

Social Participation for Universal Health Coverage

Technical Background Paper

DRAFT FOR CONSULTATION



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This Technical Background Paper on social participation synthesizes key messages from the World Health Organization publication ‘Voice, agency, empowerment – handbook on social participation for universal health coverage’¹ (‘Handbook’). It has been developed as the basis for consultation to identify priorities for Member States to institutionalise social participation in health decision-making processes. This draft will be updated to reflect feedback from consultations later in the year.

Key messages

As attested through declarations and resolutions at global, regional and national levels, Member States agree on the importance and relevance of the principle of social participation in health governance. However, the principle of social participation is not sufficiently implemented in practice. This background paper identifies priorities for Member States to institutionalize social participation in health decision-making processes:

- (a) Investing adequate, stable and predictable **financial resources** for participation
- (b) Building government **capacities** to design and implement meaningful participation and facilitating the capacity strengthening of participants
- (c) Establishing and/or strengthening mechanisms for **sustained regular** participation
- (d) **Monitoring and using data** routinely to evaluate participatory processes and their impact on decisions made.

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1. Introduction

This technical background paper is the basis for stakeholder consultations to identify priorities for Member States to institutionalize social participation in health decision-making processes.

The World Health Organization Handbook² provides the technical basis for this background paper. The Handbook was developed through extensive consultations with technical and civil society stakeholders as well as case studies from nine countries differing in geographies, income groups and types of government. The purpose of the Handbook is to provide technical support and practical guidance to WHO member states on steering engagement with the population, communities and civil society organizations to ensure their voices and needs inform decision-making in health. This technical background paper distils key messages from the Handbook to advocate for sustained prioritization and commitment to implementing social participation.

Whilst many countries are making important efforts to involve and listen to their populations in health decision-making processes, all countries can do better towards institutionalizing and using such participation to consistently inform the decisions that are made across the health sector.

2. Relevant terms and concepts

What is meant by “social participation”?

The concept of participation has developed and evolved differently across regions and settings, as is reflected in the divergent terminology used. “Social participation” is used in this background paper to mean empowering people, communities and civil society organizations to have voice through participation in decision-making processes that have an impact on health and influencing the decisions that are made.³

Box 1: Who should participate for social participation?⁴

People, communities and civil society organizations entail three different types of ‘publics’:

- (a) The ‘unaffected’ public: assumed to be unfamiliar with the issues, i.e. lay citizen, ordinary people;
- (b) The ‘affected’ public: with relevant personal experience, e.g. of illness, i.e. service user, patient, consumer;
- (c) The ‘partisan’ public: with a special partisan interest, technical expertise, or professional identity, i.e. civil society organizations, professional associations, advocates.

Community groups fall between the unaffected and affected publics, and patient associations fall between the affected and partisan publics.

What is meant by a ‘participatory mechanism’?

A participatory mechanism is where government comes together with its population and communities, either directly or through civil society organizations as intermediaries. A key characteristic of a participatory mechanism is that the interaction should allow for a back-and-forth between participants and/or between organizers and participants, and not only be one-way. Methods used for purely communicating information to, or solely receiving feedback from a population group, (such as surveys, polls, interviews, radio, and TV programs etc.), are also important but these are distinct from and complementary to two-way dialogue.

In general, multiple and different types of participatory mechanisms can, and should, be used by governments to inform decision-making processes, especially given that there is no single best participatory mechanism (see Boxes 2 and 3) and no one size fits all. Depending on the context, objective, participant profiles and country realities, a mix of mechanisms usually serves to balance out the cons of any single mechanism, allows for greater triangulation of findings, and increases the scope for populations to influence the decisions that are made. Thus, most country experiences of institutionalized social participation draw on a variety of the participatory mechanisms for meaningful engagement with their population. The table below summarizes the most common categories of mechanisms for social participation:

Table 1: Categories of social participation mechanisms

Category	Explanation	Examples
Open for all forums	Open to everyone. Larger groups, aiming to capture the diverse and divergent views from many different segments of the population.	Public forums and hearings, open-mic events, townhall meetings.
Consultative methods with attendance by invitation	Open forum for exchange, albeit with a smaller and closed, usually invited, numbers of representatives of population groups and technical experts (and others).	Consultative meetings, policy dialogue, stakeholder consultations, focus groups.
Deliberative engagement methods	Small group of selected participants. Emphasis is on deliberative nature to elicit informed opinions from lay people and others about a specific health topic. Key characteristics include preparing participants with data & information, allowing sufficient time to reflect and deliberate, ensuring a non-intimidating environment.	Public panels, citizens' juries, consensus conferences, planning cells, scenario workshops.
Fixed seats for the population/ communities/ civil society in administrative bodies	A fixed (at least for a certain time period) group of people coming together to make recommendations and/ or decisions. Certain seats are reserved for the lay population, community-based organizations, and/or civil society representatives. The mechanism may be anchored in a legal framework.	Health council, health committee, district committees, civil society advisory boards, representation on steering groups and review boards.

Box 2: Societal dialogue for health in Tunisia

The Societal Dialogue for Health (SDH) program in Tunisia created multiple participatory spaces for exchange between 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 was 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 upon 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 and groups who were not participating in other participatory mechanisms. Marginalized and vulnerable groups were targeted in these small group, homogenously constituted sessions.

Citizens' 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 others came together here to validate policies and decisions.

Box 3: Etats généraux de la bioéthique in France

The Consultative National Committee on Bioethics (CCNE) has the mandate to lead the drafting of a Bioethics law every seven years. In 2018, the CCNE used a variety of participatory mechanisms to obtain broad-based input on topics of bioethical relevance. Based on submitted statements of interest on the EGS' priority topics, the CCNE selected organizations, associations and interest groups for more in-depth hearings. A combination of participatory mechanisms was used to reach out different types of target populations:

Regional discussion events open to the general public – A self-selection strategy was used to hear the voice of interested and affected people. The open-for-all events served to convey the openness of the CCNE approach.

Online consultation via website – This mechanism enabled inputs from those who may not be able to attend the events in person. The online platform was used to disseminate in-depth information to and gather inputs from a broader audience.

Hearings for the partisan public – Organizations, associations and interest groups that had submitted statements of interest were selected by the CCNE, based on special interest or expert knowledge, for in-depth hearings.

Citizens' jury – Citizens were selected by an independent third-party to be part of a jury, and were asked to feed back on the process and deliberate on the key topics enabling a more targeted and deeper engagement.

3. Rationale for prioritization and investment

The reasons to prioritize and strengthen social participation are many: it is not just morally the right thing to do in pursuit of realizing the right to health for all, democracy, transparency and accountability; but it can also inform more responsive, equitable and effective health policy choices and help to achieve better health outcomes.

Social participation is core to primary health care (PHC) and necessary for progressive realization of universal health coverage (UHC)

Social participation is a core component of Primary Health Care (PHC), as a means to empower people and communities.⁵ PHC is a priority health system reform agenda for accelerating progress towards universal health coverage (UHC) - a noble goal that all countries have committed to as part of the sustainable development agenda.

Progressive realization of the goal of UHC requires health systems reforms and policy choices that can be politically challenging and relate to who benefits and who is left behind. In the post-pandemic context of exacerbated societal inequalities and diminished trust in government and public services, more inclusive and participatory governance can help to overcome this disconnect.

UHC is about ensuring necessary health services to all people without incurring financial hardship⁶ – what may be deemed ‘necessary’ cannot be de-linked from people’s perceptions and lived experiences, as well as civil society’s contextual expertise. Participatory processes can shape policies and plans to be more responsive and increase uptake. The universal goal of covering ‘all’ people requires overcoming health inequities, embedded in broader structural inequities. Certain population groups have worse health outcomes, warranting specific attention from the health system and adapted service delivery strategies. This starts with an in-depth understanding of why the health outcomes of these groups are poor and what structural and health barriers they face, which can only be ascertained through outreach and dialogue with those population groups. Social participation can be an important means to achieve a more inclusive health system and more equitable health policies that leave no one behind.

In the past, the UHC discourse centered on health system reforms with particular focus on health financing and service delivery models, without adequately considering the necessary health governance reforms needed to underpin them. It is now high time to acknowledge the need for strategic governance reforms – including institutionalizing social participation - which can accelerate progress towards the health system performance goal of UHC.

Social participation fosters trust and health system resilience

In preparing for future health emergencies and to build health system resilience, the need for a health system which people trust to be responsive to their needs cannot be overstated.⁷ Long-standing participatory mechanisms, embedded within health system operations, can help build that trust before a crisis occurs, so that in times of emergencies, governments can leverage these participatory mechanisms and thereby improve the effectiveness of risk communication and better contextualize response measures. Indeed, a coordinated whole-of-society response in times of emergencies was already envisaged in the International Health Regulations (2005) as well as the post-COVID 74th resolution of the World Health Assembly (2021).⁸

The Covid-19 pandemic exposed the weakness of emergency preparedness across countries, including high-income ones. In many contexts, where the health system struggled to respond, communities and civil society stepped in, demonstrating remarkable resilience by taking on tasks to protect against viral spread and reduce transmission, either substituting for or complementing health system operations.⁹ Unfortunately, communities' and civil society's Covid-19 response was mostly disconnected from the government response, with government losing out on valuable community insights for more adapted policies and adherence to pandemic restrictions.¹⁰ Insufficient government outreach and support to marginalized population groups during the pandemic exacerbated vulnerabilities and inequities, adding to the Covid-19 morbidity and mortality toll.^{11,12} Integrating community resilience into the health sector modus operandi through social participation mechanisms brings government actions closer to people's needs, strengthening foundations for preparedness for the next pandemic.

Social participation advances health system accountability

Institutionalized participatory mechanisms can also serve as mechanisms for shared ownership between governments and their population through collective, iterative processes of policy conception, review, and adaptation. Forums for dialogue and consultation provide opportunities for people to interrogate policy choices and monitor implementation. Participatory forums can provide space for people to air grievances and address poor performance, improving overall health governance and accountability. The importance of such social accountability measures is also echoed in the World Health Assembly resolution 69.1 that urges Member States to "show leadership and ownership in establishing effective health governance...through establishing and enhancing monitoring, evaluation and accountability mechanisms and capacities".¹³

The integrity and legitimacy of the participatory mechanisms must be maintained through appropriate mitigation of potential conflicts of interest to ensure that narrow interests do not override overall public health. The deliberate inclusion of marginalized voices within these mechanisms can help expand policy

reach while balancing competing interests. Transparent access to knowledge and information as well as continuous documentation and communication of the results of participatory processes further enables duty bearers to be held accountable for decisions made.

4. Moving from principles to concrete action

Member States have endorsed the principle of social participation in multiple intergovernmental commitments and resolutions, see Box 4. Yet, in practice, the necessary investments to translate the principle into action have been inadequate, with countries' experiences of social participation often ad hoc, and fragmented due to the siloed nature of many health systems. All countries can do more to improve how people, communities and civil society participate in health decision-making processes and the extent to which their participation affects the decisions that are made, depending on their political context, policy and planning cycles, and resources.

Box 4: Global commitments to participatory governance

The 2030 Agenda for Sustainable Development, adopted by all United Nations Member States in 2015, sets clear targets around 17 collective goals that represent a commitment to action by all countries. Within Goal 16 of the Sustainable Development Goals (SDGs) on peace, justice and strong institutions, target 16.7 aims specifically to “ensure responsive, inclusive, participatory and representative decision-making at all levels”.¹⁴

This theme is explicitly articulated in the UN High Level Political Declaration on Universal Health Coverage that recognized that “the inclusion of all relevant stakeholders is one of the core components of health system governance” (Paragraph 20).¹⁵ The Declaration goes on to elaborate that engagement of all relevant stakeholders should be “through the establishment of participatory and transparent multi-stakeholder platforms and ... partnerships, to provide input to the development, implementation and evaluation of health ... policies ..., while giving due regard to addressing and managing conflicts of interest ... and undue influence.”¹⁶

The UHC Political Declaration reiterated Member States' commitments in the Astana Declaration on primary healthcare in 2018 to “involve more stakeholders in the achievement of Health for All, leaving no one behind, while addressing and managing conflicts of interest, promoting transparency and implementing participatory governance.”¹⁷

Political will is decisive for effective participation, driving the prioritization and investment of human and financial resources, and this must be sustained over time to help foster a culture of participation.

This section highlights key interconnected priorities for Ministries of Health in order to move towards institutionalizing the principle of social participation.

(a) Investing adequate, stable and predictable financial resources for participation

As further sections will detail, moving towards the institutionalization of social participation requires strengthening the capacities of government cadres; facilitating the capacity building of participants; creating and sustaining participatory mechanisms; and monitoring and evaluating progress and outcomes – all of which require stable and predictable funding. Without stable funding, participatory mechanisms are likely to be more ad-hoc and peripheral to the health system modus operandi. Funding shortfalls can also lead to an over-reliance on volunteers or intermediaries whose interests may not always align with public health goals. These characteristics – of being stable and predictable – are perhaps more important than high levels of budget allocation to social participation.

There are various ways to protect and sustain funding for social participation - for instance, through legal endorsement or earmarked funding (see Box 5).

Box 5 Thailand: Regular government budget allocation for participatory activities in health

The National Health Commission Office (NHCO) is a publicly funded parastatal body, mandated to implement the National Health Assembly (NHA) each year. The NHA is a three-day event geared at discussing prominent policy-relevant health issues with different population groups and civil society. Anchored in a legal framework, the statutory nature of the NHCO ensures the stable allocation of funding. It maintains a degree of independence from government ministries, and manages its own resources.

The Thai Health Promotion Foundation ('ThaiHealth') is mandated to support health promotion activities with explicit funding to build the capacity of civil society for health sector advocacy, evidence generation, and building and maintaining ties to communities. ThaiHealth is an autonomous government body, whose revenue comes from a 2% surcharge of excise taxes on tobacco and alcohol, so somewhat less susceptible to government changes and politics.

It may also be important for Ministries of Health to fund the participation of communities and civil society, as well as resourcing and/or facilitating capacity strengthening for meaningful involvement. This may require leveraging legal provisions for civil society to receive funding, or advocating for these to exist in their absence.

(b) Building government capacities to design and implement meaningful participation and facilitating the capacity strengthening of participants

Meaningful participation requires adequate government capacity to convene, communicate and listen the voices of participants. This is acknowledged in a Pan-American Health Organization resolution from 2014 on expanding universal access to health, urging member states to “*strengthen the leadership capacity of health authorities... for social participation*”.¹⁸ While most government health institutions are well-endowed with medico-technical expertise, they may not acknowledge or prioritize the skills to manage a participatory mechanism - a task that is not as straightforward as it may seem. This capacity deficit has also been evident in the response to the Covid-19 pandemic when many governments struggled to bring civil society and community voices into the response, at times resulting in communities’ mistrust and misinformation.¹⁹

Policy-makers’ capacity needs involve knowing how to design and manage a participatory mechanism that allows for meaningful social participation, mitigates societal power differentials, manages conflicts of interest, respects and listens to experiential expertise, and facilitates dialogue that can inform a specific policy purpose. First and foremost, the role of power dynamics in participatory mechanisms must be acknowledged so that careful design can empower the voices of those who typically have less influence. This involves particular sensitivity to the barriers for historically marginalized or excluded groups. Building and strengthening capacities for social participation is a long-term process that requires deliberate and sustained efforts to overcome inequities and be more inclusive. Table 2 summarizes selected design considerations for meaningful participation, for which essential capacities must be built.

Table 2: Design objectives for which key capacities must be built

Design objective	Explanation	Actions
Recognizing and managing the power differentials in the health sector stakeholder landscape, including one’s own role within it,	Low socio-economic status based on structural and economic inequalities may result in low access to institutional structures for the most vulnerable population groups, including participatory processes.	<ul style="list-style-type: none"> • Embedding the recognition of barriers into the formulation of objectives. • Knowledge, understanding and analysis of vulnerable communities and population groups. • Addressing barriers to participation, including direct and indirect costs of attendance. • Being mindful of and managing potential conflicts of interest.

Ensuring transparency in regard to participant selection, objectives, roles and responsibilities, and governance of the participatory mechanism.	Transparency allows for a more level playing field across participants, and for organizers to be held accountable for their commitments.	<ul style="list-style-type: none"> • Providing clear information to all stakeholders, on the objectives of the process, tools and techniques used, and each participant’s role within it.
Using diverse dialogue techniques adapted to the different population groups.	Different techniques can complement each other and strategically amplify people’s voice in participatory mechanisms.	<ul style="list-style-type: none"> • Facilitating techniques which involve all participants in an equitable way (e.g. location, seating positions, homogeneous discussion groups to avoid social hierarchies, translation etc.). • Valuing experiential knowledge/expertise and relating this to technical expertise.

Even where there are active mechanisms for public engagement, these rarely translate into appropriate policy uptake. In part, this may be due to low political priority for the topic under discussion. The link between public participation and decision-making is not automatic and requires careful translation – for which a specific skill is needed across various levels of government cadres. Not only do these skills need to be built but they must also be maintained and nurtured, particularly in light of staff turnover and movement.

Governments hold a critical role in facilitating the capacity strengthening of populations, communities and civil society to know their rights, legitimately represent their constituencies, build coalitions, understand and interrogate relevant data and policy documents, and effectively interact with government on an equal footing. Communities and populations often need a stimulus to recognize how engaging in participatory mechanisms can be beneficial to their collective interest or improving their local health system. They need to be equipped with the technical skills to fully comprehend and analyze the details of the policy agenda, understand the policy process, and apply communication techniques for example, internet literacy or language skills, to raise awareness, for advocacy, monitoring and evaluation.

Governments have an important role in providing funding or facilitating capacity strengthening, but it is crucial that the capacity-building activities should be owned by the civil society organizations or communities themselves.

(c) Establishing and/or strengthening mechanisms for sustained regular participation as opposed to ad-hoc interaction

Participatory mechanisms and the capacities of its participants thrive on regular interaction and the opportunity to ‘practice’ meaningful debate and dialogue to improve health system performance. That very regularity, and continuous engagement across the policy and planning cycle, helps foster a culture of participation through a deeper understanding of how to engage and, more importantly, how to find joint solutions. Continuity is also pivotal for building relationships and networks between those who have a stake in health, despite differing views, forming an important foundation for mutual respect and understanding. These relationships, trust and respect take time to develop and go beyond individuals and short-term politics, requiring institutionalized structures and processes over the long-term with sustained funding and capacities.

Governments can move towards more regularized participatory engagement over time through a variety of strategic and synergistic actions. These include building long-term partnerships with civil society and community groups; securing legal and/or institutional frameworks to sustain social participation; providing protected time within decision-making processes for adequate engagement; and evaluating and learning from how the participatory mechanism went to inform the way forward.

Legislative frameworks that mandate a specific public entity to implement social participation mechanisms can be important for ensuring regular and sustained engagement over time. For example, the National Health Council in Portugal, and the Consultative National Committee on Bioethics in France are backed by legal provisions. Three key areas that need careful consideration in any legislative framework for participation are: representation and selection processes; roles and responsibilities in participatory mechanisms; and funding modalities. Ideally, all three aspects should be addressed concomitantly to ensure meaningful participation. Health ministries have a role in advocating for and shaping such legislation, which can provide some protection from waning political support.

(d) Monitoring and using data routinely

If social participation is integral to health system governance, then a robust monitoring and evaluation framework to measure progress is vital. Progress means not just the implementation of participatory mechanisms, but also an appraisal of how they are implemented, the quality of the dialogue itself, and crucially, their impact on the health decisions that are made and the priorities that are set. Both quick wins and longer-term impact should be pursued.

The World Health Organization, as part of its technical mandate, will identify specific indicators to evaluate participation in health decision-making processes, with consultation at global and regional levels. This work will focus on key aspects towards institutionalizing participation as outlined in this

paper, such as financial investment, capacities, and regular or continuous engagement. It will also be important to specify how any proposed indicators can be captured using existing data collection mechanisms to avoid exacerbating the burden on country systems. Data collection will likely require government collaboration with private and non-governmental sources. There should also be consideration of targets and/or milestones, to help mobilize investment and assess progress. The indicators, and progress towards any stipulated targets, can then be reported by Member States through a collectively agreed upon mechanism for review.

5. The role of WHO in advancing social participation

The WHO should champion social participation in health decision-making processes, delivering on its mandate to provide technical support to countries, such as capacity strengthening; document and share lessons/best practices; ensure cross-country and cross-regional learning and collaboration; develop a framework for the monitoring and evaluation of social participation; take stock of the situation in countries; and periodically report back to the World Health Assembly on progress made. This work should be done in close collaboration with civil society and community representatives, leveraging the networks of UHC2030.

6. References

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- ² Ibid.
- ³ As part of their stewardship role, it is of course important for governments to engage with other actors, such as the for-profit private sector and development partners, but these goes beyond the remit of social participation.
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