spaces when its design adequately addresses ingrained socio-political power imbalances with provisions for levelling them out (12, 41). The framework's details should be purposefully designed so that it works in favour of, and not against, increased people's voice (42). In this vein, three key areas stand out as pivotal: representation & selection processes, roles & responsibilities in participatory spaces, and funding modalities. An essential point here is that, usually, all three aspects should ideally be addressed concomitantly to ensure meaningful participation. For example, roles & responsibilities may be stipulated clearly in legal text but without any budgetary mention, it will be challenging to practically take on those roles (43). Or budgetary arrangements may be laid out legally but without (legal) clarity regarding who should be participating, monies might be spent on consulting, for example, interest groups and large NGOs who already have access to government circles, and not necessarily those whose voice needs amplification.

Basically, increasing people's voice, and building agency vis à vis health decision-making is complex and requires a committed and holistic approach. The different facilitating factors are synergistic; documented experience shows that leveraging legal frameworks to address one without the other can end up in non-implementation (36) or insufficient implementation (8, 16).

The three key areas which require integration into legal texts are elaborated upon further in the following section.

Box 6.4

A legal framework: (just) one of several elements to amplify people's voice in health decision-making

Several actions must accompany the introduction of a legal framework to facilitate its intended effect in practice:

- foster an environment within participatory spaces which minimizes power imbalances as a key means to achieving meaningful and equal social participation;
- be crystal clear about the objectives of the participatory space, and communicate those objectives well;
- be transparent about selection process, format, and design;
- invest in capacity-building to empower all stakeholders involved in the participation process (and thus, to meaningfully contribute);
- create links between the participatory space topics and the decision-making institutions which have authority over those topics; and
- provide feedback to and continue engaging with populations, communities, and civil society on follow-up actions.

(a) Representation and the balance of power in participatory spaces

The question of who takes part in participatory spaces (representation) is of huge significance in terms of levelling out the playing field in terms of power and influence (see Chapter 3). Safeguards should be put in place within the legal text to reduce the disproportionate influence by those with more power (government, interest groups (especially those with large commercial interests or potential conflicts of interest), majority groups, etc.). Bureaucratic culture, professional paradigms, and societal hierarchies are formidable barriers to overcome (16, 37); a legal framework can serve as a catalyst for barrier break-down by explicitly handing over structural influence to certain population groups by stipulating details of the set-up of participatory spaces. For example, Thailand's 2002 National Health Security Act specifically mentions that the National Health Security Board, which steers decision-making on the Universal Coverage Scheme, should include five representatives from nine civil society constituencies (44). Those nine constituencies represent underserved or marginalized communities (mental health patients, ethnic minorities, people living with HIV, etc.), thereby (at least) structurally ensuring that those voices are included.

When the wording and specific language is not adequately thought through from the perspective of a representation and a level playing field for participation, a legal framework can end up being yet another limiting factor, in addition to all of the other societal and social ones, to meaningful population and civil society engagement. For example, South Africa's Western Cape Health Facility Boards and Committees Act (2016) stipulates ministerial appointments to the health committees with nominations from "a body that, in the opinion of the [Health Minister], is sufficiently representative of the interests of the community or communities concerned" (45). This stipulation, and the formulation used to explicate it, highlights the great discretion conferred to a government official to either bring in community interests into facility committees, or not (8).

The above quote also lays bare the inherent risks in designing a legal framework without considering the consequences for the balance of influence within the participatory space. In the above example, the legal text ends up consolidating the perspective and voice of a government official whose views are already dominant anyway, despite the very intent of the facility boards and committees to give voice to views which are less heard.

Box 6.5

Lucidity regarding "who is supposed to do what" lends legitimacy because:

(a) the person fulfilling the role is empowered through legal clarity to undertake a new task;

(b) other relevant stakeholders are compelled to recognize the new authority conferred by law;

(c) it confers transparency and public accountability regarding decision-making.

(b) Clarity of roles contributes to legitimacy of voice

Lack of role clarity has been cited in numerous analyses of decentralization, and other legislation fostering participatory spaces, as a hindering factor for implementation (8, 12, 38, 46-48). A case in point can be found in the Kenyan experience where health sector decentralization was challenged by "no clear terms of reference [n]or guidelines provided by national or county governments for the composition, roles, and mandates of [newly created, county-level] structures" (46) (see Box 6.6). The same study lamented the lack of clear role delineation between the centre and the periphery, an issue which has been documented widely (8, 12, 38, 46, 47). When unclear roles and responsibilities are compounded by capacity deficiencies within a newly created decentralized health authority, activities perceived to be less urgent, low in priority, or difficult to undertake such as community engagement do not happen, or do not happen as they should (8, 12, 38, 46, 47). For laws creating new, or formalizing existing, participatory mechanisms (see Box 6.2), role clarity is key to empowering each participant to contribute equally while voicing their views, expertise, and experience during deliberations.

A clearly defined function is thus crucial to legitimizing the new role, especially when it is potentially contested. New authority at local level to engage with populations and communities, and accord them a formalized say in decision-making, can upset the local balance of power. However, when local authorities are obliged to fulfil this responsibility with legal clarity, the law can serve as a catalyser for a new way of working. More importantly, a legally legitimized role handed over to those in society who traditionally wield less influence over policies does not leave the door as open for elite capture.

Meier et al. thus argue that clearly defined responsibilities and functions should be codified in legislation, especially the roles of community representatives, and those of the health authorities vis à vis the community (12). The more the details of engagement are spelled out in legal frameworks, the more evident it is to each stakeholder what they are supposed to do and how they are supposed to do it (22). Otherwise, experience shows that loosely worded decentralization laws based on principles alone have major difficulties in fulfilling its intent of bringing health decision-making closer to the people (12, 19, 22, 47, 49, 50).

Box 6.6

Role delineation during decentralization: an example from **Kenya**

A public vote on decentralization in Kenya in 2010 led to the decision to shift public sector governance, including health, to 47 newly created semi-autonomous county governments. Following the vote, the central government originally intended to progressively shift functions from central to county level by helping to set up new county government structures and by providing capacity training. However, increasing political pressure led to functions and mandates being shifted to the county governors earlier than planned. Mechanisms and structures to undertake new functions were not yet operational nor was there sufficient capacity in the existing workforce to take on new roles. Compounding the challenge was the confusion around how roles and responsibilities were supposed to be newly distributed between national and sub-national government levels. This ambiguity led to interruptions in health service delivery due to the inability of counties to take up their management and payroll functions. Health workers subsequently went on a country-wide strike in 2013 which further disrupted health sector operations.

Documentation on Kenya's decentralization process shows that, over time, some counties did manage to set up well-functioning structures and assume decentralized functions, including community engagement activities. Indeed, these county government cadres used their decision-making power more frequently, fulfilling their decentralization mandate.

The Kenyan experience is a stark reminder of the importance of establishing within decentralization legislation clear and distinct roles between the national and sub-national levels. This experience also underlines the need to build knowledge and skills (i.e. capacities) among the different actors to prepare the implementation of decentralization. Finally, the Kenyan example highlights how shifting power closer to communities needs to be accompanied with capacity training and adequate resources (46).

(c) Financial resources

Many practitioners and experts elevate sustained funding for participation to a pre-condition to effective participation [8, 11]. Funding is required for the government/organizer side to ensure adequate preparation and supervision of participatory processes, capacity-building, and a smooth running of the participatory space itself [35, 36, 48, 51]; funding is just as crucial for communities and civil society to off-set costs for volunteer participation [22, 52], permit core administrative operations [47], enable collective deliberation [18], and undertake many other tasks [see Chapter 3, Section 3.6, and Chapter 4, Section 4.7] . If a minimal level of financial resources is seen as a pre-requisite for participation, a logical consequence would be a mention at the very least, and detailed stipulation at best, of budget requirements for participatory spaces in relevant legal frameworks [8].

The critical features of funding needed for participatory spaces are stable and predictable funding and not necessarily high levels of it. A secure budget backed by a legal mandate can facilitate funding stability enormously, besides

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providing a basis to claim due funding (53). Global documentation on decentralization legislation evinces considerable challenges faced in not only ensuring funding allocation but, even when it is secured, problems with fund disbursement (35, 42). When funding does not flow as expected, lower-priority activities such as community engagement are often the first to be cut, especially given the scepticism and sense of helplessness which prevails in government and health facility management circles in terms of the 'how' of participation (37). A budget line, approximate budget levels, budgetary arrangements and/or a budget formulation process specified within the legislation for the activities touted as the very rationale for decentralization helps to pave the rocky path towards implementation (19).

As elaborated upon previously, new roles are often conceived in participation-related legislative frameworks which may not be completely accepted by all stakeholders. Predictable and legally stipulated funding can add legitimacy to a new role, empowering the new role-holders (53). Frumence et al. describe how the Tanzanian policy framework for decentralized responsibilities was left vague on funding levels and schedules, ultimately leaving it to the discretion of central government in practice. Study authors document how that essentially led to inefficient and inadequate funding, with weakened decentralized authority (35). The same can happen when resources which are supposed to be used at the discretion of sub-national actors are pre-allocated by central government (8, 36, 42). A legal stipulation of budget levels can forestall funds being thus earmarked, thereby permitting more spending flexibility for local actions such as community engagement (38).

Finally, legally fixing budgetary arrangements for participatory spaces can nudge budgeted activities to actually happen, despite the numerous hurdles such work often faces. Activities which are budgeted need to be undertaken, documented, and reported on, regardless of stakeholders' views or capacities to conduct the activity. And, as stated throughout this handbook, the existence and maintenance of a participatory space is generally positive, even if it is not entirely functional – with all its faults in practice, it can give exposure to all sides to 'learn' participation, build their capacities, refine the format & design, and institutionalize the participatory modus operandi (see Chapter 1).

Box 6.7

The Community Health Fund in **Thailand** as an integral part of the National Health Security Act

The National Health Security Act passed in 2002 following many years of advocacy by civil society organizations. It was a milestone in Thailand's push towards universal health coverage as it granted health service access to 18.5 million previously uninsured people (54). Participation is a prominent element of the Act, implemented through measures such as fixed civil society seats in the National Health Security Board and regular public hearings (41).

Another manifestation of the participation clauses in the Act are the Community Health Funds which are also operated jointly by government officials and community representatives (55). The budget for local health promotion and prevention activities are thus decided on with strong community input (56) – activities such as raising public awareness of preventive health measures and improving cooperation between communities and local government for more responsive health service delivery (51).

The Community Health Fund demonstrates how the formal institutionalization of a budgetary mechanism can lead to practical community engagement and increase community ownership.

An independent body to enforce human rights

Rights are a source of power when enforced. Examined from the balance of power lens of a participatory space, an independent rights-enforcing institution would bring compelling countervailing power to those who have less of it, namely those whose voices are generally weaker, and whose health status generally poorer.

The right to health and participation within the health sector is linked to functional and sincerely run participatory processes. Independent institutions may be beneficial not only to monitor the effectiveness of participatory processes but also to propose and enforce sanctions and remedies for failures (11). One such example is Thailand's Independent Complaints Unit set up within the remit of the Universal Coverage Scheme – besides disseminating simple information on patient rights, its mission is to act as a mediator between the population and the health system and take action when appropriate services are not received (41).

The global human rights community has long advocated for the set-up and operationalization of national-level human rights institutions (NHRI) to ensure enforcement of the population's rights (57). The principle of a NHRI is a publicly-funded institution whose statute allows it to operate independently of government with the mandate to protect, monitor and promote human rights (see Box 6.8). Given that the right to health is intrinsically linked to the right to participation, Potts asserts that "the State has the ultimate obligation to...develop the institutional mechanisms to ensure that participation takes place" (11), whether it be through NHRIs or a separate, specialized public body.

Potts thus emphasizes the importance of a legislative requirement for participation backed by an independent body tasked with supporting and supervising fair and transparent participatory processes (see Section 6). The existence of such an institution with real powers to do so has shown to be a defining factor in fostering participation in many settings (11, 17). In other contexts, advocates and researchers lament human rights which mainly exist in theory and urge the operationalization of such an institution for rights enforcement (8, 32).

Box 6.8

Accrediting and supporting National Human Rights Institutions: the Global Alliance of National Human Rights Institutions (GANHRI)

National Human Rights Institutions (NHRIs) are state institutions set up with the intention of protecting and promoting human rights. They are explicitly independent from the government, with specific legislative mandates varying across countries. Usually a constitution, a human rights act or institution-specific legislation lends the legal basis for a NHRI. Examples of NHRIs are Human Rights Commissions, Human Rights Ombudsman Institutions, and Consultative and Advisory Bodies for Human Rights. NHRIs are seen as an essential bridge between individual rights and freedoms, and the responsibilities of the state as an upholder of rights (58).

The Office of the United Nations High Commissioner for Human Rights (OHCHR) has invested heavily in technical advice and support in setting up and/or running an effective NHRI. OHCHR houses the Global Alliance of National Human Rights Institutions (GANHRI) which has 114 country members who are accredited on a regular basis (57). GANRHI offers an accreditation process for NHRIs to be officially recognized as such, based on the UN Paris Principles and strongly encouraged by the UN General Assembly and the UN Human Rights Council.

GANRHI's governing body consists of a General Assembly, the Bureau (i.e. a board of directors) and its accreditation and finance sub-committees. GANHRI´s secretariat engages in global advocacy and capacity building in the areas of business & human rights, migration, persons with disabilities, gender equality, rights of older persons, shrinking democratic space, NHRIs in conflict and post-conflict settings, and SDGs.

The independence of such an institution is crucial given that claiming rights can be dangerous and can upset established interests. In India, more than 70 murders are attributed to requests for access to documents under Freedom of Information legislation (18). In Guatemala, community members who addressed local government officials with access to medicine complaints were harassed and intimidated (31). Such grim realities stress the need for institutional support to those claiming rights through whichever means, including through participatory spaces.

6.6 Capacity aspects to consider: Fulfilling the intent of legal frameworks on participation

A provision which is often left out of legislation which facilitates participation is the need to build the capacity to enter, engage with, and maintain a participatory space. For example, decentralization laws mostly do not make provisions for capacity-building for decentralized entities to take on new responsibilities, including the task of reaching out to communities to bring in their voice into localized decision-making. Tsofa et al. lament the hasty drafting and passage of Kenya's new constitution in 2010 which places extensive (additional) requirements on devolved governments to engage with the public but without the requisite training, coaching, and supervision for county authorities to do so [31, 46]. Yet the need for capacity-building offers a fitting entry point for governments to engage more closely with communities following the passage of a new legal framework affirming participation. Governments can, for example, seek out civil society organizations to partner with as many are prompted by new legislation to support communities with capacity-building initiatives [31].

Overall participation-related capacity needs for populations, communities, and civil society, and for government, is covered in depth in chapter 4 of this handbook. In this section, however, we wish to raise awareness on specific capacity issues which may serve as an indicator for the optimal moment to bring in legislation affecting participation. These same issues can also be seen as preparatory steps which can smoothen the path towards implementation of a law, in anticipation of its passage.

Grassroots movements & civil society action supporting participation: fertile ground for legal frameworks?

A political window of opportunity for legal frameworks anchoring the right to participation is often linked to times of change, post-crisis reform, and other far-reaching, historical circumstances. The examples are endless, from the post-Apartheid democratic start in South Africa to the Burkina Faso uprising of 2014 to Tunisia's 2011 Arab Spring revolution. Events such as these are usually a culmination of civic action laying claim to a fairer, more democratized society and, in terms of health, a right to have a say in how health systems are shaped.

Legal frameworks which are ushered in during such moments can help introduce and anchor a mentality of participation in the health and public sectors by formalizing mechanisms which exist and already work well. For example, in Apartheid-era South Africa, civil society organizations were active in providing health services to township communities. The post-Apartheid democratic government sought to capitalize on this experience and capacity by formalizing Community Health Committees in its 2003 National Health Act [12]. Another example comes from Peru where the Local Committees for Health Administration (CLAS) were anchored in the legal texts linked to health sector reform in the 1990s; the CLAS was borne out of "grassroots self-help circles that developed from the economic and political crises of the 1980s" [48], capitalizing on their organization, links to communities, and experience in social participation.

Box 6.9

The recognition of the right to health in the 2014 Egyptian constitution

Following Egypt's popular uprising in 2011, a new constitution that would explicitly state fundamental rights was seen as an important foundation for tackling prevailing social and economic inequalities. Past constitutions did not explicitly mention people's right to health (59). This issue, however, mobilized civil society organizations that began organizing to effectively influence the Constitution's content to be inclusive and broad in its formulation of the right to health.

A draft constitution was approved in 2012. Despite being a big leap forward compared to previous ones, it failed to fully meet civic demands and expectations, with civil society especially criticizing the omission of an explicit commitment to the right to health. Looking back, civil society recognized their own lack of a coordinated approach to the 2012 draft, with separate proposed articles on health sent in a piecemeal fashion to the Constitution Writing Committee (59).

However, a window of opportunity to revise the document and address persisting defects arose with some political turmoil and a change in government. Civil society took stock of their first round experience and, this time, formed a coalition to jointly coordinate advocacy efforts targeting policy-makers. Given the political context, the latter were particularly sensitive to people's perceptions.

The coalition conducted a two-month, internal consultation process which included working group sessions and meetings with political parties, ministry officials, academics, labour unions, etc. Their first proposed article was returned by the Constitution Writing Committee with a request for modifications. The civil society coalition then brought in further partners to ensure an even more broad-based coalition membership and formulated 'Minimal Requirements Documents', a list of simple, one-phrase,

minimal requirements covering all human rights, including four on health, including the right to health (60).

In parallel, civil society invested heavily in a public advocacy effort to build large-scale buy-in not only within the actors of the coalition but also with other key stakeholders, including the public. In the end, most of the minimal requirements for health were taken forward by the Writing Committee and later approved in a public referendum in 2014. Finally, Article 18 of the Egyptian constitution included the right to health to all without discrimination, a milestone in the country's history (61), and fruit of a collective cooperation and coordinated effort at all levels.

All in all, the Egyptian grassroots movement and civil society action provided fertile ground for the passage of a landmark legal framework, its 2014 constitution. Civil society's agile alliance-building helped channel and coordinate successful efforts targeting decision-makers and the public. The fruits of Egypt's active grassroots and able civil society is the state's legal obligation to fulfil the population's right to health.

When an opportune moment arises to bring in a legal framework which opens avenues for more participatory activity in health, policy-makers would do well to review and understand existing mechanisms and know-how. The intention for doing so would be to formalize those community structures, or elements of them, which function well and enjoy broad acceptance in the population (8) (for caveats in doing so, see Chapter 7, Section 7.5). Existing community knowledge can thus be leveraged right away to put the legal framework into action, thereby facilitating its anchorage into the mentality of sectoral operations (32, 37). At the same time, an indication that the time is ripe for a legislative text may be the level of grassroots action and civil society activity already 'doing' participation in a sophisticated way (22, 41). A high level of grassroots action is often a product of increasing civil society capacity and a growing population consciousness of their own rights (31). Bestowing a legal framework upon such action can ensure that the realization of health rights withstands the test of future politics.

The challenge here is to ensure that the readiness of communities to play an active role in participatory spaces is matched by a readiness of government stakeholders to recognize its potential to improve policy-making and their capacity to manage participatory spaces. This is the moment where investment in government capacity-building needs to be prioritized in order for participation to become part of the health sector's modus operandi (see Chapter 4).

Functional structures to make participation happen when the legal mandate enters into force

As iterated previously, legal frameworks in and of themselves do not make participation happen in practice. Even with sincere intent, the challenge of implementation can be formidable, especially when a new way of working or novel structures need setting up and operationalization.

Making a legal framework work practically means preparing it well; this includes not just drafting the legal text but also working with all relevant stakeholders to ensure that functional structures are in place to take on new roles and responsibilities once the text enters into force (35, 38, 53). Ideally, strengthening existing or creating new structures to be ready and functional would happen in parallel to outlining the legal text. In fact, the two tasks go hand in hand as those very structures should be detailed in the legal framework with input from those involved in those structures on the ground. In essence, the process of jointly stipulating legal framework details is vital for a common understanding of what the participatory space is and will be (8). Contestation of what a participatory space is can paralyze it, thereby making in non-functional.

"Functional" in this case refers to human resources to match new or restructured roles and the capacity to fulfil the roles as per the terms of reference within the new structures. Otherwise, experience has shown the high risk of legal frameworks not being implemented (62), being implemented with considerable delays (12, 46), of faulty implementation (8, 43, 46), or implementation which goes against the spirit and objectives of the framework itself (31). In practice, this can mean infrequency of meetings or events, poor attendance not always including the target audience, high turnover of members or volunteers, administrative problems such as lack of minute-taking and poor financial management (8, 22).

More fundamental challenges given prominence earlier in this chapter can crop up in the vacuum that exists when functional structures are missing. Elite capture, conflicts of interests, and disproportionate influence of vested interests all strike fertile ground when structures are not functional to counter-balance and manage them (31).

Capacities of the people working in the participatory structures are basically what renders them functional (19, 46). Having the necessary absolute number of human resources needed for the new roles can be achieved by either strengthening existing structures (building their capacities and potentially repurposing them) (18), or by hiring new staff with the right capacities to set up a new structure. Even for the latter, capacity-building initiatives might be necessary to fine-tune skill sets to match the needs of the participatory space. Functional structures which exist and are doing well may be an indication of an opportune moment to introduce the idea of a legal framework to formalize them.

Otherwise, functional structures take time to set up and operationalize; therefore, relying on existing structures based on context may be advisable in some settings (see Chapter 7). Either way, the time factor also highlights the need to work on those structures in preparation of a legal framework to come and not after the fact.


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6.7 Conclusion

Legal frameworks affect the quantity and quality of participation. They have the potential to contribute to an equalization of power relations by stipulating a legitimate role, backed by a budget, to those whose voices are traditionally less heard – thereby giving both a legal and a practical boost to the very objective of participatory spaces. The potential of legal frameworks to facilitate a level playing field within a participatory space is huge as the imbalance of power relations is a reflection of entrenched norms and practices in society which are formidable barriers to overcome otherwise.

That being said, it is important to keep in mind that one need not wait for legislation to pass for participatory activity to take place in the health sector. Indeed, this chapter offers insights into vibrant participatory spaces which began informally before becoming formalized in law. In fact, there might be an opportune, or 'right', time for formalization in some settings as formalization has its caveats. For example, formal participatory mechanisms tend to be steered and influenced by those in formal positions, i.e. those who already wield influence and power, potentially exacerbating marginalization.

Nevertheless, a participatory space or a right to participation enshrined in a legal text gives populations the possibility, at least theoretically, to claim a right. It is better to have it than not; it certainly helps instil a culture of participation which needs to be built over time. Those long-term investments include preparing the ground for legal framework implementation by investing in capacities and stakeholder buy-in for the practicalities of implementation.

References

1 Office of the High Commissioner for Human Rights (OHCHR). CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12), E/C.12/2000/4, (2000).

2 World Health Organization (WHO). Declaration of Alma-Ata. International conference on primary health care Alma-Ata, USSR: World Health Organization (WHO); (1978).

3 Clarke D. The legal framework reverse pyramid. Geneva: World Health Organization (WHO); Forthcoming 2021.

4 Merriam-Webster. Definition of constitution [Available from: https://www.merriam-webster.com/dictionary/constitution].

5 Merriam-Webster. Definition of legislation [Available from: https://www.merriam-webster.com/dictionary/legislation].

6 TransLegal. Legal framework [Available from: https://www.translegal.com/dictionary/en/legal-framework/noun].

7 Rohrer K. Strategizing for health at sub-national level. In: Schmets G, Rajan D, Kadandale S, editors. Strategizing national health in the 21st century: a Handbook. Geneva: World Health Organization (WHO); 2016.

8 Haricharan HJ. Health committees in South Africa: the Influence of power on invited participation in policy and practice. Cape Town, South Africa: University of Cape Town; 2019.

9 Uganda Legal Information Institute. The Local Governments Act, (1997).

10 World Health Organization (WHO). Constitution of the World Health Organization, (1946).

11 Potts H, Hunt P. Participation and the right to the highest attainable standard of health. Human Rights Centre; 2008.

12 Meier BM, Pardue C, London L. Implementing community participation through legislative reform: a study of the policy framework for community participation in the Western Cape province of South Africa. BMC International Health and Human Rights. 2012;12(1):15.

13 Hunt P, Backman G. Health systems and the right to the highest attainable standard of health. Health and Human Rights. 2008:81-92.

14 Rajan D, Mathurapote N, Putthasri W, Posayanonda T, Pinprateep P, de Courcelles S, et al. The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016). World Health Organization (WHO); 2017.

15 Ocloo J, Garfield S, Dawson S, Franklin BD. Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a protocol for a systematic review of reviews. BMJ Open. 2017;7(10):e018426.

16 Matos AR, Serapioni M. The challenge of citizens' participation in health systems in Southern Europe: a literature review. Cadernos de Saude Publica. 2017;33(1):e00066716.

17 Colectivo Meta (COMETA). Case study on civil society involvement in policy processes in Mexico. Unpublished work.

18 Swamy R. Explorations in the concept of social accountability from theory to practice, and from practice to theory. India: Centre for Budget and Governance Accountability (CBGA); 2019.

19 Hammamy D. Decentralization in the public healthcare of Jordan - A situational analysis. Washington: United States Agency for International Development (USAID); 2017.

20 Organisation for Economic Co-operation and Development (OECD). Recommendation of the council on open government, OECD/LEGAL/0438 2017 [Available from: https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0438#_ga=2.37822115.1251313301.1554450220-751648841.1537891795].

21 Rohrer K, Rajan D. Population consultation on needs and expectations. In: Schmets G, Rajan D, Kadandale S, editors. Strategizing National Health in the 21st Century: a Handbook. Geneva: World Health Organization (WHO); 2016.

22 Ruano AL. The role of social participation in municipal-level health systems: the case of Palencia, Guatemala. Global Health Action. 2013;6(1):20786.

23 Business News. Conférence nationale de la Santé: vers un projet de réforme structurelle 2019 [Available from: https://www.businessnews.com. tn/conference-nationale-de-la-sante--vers-unprojet-de-reforme-structurelle,520,88972,3]. French.

24 Espace Manager. Conférence Nationale de la Santé: Un nouveau mode de gouvernance basé sur la décentralisation et la démocratie sanitaire 2019 [Available from: https://www.espacemanager.com/ conference-nationale-de-la-sante-un-nouveaumode- de-gouvernance-base-sur-la-decentralisation- et-la]. French.

25 Muhe L. Community involvement in rolling back malaria. World Health Organization (WHO); 2002.

26 World Health Organization (WHO). Community involvement in tuberculosis care and prevention: towards partnerships for health - Guiding principles and recommendations based on a WHO review. World Health Organization (WHO); 2008.

27 República Portuguesa. Lei Básica de Saúde, Lei n. 48/90. Assembleia da República, (1990). Portuguese.

28 World Health Organization (WHO). 'The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal' dataset. In: World Health Organization (WHO), editor. Year of data collection: 2019. Portuguese.

29 Mdaka K, Haricharan H, London L. The role of health committees in equitable, people-centred health systems in Southern and East African Region. Learning Network for Health and Human Rights and Centre for Health: University of Cape Town, Cape Town; 2014.

30 Ruano AL. The role of social participation in municipal- level health systems: the case of Palencia, Guatemala. Umeå, Sweden: Umeå University; 2012.

31 Flores W, Hernández A. Health accountability for indigenous populations: confronting power through adaptive action cyles. Institute of Development Studies (IDS) Bulletin. 2018;49(2): 19-34.

32 Ciconello A. Social participation as a democracyconsolidating process in Brazil. From poverty to power: how active citizens and effective states can change the world. Oxfam Digital Repository. 2008:207-17.

33 Madagascar case study interviewee #12. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

34 Faguet J-P. Transformation from Below in Bangladesh: decentralization, local governance, and systemic change. Modern Asian Studies. 2017;51(6):1668-94.

35 Frumence G, Nyamhanga T, Mwangu M, Hurtig A-K. Challenges to the implementation of health sector decentralization in Tanzania: experiences from Kongwa district council. Global Health Action. 2013;6(1):20983.

36 Kapiriri L, Norheim OF, Heggenhougen K. Public participation in health planning and priority setting at the district level in Uganda. Health Policy and Planning. 2003;18(2):205-13.

37 Mosquera M, Zapata Y, Lee K, Arango C, Varela A. Strengthening user participation through health sector reform in Colombia: a study of institutional change and social representation. Health Policy and Planning. 2001;16(suppl_2):52-60.

38 Ramiro LS, Castillo FA, Tan-Torres T, Torres CE, Tayag JG, Talampas RG, et al. Community participation in local health boards in a decentralized setting: cases from the Philippines. Health Policy and Planning. 2001;16(suppl_2):61-9.

39 Simões JdA, Augusto GF, Fronteira I, Hernández-Quevedo C. Portugal health system review. European Observatory on Health Systems and Policies; 2017.

40 Ruano AL, Dahlblom K, Hurtig A-K, Sebastián MS. 'If no one else stands up, you have to': a story of community participation and water in rural Guatemala. Global Health Action. 2011;4(1):6412.

41 Kantamaturapoj K, Kulthanmanusorn A, Witthayapipopsakul W, Viriyathorn S, Patcharanarumol W, Kanchanachitra C, et al. Legislating for public accountability in universal health coverage, Thailand. Bulletin of the World Health Organization. 2020;98(2):117.

42 Bossert TJ, Beauvais JC. Decentralization of health systems in Ghana, Zambia, Uganda and the Philippines: a comparative analysis of decision space. Health Policy and Planning. 2002;17(1):14-31.

43 Regmi K, Naidoo J, Greer A, Pilkington P. Understanding the effect of decentralisation on health services: the Nepalese experience. Journal of Health Organization and Management. 2010;24(4):361-82.

44 National Health Security Office Thailand. National Health Security Act BE 2545, (2002).

45 Provincial Parliament of the Western Cape. Western Cape Health Facility Boards and Committees Act, (2016).

46 Tsofa B, Molyneux S, Gilson L, Goodman C. How does decentralisation affect health sector planning and financial management? A case study of early effects of devolution in Kilifi County, Kenya. International Journal for Equity in Health. 2017;16(1):151.

47 Seshadri SR, Parab S, Kotte S, Latha N, Subbiah K. Decentralization and decision space in the health sector: a case study from Karnataka, India. Health Policy and Planning. 2016;31(2):171-81.

48 Iwami M, Petchey R. A CLAS act? Community-based organizations, health service decentralization and primary care development in Peru. Journal of Public Health. 2002;24(4):246-51.

49 Kilewo EG, Frumence G. Factors that hinder community participation in developing and implementing comprehensive council health plans in Manyoni District, Tanzania. Global Health Action. 2015;8:26461-.

50 O'Meara WP, Tsofa B, Molyneux S, Goodman C, McKenzie FE. Community and facility-level engagement in planning and budgeting for the government health sector – a district perspective from Kenya. Health Policy. 2011;99(3):234-43.

51 National Health Security Office Thailand. People's Participation of the Universal Coverage Scheme (USC) in Thailand. 2019.

52 Healthy Caribbean Coalition. A Civil Society Report on National NCD Commissions in the Caribbean 2015 [Available from: http://www.healthycaribbean.org/civil-society-report-national-ncd-commissions-caribbean/].

53 Rajesh K, Thomas MB. Decentralization and interventions in the health sector. Journal of Health Management. 2012;14(4):417-33.

54 Towse A, Mills A, Tangcharoensathien V. Learning from Thailand's health reforms. BMJ. 2004;328(7431):103-5.

55 Saengow U, Phenwan T, Laohaprapanon A, Ketwongkot T. Challenges in implementation of community health fund in Thailand.

56 Patcharanarumol W, Panichkriangkrai W, Wangmo S, Thammatacharee J, Uechi M, Wanwong Y. Diabetes prevention and care in the universal health coverage context: the example of Thailand. WHO South-East Asia Journal of Public Health. 2016;5(1):27-33.

57 Global Alliance of National Human Rights Institutions (GANHRI). [Available from: https://ganhri.org].

58 High Commissioner for Human Rights United Nations. National human rights institutions: history, principles, roles and responsibilities: UN; 2010.

59 Sabae A. Four strategic pathways for the realization of the right to health through civil society actions: Challenges and practical lessons learned in the Egyptian context. Health & Human Rights Journal. 2014;16:104.

60 The Egyptian Initiative for Personal rights. The constitutional minimal requirements document. 2013 [Available from: https://eipr.org/sites/default/files/pressreleases/pdf/lhd_ldn_mn_ldstwr_3.pdf]. Arabic.

61 The Arab Republic of Egypt. Constitution of The Arab Republic of Egypt. 2014 [Available from: https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/97325/115440/F281017262/EGY97325%20Ara.pdf]. Arabic.

62 Von Lieres B, Kahane D. Inclusion and representation in democratic deliberations: sessons from Canada's Romanow Commission. In: Cornwall A, Coelho VSP, editors. Spaces for change? The politics of citizen participation in new democratic arenas 2007.

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Chapter 7

Sustaining participatory engagement over time

DHEEPA RAJAN
CSONGOR BAJNOCZKI

Handbook on Social Participation
for Universal Health Coverage

7.1 Introduction

The handbook has until now focused strongly on setting up and/or strengthening participatory spaces which feed into the formulation of health policies. The issue of how to ensure longer-term sustainability of these spaces is often ignored in the midst of the considerable effort it takes to set up and manage participatory processes. Yet the inevitable challenge of sustaining participatory engagement will emerge once the spaces are operational, either sooner or later – but the actions required to ensure sustainability are most effective when reflected on as part of its set-up and operationalization.

Sustaining participatory engagement over time implies ensuring long-term motivation, interest, capacity, and funding for participatory spaces by all stakeholders – government cadres as well as the population, communities, and civil society. It is important to think it through well as it affects not only the continuity of these spaces in the future, but also how far a culture of participation becomes rooted into a country's health sector psyche, thereby impacting on the extent of institutionalization of the participatory mindset.

Institutionalization of participation within the health sector landscape requires giving people a good reason to keep participating on a regular basis over time. It involves constant exposure to participatory activities, and the relation-building which is necessary to support meaningful interaction. Putting all stakeholders at ease and familiar with the notion of interacting with each other requires not only the participatory platform itself but one which sufficiently galvanizes people to come and give their input repeatedly over time.

7.2 Objectives of the chapter

This chapter aims to provide readers with an overview of actions which a policy-maker can undertake, issues they can attempt to influence, and/or simply keep in mind which positively contribute to participatory spaces remaining functional and sustainable in the long run.

It will become increasingly clear that many of the actions recommended overlap with best practice examples or guidance already cited in this handbook for general participation-related objectives such as ensuring good representativeness, strengthening capacity, and increasing policy uptake. Here, however, we focus on how those actions as described in chapters 3-6 also contribute to the goal of a long-term sustainable participatory space. The overlaps across the best practices highlighted in the various chapters of this book illustrate the synergies that many of these actions can achieve as they bolster different features of a robust participatory space simultaneously. As explained in chapter 2, well-functioning participatory spaces can invigorate the surrounding participatory environment and culture and render it more enabling. The virtuous cycle stimulated and supported by targeted measures to maintain capacity and enthusiasm to participate should therefore not be underestimated.

In the next section, a brief conceptual clarification will be given on what is meant in this chapter by 'sustaining participatory engagement over time'. Some key issues to consider will then be laid out, followed by an explanation of factors for policy-maker reflection which increase sustainability in participation. The latter explanation is divided into a section related to format and design factors of the participatory space and a section on the necessary capacities needed by stakeholders to engage adequately in a participatory space.

7.3 Sustaining participation over time: conceptual clarification

The participatory spaces which have been in operation for longer periods of time all meet roadblocks in keeping participants motivated to continue giving their volunteer, mostly unpaid, and at times unrecognized, effort. Unlike the policy-makers and experts who often engage in participatory spaces as part of their core areas of work, and are thus remunerated, appreciated, and even lauded for their effort, volunteer-participants have opportunity costs, sometimes enormous, for partaking in participatory processes (1-3). Hence, addressing many of the underlying reasons for those large opportunity costs, or providing motivating reasons for people to accept them, can help sustain participatory spaces. In addition, building and maintaining capacities of government cadres is crucial to fostering a public sector mindset which sees participation as unambiguously necessary rather than an added extra.

Political will is an overarching theme which clearly affects the sustainability of participatory spaces. This is not specifically addressed here; however, when all of the factors mentioned in this chapter come together to nurture a culture of participation and its institutionalization, participatory spaces can become more independent from political will (4). In a sense, this is the ultimate form of sustainability as participation becomes linked to institutions rather than people and politics.

7.4 Factors which contribute to increasing sustainability of participatory engagement: key issues to reflect on

Virtuous cycle: a culture of participation fosters sustainability of participatory spaces and vice versa

A culture of participation includes a package of legislation affirming the right to health and participation (see Chapter 6) as well as the institutions to accompany the legal framework to build capacities (see Chapter 4), ensure adequate representation (see Chapter 3), and enable regular, broad-based government—people-civil society dialogue. It also implies that the population feels a sense of duty to provide input, express oneself, and participate with a feedback loop (see Chapter 5) demonstrating that participatory processes are not conducted in vain, and are taken seriously. These different elements of a culture of participation interact with each other synergistically to strengthen its foundation, making participatory spaces resilient to shocks and sustainable in the long term.

As reiterated throughout this book, repeated exposure to participatory processes which foster dialogue with people and groups who are different from oneself is the best way to build a culture of participation. For policy-makers, this means that even a minimum of effort to maintain dialogue and interaction with the population, communities, and civil society can go a long way in the capacity-building process for all sides, including for policy-makers themselves.

Exposure of different stakeholders to each other, and to the varied perspectives on the same topic, can break down barriers of communication and build respect for each other despite differing views – a basis which smoothens the path towards policy solutions. This is at the heart of a 'culture of participation', i.e. seeking policy solutions through dialogue and institutionalized exchange. Once it becomes part of a health sector's DNA, sustaining participatory spaces in the longer term need not require an extra effort as it happens more organically.

A culture of participation relies on trust and respectful relationships. As a Mexican civil society representative reflects on interaction with policy-makers: *"[T]hey saw us arrive with our analysis and saw that... there was feedback, a relationship of professional trust was established, which you have to earn"* (5). A Mexican government representative shared the view, explaining why the collaboration with civil society was fruitful: *"There was already a relationship. [Civil society] has been part of the inter-agency group on reproductive health for many years. I already knew [them] and there was already a cordial relationship"* (6). Such relationships can sustain participatory spaces even when enthusiasm abates or politics shifts priorities away from participation.

Patiently sowing the seeds for a long-term and sustainable participatory culture, one where stakeholders from all sides feel that they co-own participatory spaces (1), goes hand in hand with formalizing them, as explained in the next section.

Formalization and institutionalization of participatory spaces can contribute to long-term sustainability

Ultimately, maintaining participatory engagement in the long term means moving towards institutionalization of the participation mindset into the modus operandi of a country's health institutions. The repercussions of formalization and institutionalization can be significant in terms of the mandate given to stakeholders to participate and conduct participatory processes, the funding available for participatory spaces and civil society, and the value it is given in policy circles.

Formalization does not necessarily require a legal mandate although it is eventually more advantageous to have one than to not have one (see Chapter 6). What formalization implies in the context of this handbook is that policy-makers have a work plan and budget for participatory processes at the very least, and are thus also evaluated against it. A step further would be to institutionalize the participatory process through policies and directives. By rendering participation mandatory, stakeholders' exposure to each other is also inherently mandatory, increasing the frequency of face time which fosters a sustainable culture of participation.

An example can be found in the decentralization legislation of many countries which has opened up formal mechanisms for community participation in health – in some settings, they did not exist before decentralization happened; in other places, decentralization served to formalize pre-existing dialogue initiatives (see Chapter 6). In Canada, for example, "regionalization" facilitated the latter, by giving local authorities, who were closer to communities and local civil society, a more formal mandate to strengthen partnerships to the benefit of people's health in the region (7). In Guatemalan mountain communities, the decentralization law's Community Council mechanism legitimized existing participatory spaces at local level, giving them more access to funding and capacity training (8).

Policy or legal initiatives to formalize, legalize, and/or institutionalize participatory engagement offer opportunities to plant strong roots for an inclusive way of working in health. It offers continuity in engagement, predictability of participatory space operations, and most importantly, safeguards its future from potential political interference. As a Steering Committee member of the Societal Dialogue for Health in Tunisia aptly put it: *"[A]n institution for societal dialogue must be maintained, it must remain in continuity, [therefore] it must become one of the institutions of the State, it must not be eliminated"* (9). While there may be caveats for institutionalizing too hastily (see Chapter 6), it should be reflected on thoroughly with regards to sustaining participation as a modus operandi into the future.

Long-term, stable funding for participatory spaces and for civil society

Ensuring that participatory spaces are sustained over time involves stable and predictable funding for those spaces. Studies point to the features of *stability* and *predictability* rather than to high amounts of funding as pivotal to sustainability. Indeed, Jacobs et al.'s comparative study of local participatory structures versus international NGO-financed ones in Cambodia found that the former had higher participation levels compared to the latter (10). Local structures usually only had small levels of funding from local sources but they were more predictable than monies coming from foreign sources.

Mexican civil society stakeholders also alluded to stability in funding as a key factor enabling long-term operational planning and sustainability in participation (5), as did civil society members of the National Health Council (NHC) in Portugal (11). The costs for NHC civil society participation were not reimbursed by a dedicated budget which meant that a heavy reliance on volunteers was necessary, threatening the ability to continue participatory activities. Here also, civil society reflections were largely centred around cost off-setting and not necessarily on high levels of operational funding.

Of course, a lack of sufficient levels of funding can negatively affect capacity and the ability to engage with stakeholders. The issue of civil society capacity is a key factor interrelated with sustainable participatory engagement, and is elaborated upon further in section 6.

Funding shortfalls carries with it the risk of overreliance on volunteer individuals rather than on the institution of civil society (12). Civil society stakeholders in Burkina Faso stressed the need for stable, and not project-based, funding for CSOs to do basic tasks such as coordinate, dialogue with each other, and create networks (13) – very much akin to civil society institution-building.

It is important to note that stable funding for government's own tasks of maintaining and managing participatory spaces is needed as well – the lack of a fixed budget line can render the participatory space more susceptible to individual civil servant and political will (see Chapter 6). The very notion of sustainability in participatory spaces rests on its long-term staying power, regardless of individuals or politics.

7.5 Format and design elements which support sustainability of participatory engagement

Follow-up mechanisms help maintain the motivation to participate

An unsurprising yet key finding from the handbook analysis is that seeing the fruits of the effort made to participate is a powerful motivator for people to continue participating. In Mexico, the budget advocacy efforts by the civil society coalition recorded small successes (such as state governments' timely publication of the quarterly expenditure report) which kept motivation high for civil society to push further to ultimately achieve larger wins (12). In Portugal, Health Council civil society members repeatedly held up the Council's legal mandate and its official advisory role to the Health Ministry as an encouraging factor for participation (11). The link to decision-making spheres (in other words, an explicit link between 'data' and 'decision' from the chapter 5, figure 1) and the opportunity to directly influence them obviously helped attract volunteers.

On the flip side, disappointment was expressed by not only civil society but also private sector participants of the Thai National Health Assembly (NHA) that many resolutions were not always sufficiently followed up on by government cadres, leading to waning enthusiasm for participation amongst some population groups (4). Indeed, stakeholders in Tunisia echoed this sentiment as well after the first few years of the Societal Dialogue for Health. One civil society participant underlined that *"[p]eople [are getting] tired... because there is no political will"* (14). He regretted further that the Societal Dialogue for Health proposals *"could not have [the attention of] the ministry. I was a member in several workshops and in reality we got tired"* (14).

A solution to this is offered by the Thailand example where a Committee for Resolution Follow-up was created in response to complaints that the fruits of people's tremendous NHA inputs needed to lead to visible results (4). This Committee includes civil society, and specifically scrutinizes all NHA resolutions which have not had policy follow-up, analyses why not, and takes action at the necessary political level to find a solution. This might mean working with targeted civil society organizations and regional health authorities to ensure unblocking of funds to move implementation forward. It has also meant contacting Minister-level cadres to begin a dialogue on the resolution topic.

Having visible results for a participatory process implies that stakeholders are clear in the first place with regards to what the expected results should be. As explained in earlier chapters, policy-maker-organizers of participatory spaces often do not sufficiently outline the objectives nor expected results of a participatory process. Not doing so can distort people's expectations, cause disappointment, and lower the motivation to participate.

Once the objective and expected results are understood broadly by all stakeholders, the Thai example suggests that a formal mechanism for follow-up may be necessary in some cases. Including civil society in that follow-up venture, similar to the NHA Resolution Follow-up Committee, gives civil society the same perspective as government (and others) of the challenges of implementation and demonstrating results, while in the full knowledge that the efforts are being (jointly) taken.

Another lesson one can draw from the Thai example is that the solution may not always involve an official health policy. Implementation on the ground can be undertaken in many ways; sometimes, it simply involves speeding up administrative procedures to ensure that funds are available and partnering with civil society to launch concrete action where needed.

Locally respected and trusted community representatives are crucial resources to integrate into a participant selection strategy

Examples from the handbook case studies and the literature demonstrate that community and civil society leaders have a significant role to play in increasing and maintaining population, community, and civil society participation levels. In Calgary Health Region (CHR), Canada, the Salvation Army was a trusted civil society leader on women's health issues (see Box 7.3)); the collaboration between the CHR and the Salvation Army was pivotal in maintaining women's voice in local health policy when regionalization threatened to go in a different direction (7). In the Islamic Republic of Iran, dialogue with community leaders helped maintain participation levels in Community-Based Health Programmes (15). In Cambodia, monks as faith-based community leaders were used as a vehicle for community participation by development agencies due to the trust and respect they enjoyed. In fact, the interviews conducted with Cambodian women in Jacobs et al.'s study demonstrated that they were more willing to disclose a health or personal problem with a faith-based community leader than with a community representative who was elected into the newly formed district

health committee system (10). Finally, in the Guatemalan example mentioned earlier, the mountain community's Council members were clearly trusted and respected leaders who were sensitive to community needs and perceptions which positively influenced the success of a local water management programme (8).

A caveat with local leadership is that they, indeed, must be sensitive to community needs, especially of those whose voices are less heard. The risk of reinforcing long-standing power relationships and gender biases is real when collaborating with local leaders, as highlighted by a study from rural Ghana's Community-Based Health Planning and Services (CHPS) programme. Baatiema et al. found that community participation was well-sustained by using pre-existing community structures as it facilitated the use of local resources and alignment with community interests (16). However, local structures also reinforced a male-dominated community leadership committee and a vertical management style which continued to leave women and young people behind. As highlighted in chapter 2, power imbalances exist at the micro levels of society as well, and these need to be accounted for while keeping the vision to sustain participatory spaces in the long term.

A lesson for country governments is to analyse, understand, and get sensitized to broader power structures, including local dynamics, while engaging with communities (see Chapter 2). In addition, as emphasized in chapter 3, combining different participatory techniques to engage differently with different community sub-groups might allow for frank feedback from all groups. For example, in addition to working with community leaders on programmatic issues, it might be useful to do specific focus group sessions with groups

whose voices are heard less, such as women in the Ghana example. This approach bore fruit in Tunisia during the phase 1 of their Societal Dialogue for Health programme which involved mixing various population and community engagement methods, including open-mike sessions, focus groups, and citizen jury consultations. The focus groups targeted those who were not participating actively otherwise, such as single mothers, handicapped people, etc. This enabled a wide range of views to feed into the societal dialogue to re-orient the health sector after the Arab Spring revolution [17].

Clearly, not all local leaders are the same; governments interested in sustaining community participation must find a way to seek out leaders with requisite (local) expertise and knowledge. The leaders in the positive examples mentioned above have demonstrated long-term commitment to the community, which has earned them trust and respect. Their own intrinsic motivation lent them a drive and an organic sense of ownership for initiating, managing, and monitoring projects to the long-term benefit of the community.

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Box 7.1

Cambodia: using established community structures to maintain community engagement over time

Introduction

Based on reviews of earlier community participation experiences, the Cambodian government's National Health Policy in 2002 embedded a social participation mechanism into health centre management. A Health Centre Management Committee (HCMC) and a Village Health Support Group (VHSG) were created in the 2002 Policy, the former being community-led support to health centre operations and the latter being a liaison between the community and the health centre.

Both Ui et al. (18) and Jacobs et al. (10) examined how NGOs can facilitate and strengthen community participation in Cambodia. Ui. et al. focused on local, Cambodian-based and Cambodian-run NGOs (with no international links); Jacobs et al. compared two aid-supported programmes – one which created new community structures and one which sought out existing structures to strengthen.

Using existing community structures has advantages

External aid-dependent community structures have been criticized as difficult to sustain when funding ends. In addition, stakeholder motivation may be linked to extrinsic financial factors rather than being primarily based on a real commitment to the community. Ui et al. found that locally-based, -funded, and -run NGOs displayed a clear long-term commitment without large financial inputs. In fact, they argue that not being aid-dependent meant that they were more pro-active in pursuing their objectives, without an attitude of dependency towards government or external funding.

In many Cambodian districts, the HCMC and VHSGs existed only nominally. Collaboration with local NGOs were found to make these structures more functional as the local NGOs nurtured a community base over the

long term, liaised and communicated with the community, and assisted in health centre management. These three functions are very similar to what the HCMC and VHSG are supposed to do but, as Jacobs et al. corroborate, using existing local community structures is more effective than creating new ones. By linking existing structures to the newly created HCMC and VHSG in this case allowed the latter to be more immediately functional.

Jacobs et al. also emphasize that the selection of the right leaders, i.e those who are locally respected and trusted, contributed to sustained participation; these findings are supported by other studies from diverse country contexts [19-23]. In Jacob et al.'s Cambodian comparative study, local NGOs were immediately able to identify and connect with the right leaders due to their intimate local knowledge and longstanding connections.

Implications for policy-makers

These two in-depth insights into community participation initiatives in Cambodia offer several lessons for national governments to ensure long-term community participation over time. The most obvious one is to be aware that, when engaging with communities for policy-making, existing, trusted community structures may be more functional and reliable in terms of community needs. If policy-makers are working on civil society and community capacity-building, seeking out existing structures and evaluating their functionality is therefore key.

When local NGO and community structures orient authorities towards real community health needs, an enabling environment for participation is nurtured [18]. Study authors conclude that "the importance of a long-term community-based and comprehensive approach... leads to increased participation with sustainable motivation of stakeholders" [18]. In contexts of external funding for NGOs, national governments would be well placed to encourage small seed funding for community participation work over longer periods of time to discourage attitudes of dependency and allow sufficient time and effort to build social capital in communities.

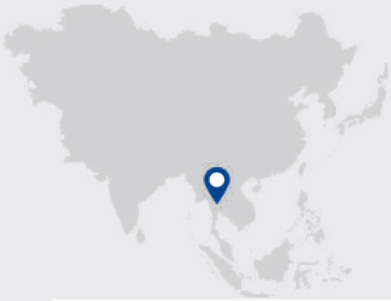
7.6 Capacities & their influence on maintaining the motivation to participate

High capacity of community groups and civil society, as well as government, contributes to a long-term outlook for participatory spaces

As laid out in chapter 4, high-capacity groups or organizations such as the Community Council members in the mountain communities of Guatemala or the Salvation Army in Alberta, Canada are able to better engage with decision-makers and policy processes. Their capacity is linked to knowledge and experience with a community or certain issues, a legitimacy they enjoy in the eyes of the public, the ability to access funding, etc. A robust civil society has an interest in ensuring that participatory spaces continue to exist and are adequately maintained and funded over time.

Strong government capacities in the area of participatory governance is also key to anchoring participatory thinking into the health sector modus operandi. Government cadres who do not understand the need for participatory spaces nor feel confident to undertake participatory action are obviously more likely to let go of tasks related to participatory engagement. In chapter 4, the different capacity dimensions are explained in depth, beginning with the *recognition* that participation is necessary and can give added value to policy processes; *technical skills* to be able to manage the complexity of a participatory process; and *communication skills* to enable fruitful collaboration with the population, communities, and civil society. These capacities mutually reinforce each other, and investing in them can firm the foundations for a strong participatory mentality in the health sector.

Government support for capacity-building initiatives have shown to be a motivating factor for volunteers to continue giving their time. For example, non-financial incentives such as training programmes and upskilling courses proved effective in Iranian Community-Based Health Programmes (CBHP) in attracting and maintaining volunteers' participation (15). Community health workers in India were also given extensive training and capacity-building as part of their incentive package in order to attract volunteers (24). An example of Thailand's long-term civil society capacity-building strategy through sustainable funding is given in box 2, and can be used as an inspiration for other countries.



Box 7.2

Investing in civil society capacities: an example from **Thailand**

Thailand supports capacity-building activities for civil society in the health sector through many means, including through the Thai Health Promotion Foundation and the National Health Commission Office.

The Thai Health Promotion Foundation ('ThaiHealth') receives its revenue from a two percent' surcharge of excise taxes on tobacco and alcohol [25]. The fund is an autonomous government body, so somewhat less susceptible to government changes and politics. It supports health promotion activities with explicit funding to civil society to build its capacity for health sector advocacy, evidence generation, and building and maintaining ties to communities and affected parties.

The National Health Commission Office (NHCO) in Thailand conducts the National Health Assembly each year, a three-day event geared at discussing prominent health issues with different population groups and civil society for purposes of health policy development. The NHCO spends much of its staff time and resources in building capacity of those very population groups and civil society organizations to engage more effectively with the Health Assembly process. The NHCO's efforts have greatly contributed to increasing civil society ability to liaise with the grassroots and better understand and represent communities, thereby increasing their legitimacy in the eyes of both the communities themselves as well as government bodies [4].

The funding provided by ThaiHealth as well as the capacity-building efforts of NHCO have aided civil society organizations to invest in evidence generation and partnerships with research institutions, thereby allowing them to negotiate and advocate with government partners with feasible and evidence-informed policy options [26]. It has fostered a strong civil society base who support and keep up demand for participatory spaces to be maintained and given priority.

Capitalizing on intrinsic motivation to participate

Intrinsic motivation of communities and the population to contribute to their country's development can be leveraged more effectively by governments to ensure sustained participation over time. In a review of 13 community-based health programmes in the Islamic Republic of Iran, altruism came out as a key motivating factor drawing in volunteers (15). In a recent Pacific Island study examining community participation in a malaria elimination programme, community cohesion and high levels of social capital led to sustaining good levels of participation (27). In a Cambodian study, the existing pagoda structure was used to strengthen community participation in health because of the monks' non-materialist, selfless community commitment (18). These examples demonstrate how powerful intrinsic motivation can potentially be, giving policy-makers a good reason to capitalize on it.

How best can that be done? In the Islamic Republic of Iran, making volunteers feel appreciated, either simply verbally or through non-financial means (training and refresher courses, upskilling), came out of stakeholder interviews as a factor which reinforced intrinsic motivation (28). In Cambodia, seeking out intrinsically motivated community members and leaders led to increased community participation and higher health centre utilization rates in relation to the district in comparison (10). Other studies have demonstrated that witnessing tangible and timely follow-up to one's input (see Section 7.5) keeps intrinsic motivation levels high (29, 30).

An illustration from Guatemala's mountain community underlines that intrinsic motivation cannot be taken for granted, and must be cultivated and supported in younger generations (8). Interviews with Community Council members evinced a lucid and unambiguous intrinsic motivation by the members who had been participating for over 30 years. Study authors even observe that "the cohesion and integration that exist in this community... is a product of the villagers' capacity to feel connected with each other through their similarities in work, values, family bonds and religious beliefs" (8). Yet they equally acknowledge that the younger generation is not necessarily motivated in the same way; kindling such intrinsic motivation may rely on support through other government actions as laid out in this chapter.

Strong partnerships can help sustain participatory engagement in the longer term

Networks, partnerships and alliances amongst civil society organizations, or between community groups and CSOs, or government and CSOs, can contribute to a robust foundation for sustainable participation. Again, alliances and partnerships contribute to building the institution, and culture, of civil society which can outlast individual effort.

For example, Mexico's multi-faceted civil society coalition provided the persistence needed over several years to achieve the impressive gains made in budget advocacy efforts (12). The fact that civil society worked

in partnership with each other was seen as a factor of longevity and success: *"The process was a very powerful one because it was revitalizing, creating something new. Alliances… have existed for many decades, what was new were the principles that formed the coalition, horizontality, not competing for financial resources, respecting the capacities and conditions of each organisation. Sometimes there were organisations that were going through more critical moments, so their participation was more sporadic and that was respected. But as it [is] a collective that has lasted several years"* (31). This quote also hints at the culture of participation and collaboration, as well as the development and strengthening of the institution of civil society.

Governments would thus do well in encouraging and incentivizing partnerships and alliance-building with the objective of long-term sustainability of a participatory space. An example of a government-CSO partnership is given in box 3.

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Box 7.3

A CSO-government partnership ensured that women's health remained a priority in Alberta, Canada

Increased population, community, and civil society voice in health planning was one of the reasons behind the push to decentralize the Canadian health system. One group who felt that their concerns were not sufficiently included in planning processes was women. Calgary has several women's health NGOs which worked to improve this, amplifying women's voice by listening to their issues and liaising with policy- and decision-makers. One such NGO is the Salvation Army (SA) who has long-standing, recognized expertise in women's health, along with a strong working relationship with the Calgary Health Region (CHR) (7).

Regionalization of health opened up a window of opportunity for local health authorities to focus on issues of importance in their populations. When hospital contracts were re-negotiated, the SA was able to demonstrate the need to keep women's health an integral part of the discussions. The CHR authorities' partnership with the SA gave health authorities deeper insight into an important area of health which they would not have had otherwise (32). The result is that, compared to other decentralized regions' health systems, women's health has remained more of a government priority in Calgary.

The SA's strength was the respect it enjoyed in local communities, stemming from its dedication to its core values of community action. It also had an administrative structure to back its longstanding knowledge and experience with the local health system to "advocate for its needs when discussing... governance under the legal agreement [with CHR]" (7).

The CHR benefitted from a strong, well-funded SA and local civil society landscape. In addition to the SA's "material and symbolic resources and personnel" which was drawn upon extensively for influence and action, a significant factor of success is also steady funding independent of the government through an affiliated fund-raising body. The latter allowed the SA to collaborate with the government while keeping its ideals intact in the interest of those they aimed to serve: women.

A study which specifically reviewed the CHR-SA partnership concluded that "the greatest success for women was maintenance of a political space in which women's health as a priority could be discussed in a context where the forces against gender equity talk are strong". The SA as a civil society organization championing women's issues thus helped keep this space open for other "women's organizations to challenge the status quo in health service delivery and to advocate for equity" (7).

A key lesson here from the government perspective is that long-term partnerships with civil society is clearly fundamental for positively influencing health. This needs to be nurtured and invested in as a strong civil society is mutually beneficial to both the interests of government and communities. Partnerships with respected and trusted organizations such as the SA can and should be sought out where useful, perhaps with a word of caution that they are truly respected and trusted by the communities they intend to serve.

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7.7 Conclusion

Sustaining the engagement of all stakeholders – policy-makers as well as the population, communities, and civil society – in health sector participatory activities over the long term is a key challenge for governments who are serious about anchoring participation as a real mind-set in health. This chapter offers valuable reflections and lessons for ensuring that motivation and engagement levels of stakeholders remain high.

First and foremost, people are highly motivated to continue taking part in participatory spaces when they see that it leads to achieving an objective. Seeing the fruits of one's efforts is a great incentive to continue that effort. Using local resources and leaders can help keep up trust and interest in a participatory space, while also more effectively moving towards a policy objective.

Secondly, formal and institutionalized mechanisms for participation can give both a funding and capacity boost to existing and new community groups and civil society. In many countries, this formalization has come via administrative decentralization processes, an opportunity which can be leveraged more for increasing participation levels and maintaining them over time. It can also come with a new budget accorded to creating and managing a participatory space, or by formal meetings claimed by civil society to discuss community health issues.

Independent community and civil society funding to help amplify people's voice and pursue community-focused objectives should be facilitated at the very least, with the caveat that it might need more regulation and governance capacity in government institutions. This last point is significant in that steady funding, if steered smartly, can create and maintain high-capacity organizations with close ties to communities which increases intrinsic motivation to participate and stay participating, despite the inevitable ups and downs of policy-making and politics.

Overall, the actions needed to support sustainability in participatory policy-making are ones which generally consolidate a high-quality participatory space. Hence the actions as mentioned in this chapter are deliberately reprised from previous handbook chapters; the point here is that by making headway on sustainability, policy-makers can also address other relevant issues such as an enabling environment (Chapter 2), representation (Chapter 3), capacity-building (Chapter 4), policy uptake (Chapter 5), and legal frameworks (Chapter 6).

References

1 Alves I. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work.

2 Petit D. Madagascar case study report: Étude de cas sur les mécanismes d'engagement de la communauté. Unpublished work. French.

3 Zongo S. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French.

4 Rajan D, Mathurapote N, Putthasri W, Posayanonda T, Pinprateep P, de Courcelles S, et al. The triangle that moves the mountain: nine years of Thailand's National Health Assembly (2008-2016). World Health Organization (WHO); 2017.

5 Mexico case study interviewee #1. Case study on civil society involvement in policy processes in Mexico. Unpublished work. Spanish.

6 Mexico case study interviewee #2. Case study on civil society involvement in policy processes in Mexico. Unpublished work. Spanish.

7 Thurston WE, Vollman AR, Meadows LM, Rutherford E. Public participation for women's health: strange bedfellows or partners in a cause? Health Care for Women International. 2005;26(5):398-421.

8 Ruano AL, Dahlblom K, Hurtig A-K, Sebastián MS. 'If no one else stands up, you have to': a story of community participation and water in rural Guatemala. Global Health Action. 2011;4(1):6412.

9 Tunisia case study interviewee #5. Tunisia case study report. Unpublished work. French.

10 Jacobs B, Price N. Community participation in externally funded health projects: lessons from Cambodia. Health Policy and Planning. 2003;18(4):399-410.

11 Portugal case study interviewee #1. The Portuguese Health Council Case Study - A mechanism for Civil Society Organizations' engagement in national health planning and policy-making in Portugal. Unpublished work. Portuguese.

12 Colectivo Meta (COMETA). Case study on civil society involvement in policy processes in Mexico. Unpublished work.

13 Burkina Faso case study interviewee #18. Burkina Faso case study report: L'engagement de la société civile dans le processus d'élaboration et de mise en œuvre de la stratégie nationale de financement de la santé en faveur de la Couverture Sanitaire Universelle au Burkina Faso. Unpublished work. French.

14 Tunisia case study interviewee #11. Tunisia case study report. Unpublished work. French.

15 Eftekhari MB, Mirabzadeh A, Forouzan AS, Dejman M, Afzali HM, Djalalinia S, et al. A qualitative study of community-based health programs in Iran: an experience of participation in IR Iran. International Journal of Preventive Medicine. 2014;5(6):679.

16 Baatiema L, Skovdal M, Rifkin S, Campbell C. Assessing participation in a community-based health planning and services programme in Ghana. BMC Health Services Research. 2013;13(1):233.

17 Rohrer K, Rajan D. Chapter 2: Population consultation on needs and expectations. In: Schmets G, Rajan D, Kadandale S, editors. Strategizing national health in the 21st century: a handbook. Geneva: World Health Organization (WHO); 2016.

18 Ui S, Heng L, Yatsuya H, Kawaguichi L, Akashi H, Aoyana A. Strengthening community participation at health centers in rural Cambodia: role of local non-governmental organizations (NGOs). Critical Public Health. 2010;20(1):97-115.

19 Walt G, Perera M, Heggenhougen K. Are large-scale volunteer community health worker programmes feasible? The case of Sri Lanka. Social Science & Medicine. 1989;29(5):599-608.

20 Woelk GB. Cultural and structural influences in the creation of and participation in community health programmes. Social Science & Medicine. 1992;35(4):419-24.

21 Marchione TJ. Evaluating primary health care and nutrition programs in the context of national development. Social Science & Medicine. 1984;19(3):225-35.

22 Phillips DR. Primary health care in the Philippines: banking on the barangays? Social Science & Medicine. 1986;23(10):1105-17.

23 Berman PA, Gwatkin DR, Burger SE. Community-based health workers: head start or false start towards health for all? Social Science & Medicine. 1987;25(5):443-59.

24 National Health Mission. Update on ASHA programme. National Health Systems Resource Centre (NHSRC); 2019.

25 Pongutta S, Suphanchaimat R, Patcharanarumol W, Tangcharoensathien V. Lessons from the Thai Health Promotion Foundation. Bulletin of the World Health Organization. 2019;97(3):213.

26 Rajan D, Mathurapote N, Weerasak P, Posayanonda T, Pinprateep P, de Courcelles S, et al. Institutionalising participatory health governance: lessons from nine years of the National Health Assembly model in Thailand. BMJ Global Health. 2019.

27 Watanabe N, Kaneko A, Yamar S, Taleo G, Tanihata T, Lum JK, et al. A prescription for sustaining community engagement in malaria elimination on Aneityum Island, Vanuatu: an application of Health Empowerment Theory. Malaria Journal. 2015;14(1):1-11.

28 Rajan D, Hadi Ayazi M, Moradi-Lakeh M, Rosami-Gooran N, Rahbari M, Damari B, et al. Chapter 4: Public voice and participatory governance in the health sector: status quo and way forward. In: Hsu J, Majdzadeh R, Harirchi I, Soucat A, editors. Health System Transformation in the Islamic Republic of Iran: an assessment of key health financing and governance issues. Geneva: World Health Organization (WHO); 2020.

29 Manderson L, Mark T. Empowering women: participatory approaches in women's health and development projects. Health Care for Women International. 1997;18(1):17-30.

30 Ofuoku A. Effect of community participation on sustainability of rural water projects in Delta Central agricultural zone of Delta State, Nigeria. Journal of Agricultural Extension and Rural Development. 2011;3(7):130-6.

31 Mexico case study interviewee #3. Case study on civil society involvement in policy processes in Mexico. Unpublished work. Spanish.

32 Pedalini LM, Dallari SG, Barber-Madden R. Public health advocacy on behalf of women in Sao Paulo: Learning to participate in the planning process. Journal of Public Health Policy. 1993;14(2):183-97.

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