The value proposition for social participation

- Defining social participation – what it is and what it is not
- Ensuring policy uptake of results
- Addressing power imbalances with representation
- Strengthening government and civil society capacities
- Monitoring and evaluating processes and results
- Securing adequate and sustainable financing
- Embedding social participation in health systems
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This special issue seeks to clarify and explain what social participation is about and what it is not, why it should be prioritised, and how it can be advanced at country level. It brings in the voices of key constituencies and experts on the agenda, and is complementary to seminal WHO publications: *Voice, agency, empowerment — Handbook on social participation for universal health coverage* (2021), which provides normative guidance peppered with country experiences; and *Social participation for universal health coverage: technical paper* (2023), which synthesises key recommendations from the Handbook and multi-stakeholder and regional consultations to identify priorities for Member States in advancing social participation.

To begin, this special issue presents perspectives from key constituencies – the WHO Director-General, the Core Group of Member States who are pursuing a resolution on social participation at the 77th World Health Assembly, civil society, and the WHA President and Chair of the WHO Executive Board – on the pertinence of social participation for them now, and their priorities for its implementation.

These are followed by a spotlight on youth participation where the WHO Regional Director for Europe and the former WHO Executive Board Chair are interviewed.

The first two articles frame the agenda by first explaining what social participation is and what it is not, clarifying terms and concepts, and second why it is an important agenda and how it can improve health system responsiveness, advancing equitable progress towards universal health coverage (UHC), strengthening accountability, and fostering trust.

The subsequent seven articles seek to demonstrate how social participation can be implemented within countries, emphasising key considerations and reflecting on countries’ experiences. The first article focuses on the policy uptake of participatory results, exploring what can be done to harness population’s views and perspectives for better-informed decision-making. This is followed by an article focusing on how to ensure diverse, equitable and inclusive representation to mitigate power imbalances and foster expression of all voices, including those who are most in need. The next two articles look at key capacities that must be strengthened among both government cadres and civil society for meaningful engagement – namely technical, recognition and communication skills. Initial work on indicators for monitoring and evaluating social participation processes and their results follows – an area which is still underdeveloped globally but key for learning, improvement, and accountability. Next, the different ways countries finance social participation processes is discussed, with a reflection on how to secure adequate and predictable funding to facilitate social participation. The final article explores how social participation can progressively be institutionalised across the system as a modus operandi of governance for health, fostering a culture of participation.

For countries to strengthen and sustain social participation, progress is necessary across all of these aspects. They are mutually dependent and must be pursued in parallel to realise the full potential of social participation to advance our common goals of responsive, resilient, equitable, and accountable systems for UHC, health and well-being. It is an iterative learning-by-doing process that must be adapted to the context and the policy issue at stake. Achieving this ambition requires high-level political commitment and systematic implementation. We hope this special issue helps to bring all stakeholders onto the same page in understanding and mobilising efforts to advance social participation so that no one is left behind.

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Perspective from the WHO Director-General

Social participation is an important paradigm shift in global health.

In the face of multi-dimensional global challenges and widening inequalities between and within countries, the world is off-track to achieve our collective goal of health for all. Business as usual will not suffice. Social participation is an important paradigm shift in global health that offers great potential for meeting the health needs of people, in particular those who are in vulnerable or marginalised situations.

Social participation also helps promote transparency and accountability, and fosters trust – which is an especially important issue in these times of diminishing public trust in science and institutions. As the COVID-19 pandemic exposed, building and maintaining public trust is essential for an effective pandemic response and for health system resilience. Without trust, our health systems will simply fail, both when an emergency strikes and in normal times.

Social participation empowers people, communities, and civil society through inclusive participation in decision-making processes that affect health, across the policy cycle and at all levels of the system, so that policies, plans, programmes and services respond to their needs and preferences, especially for those in vulnerable or marginalised situations. This means valuing their lived experiences and, fundamentally, addressing power imbalances.

Social participation is not a new concept, but its potential has yet to be fully realised. While Member States have endorsed the principle of social participation in various global commitments, practice within countries often remains insufficient. More needs to be done to make social participation a meaningful reality in governance for health.

Empowering people and communities is a core component in a primary health care approach and should be a priority in health system reforms to accelerate progress towards universal health coverage and the health-related Sustainable Development Goals.

At WHO, we are committed to improving the participation of civil society and youth across our work at the global, regional and national levels. The newly convened WHO Civil Society Commission and Youth Council are examples of our efforts to foster greater social participation in global health policymaking and planning. WHO supports Member States in their efforts to strengthen social participation in the health sector.

We must prioritise the social contract between the government and the people so that we can realise the right to health for all. Only by working together, and listening to the voices of those we serve, can we make this happen.

Dr Tedros Adhanom Ghebreyesus

WHO Director-General

Perspective from ministers

People are key to addressing health challenges: How health ministers are leading the way with social participation in Brazil, France, Norway, Slovenia, Thailand, and Tunisia.

During the last High-Level Meeting on Universal Health Coverage (UHC), which took place in September 2023, Member States agreed that we are off-track to achieve UHC and the health-related Sustainable Development Goals (SDGs). The progress has been undermined by several world crises – the COVID-19 pandemic, climate change and political unrest have all had a devastating impact on health, social development and the economy, widening inequalities between and within countries. Furthermore, misinformation, disinformation, and hate speech have eroded trust in governments, with negative implications for the effectiveness of our health systems both in normal times and when an emergency strikes.

The complexity and vast scope of these challenges are too much for any single actor to solve alone. We, six ministers from different regions of the world, share the same vision for the solution: that only by working together with people and communities can we overcome the challenges we face. We believe that the World Health Assembly (WHA) draft resolution on social participation for UHC, health and well-being will help us harness the potential of communities and refocus priorities in order to get back on track to achieve the SDGs.

Social participation engages people, communities, and civil society in decision-making processes that affect health and well-being across the policy cycle. It is the two-way communication process in which the voices of people across the life course – and especially those in vulnerable and/or marginalised situations, people with disabilities, and women – are heard and influence the design of the health policies and programmes to better respond to their needs.

Social participation can promote equitable outcomes by broadening participation and representation for more inclusive decision-making processes. It also gives governments an opportunity to clearly and transparently communicate their strategies and goals to the population. And, crucially, it can help to build and sustain trust in the government, while promoting transparency and accountability.

Building trust takes time, but it will happen eventually if we invest in regular mechanisms for inclusive, equitable, and transparent participation, enhance the capacities of the public sector and civil society for meaningful engagement, and monitor and evaluate the quality and impact of social participation to learn and improve.

We believe that all countries engage people, communities, and civil society in their health systems in one way or another. Some countries are effective in implementing social participation at the primary health care level; some focus on participation in policy design for UHC; others use non-communicable disease prevention and control as an entry point – these are just a few examples. Every country can be a champion in its own way.

We encourage everyone to make a conscious effort to take stock and take the next step. Learn from each other. If you have not started yet, do so now. If you are implementing social participation, improve and expand it across the system. And if it is strong and effective, sustain it over time.

Considering the magnitude of global tensions and health challenges at present, building trust and resilience must be a priority, and social participation is a key means to do this. We must now move beyond principles and take action in order to get back on track. “Walking the talk” will not be enough – we need to hit the ground running in order to reach the finish line and achieve our goals on time. And this resolution will enable us to do just that.
“Social participation is fundamental to make sure that health systems are responsive to people’s needs. Brazil’s National Health Council, where civil society is fully represented, plays a key role in ensuring the effectiveness of health policies. By enhancing social participation, all national authorities will be in a better position to address their own challenges.”

Dr. Nísia Trindade Lima
Minister of Health of Brazil

“France has put into place a number of bodies and initiatives for strengthening social participation, ranging from territorial health councils to citizens’ conventions on specific issues such as end-of-life. The latter has proven to be extremely valuable by formulating key recommendations that fed into the “end-of-life bill” that is now being discussed in our parliament. France is ready to share experience in the field with other countries.”

Ms. Catherine Vautrin
Minister of Labour, Health and Solidarity of France

“Thailand has invested in social participation processes and mechanisms for decades, for example the National Health Assembly. It has been proven that engaging people strengthens our health system, making it more responsive and effective. We commit to strengthening and sustaining social participation for UHC, health and well-being.”

Mr. Somsak Thepsutin
Minister of Public Health of Thailand

“The world faces multiple shocks that threaten earlier gains in poverty reduction and health outcomes. Now more than ever it is critical that governments truly listen to their citizens through open and inclusive processes. Meaningful citizen engagement, built on transparency, good evidence and reason-giving, can promote more equitable health outcomes and build public trust. This is fundamental to the Norwegian system.”

Mr. Jan Christian Vestre
Minister of Health and Care Services of Norway

“In Slovenia, our long tradition of involving and supporting civil society in decision-making for health has fostered trust between people and health workers; trust that deepened during the COVID-19 pandemic and recent floods. Together with community nurses and social services, NGOs play a crucial role in expanding health promotion and access to services to those living in vulnerable and hard-to-reach situations. Our experience is that investing in such cooperation pays off.”

Dr. Valentina Prevolnik Rupel
Minister of Health of the Republic of Slovenia

“The draft WHA resolution on social participation for UHC, health and well-being is a crucial stride towards amplifying community voices in healthcare policies. Tunisia, spearheading this effort in the Eastern Mediterranean (EMRO) region and globally, is committed to establishing sustainable frameworks for social participation in health. Our ministry’s health participatory governance committee is actively shaping a national strategy in collaboration with civil society representatives to create a healthcare system that genuinely reflects the needs and voices of the people.”

Prof. Ali Mrabet
Minister of Health of Tunisia
Perspective from Civil Society

Building stronger, equitable and more responsive health systems for universal health coverage: engaging civil society and communities through social participation.

A world without social participation

For decades, and particularly during the recent COVID-19 pandemic, we have seen governments fail to systematically engage people, communities, youth, and civil society to address a multitude of public health challenges. Instead, governments in many countries have resorted to top-down hierarchical approaches to making decisions and policies based on elite views and perspectives, often backed by international agencies and development finance, with little to no participation from affected communities and/or civil society. This has contributed to inaccessible, low quality, and non-responsive health services that populations, particularly those in vulnerable and marginalised situations, do not trust or use. As per the 2023 Global Monitoring Report tracking progress towards Universal Health Coverage (UHC), the global health community is now faced with the fact that 4.5 billion people (more than half of the world’s population) are still not covered by essential health services.

People at the centre of health

Social participation places communities and civil society at the centre of decision-making to ensure health services are tailored and responsive to people’s needs so no one is left behind (see Box 1 for examples of achievements in social participation globally).

Participatory spaces are important for:
1. holding governments accountable for their commitments,
2. building trust with the population, and
3. ensuring health policies and services adhere to human rights, including the right to participation, promote equity and quality, while also overcoming social factors that discriminate against certain sub-populations (such as children, women, LGBTQIA+ communities, youth, older people, migrants, refugees, prisoners, and people living with disabilities) as well as the wider population.

Call to action

As the world faces unprecedented challenges caused by climate change, natural disasters, pandemics, migration, humanitarian crises, and rapid demographic and technological changes, it is imperative that governments create an equitable space for people, communities, and civil society to meaningfully contribute to health policy development, implementation, and accountability. Therefore, we welcome the Social participation for universal health coverage, health and well-being draft resolution and call on all Member States to support the draft resolution at the 77th World Health Assembly (WHA).

We also urge governments to fund civil society, mindful of the need to mitigate conflicts of interest, to ensure the broader community can regularly attend and/or lead social participation forums. This will energise the government’s ability to motivate, incentivise and empower civil society members with lived experiences, particularly those in vulnerable and marginalised situations, to participate. Providing inclusive spaces for these groups will ensure equity, equal representation, and diversity of thought in these decision-making forums.

Lastly, we recommend that both governments and civil society develop multi-sectoral accountability frameworks to monitor the frequency, quality, and outcomes of social participation efforts. These frameworks can also serve to document successes, challenges, and lessons learned, thereby facilitating ongoing improvements in social participation methods and ensuring their contribution to positive health impacts towards achieving UHC by 2030.
Box 1: Achievements of social participation across regions of the world

Social participation is not simply an ideological concept; it saves lives. The practice of systematically and meaningfully engaging affected communities in designing their own health programmes and services creates trust between people and their governments – a trust that the COVID-19 pandemic demonstrated to be exceptionally weak. In fact, recent evidence from low-, middle-, and high-income countries shows that people have more confidence in the health system when governments take into account populations’ views and perspectives.

This trust, alongside more responsive health policies and programmes, stimulates demand for health services as people are far more likely to use them, resulting in more positive health outcomes (see examples below).

In Jamaica, a Youth and Adolescent Working Group was instrumental in advising the government and UN partners on how to develop health policies and programmes that reach young people. As a result, two non-traditional health access points called “teen hubs” were co-created by youth and the government, with plans for more to be put into place.

In Ukraine, the civil society organisations (CSOs) in collaboration with the TB Parliamentary Platform, were able to ask the Ukrainian Ministry of Health to revise the country’s TB law to align it with their UHC goals. This revised TB law has been approved with participation from CSOs, patient groups, and other key stakeholders.

Over the past four decades, Australia has systematically benefited from a sustained, inclusive social participation response to the HIV/AIDS movement. From the very beginning of the epidemic, key populations (including men who have sex with men, sex workers, injecting drug users, and others) were brought ‘inside the tent’ and encouraged to design responses which would speak to their communities. Currently, some states are well on the road to eliminating HIV transmission.

Ms. Eliana Monteforte, Advisory Group member of the Civil Society Engagement Mechanism (CSEM) of UHC2030, member of the World Health Organization Civil Society Commission Steering Committee, SPHERE Core Committee member

Ms. Christina Williams, Member of the World Health Organization Youth Council

Dr. Hamaiyal Sana, Vice Chair of the World Health Organization Youth Council

Dr. Justin Koonin, Member of the Political Advisory Panel for the UHC Movement, SPHERE Core Committee member

Dr. Ravi Ram, Co-Chair of the World Health Organization Civil Society Commission Steering Committee

Mr. Zahedul Islam, Advisory Group member of the Civil Society Engagement Mechanism (CSEM) of UHC2030

Mr. Waiswa Nkwanga, Coordinator of the Civil Society Engagement Mechanism (CSEM) of UHC2030, SPHERE Secretariat.

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Perspective from the World Health Assembly President and WHO Executive Board Chair

Social Participation is indispensable to address current challenges

The public health challenges facing the global community today are multifaced, complex challenges – climate related health issues; antimicrobial resistance; geopolitical conflicts; healthcare workforce resource management.

Reaching towards mitigation – let alone solutions – of these global health problems requires a concerted, whole-of-society sustained effort.

The expectation that these challenges can be addressed by the medical class alone – or even by politicians – is nothing but an illusion.

Social participation at all levels of the policy cycle is not only desirable; it is indispensable to address these challenges.

For example, the climate crisis is widely recognised as a health crisis – but the response cannot be found in the healthcare sector. The impacts of climate change on health from excess mortality due to extreme events, to food scarcity and water concerns, mass migration, spread of vector borne diseases – to mention but a few – are far reaching and all encompassing. Failure of the society as a whole to engage in effective action to adapt to, and mitigate climate change, will lead to overall failure.

Likewise, the emergence of antimicrobial resistance cuts across the One Health spectrum – human, animal, plant and environmental health. Multistakeholder involvement – carefully co-ordinated and led – is essential.

At a clinical level social participation applies as well. As healthcare demands increase – including demands on mental healthcare and well-being – the current and, possibly future, healthcare workforce is finding it increasingly difficult to cope. Empowering individuals to take charge of their own healthcare and well-being needs to be part of the solution. The digital tools now exist to start making this possible.

All of this requires a level of social participation and health literacy in public and clinical healthcare beyond anything we have witnessed so far.

The pandemic years were a special case – indeed social participation and buy-in in the mass response and mobilisation of society as a whole during the pandemic was exceptional and illuminating.

The societies which fared best during the COVID-19 pandemic were the societies with a high level of trust in their healthcare systems – trust in turn comes from transparency and involvement.

This is exactly why a structured framework to induce, encourage and embrace social participation is a need at local, regional and national levels.

Transparency, accountability, and direct involvement at all stages and levels will increase trust and ensure good governance. Healthcare professionals need to partner with citizens: healthcare is a service, but wellness belongs to everyone. The involvement of minority groups and interests in society is also necessary to ensure equity and inclusivity in the services provided.

We look forward to the debate and the adoption of the proposed WHA 77 resolution on social participation.

Hon Chris Fearne
Former Deputy Prime Minister of Malta, Minister for European Funds, Social Dialogue and Consumer Protection and World Health Assembly President

Her Excellency Dr Hanan Mohamed Al Kuwari
Minister of Public Health for the State of Qatar, Managing Director of Hamad Medical Corporation and WHO Executive Board Chair
Spotlight on youth participation: Interview with Hans Henri Kluge and Vesna Kerstin Petrič

In pursuit of health and well-being for all, social participation – including the participation of young people – is a key strategy to ensure no one is left behind.

Through initiatives such as the WHO Youth Council, the WHO Regional Office for Europe’s Youth4Health Initiative, and by encouraging the inclusion of youth delegates to governing body meetings and high-level Ministerial events, WHO is providing platforms for young people to meaningfully engage in health and well-being policymaking processes at global, national and subnational levels – reflecting the Organization’s determination to leave no one behind.

As former President of the International Youth Health Organization, and a passionate youth engagement advocate, I have always found that health is of vital importance to young people. Specifically, young people want to better understand the public policy context, contribute to solutions, and see the results of their participation shaping policies and programmes within countries and across WHO’s work. They want an equal voice. They want to be heard.

I caught up with the WHO Regional Director for Europe, Dr Hans Kluge, and the 2023 Chair of the WHO Executive Board, Dr Vesna Petrič from Slovenia, to share their perspectives on this important agenda.

Let’s get straight to the point – what, for you, is the key benefit of youth participation?

Hans: The health policy environment is rapidly changing and becoming more complex. For example, while digital tools can enable the rapid dissemination of health information, we also face the insidious influence of commercial determinants – such as harmful marketing practices by the tobacco and alcohol industries, and misinformation and disinformation spread through social media, which have detrimental impacts on health behaviours. It is increasingly apparent that we can only find solutions to pressing public health challenges with a whole-of-society approach, which importantly includes social participation, where youth is a key constituency.

The world currently has the largest generation of youth in history: in the WHO European region, every third person is under 30. Investing in youth participation in decision-making for health and well-being at all levels empowers them to shape their realities and futures towards building a sustainable world for all.

Young people are unafraid to take risks and raise their voices on topics of importance to them. They also understand best the resources, needs and preferences of their peers and communities. Their innovative perspectives help to strengthen WHO’s work and ensure that policies, programmes and services respond to their needs – which can positively impact on health, social outcomes and norms.

Vesna: I agree, organised youth have a lot of potential. They pay attention to health, environment and climate change and are keen to contribute to the common good. They can also reach their peers much better than us professionals, are very good at networking, and advocating for sound solutions.

Indeed, when addressing lifestyle behaviours, if the measures we plan are understood and accepted by youth, we can expect better results. Let me explain. Working in tobacco control for decades, I realised that scientifically grounded measures, such as age limits for purchasing tobacco products, work much better if planned and promoted in collaboration with organised youth. It was organised youth in Slovenia that advocated most successfully for the ban on smoking in closed spaces – a ban that initially faced resentment and stiff opposition. By making a compelling case about the hours of smoke exposure that young people endured while working in bars and restaurants – where students are typically employed – they shifted the public’s view and mobilised support for the ban.

How do we ensure that participation is effective – that their voices make a difference? What can governments and WHO Regional Office for Europe do to promote accountability?

Hans: In 2021, the WHO Regional Office for Europe launched a region-wide initiative, Youth4Health, which aims to amplify and embed youth voices and perspectives into all areas of our work – from youth representatives on Technical Advisory Groups, to collaboration on campaigns and publications, and co-creating WHO events.

At the Youth4Health forum in Albania in 2022, youth delegates issued the Tirana Statement specifying concrete actions to strengthen youth engagement and improve youth health and well-being. Fulfilling our commitment, we launched the Youth4Health network in 2023, which currently comprises 32 youth organisations and 155 individual representatives from 35 countries across the region.

The Youth4Health network has developed indicators to assess implementation of the Tirana Statement, and will give me a transparent progress update before this year’s Regional Committee.

To be meaningful, social participation requires investment. At the WHO Regional Office for Europe, we are building our staff’s capacities for youth engagement through online training, coaching, and a WHO toolkit. Equally, we need to give back. We should provide fair remuneration to youth for their time, mentorship, and training to equip them with the skills and knowledge to effectively contribute to decision-making processes. Our relationships with young
people need to be strengthened, nurtured, sustained – they are our key champions in promoting health and well-being priorities.

The WHO Regional Office for Europe wants youth to sit alongside us at the decision-making table. We encourage our Member States to include youth representatives in their delegations to Regional Committees – on this, Slovenia leads by example. Together, we need to lower barriers and make sure our processes are inclusive.

**Vesna:** Speaking of accountability, we all have to be accountable to one another. The government should first invest in strengthening youth organisations’ capacities by facilitating knowledge transfer, training, and engagement opportunities. For instance, in advance of the 2023 Tallinn conference on health system trust and transformation, Slovenia hosted a pre-meeting of youth organisations with the WHO Regional Office for Europe, some of whom attended Tallinn to present their views.

More work is needed for the public health community to consistently recognise organised youth as one of their most important stakeholders and systematically involve them in developing and implementing health policies. This is why the National Public Health Institute in Slovenia now has a dedicated unit on social participation, with a focus on youth.

Youth organisation development requires sustainable financing through operational and project funding, with evaluation mechanisms in place for accountability. In funding applications, youth organisations are held to the same standard as any other NGOs; they are often among the most successful with innovative, evidence-based bids. Slovenian youth organisations have received several national and international prizes for their work, motivating them further and strengthening their accountability.

**What impact can youth participation at country or regional levels have on the ground and in communities where it matters most?**

**Hans:** Top-down approaches alone simply don’t work. Young people know much better than us how to reach their peers, with established connections and trust in their communities.

Specifically, they can contribute to the design, promotion, implementation and monitoring of policies and programmes for health and well-being, providing peer-to-peer training and mentoring, and supporting underrepresented and marginalised groups to engage with decision-makers.

Our WHO Country Offices also drive impact by connecting us to local youth organisations and communities to advance our common objectives.

**Vesna:** There are many examples how organised youth can contribute to decision-making. I want to share one where they improved the implementation of legislation. In Slovenia, organised youth demonstrated that simply banning tobacco product sales to underage consumers does not work, producing evidence that the under-15 age group could buy cigarettes despite the ban in 95% of cases, which they shared with the media. In response, the government introduced a tobacco sale licensing requirement, as well as legal “mystery shopping” in collaboration with organised youth. With the threat of license withdrawal in the case of violations, vendors’ compliance substantially improved.

**Would you like to share any particular experiences or results that stand out for you when working with young people?**

**Hans:** In the WHO European region I have seen the passion and power of youth advocacy in action. At the youth forum, the day before our Ministerial Conference on Environment and Health last year in Budapest, I was inspired by the perspectives and innovative ideas of youth in response to the triple planetary crises – including those of my own daughter Anastasia. Their Youth Declaration was adopted and fed into the wider Budapest Declaration on Climate and Health that now serves as a blueprint for our Region.

Ever since, Anastasia holds me accountable for involving young people meaningfully in health decision-making processes.

**Vesna:** For more than 20 years, organised youth have been my best allies when struggling to introduce and implement public health policies. As they grow up, many young activists make excellent public health professionals, like you Andrej.

I am very proud that organised youth from my country started the International Youth Health Organization, headquartered in Slovenia, with over 60 partners around the world promoting youth participation in global health.

As a public health professional, I learned early in my career that nothing can be done well for young people without young people; I am now convinced that we can only succeed in leaving no one behind and ensuring health for all by working hand-in-hand with organised youth.

**Andrej Martin Vujkovac**

First Secretary, Permanent Mission of the Republic of Slovenia to the United Nations Office and other international organisations in Geneva.
CLARIFYING TERMS AND CONCEPTS: **WHAT IS MEANT BY SOCIAL PARTICIPATION IN DECISION-MAKING FOR HEALTH**

**Summary:** Social participation is crucial for reorienting health systems towards primary health care in pursuit of universal health coverage and overall population well-being. It means empowering people, communities, and civil society through inclusive participation in decision-making processes that affect health across the policy cycle and at all levels of the system. However, implementation thus far has often been insufficient. Inconsistent definitions and interpretations of participation-related terms can result in technical ambiguity and a lack of common understanding among stakeholders. This article seeks to clarify key terms, define social participation, and unpack what it is and what it is not.

**Keywords:** Social Participation, Empowerment, Primary Health Care, Health System Governance, Universal Health Coverage

**Introduction**

In recent years, marked by exacerbated inequities due to the COVID-19 pandemic, climate change and increased conflicts, engaging with people and better understanding their views and needs has become more relevant than ever in pursuit of universal health coverage (UHC) and overall population well-being. Anchored within the primary health care (PHC) approach, the participation of people, communities, and civil society in decision-making has long been deemed an essential way of building trust, resilience and people-centredness (see the article by Rajan et al. in this issue). However, despite a long-standing history of commitments to the principle of participation (see Box 1), implementation to date has often been ad-hoc, siloed, and/or tokenistic, leading to limited uptake of recommendations derived from participatory processes and tangible outcomes in communities.

Within this context, in November 2023, Member States of the World Health Organization (WHO) began the process of negotiating text for a resolution on the topic of social participation, testament to the relevance and growing interest in this topic across regions. During the process of Member State negotiations, it has become clear that terminology is used in different...
Box 1: Global commitment to participation

UN High-Level Political Declaration on Universal Health Coverage (2023): ‘Promote participatory, inclusive approaches to health governance for UHC, including … social participation, involving all relevant stakeholders, including local communities, health workers and care workers in the health sector, volunteers, civil society organisations (CSOs) and young people in the design, implementation and review of UHC, to systematically inform decisions that affect public health, so that policies, programmes and plans better respond to individual and community health needs, while fostering trust in health systems.’

HRC 48/2 Equal participation in political and public affairs (2021): ‘Bearing in mind the crucial importance of full, equal and meaningful participation for the recovery from the impact of the pandemic, and recognising that the broad-based participation by civil society actors can help to ensure that the recovery responds to real needs and leaves no one behind.’

Declarations of Astana, Global Conference on Primary Health Care (2018): ‘VI Empower people and communities: the involvement of individuals, families, communities and civil society through their participation in the development and implementation of policies and plans that have an impact on health.’

SDG Goal 16 (2015) on peaceful and inclusive societies, justice, and effective, accountable and inclusive institutions, with target 16.7 to: ‘Ensure responsive, inclusive, participatory and representative decision-making at all levels.’

Rio Political Declaration on Social Determinants of Health (2011): ‘Promote participation in policymaking and implementation’ as one of the five key action areas critical to addressing health inequities.

Declaration of Alma Ata, International Conference on Primary Health Care (1978): ‘IV The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.’

Box 2: Overarching concept linked to health system governance

Plethora of participation-related terms and divergent interpretation

Across countries, a plethora of participation-related terminology is employed in various ways in different contexts, such as public participation, population involvement, citizen engagement, public deliberation, participatory governance, community engagement, health democracy, social participation, among others. This diversity of terms poses a fundamental challenge, as inconsistent definitions and important nuances in the interpretation of such terms can cause technical ambiguity and impede consistent comprehension.

In France, a review of participatory mechanisms from 2015–2019 revealed that the lack of common terminology resulted in wide methodological discrepancies in organising regional participatory spaces and thus negatively affected inclusiveness, effectiveness and legitimacy of the process. Put differently, using simply the term ‘participation’ does not suffice to clarify important distinctions, such as who participates and how their participation should occur – from merely conveying information or consulting views to fostering two-way dialogue for joint decision-making.

To better understand how terms are used among policymakers and civil society activists, Box 2 provides an overview of common participation-related terminology seen in the literature. While not intending to provide normative definitions, the principal attributes are described while clarifying their multifaceted nature and diverse use.

Social participation, as defined in WHO’s technical documents and referenced in the draft resolution text, means “empowering people, communities, and civil society through inclusive participation in decision-making processes that affect health across the policy cycle and at all levels of the system.” Viewed as an overarching concept linked to health system governance, the objective is to amplify people’s voices, especially those who are typically marginalised, in decision-making processes, to render policies, strategies and programmes more responsive to their needs. It calls for a shift in the modus operandi of governance, whereby governments respect, value, regularly engage and collaborate with people, communities, and civil society to co-develop health systems – whether for setting priorities, developing policies, implementing programmes or reviewing and evaluating processes.

Box 2: Participation-related terminology

Public engagement: an overarching term that encompasses the full spectrum of government engagement with civil society in policymaking. This includes one-way public communication to convey information from the government to the public, public consultation with the mere purpose of gathering information from the public, or more active participation in decision-making. The distinction lies in the directional flow of information.

Participation, public participation: An umbrella term often used in relation to democratic ideals and empowerment. Public participation in (health) policy is viewed as a process by which the government actively seeks out the public’s views about a decision or a way for civil society to influence the political agenda. Participation can range from passive input-seeking to active citizen involvement in decision-making processes. Typically, governments aim for responsiveness, stakeholder ownership and uptake of policies while civil society aim to hold governments to account. A focus is placed on including marginalised and vulnerable groups to influence planning, research and action in the health sector.

Public consultation: described as a process initiated by government actors to gather information from the public, typically for policymaking purposes. It is emphasised as a crucial aspect of democracy, enabling the public to air their viewpoints and concerns, to which the government may then respond.

Deliberativeness/deliberative processes/public deliberation: closely linked to participation, is described as ‘democratic talk’, with an emphasis on providing balanced factual information to non-expert members of the population to enable them to ‘deliberate’ collectively on the subject at hand. While participation aims to seek broad and diverse views, with a focus on reaching vulnerable and marginalised groups, the objective of deliberative processes is to create reasoned dialogue with an emphasis on lay citizens and non-subject matter experts, allowing participants to refine their viewpoints during deliberations as they consider feasibility concerns, opposing views by other groups and/or the implications for society, and not just individuals.

Citizen participation: highlighted as a term used in countries transitioning towards increased democracy, often following citizen movements aimed at challenging the status quo and advocating for reform. This term suggests active involvement by the citizenry to push for reform changes, distinguishing it from community participation.

Citizen engagement: a form of public participation often used by governments or public entities to inform effective policymaking. It involves an active, intentional partnership between citizens and decision-makers, which is promoted and conducted by government authorities. As such, it distinguishes from community engagement that tends to focus on particular communities of place or interest, and therefore may be more appropriate in the context of local health services, or social participation that compasses the full spectrum of societal views, including those of CSOs. Depending on the country context, the term ‘citizen’ may exclude vulnerable groups, such as illegal migrants.

Community engagement, community participation: Broadly defined, it refers to involving communities in (local) decision-making, planning and implementation, including needs assessment, community development, delivery, and evaluation. WHO defines community engagement as a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes. While most of the sources use community engagement and community participation interchangeably, some authors distinguish between engagement as being initiated by the government or policymaker, and participation which can also be initiated by communities with a view of enhancing their well-being.

Patient engagement: according to WHO, a process of building the capacity of patients, families, carers, as well as healthcare providers, to facilitate and support the active involvement of patients in their own care, in order to enhance safety, quality and people-centredness of healthcare service delivery.

Participatory governance: often used interchangeably with social participation, refers to seeking population views to feed into health decision-making processes. For some, the term is broader in scope, facilitating multistakeholder and multisectoral engagement.

Social participation: according to WHO, empowering people, communities and civil society through inclusive participation in decision-making processes that affect health across the policy cycle and at all levels of the system. As part of the essential public health functions, the Pan American Health Organization considers this function to encompass the collective actions through which civil society and the organised community intervene and directly influence the organisation, social control, management, and oversight of health institutions and the health system as a whole.

Source: adapted from WHO 2021.
In contrast, other terms may be more specific, for example to leverage engagement with certain target groups, such as citizens for a policy question (citizen engagement/participation) or patients in co-developing care programmes (patient engagement/participation). Community engagement places an emphasis on relationship-building among actors within a community to work together, often in the context of service redesign and health promotion. Other terms such as deliberation emphasise a particular engagement method to create reasoned dialogue, which typically requires more time and resources. While often used interchangeably with social participation, participatory governance may be used with the added dimension of multisectoral collaboration, in addition to multi-stakeholder cooperation, facilitating all actors and sectors, often in institutionalised entities with designated seats for community, civil society, and other sector’s representatives. Tunisia’s newly established ‘participatory governance committee’, for example, is mandated to work on social participation, public private partnership and multisectoral engagement. In sum, it is important to note that these boundaries are blurry, and use of these terms is often interchangeable in practice.

**Social participation and how it relates to the term ‘empowered people and communities’, a component of the primary health care approach**

PHC is a whole of society approach considered most equitable and efficient to effectively bring services for health and well-being closer to people. It has three core components: empowered people and communities, multisectoral policy and action and integrated health services. Among these, social participation is a principal contributor to the empowered people and communities component, as it gives people and communities voice and agency as active advocates and co-developers of health systems, not just passive recipients of services. By creating participatory spaces at various levels, people and communities, either directly or via legitimate intermediaries such as CSOs, can influence decision-making for improved health outcomes. For example, Brazil’s Health Councils allow people to take an active role in reorienting health systems towards primary health care, by voicing concerns and views in strategic discussions at national level, organisation and design of services at regional level or prioritisation of resource allocations at local level.

Through continual dialogue, trust can be cultivated in government and public institutions, while collaborations between government, communities and civil society enhance the development of more responsive strategies and the effectiveness of programme implementation in addressing structural inequalities and improving access to services for vulnerable groups, as exemplified by Slovenia’s long-standing cooperation between decentralised Health Promotion Centres (which provide primary health care services) and local community-based organisations and NGOs. This collaboration enables the Health Promotion Centres a much broader reach within communities than it would have otherwise, demonstrated by its higher utilisation rates since collaboration began.

Moreover, collectively engaging as individuals in participatory processes to influence governance decisions can strengthen individual’s willingness to take care of their own health needs – for instance, in the adoption of a healthy lifestyle or in well-informed decisions when managing illness in close collaboration with trusted health providers. Social participation is thus complementary to, and at times used as a part of, health promotion and health literacy strategies, risk communication as well as community engagement to ensure integrated, people-centred health services close to where people live, thereby contributing to the integrated health services component.

Social participation can also contribute to enhance the multisectoral policy and action component. For example, when civil society and community representatives are included in committees or working groups, they are able to bring lived experiences into discussions to inform decisions on issues such as antimicrobial resistance, WASH or climate change.

**Characteristics of social participation**

As alluded to above, social participation should happen at all levels, at national, sub-national, and local levels, as well as across the policy cycle, from situation analysis, priority setting, planning, and budgeting, to implementation, monitoring, evaluation and review. It pertains to any decision-making process that affects people’s health and well-being, both within and beyond the health sector, giving due
Empowering people, communities, and civil society through social participation

attention to social, economic, commercial, and cultural determinants of health that often sit beyond the health system. Unpacking the concept of social participation helps identify important characteristics for meaningful participation, that also clarify how it is distinct from other types of engagement, as explained below:

Two-way dialogue: A key characteristic of any social participation process is the two-way flow of information between governments and people, communities, and/or civil society, as opposed to one-way communication. This back-and-forth exchange of information and dialogue can foster a common understanding and shared values and can be facilitated using various participatory mechanisms (see section below and Table 1).

Safe and constructive spaces by mitigating power imbalances and addressing conflicts of interests: Hierarchies and power imbalances exist in all societies, shaped by social, economic and political dynamics – and social participation happens within such contexts. As such, government officials, academia, medical professional and community representatives do not inherently come with the same levels of perceived legitimacy, knowledge and power to influence debates. Acknowledging and managing these power imbalances is a fundamental premise for meaningful social participation. Through format and design elements, safe spaces can be created where conflicts of interests are mitigated, and participants are empowered to be on an equal level as far as possible to express themselves freely without fear of repercussions, allowing for more constructive discussions to find policy-relevant solutions. In the early stages of Tunisia’s Societal Dialogue, for example, tensions and mistrust between lay people and health professionals led to the separation of these groups initially, allowing each group to speak frankly amongst themselves and contribute to debates.

Inclusive participation in relation to the policy question: Who to engage in social participation processes depends on the policy question at hand. Generally, the prefix ‘social’ alludes to seeking broad and diverse views across all walks of society, either directly from people or through communities and civil society. However, in practice, not everyone can participate due to time and resource constraints. Thus, the crux lies in finding the right people, at the right time, for the right policy question, which should guide the selection strategy of participants.

Targeted efforts to reach vulnerable and marginalised groups: In view of advancing UHC, reaching first those most in need towards the noble goal of leaving no one behind, a particular focus should be placed on seeking inputs from vulnerable and marginalised groups, who are generally less heard. This requires additional targeted efforts by governments to reach them, for example, by going to communities rather than expecting them to come to participatory spaces in bigger cities or the capital, building health literacy, or providing translation into local languages.

Regular and sustained over time: A key characteristic of meaningful social participation is that mechanisms are both regular and sustained as part of a shift towards institutionalising social participation. Fostering a culture of participation involves formal participatory mechanisms coupled with a vibrant civil society and grassroot movements that can claim new spaces. Over time, stakeholder can ‘learn by doing’, refining and improving participatory approaches. During the past 15 years, Thailand’s National Health Commission Office has fine-tuned engagement methods by enhancing the effectiveness of constituency groups, facilitating capacity-building for civil society and communities, and organising various participatory initiatives at the local levels to feed into the annual National Health Assemblies.

For social participation to be meaningful, it requires strong political commitment and long-term capacity building for both government as well as people, communities and civil society to ensure equitable, diverse and inclusive representation in decision-making processes that can yield more responsive strategies and implementable programmes for enhanced population health and well-being. Moving towards a new governance modus operandi requires time and a cultural shift, with openness to the co-development of health systems underpinned by equity, transparency, and accountability – embracing a social justice and a human rights approach.
### Table 1: Common categories of social participation mechanisms

<table>
<thead>
<tr>
<th>Category</th>
<th>Explanation</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open for all forums</td>
<td>Open to everyone. Larger groups, aiming to capture the diverse and divergent views from many different segments of the population.</td>
<td>Public forums and hearings, open mic events, town hall meetings.</td>
</tr>
<tr>
<td>Consultative methods with attendance by invitation</td>
<td>Open forum for exchange, albeit with a smaller and closed, usually invited, number of representatives of population groups and technical experts (and others).</td>
<td>Consultative meetings, policy dialogues, stakeholder consultations, focus groups.</td>
</tr>
<tr>
<td>Deliberative engagement methods</td>
<td>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 and information, allowing sufficient time to reflect and deliberate, ensuring a non-intimidating environment.</td>
<td>Public panels, citizens’ juries, consensus conferences, planning cells, scenario workshops.</td>
</tr>
<tr>
<td>Fixed seats for the population/communities/civil society in administrative bodies</td>
<td>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 organisations, and/or civil society representatives. The mechanism may be anchored in a legal framework.</td>
<td>Health councils, health committees, district committees, civil society advisory boards, representation on steering groups and review boards.</td>
</tr>
</tbody>
</table>

Source: [1]

### Participatory mechanisms

A participatory mechanism is the space or platform where the government comes together with people, communities, and civil society, either virtually or in-person. It can be mandatory (i.e., decreed by laws) or voluntary (i.e., at the discretion of the organiser), allowing for both formal and informal exchanges.

Table 1 groups the multitude of available participatory mechanisms into four main categories: open for all forums, consultative methods with attendance by invitation, deliberative engagement methods, and formalised mechanisms with fixed seats for population, communities, and civil society. In France, a large scale participatory approach in 2018 called the ‘Etats généraux de la bioéthique’ employed a mix of these methods, including 271 regional discussions open to the general public, online consultations via a web site, 154 civil society hearing, and a citizen jury, aiming to gather diverse societal perspectives to inform the revision of the bioethics law.[12]

Typically, a mix of participatory mechanisms that best suit the objectives of the process should be pursued by governments for meaningful social participation that involves broad and diverse population viewpoints. This tends to balance out the cons of any single mechanism, allows for the triangulation of findings, and increase the scope for all people and population groups to influence decisions. Additionally, digital technologies increasingly play a role in reaching more people, such as young people and full-time working professionals. However, they are insufficient alone as they may pose barriers due to limited access by poorer, remote populations and older persons. In all instances, it is crucial for governments to regularly assess which target populations have contributed, and which have not. Almost always, additional, targeted efforts will be necessary to reach people facing vulnerability and marginalisation who are generally less heard.

### What social participation is not about

Social participation is about systematic and sustained two-way government engagement with its people, either directly or through communities and civil society, distinguishing it from siloed, one-off, and ad-hoc approaches. Yet, it’s crucial to begin by trying out social participation, even if initially conceived as a single initiative. Ad-hoc initiatives are also necessary in specific circumstances, as seen in the COVID-19 pandemic, but ideally they should be combined with a long-term vision of embedding social participation within governance processes.

While there is a risk of tokenism, social participation is not about legitimising ‘pre-decided policies’, nor is it about a pretence of inclusivity when only close allies are invited who speak ‘on behalf of the population’. Measures put in place to ensure transparency and accountability are important to ensure checks and balances.

Social participation should also be seen as complementary to purely one-way communication initiatives. Methods used for communicating information to a population, or receiving feedback from them – such as taking stock of user experience through surveys and key informant interviews, providing complaint boxes in health facilities, raising awareness of health promotion and literacy campaigns via radio and TV programmes, among others – have an important role in health systems.[13] While these channels are discrete from social participation, they can collect valuable information to inform two-way participatory dialogues.

Moreover, social participation extends beyond the individual patient-provider relationship, which primarily focuses on managing individual illness and treatment options. Trusted healthcare providers play...
a pivotal role in enhancing self-care and promoting medication adherence. They can also encourage individuals to join self-help groups or to actively engage in participatory mechanisms – such as townhall meetings or community boards, which then enable patients and caregivers to exchange lived experiences and views as part of a collective to influence service design and policies.

As the focus is placed on people, community and civil society engagement, social participation is distinct from health professional councils or government-health workforce negotiations on issues such as remuneration and working conditions, as well as from the interactions and relationships among interdisciplinary professional teams. That said, how to address health workforce shortages in rural areas may well be a topic of a district health committee. Or health professionals may engage in social participation processes and contribute valuable insights along with other actors. In such contexts, power imbalances should be considered to prevent large medical associations and unions from dominating spaces at the expense of civil society and community voices.

Similarly, social participation is not about government engagement with for-profit private entities to align towards common public goals, which require regulation and safeguards due to the risks of conflicts of interest. Nonetheless, issues concerning rising private health insurance premium may be subject to social participation processes. Furthermore, private sector entities may be organised into umbrella CSOs (e.g., professional provider associations) and take part in participatory processes, which raises important considerations in dealing with special interests or more powerful groups.

Social participation is also not the same as social contracting, whereby the government contracts out civil society to implement specific activities. Of course, one of the reasons governments do so is precisely because of civil society’s own social participation activities. Social participation is also complementary to broader social accountability activities such as health budget advocacy or community health scorecards.

Social participation thus contributes to a whole-of-society approach and complements other existing multi-stakeholder and multisectoral mechanisms, such as partner coordination platforms or parliamentary health committees. It promotes a more inclusive approach in decision-making, ensuring that people, communities, and civil society can meaningfully influence decisions-making.

Conclusion
Across countries, a plethora of participation-related terminology is employed in different ways in different contexts. This leads to technical ambiguity and lack of a common understanding of the concept of social participation and related terms.

Social participation is about empowering people, communities and civil society through inclusive participation to influence decision-making processes that affect people’s health and well-being. It is thus a key means to implement the PHC approach, by contributing to the core components, in particular to ‘empowered people and communities’.

Viewed through the lens of governance, social participation aims at amplifying people’s voices, particularly those whose voices are typically less heard, to make policies, strategies, and programmes more responsive to their needs.

For social participation to be meaningful, key characteristics need to be fulfilled. These include fostering two-way dialogue, providing safe and constructive spaces where power imbalances and conflicts of interests are mitigated, ensuring inclusive participation relevant to the policy question at hand, with targeted efforts to reach those whose voices are often marginalised, and establishing an explicit link to the policy cycle to drive implementation for improved health outcomes. By embedding social participation across all levels of the systems and maintaining sustained engagement over time, the full potential of social participation can be harnessed.

As such, social participation promotes a new governance modus operandi, where the government regularly engages and collaborates with people, communities, and civil society based on shared values rooted in equity, social justice, and anchored in a human rights approach – ultimately to co-craft a people-centred health system that leaves no one behind.

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PUTTING FORWARD THE VALUE PROPOSITION: WHY PRIORITISE SOCIAL PARTICIPATION

By: Dheepa Rajan, Kira Koch, Nanoot Mathurapote and Vesna Kerstin Petrič

Summary: Social participation can bring together the health system and communities in a structured, purposeful, equitable, and performance-enhancing way. This article highlights the rationale for embedding social participation mechanisms into the modus operandi of health sectors worldwide. It shows that social participation can help health systems effectively serve their populations by aligning services with demographic needs, expectations, and experiences. The accountability, transparency, and trust nurtured by social participation also contributes to health system resilience, particularly in the face of emergencies and crises. Social participation is thus not merely an add-on to health system governance but rather a fundamental principle that underpins its success.

Keywords: Social Participation, Civil Society, Universal Health Coverage

Introduction

Policymakers’ aim for any health system is for it to perform at its best, with health system investments and interventions leading to the achievement of overarching goals such as enhancing population health and well-being, and attaining universal health coverage (UHC). UHC entails ensuring that every individual receives essential health services without facing financial hardship. Central to this concept is the notion of defining services as ‘necessary’, implying the fulfillment of basic and indispensable health needs within a population.

However, discerning these needs, particularly within communities with poor health outcomes, presents a challenge for policymakers. Increased interaction between policymakers, service organisers, and beneficiaries enhances understanding of community health needs, thereby fostering good governance, more responsive services and ultimately improving health outcomes. Equity in access to health services across diverse population groups is inherent in the UHC definition, emphasising the importance of ensuring access for all, especially marginalised and underserved communities.

This underscores the critical role of social participation in health systems. Social participation is indispensable because it enables health systems to effectively serve their populations by aligning services with demographic needs, expectations, and experiences. Recognising this significance, a consortium of WHO...
Member States has proposed a World Health Assembly resolution, prompting the focus of this Special Issue.

The draft resolution explicitly emphasises trust and equity as foundational principles driving social participation. This highlights further the rationale for embedding social participation mechanisms into the modus operandi of health systems worldwide. This article elaborates on this specifically and other benefits of social participation, bolstered by real-world country illustrations presented throughout this Special Issue, putting forward the value proposition for social participation in health.

Parliamentary health committees and groups are accountable to the population, heavily involved in health reform, and need information/evidence on the demand side of the health system which social participation can provide. Social participation in this sense can be seen as an essential instrument for policy dialogue. Political parties are usually interested in people’s and civil society’s views to have them better reflected in political programmes. For example, in Tunisia, political parties used the Societal Dialogue for Health discussions to provide citizen-based input into their party platforms. Ministries of finance and planning are likely to show greater willingness to allocate funds to a health strategy or reform when it convincingly demonstrates its responsiveness to the needs and demands of the population. For media, social participation processes offer access to valuable information on how health policies are being implemented and received by its beneficiaries.

Systematic ‘capturing’ of people’s voice is necessary to optimise health system operations and match them to health need, thus promoting equity

One primary benefit of a structured and systematic listening to people’s voices lies in the ability to adapt services accordingly. By tuning into the concerns and preferences of service users, health systems can tailor their offerings to better meet the diverse needs of the population. Whether it involves adjusting service hours, enhancing cultural competency in service delivery, or incorporating more home-based therapies, this responsiveness ensures that health services remain relevant and accessible to all.

A particular benefit of this goes to underserved populations, highlighting that social participation is a crucial strategy for realising the health system goal of equity. A recent WHO Europe report underscores that social participation is a key driver of health equity, highlighting the fact that it helps detect the specific needs of underserved population groups and reduces biases in favour of the most advantaged in society.

Furthermore, the voices of individuals and communities provide invaluable input for updating population risk profiles. For example, in the United Kingdom, local governments through NHS commissioning bodies leverage public consultations to stay up-to-date on people’s health needs and risks. Through their lived experiences, people can shed light on emerging health threats, underlying social determinants of health, and specific vulnerabilities within certain demographic groups, thus promoting equity. This information enables health systems to prioritise resources, develop targeted interventions, and mitigate health risks more effectively.

In addition, capturing people’s voices facilitates the tailoring of health promotion messages. By understanding the communication preferences, literacy levels, and cultural norms of different communities, health communicators can design messages that resonate with their intended audience. This increases the likelihood of message uptake, behavior change, and ultimately, improved health outcomes.

How exactly does social participation add value to health systems?

Social participation processes offer a key source of information for policymaking

A range of stakeholders value the information, data, and insights coming from civil society and population engagement mechanisms for a variety of reasons. For example, governments and ministries of health have high technical expertise and access to evidence but often have limited knowledge of the realities on the ground, including the expectations, demands, lived experiences and needs of the populations they serve. Collaborating with civil society organisations who work in and with communities allows for community-level insights to underpin policymaking.

Moreover, the insights gleaned from lay people, testimonies of lived experiences, and civil society’s perspectives are instrumental in increasing service utilisation. It is through a deeper understanding of barriers to access – for example, transportation issues, language barriers, or financial constraints – that health system actors can design adapted ways to address them. For example, during the HIV crisis in late 1980s and 90s, the Slovenian government worked hand in hand with the HIV community and NGOs representing them to jointly put in place harm reduction programmes for drug users. This approach, with a programme
health services, including underserved communities where government reach is generally poor and where a disconnect often exists between government efforts and community needs.

It is important to remember that health sector planning and policymaking is not usually very visible to people and communities, despite the fact that they are the ones for whom it is done. By providing a forum where the content of planning and policymaking are discussed, social participation processes nurture a better understanding by the population of policy priorities.

Social participation is a key pillar for increasing population trust in the health system, in health services and institutions, and in government in general

Trust is pivotal not only to ensure that the population uses health services when in need but has also been associated with effectively managing a health emergency, smoother implementation of health policies, and achieving better health outcomes.

Central to the creation, fostering, and sustainability of trust within health systems is social participation. Social participation helps to build interpersonal trust in society, a notion which was studied empirically during the Covid crisis, demonstrating, in certain settings and conditions, associations with improved adherence to Covid containment measures and Covid outcomes.

Social participation also validates people’s lived experiences and perspectives by actively engaging individuals, communities, and civil society in policy development, implementation and service delivery. This validation is a key aspect of building trust between people and their policymakers, providers, and governments, i.e. those responsible for the health system. Listening to and validating people’s perspectives also facilitates the co-production of care, where individuals become active partners in their own health management, fostering and fostered by a trustful relationship between provider and patient.

The recent policy brief published for the WHO Tallinn Health Systems Conference (December 2023) entitled ‘Trust and Transformation’ further underscores the importance of social participation in cultivating trust within health systems as a foundational element for health system transformation. The brief highlights that trust is the fabric which binds together the society and health system; much of the loss of trust which occurred during the Covid crisis and is currently occurring in an increasingly polarised world needs to be won back through measures such as investing in social participation – at least if countries are serious about health system transformation.

Social participation is an absolutely vital element of health system resilience

Proactive engagement between government and people enables health system planning and decision-making to align with evolving needs, challenges, and emergencies, thus enhancing its adaptability and resilience. By actively soliciting feedback, listening to diverse perspectives, and involving stakeholders in health service planning, the health system becomes more responsive and agile in addressing emerging health issues and crises. Furthermore, as described previously, such interaction builds a sense of ownership and shared responsibility among stakeholders, who already possess a deep understanding of each other’s skills and expertise. This synergy obviates the need for extensive mapping exercises that were conducted in numerous settings at the onset of the COVID-19 pandemic, besides fostering a collaborative approach to health which is resilient when a disruption or health system shock hits. For example, in Thailand, the health assembly platforms at provincial and local levels were key vehicles for clear emergency response communication between national Covid-19 policymakers, implementing authorities at regional levels, and local government.

The Thai example underscores the importance of pre-existing channels for information and communication (social participation mechanisms) between crisis responders and those affected the most by a crisis to be invested in before a health emergency arises; relationships need to have been built prior to a crisis.
and trust already fostered. This can then be leveraged in service of the emergency response, as in Thailand. A hallmark of resilience are thus social participation mechanisms which are fully functional and integrated into health system operations as they lend the system the capacity to ‘bounce back’ after a shock. In the majority of health service delivery contexts, social participation predominantly takes place within the realm of primary health care, as it serves as the convergence point between the health system and communities, addressing the holistic health requirements of both individuals and populations. Close interaction between those who provide services and the communities themselves is especially crucial for vulnerable groups who are usually disproportionately affected by shocks, and where government reach is limited. The grassroots resourcefulness of civil society and community groups can counteract those disproportionate effects with their trustful links to people as well as the primary care services of the health system.

Social participation forms the cornerstone of accountability and transparency

Social participation processes give stakeholders the opportunity to voice concerns, provide feedback, and contribute to shaping the direction and priorities of initiatives. Such processes thus empowers individuals and communities to hold institutions accountable for their actions, policies, and use of resources. By actively engaging with stakeholders and soliciting their input, governments demonstrate a commitment to responsiveness and integrity, thereby enhancing public trust and confidence in their operations. An important point here are feedback loops which keep information flowing in both directions between people and policymakers – transparency and accountability are increased when communities are informed how the results of a participatory process are used. Governments who engage in social participation as part of the health sector modus operandi are thus put in the position of explaining health policies and interventions and being accountable if they are not done or done differently.

Transparency is fostered through social participation by providing people and civil society joint access with policymakers and other stakeholders to much of the same information, reflections, and deliberations. Such a transparent system makes government actions more visible to all stakeholders, favouring more accountable conduct and a greater consciousness for policy responsiveness.

Social participation provides a key means for monitoring health system performance

Monitoring health system performance requires a thorough examination of data and health system information in order to identify problems and understand the reasons behind them in view of a solution. Social participation as an integral part of monitoring efforts can shed light on a wide variety of root causes and possible solutions which require different perspectives on the data and information. Performance assessments also require context to understand much of the (quantitative) data, context which participatory processes can provide. Participatory monitoring and evaluation also create a learning system that then can generate better information for improving health services and, ultimately, overall system performance. For example, in one comparative study of maternal & newborn health programmes in several districts in Mombasa County, Kenya, districts which employed participatory monitoring and evaluation approaches were found to have better quality decision-making than those that did not.

Social participation basically facilitates the collection of real-time data and feedback on various aspects of health system performance through mechanisms such as community meetings, citizen surveys, and public consultations, among others. These platforms provide policymakers with firsthand information on the experiences and satisfaction levels of service users, enabling them to identify both strengths and weaknesses in service delivery. In addition, by engaging with local leaders, community organisations, and civil society groups, local knowledge, resources, and networks can be leveraged to find locally adapted solutions to improve performance.

Conclusion

Social participation is a key means to bring together the health system with its communities in a structured, purposeful, equitable, and performance-enhancing way. It is that purposeful commingling of communities’ lives and health system operations which fosters accountability, transparency, and trust in health systems.

The accountability, transparency, and trust nurtured by social participation contributes to health system resilience, particularly in the face of emergencies and crises. A close and trustful connection between the health system and the people and communities it serves allows for the adaptation to evolving needs and a tailored emergency response, ensuring a more effective recovery process.

In addition, social participation’s strength and necessity for health systems lies in its ability to provide a source of insight, understanding, and information for monitoring health system performance. Participatory mechanisms such as community meetings, surveys, and consultations, lay citizens and health stakeholders offer real-time feedback on the accessibility, quality, and effectiveness of health services. This invaluable input not only helps identify areas for improvement but also facilitates the development of contextually relevant solutions tailored to local needs and circumstances, making it a key driver of health equity.

Contextually relevant solutions which arise from structured interactions in participatory spaces need not only be implemented by government but by all parties – beyond government, civil society and community groups can be the lead implementing parties where it makes sense and where government reach or capacities are limited – or where civil society’s added value and trust enjoyed locally makes it a more viable implementation option.

Social participation is thus not merely an add-on to health system governance but rather a fundamental principle that underpins its success. This is precisely why the proposed World Health
Empowering people, communities, and civil society through social participation

Assembly resolution calls on investing in and strengthening social participation mechanisms now more than ever.

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INFORMING DECISION-MAKING FOR HEALTH: HOW TO STRENGTHEN POLICY UPTAKE OF SOCIAL PARTICIPATION RESULTS

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Summary: One aim of social participation is to provide new input for better informed health policymaking. However, this is not always perceived as a priority, and several conditions are required to avoid this “deliberation to policy gap”. Some are linked to political will and commitment as preconditions for building a culture of participation in strategic and political debates. Others depend on the format and design of participatory spaces, to level out power imbalances and to allow all participants to speak with an equal voice. Through illustrations from Thailand, Ecuador, Tunisia and Mali, this article provides a flexible approach for thinking about how to ensure policy uptake in each context.

Keywords: Policy Uptake, Social Participation, Decision-Making, Dialogue Spaces, Representativeness

Introduction: How social participation can change the game in decision-making for health?

One aim of social participation is to provide new input for better informed health policymaking. This is not to say that other social participation objectives beside policy influence are not relevant nor desired, but that social participation can add value to decision-making by providing missing users’ perspectives and experiential knowledge to build more user-centred, responsive, and resilient health systems.

In practice, most countries have multi-partner coordination bodies and some level of consultation and participation with representatives of the population, communities and civil society. Yet only a few integrate them into policy- and decision-making.

The disconnect between participatory processes and decision-making is referred to in the literature as a “deliberation-to-policy gap” and can be explained through Figure 1 which illustrates how decisions should ideally be taken within a national health planning dialogue process.
Empowering people, communities, and civil society through social participation

Taking policy decisions based on relevant data raises no major question. Yet, the evidence used must extend beyond research-based and classical scientific evidence to more qualitative data and experiential knowledge about how the implementation of health policies can impact on the daily life of populations and their interactions with the health system. The public targeted by the policy issue must be given a real voice by supporting their capacities and creating open and inclusive dialogue spaces (also called participatory spaces). Not all social participation approaches intend to influence policy decisions, but when they do, this last step is often a major challenge.

Such a deliberation-to-policy gap exists in many contexts, although little guidance and documentation are available on the subject. This article aims to contribute to filling this gap by exploring how countries like Thailand (see Box 1), Ecuador, Tunisia, Mali and others are leveraging the power of social participation to meet their own policy objectives and positively impact the health and well-being of populations.

The devil is in the details: how participatory processes are implemented heavily influences policy uptake

Integrating the outcomes of social participation into policy decisions is highly context-dependent. It requires a transformation of institutional and organisational arrangements, the acquisition of soft and hard skills by both government actors and participants to the dialogue space, to progressively

**Box 1: Developing policy recommendations through the National Health Assembly in Thailand**

Since 2008, the National Health Assembly (NHA) has been convened annually as specified by the National Health Act in 2007. It brings together representatives from the government sector, civil society, academia, the private sector and youth for the development of public policy recommendations to the National Health Commission (NHC). Civil society involvement is not limited to consultations and public hearing, but extends to all steps of the NHA, including agenda setting, drafting resolution, and policy adoption. The NHA then passes resolutions on the principle of consensus, yet they are not binding for policymakers (NHC and Cabinet).

Civil society organisations have a certain number of seats in all NHA mechanisms to ensure that the voices of people are reflected in decision-making and health policies. In addition to the NHC and the NHA organising committee, these mechanisms were extended to include the NHA resolution follow-up committee, with a specific role to monitor the progress and improve transparency and accountability.

As of 2023, 36 out of 96 resolutions are considered as achieved according to four criteria: (1) being completely implemented, (2) having key outputs produced, (3) being accompanied by an action plan, strategy, or other mechanism involving the responsible government agency, and (4) having been implemented in more than five sites. Once one of the four criteria is met, those resolutions are no longer monitored by NHA mechanism.

Despite significant progress, some challenges remain for improving policy uptake of participatory input. This includes strengthening the capacities and knowledge of civil society and addressing the high turnover of government civil servants and decision-makers to ensure the long-term commitment of responsible government agencies.
change the modus operandi on how to approach participatory governance and policymaking.

This section provides an overview of three essential determinants that facilitate policy uptake: (1) political commitment; (2) format and design of the participatory space; (3) and government capacities needed.

**Political commitment**

*Why is it essential to make social participation impact on decisions in the long run?*

The first condition for policy uptake is that decision-makers are willing and committed to open the floor to new perspectives and invest in establishing a transparent culture of participation.

Such a cultural shift does not happen overnight. Instead, it is cultivated by increased exposure of all stakeholders to participatory processes. One-off exercises can, of course, help provide specific solutions to specific issues, but participants need regular interactions and long-term relationships to forge a shared identity of participation and understand how considering different perspectives can better serve both their respective and mutual interests. A certain level of political will is required to ensure that interaction is, indeed, regular, and not ad-hoc.

Examples from Thailand and Ecuador (see Boxes 1 and 2) also illustrate how regular exchanges were determining factors in iteratively refining the format and design of participatory spaces, opting for a combination of mechanisms fitting the target public and policy issues at stake, and progressively strengthening the capacities of all to exchange on a level playing field. By fostering the participatory culture in tailored spaces and processes, they concretely improved the influence of populations on policies.

That multi-stakeholder participatory culture can help to sustain political will during the inevitable ebb and flow of political attention and support for social participation. This is exemplified by the Tunisian case (see Box 3), where sustained efforts from the civil society allowed overcoming a temporary drop in the government’s commitment to social participation, which is becoming an integral part of health policies and participatory governance processes.

Box 2: Quito Municipality’s social participation system in Ecuador

In Ecuador, social participation rights have long been supported by a strong legal framework, beginning with the Republic’s Constitution and national laws. Building on this foundation, the Quito Municipality has been investing since 2006 in developing, regulating, and improving a comprehensive social participation system. This system aims to implement the principles of democracy and inclusion in health and other sectors. A further step was taken in 2022 with the issuance of the Municipality’s Code, which delegates an increased role to assemblymen as social participation representatives in bottom-up decision-making processes on all municipality policy issues. The Directorate of Citizen’s Participation and Social Oversight of Quito Municipality is the department in charge of organising and coordinating the system. Within this revised system, perspectives and needs from all sectors are reflected through a vast network of neighbourhood, parish, and commune assemblies, represented in the Quito Assembly and the city’s planning council.

The Quito Assembly is the highest authority ensuring that social participation inputs directly feed into the Municipality’s public policy cycle, from the definition of investment priorities proposed by the basic units of planning (local assemblies) to annual budget project approval and participatory review of the quarterly execution plans. It then plays a major role in holding health authorities accountable to the population they serve.

Another important process of social participation in Quito is the so-called “participatory budget”, which has been in place since 2006 and has also been strengthened in 2022. In this mechanism, citizens gather in parish assemblies to decide on the priority infrastructure and social projects to be supported, and on the allocation of at least 60% of the city’s related funds. The Municipality’s role is limited to providing the necessary expertise and technical support to help citizens make informed choices, with a budget amounting to USD 23 million in 2024.

These elements contribute to a democratic governance between the District’s Municipality and its citizens, positively impacting on various social determinants of health such as public spaces, mobility, healthy habits, risks management, and the economic environment.

Source: [1]
Box 3: The resilience of civil society in Tunisia in pushing the population’s voice on the policy agenda

The process of Societal Dialogue (SD) for Health in Tunisia started just after the 2011 revolution, as a bottom-up request from civil society to respond to population needs and to ensure right to health. The government rapidly recognised the political importance of the movement. With support from WHO and EU, in 2012 it launched an unprecedented nationwide dialogue process, gathering population, civil society, parliament representatives, experts, and government representatives in various participatory spaces, for open debates on their views, expectations, and recommendations on health. The SD produced a White Book in 2014, which provided a shared situational analysis and vision for the Tunisian health system. Subsequently, in 2019, the first National Health Policy was developed and officially adopted by the government in 2021. However, the relations between SD Technical Committee (TC), acting on behalf of populations, and the ministry of health (MoH) slowed down from 2015 to 2016 due to high turnover in ministers’ positions, subsequent loss of institutional memory, and a retreat to traditional positions of dialogue between experts, accompanied by a fear of challenging positions emerging. During this period, the SD exerted no influence on policymaking.

Three factors facilitated a more conducive environment for dialogue since 2017. First, the TC sustained support to grassroots population groups and civil society, which helped renew the Minister’s engagement towards social participation. Second, the government could not ignore the positive perception of the SD that was garnering increasing attention on the international scene. Third, several non-state health partners continued to adopt similar mechanisms and maintain a participatory culture in their projects and programmes. These factors, supplemented by sustained advocacy efforts from the TC and some MoH cadres, convinced the government and ministers about the benefits SD could bring for better-informed decision-making processes.

Today, the government is firmly committed to social participation, and policy uptake is on its way. Sustaining and institutionalising SD is one of the strong recommendations of the National Health Policy adopted in 2021, and a national participatory governance committee was created within the MoH to implement it through a national strategy for citizens’ participation in health decision-making and a dedicated regulatory framework.

Source: Eurohealth — Vol.30 | No.1 | 2024

with decision-making authority, but also involved the mid-level hierarchy (departments, regions, among others) as key informants and decision-makers regarding the actual implementation of orientations into concrete strategies and activities. This was not done during the first phase of the Societal Dialogue for Health in Tunisia, creating many challenges for policy uptake. Reverting back to Thailand and Ecuador, having mid-level government cadres on board there helped to recognise the need for specific follow-up mechanisms to iteratively improve participatory processes by reporting on policy uptake and implementation results to population representatives.

These feedback loops between policymakers and participants of a deliberation exercise are precisely one of the mechanisms to transform governance practices in the long run. On the public’s side, it contributes to building trust and maintaining their motivation by concretely presenting how their input was used in decision-making and explain why if it was not. On the policymakers’ side, improving accountability and transparency raises their awareness about the benefits of social participation and improves the likelihood of public input being incorporated into policies and guidelines.

A distinction can be made between social participation approaches aiming at improving service delivery and those oriented toward participatory governance. The former seeks to raise awareness and mobilise communities on specific health issues through a community health approach (e.g., vaccination campaign) and mainly requires one-way communication flows. The latter focuses more on a two-way dialogue process to nurture fruitful dialogue between stakeholders on how to improve responses to complex issues, whether at national level (NHA in Thailand and SD in Tunisia), regional level, (Quito Municipality in Ecuador) or local level (participatory governance of health facilities in Mali, see Box 4). Yet none of them is limited to one level. For example, the MoH in Tunisia capitalises on local dialogue spaces and the support from SD Technical Committee, while in Mali, population expectations are channelled up to regional and national levels through a network of federations.

Similarly, both approaches overlap considerably. Although most service delivery approaches do not intend to influence policies, they also generate a wealth of population insights. As they are common in countries, they provide an excellent opportunity to instil social participation values and enlarge the knowledge base on users’ needs and preferences. One should then consider them as complementary and seize all opportunities to inform decisions and improve governance.

In doing so, population representatives are not only considered as beneficiaries, but as key informants and partners in decision-making with a valuable perspective on the solutions to be provided. In some cases, citizens can even act as the sole decision-makers as illustrated by the “participatory budget” approach in Ecuador (see Box 2). The more their representation role will
Box 4: The local and bottom-up participatory governance processes in Mali

The story of Community Health Associations (ASACOs) in Mali dates back to the early 1980s. At that time, studies conducted on the positive effects of grassroots women’s associations on access to health services convinced the government of the untapped opportunity such associations represented for decentralising the governance of health areas to those who were the most in touch with local realities.

The first ASACO was created in 1986, and the model rapidly spread throughout the country. Each ASACO is now organised in a Board, a management committee, and a surveillance committee, elected by its members. They sign a “Mutual Assistance Agreement” with the local Mayor on behalf of the government, clarifying mutual roles and responsibilities.

The ASACOs fill two essential functions. First, in terms of service delivery, they ensure the local management of the community and reference health centres. This includes not only support to promotive, preventive and curative care, as in other sub-Saharan countries, but also community leadership on all strategic, operational, and management decisions (including annual planning, recruitment, salary, stock, among others). Decentralising decisions proved essential during the COVID-19 pandemic, where ASACOs demonstrated resilience and creativity in maintaining services for the population.

Second, ASACOs contribute to decision-making for health through a nationwide bottom-up planning process supported by a network of federations composed of ASACO representatives, through FELASCOMs at the district level, FERASCOMs at the regional level, and the FENASCOM at the national level.

As representatives of the population, these federations are considered to have a legitimate voice to actively contribute to national health policies and strategies, although this is not materialised through voting rights or similar processes and hence difficult to demonstrate. Yet they have proven to have a decisive role in some key policy issues, including the passing of the decentralisation policy, the community health law, or the opposition to initial rules for ASACOs that were considered too instrumental.

Recurring challenges include power struggles in some ASACOs that undermine public confidence and community dynamics, with insufficient mechanisms to arbitrate potential conflicts, and weak regulation by the State.

Source: 12

be valued and legitimated, the more policymakers will be willing to endorse participation-based input of all sorts into policymaking.

Another distinction can be made between “invited spaces” that are created by the government to dialogue on a policy issue, and “claimed spaces” that are initiated by civil society or researchers with or without the objective to influence policies. Both are needed in practice and have their own down- and upsides. Policy uptake is more likely with invited rather than claimed spaces, as the underlying issue is already valued by authorities. Yet, as exemplified in the Tunisian case (see Box 3), claimed spaces can contribute to changing the game by pushing onto the political agenda topics or viewpoints which were neglected or not identified as important. In case they end up being considered as legitimate by authorities and become institutionalised, claimed spaces have a strong potential to influence policies through the virtuous circle on shared views it creates between policymakers and communities.

That said, participatory input will more easily be considered for policy decision if it aligns with the government views. It does in no way mean that participatory process can be used simply as a rubber stamp to legitimise preconceived decisions by authorities. Contributions and experiential knowledge of the population must be valued in policy debates, including to challenge the policymakers initial positions. This is what happened in Mali where the government understood how ASACO could become partners for decentralisation policies (see Box 4).

Tokenism leads to mistrust and frustration on all sides and may raise scepticism toward the very principle of participatory approaches in the long run. It is also important that population representatives feel they are given equal consideration if final decision results from a vote. It is one of the frustrations raised by civil society organisations in Portugal who hold six of the 30 seats in the National Health Council, and report being overcrowded on controversial topics by professional associations, health authorities and academia. 13

Finally, participation-based input can be more easily translated into actual policy decisions if it is backed by some form of legal framework. This provides an official mandate for public participation that helps ensure the regularity of structured stakeholders exchanges in the health sector’s modus operandi. It is key for fostering a culture of participation which gives people, including those with the weaker voice, the necessary exposure to each other to find common solutions and ultimately shape policies accordingly.

However, legal frameworks offer no guarantee, and countries have different stories to share. In Portugal, the Basic Health Law was adopted in the early 1990s but took 25 years before leading to the creation of the National Health Council. In Tunisia, the Societal Dialogue process that followed the 2011 revolution emerged from a request for more dialogue from grassroots movements, and only then started being secured under legal frameworks and policies. Meanwhile, countries like Thailand continue to progressively build and enforce their
nationwide participatory model thanks to favourable political will and policy environment.

**Format and design of participatory spaces**

**How to foster the influence of populations and communities on policy decisions?**

If political will and commitment set the direction, the format and design of a participatory process provide the concrete conditions for increasing the likelihood of policy uptake. This section draws attention to key points to be considered in developing, moderating and adapting participatory spaces.

Firstly, framing the right policy question and submitting it to the right public is pivotal to be considered as legitimate for both participants and policymakers. It secures their interest and willingness in taking participatory process results seriously, thereby increasing policy uptake. The policy question to be addressed will determine the type of participant and public to be included in the debate. For example, discussing migration, HIV/AIDS, or sanitation issues will not require insights and experiences from the same participants, although there are often overlaps.

The more justified, open, and transparent the selection process is, the more legitimate it will appear to stakeholders, and the more likely it is that the results are taken into account for policymaking. For example, informing and making clear to all stakeholders why each participant or group’s presence is required avoids questioning any single participant’s legitimacy to contribute. It also acknowledges the respective wealth each type of participant brings to debates and decisions.

The selection of participants can extend to hard-to-reach groups who might be neglected (e.g., older people, disabled, migrants), and individuals with personal lived experience to provide qualitative input on how the policy issue affects their daily life (e.g., COVID-19). As they can feel uncomfortable with the process, participatory mechanisms can extend to separate meetings or events to document their views and then feed them separately into the debate. All of these measures increases the legitimacy of the discussions, the results of which are more likely to be taken up into policy decisions.

Secondly, bringing together evidence and participation increases the likelihood of policy uptake. The experts’ mandate here is about orienting lay citizens or civil society towards a greater understanding of the evidence which may not be otherwise accessible to those who are not from the specific technical field. Such processes where technical experts and civil society and community members come together allows for a practical, implementation-oriented discussion on the evidence which is useful for policy. In Thailand, the National Health Commission organises thematic working groups constituted by members from the community, government and academia. These working groups propose resolutions for the National Health Assembly which include concrete orientations for implementation. In Ecuador, under the participatory budget approach, the Quito Assembly supports citizens in managing evidence and making informed choices.

In practice, many highly professionalised civil society organisations may have in-house experts and may be well-known evidence generators themselves. Such civil society groups are often better able to influence policies. The role played by the SD Technical Committee in Tunisia was determinant to sustain social participation approaches among populations and translate their inputs into proposals likely to catch policy attention. In other cases, professionalising might also bring the risk of losing the link and perspective of communities and lay people, and hence their capacity to represent people’s voice. For better policy uptake in these contexts, maintaining community linkages or partnering with those who do is essential. In countries like Mexico, professionalised civil society organisations partner with local community groups to leverage grassroots voices and experiential knowledge to complement more technical analyses. This alliance has helped Mexican civil society influence health budget decisions through targeted advocacy, combining highly technical budget analyses with information from the ground on how budgets are actually implemented as planned. This may be a weakness in the Mali model, where communities’ input mainly results from a bottom-up approach rooted in the realities of local health centres and could miss out on some important technical issues.

Those alliances are powerful tools to improve policy uptake. By bringing together different groups concerned about the same subject (civil society, population, academia, among others), alliances leverage complementarity of skills and knowledge, increase legitimacy, and lead to more feasible solutions. For example, in Burkina Faso, a civil society coalition was able to amplify the voices of individual civil society organisations in the development of the free healthcare policy for pregnant women and children under five years old.

Finally, as discussed across this section, regularity of interactions proves to be essential to strengthen mutual trust and help all participants progressively developing a shared identity and fruitful collaboration processes. It increases the likelihood to align on solutions and build concrete recommendations facilitating policy uptake. Long-term relationships also increase the opportunity to reach a consensus, or more realistically a compromise, where all parties understand they cannot get everything they want in the debate but feel they have reached the best possible and viable solution thanks to the quality of interactions and mutual trust.
Government capacities

What needs to evolve to harvest the benefits of social participation?

Political willingness and appropriate format and design do not guarantee the development of a participatory culture that yields positive policy decisions for all. It still needs to be accompanied by adaptation in capacities and attitudes of authorities to turn principles into mechanisms and decisions (see the article by Greenley et al. in this issue).

The first issue is that in most countries, health authorities are staffed based on their medico-technical background. Their capacity to steer, convene, manage divergent views, and broker consensus and solutions is not a given, and often requires support and coaching. It is well understood in Thailand, where facilitation skills are the principal expertise sought when selecting chairpersons of a resolution drafting group and many deliberative committees. It is also at the heart of the Quito Assembly in Ecuador, whose mandate is precisely to bring together the perspectives and needs of neighbourhood, parish and commune assemblies. While in Tunisia, skills are being developed within the MOH with the support of key technical experts from the MOH and civil society, who supported the Societal Dialogue since 2011.

It extends to participation-based input, which is in part of a different nature than the usual data and evidence policymakers use in decision-making. Decision-makers need to learn how to interpret the plurality of information and viewpoints produced by open dialogue processes (including experiential knowledge, social dynamics, consideration for multi-sectoral conditionalities) and translate them into priorities for policy. For example, the United Kingdom developed clear guiding instructions on how to handle results from public consultations that proved to be pivotal in incorporating them into decisions. In some countries, this role is mediated by an independent institution or separate unit providing the necessary neutrality in results interpretation for policy uptake. Others privilege the development of specific in-house staff or a full department specialised in public involvement. All approaches are valid as long as they evolve with lessons learnt and progressively contribute to changing governance practices.

In practice, participatory input will only be taken up by governments if they feel that it is in their interest to do so. A big deterrent is when government officials see the participatory process as competing rather than complementary to their views or have the feeling the population will only raise complaints. In Thailand, as civil society groups increasingly came to the table with solutions rather than complaints about problems, the perceived validity of participatory-based input on technical subjects increased in the eyes of policymakers. In Mexico, civil society organisations insisted on having regular meetings with state-level authorities, which turned them from sceptical opponents to allies. Failing to adapt the government perspective can lead to failed promises on the participatory process objectives and durably create mutual mistrust and frustration.

Conclusion

The gap between participatory input and policy decision is not inevitable, but it requires concerted efforts and willingness from all actors concerned about the future of health and well-being in a specific context.

A first condition lies in the political commitment to invest in the long-run in making governance cultures and practices evolve progressively at all levels of the health system. Additionally, the understanding of what is considered valuable evidence must be extended to embrace the wide range of qualitative and lived experience inputs that influence the behaviours and interactions of populations and health professionals.

Such a cultural shift cannot happen overnight; rather, it results from regular exchanges and iterative development of the format and design of dialogue spaces. Selecting the right public for the right policy question, extending to hard-to-reach groups, and openly justifying choices strongly contributes to the perceived legitimacy of participants. In addition, providing support and expertise to all population groups concerned about the issue being debated is essential to help them translate their insights into inputs piquing the own interest of policy makers. Doing so often requires designing specific mediation and coaching functions.

Finally, government officials must also be supported in acquiring the soft skills needed to meaningfully engage in fruitful dialogues with legitimate population representatives, progressively building common trust and a shared understanding of the benefits of participatory governance practices. The more they understand their own commitment of responsible government agencies, while in other countries, it will be related to bureaucratic constraints and cultural resistance.
and adapt to a multiplicity of challenges by developing more people-centred, responsive, and resilient health systems.

References


EMPOWERING PEOPLE: HOW TO ENSURE EQUITABLE REPRESENTATION FOR IMPROVED HEALTH SYSTEM GOVERNANCE

By: Clara De Ruysscher, Jonathan Tritter, Dina von Heimburg, Ottar Ness, Kristina Bakke Åkerblom, Torbjørn Mohn-Haugen, Naomi Limaro Nathan and Gabriele Pastorino

Summary: Social participation in health system governance can help develop effective and efficient health services and promote health system legitimacy and transparency. This article presents a framework for social participation that stresses the importance of diverse representation to ensure all relevant voices are heard. The framework is illustrated with case studies from the United Kingdom, Norway and Portugal. Realising this vision requires investment in capacity-building for individuals, communities and state actors, alongside institutional reforms and community engagement strategies. Together these efforts can promote an ecosystem of social participation that reinforces health system governance and advances the goal of health equity and well-being for all.

Keywords: Social Participation, Representation, Health System Governance, Equity

Introduction

In recent years, the link between formal representation and social participation has been recognised as a key factor driving health system governance and health sector reforms. This article explores how equitable, diverse and inclusive representation in participatory processes can be achieved. Participation and representation are tangible and visible manifestations of the right of individuals and groups to collectively influence decisions concerning health and well-being. When all relevant populations are meaningfully represented in all steps of the policy cycle, social participation contributes to realising the human right to health for all, promoting health equity and creating inclusive and responsive health systems that leave no one behind. It represents a fundamental shift from viewing service users, communities and members of the public as passive recipients to active collaborators in shaping decisions and supporting the co-production of services.

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The article emphasises the importance of fair and transparent representation, where the voices of relevant and affected stakeholders are brought into the social, professional and political fabric of healthcare systems (bottom-up approach), as a pre-requisite for social participation. It is suggested that this cannot be achieved without putting in place appropriate legal and regulatory mechanisms to ensure representation and participatory processes are socially just.

Recognising the importance of shaping evidence-based policy and practice, health system governance has traditionally adopted a top-down approach, where policy decisions are mainly influenced by a select group of medical-technical experts, filtered through a political lens. Despite the growing emphasis on patient-centred healthcare and individual choice in health policy and care, this approach risks reinforcing existing power imbalances and promoting inequalities in terms of healthcare access and outcomes. Social participation is a powerful and empowering mechanism to develop effective and efficient health services and is closely linked to health system legitimacy and transparency. In essence, it is built on the fundamental recognition that the voices of all members of society matter, rather than the loudest or most powerful.

Representation is crucial for generating policy impact. While participatory processes in health system governance tend to emerge bottom-up, top-down mechanisms are required to amplify the voices of those that are usually marginalised or disempowered and to facilitate empowerment, thus fueling impactful outcomes. Together, these bottom-up and top-down dynamics mutually reinforce and facilitate social participation and help realise fair representation in health system governance. Ultimately, a sustainable and systematic approach that promotes inclusivity is needed to make participation in health system governance trustworthy, accountable and effective. Effective participation requires that those who are involved reflect the diversity of perspectives and sensitivities of service users and the public. Moreover, inclusive participatory spaces should be designed and curated to strengthen the capacity, trust and self-confidence of the least empowered. Accordingly, effective representation needs to identify relevant target publics for specific policy issues. This requires the deployment of a combination of recruitment and selection methods to ensure the involvement of different kinds of public in ways that are most appropriate for them. Target publics may be directly or indirectly affected; for example, service users and informal carers are both impacted by changes in service provision.

Figure 1 provides an overarching framework for social participation as a catalyst for health system governance. The framework is built on interdependent bottom-up and top-down efforts that foster the inclusion of relevant and affected voices. In the following sections, the key components of this are discussed and provide three short case study narratives from the United Kingdom, Norway and Portugal, showcase how top-down and
bottom-up approaches together reinforce social participation and representation in health system governance.

**Health systems are shaped by relevant and affected actors and stakeholders**

Health and well-being are created in society as a whole and health system governance refers to “ensuring strategic policy frameworks exist and are combined with effective oversight, coalition-building, provision of appropriate regulations and incentives, attention to system design, and accountability”.[1] Health systems hold the power to shape lives and influence communities, and the health sector has a pivotal role in advocating, promoting and protecting health and well-being and alleviating disease and suffering. At the heart of effective health system governance lies the involvement and representation of individuals, communities, and civil society in policy formulation, decision-making, implementation, and evaluation. Participation must be based on identifying and recruiting relevant publics to specific participation activities that relate to decisions that affect them. Participation should be ongoing rather than one-off ad hoc activities. This may be managed by having a fixed panel composed of representatives from service user organisations.

**Promoting inclusive representation and participation**

*Figure 1* highlights how social participation cultivates trust and legitimacy in decision-making, enhances the efficiency and responsiveness of health systems, amplifies people’s sense of feeling valued, adds value to health-related processes and outcomes and ultimately contributes to the realisation of the right to health for all. Achieving this goal and creating virtuous iterations between the different components (as depicted in *Figure 1*) requires the careful consideration of the procedural, distributive, and corrective dimensions of social justice.[2]

Ensuring the inclusion of diverse voices is a fundamental principle of social participation. A wide range of perspectives and experiences is essential for shaping healthcare systems development and the thorough consideration of both the intended and unintended consequences of any change in policy as well as services. Members of the public must also be involved as they not only have a stake as potential service users but also, reflect the interests of the public that need to be embedded in health systems to ensure that it creates public value.[3] The principle of diversity and inclusion is directly linked to the human right to participate and is essential to ensure legitimacy.[4] Both individual service users and members of the public (potential service users) as well as collectivities, such as Civil Society Organisations (CSOs) with particular knowledge or expertise (e.g., a breast cancer support group or a local community organisation), should be involved. It is vital to balance invited participation with self-selected and grassroots processes, particularly of the ‘usual suspects’ or ‘active citizens’. Although, it is important to engage with the ‘usual suspects’ it should be recognised that while they are willing to participate, they may not be the most critical, the most informed or the most deeply affected.[5]

Central to broad-based, diverse and inclusive participation is the adoption of a mixture of methods enabling different types of participation, including actively reaching out to people in vulnerable situations. Similarly, communication, both about opportunities for participation and about the results and actions arising from participatory activities should be communicated in a way that reaches diverse communities. *Box 1* highlights Lived Experience Recovery Organisations from the United Kingdom to illustrate the importance of flexibility in the approaches to building social participation at local levels in a way that responds to the communities involved. This diversity of approaches encourage participation but also creates challenges for monitoring and evaluation at a regional and national level.

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**Box 1: Case study from the United Kingdom**

The United Kingdom has a long history of supporting service user participation. The Health and Social Care Act 2001 was groundbreaking as it required health service providers to undertake public and service user participation in the planning, development and operation of services. This was revised in 2007 and 2008 to require local authorities to undertake participation to support the identification of service user needs as well as the commissioning and evaluation of services. While emphasising the need for social participation, the Act lacks specificity regarding participation methods, diversity requirements for representation, transparency and monitoring. These aspects are delegated to local authorities and organisations with minimal reporting requirements.

This leads to significant variation in practices, inconsistent implementation and little systematic evidence regarding impact. Nevertheless, innovative practices are arising at the local level. For instance, Lived Experience Recovery Organisations (LEROs) are community-based services supporting people in recovery from problematic alcohol and/or drug use that are founded and led by people with lived experience of recovery. LEROs not only support individual recovery journeys, but also generate community engagement and activate social networks within communities creating “a virtuous circle of growing well-being and self-efficacy on the part of the individual, and a contribution to the community in the form of collective efficacy.”[6] Currently, there are 33 LEROs working in at least 40 local authorities. LEROs are underpinned by a community health model, in that: (1) they are informed by and act in response to the needs and aspirations of their community, recognising and employing existing assets and competencies; (2) their practice is shaped by co-production; and (3) they are informed by a human rights-based approach, including the right to live healthy lives.[6][7]
Unlocking trust, efficiency and accountability in health systems

Equitable, diverse and inclusive social participation injects vitality into governance mechanisms by fostering accountability and responsiveness that encourages trust and promotes efficiency. It transcends the traditional top-down approach, democratising decision-making processes and amplifying the voices of those directly and most deeply affected by particular health policies and specific services. Bringing a multiplicity of perspectives to enrich deliberations helps ensure policies that resonate with the complex realities on the ground. Learning from those who are the most affected by policy proposals can support policymakers to proportionately prioritise public resources to meet those with the greatest need.

Selecting the most relevant target public for a particular policy issue and the appropriate representation of the most affected groups is crucial to support policymakers in making trustworthy decisions and set legitimate priorities. Moving from legislation and policy statements to actual strategies and measures to improve representativeness and inclusive participatory practices can create the space for the inclusion of lived experiences as an essential element of knowledge-based policymaking. Such an approach challenges and complements classical expert-driven evidence used to inform decision-making processes. When the target population is unable to raise its voice, CSOs, ombudsmen and experienced experts can act as intermediaries to support health systems governance. Such representative roles can help leverage and support alliances to sustain participation and representation at all levels by laws, regulations and guidelines (The Patient and User Rights Act 1999; Health and Care Services Act 2011; Health Enterprises Act 2002).

Even though user involvement in healthcare is required by law, it is not always guaranteed. User involvement at the service and system level has strived to extend beyond tokenism by inviting representatives from user organisations. However, user organisations often argue that they are given a limited role and that key decisions are made without their input prior to their invitation.

In the last decade, the Norwegian government has promoted user participation in the mental health and substance use field by encouraging the employment of ex-service users as peer workers. A series of national policy documents showcase the role of peer workers as a mechanism to represent the service user voice in service delivery, such as the “National Health and Hospital Plan 2020–2023” (Meld. St. 7 (2019–2020)). These policy documents also highlight that increased collaboration between service users and service organisations can create more socially inclusive and effective service solutions. The government-backed plans and policy documents have introduced financial incentives to reinforce peer worker involvement, creating significant traction in peer worker employment in Norwegian mental health and substance use service organisations. Since 2017, peer workers have been united in their own organisation, Erfaringssentrum – National Association of Peer Workers, funded by the national government. They are also involved in policy development at a national level. Peer workers employment validates experiential knowledge and challenges biomedical dominance in health. Peer workers often serve as intermediaries, bridging the gap between service users and health systems and between different forms of knowledge. They play a crucial role in establishing trust between the most vulnerable citizens and their service systems.

Box 2: Case study from Norway

The Norwegian healthcare sector highly prioritises service user participation and representation at all levels by laws, regulations and guidelines (The Patient and User Rights Act 1999; Health and Care Services Act 2011; Health Enterprises Act 2002). Even though user involvement in healthcare is required by law, it is not always guaranteed. User involvement at the service and system level has strived to extend beyond tokenism by inviting representatives from user organisations. However, user organisations often argue that they are given a limited role and that key decisions are made without their input prior to their invitation.

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Box 3: Case study from Portugal

The Portuguese National Health Council (NHC) was established as an independent advisory body to the Government in the definition of health policies. It was enacted in 2016 to strengthen “citizens power” and as a “way of promoting a culture of transparency and accountability towards society” in the National Health Service (NHS). One of the reasons for its enactment was the activism and political push by CSOs, mainly patient associations.

The NHC represents a milestone in efforts to institutionalise social participation in Portugal. However, its legally binding structure, including the organisational and administrative set-up, has been criticised as hindering civil society representation, particularly in the membership composition of the Council. Currently, civil society representatives are appointed by the Assembly of the Republic (the Portuguese Parliament), which creates challenges for the representativeness of the Council, both because of the limited number of seats available solely to specified CSOs and because the selection lacks transparency and is ultimately often based on existing links between CSOs and political parties. The absence of a clear process guiding the selection of individuals or opportunities for CSOs not specified in the legislation to participate, challenges claims of broad-based representation and risk to reinforce and reproduce existing hierarchies.

The NHC functions as a national platform for dialogue and has the potential to enable civil society participation in policymaking. However, in order to fully achieve this, it is important to ensure adequate representation of citizens and regular National Health Service users in the Council, as a way to promote an ecosystem for social participation that reinforces health system governance and advances the goal of health equity and well-being for all.

Conclusion: Using representation to support an ecosystem of social participation

Representation in the governance of health systems offers significant potential for generating legitimacy and improving efficiency in the organisation of health systems and the delivery of health services. As demonstrated by the case studies in this article, fostering an ecosystem of social participation requires a virtuous interplay between formal representation and empowered participation from relevant and affected actors. Such an ecosystem can boost transformative change to promote and safeguard universal health coverage and to foster more equitable and sustainable health and well-being outcomes for present and future generations. By amplifying social participation through appropriate representation, policymakers lay the foundation for a more responsive, equitable and effective health system that responds more efficiently to people’s needs.

However, realising this vision requires concerted efforts to address structural inequalities, promote participatory cultures, and embrace the diversity of human experience. Ultimately, the journey towards health equity and justice begins with recognising the inherent dignity and agency of every individual, inviting them individually and collectively to take their rightful place at the governance table.

By selecting and giving space to relevant and affected individuals, representatives and CSOs, policymakers can harness the collective wisdom and resources of target groups and the wider public. This approach facilitates the design and implementation of more responsive and effective health policies and programs and fosters co-creation and co-production of both individual and collective health and well-being.

Prioritising investments in capacity-building initiatives for individuals, communities and state actors, alongside institutional reforms and community engagement strategies, is essential. Together these efforts will promote an ecosystem of social participation, equitable, diverse and inclusive representation in health system governance, advancing the overarching goal of health equity and well-being for all.

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ASKING AND LISTENING: HOW TO STRENGTHEN GOVERNMENT CAPACITIES FOR SOCIAL PARTICIPATION

By: Rachel Greenley, Mathieu Noirhomme, Pascal Mélihan-Cheinin and Dheepa Rajan

Summary: Meaningful social participation requires bringing all participants on an equal footing in terms of their skills and abilities to freely interact in the dialogue space, and develop a shared culture of trust, responsiveness, and people-centredness. Building and sustaining government capacities is crucial for engaging with communities in constructive participatory mechanisms in health. Governments require technical, recognition, and communication skills for social participation, as exemplified by Ecuador, France and the United Kingdom. The journey to embed meaningful social participation in health governance requires continuous learning, adaptation, and resource allocation, with practice and perseverance being vital for effective government engagement.

Keywords: Government Capacity, Dialogue Spaces, Communication Skills, Social Participation

Introduction

Good governance enables the health system to perform well. An important element of good governance is effectively incorporating people’s voice into policymaking to make policies more responsive, thereby ensuring closer alignment with the needs and expectations of the population. Although many countries apply some form of stakeholder consultation in their decision-making processes, many fail to go beyond that. For others, questions linger regarding the prioritisation of social participation within governmental agendas. Even in instances where it receives attention, governments often lack the specific capacities required to foster meaningful engagement. Many government cadres struggle to translate the results of such consultations into something actionable and policy-relevant. These capacity gaps are partly due to the lack of literature around the set of skills required for social participation and how to develop them. This article seeks to address this knowledge gap by delineating the governmental capacities necessary to catalyse social participation and elevate it to a prominent position on policy agendas.
Governments can leverage their authority and power to create an enabling environment for participation

Meaningful participation is brought about by creating a dialogue space where every stakeholder has an equal opportunity to influence outcomes. This ‘level playing field’ defines an enabling environment for participation, which governments must learn to foster – yet often do not, as most government officials come from a medico-technical background without the ‘soft skills’ training necessary to manage participatory processes.

Governments have a prominent and undisputed role in political decision-making and policy formation. Yet, creating an enabling environment for participation requires learning when to not impose a position of authority, how to listen actively, and how to extract policy-relevant information from community input. For example, in New Zealand, Māori communities define their health aspirations through the Whānau Ora approach where the government goes into listening mode to co-produce a framework which incorporates the specific needs and perspectives of families directly into the health service planning and delivery.

This article examines three capacity areas within the social participation skill set and clarifies their practical implications for government cadres. These areas encompass technical, recognition, and communication skills (as described in Box 1). It is noteworthy that while these capacities are expressed differently, all are necessary for fostering meaningful participation among stakeholders.

Governments need to cultivate a suite of capacities

Technical capacity

The first dimension of building government capacity is technical skills. Creating inclusive and dynamic participatory processes demands specific technical expertise – those needed to know how to run a participatory space. It requires a deliberate and sensitive approach to dialogue and decision-making. To foster genuine social participation, government officials must know how to select methods and tools that resonate with stakeholders’ specific policy contexts and demographic profiles as well as health policy needs. This means organising the participatory process in a way that allows for the diversity of experiential knowledge and technical knowledge to be expressed so that it feeds into policy and implementation. Moreover, governments should cultivate an adaptive, reflective capacity to refine participatory mechanisms based on past interactions, creating an iterative learning process that enhances inclusivity. A nuanced understanding of governance and of cultural contexts can thus be achieved by fostering government actors’ soft skills such as communication, interpersonal, conflict resolution and problem-solving skills. This cultural competency is vital for enabling all voices to contribute equitably and ensuring that policymaking is responsive to the varied tapestry of community insights. Ultimately, by redefining valuable policy input to include informal yet insightful contributions and aligning technical topics more closely to people’s lives, decision-makers can leverage a broader spectrum of perspectives. This evolution in approach aims to not only inform but also transform governance practices into more effective, responsive, and inclusive outcomes.

Recognition capacity

The second dimension is recognition capacity. Recognising the intrinsic value of social participation is essential for building up shared culture and practice. This means acknowledging the benefit of creating environments where different viewpoints are included, and a range of experience is
Box 2: Benchmark of Fairness in Ecuador

The Benchmarks of Fairness instrument, developed in 2000, evaluates health-system reforms’ effects on equity, efficiency and accountability. It establishes clear fairness criteria based on societal values, and emphasising specificity, inclusivity, transparency, stakeholder participation, and dynamic updates to reflect changing norms.

The government recognised that healthcare reforms for mothers and children under five required community involvement. It formed a diverse coalition, including health ministry representatives, local governments, NGOs, and civil society organisations. Next, it improved health literacy and participatory approaches around the Benchmark of Fairness tool to create equitable spaces and structures. The stakeholder group addressed financial barriers and service quality issues, advocating for equitable healthcare policies. This approach led to policy investigations and adjustments aimed at removing unjust charges and improving service efficiency and quality.

Building recognition capacities evolves through iterative learning. In Ecuador, it started by understanding and valuing the input from community member in tailoring guidelines to fit local needs. The Benchmarks required professionals from different disciplines and levels within the system to listen actively, work together and integrate their different views – which encouraged all stakeholders to take ownership of the results. For governments, this meant managing power dynamics thoughtfully to empower local voices in decision-making processes and being accountable to the population. Clear, non-technical language and engagement of local facilitators who spoke the local language were used, thereby ensuring genuine participation and reflection of local values in the process.

However, this process also reveals potential challenges. Broad coalitions face difficulties in aligning diverse interests and sustaining momentum over time. In Ecuador’s health reform, establishing the recognition of each stakeholder’s voice as fundamental to equitable interaction was the most crucial yet challenging aspect. This necessitated not only an understanding of the cultural context and existing hierarchies within the healthcare system but also a commitment to addressing and integrating these diverse perspectives into the reform process. Such benchmarks depend on the government’s willingness to act on the findings, which can vary depending on political and economic factors in other contexts.

Source: B

considered. The National Health Assembly in Thailand showcases a platform where capacities converge, fostering a participatory environment that enhances civic competence and involvement in health discourse. In Ecuador also, the foresight to use benchmarking tools evaluating equity, efficiency, and accountability helped bring grassroots perspectives to the forefront of health planning and policy reform (see Box 2). Essential to success in Ecuador was the government’s understanding of its role in levelling out power imbalances, relinquishing control by taking a bottom-up approach, and taking ownership in facilitating the process with appropriate resources and finesse. Furthermore, the government demonstrated recognition skills by paying attention to building the capacities and awareness of mid-level technical civil servants and community participants to engage in the process as well.

Communication capacity

The third dimension of capacities relates to communication. This is also properly illustrated in the case of Ecuador discussed above (see Box 2), where measures such as active listening, using diverse channels to gather input, and providing feedback meaningfully helped to develop ongoing communication and interaction with the population and civil society. Simplification of language to remove jargon, coupled with the succinct presentation of information, is also essential for making policy discussions accessible and understandable. These measures not only enable but actively support the exchange of views, engagement with contradictory voices, and an active role in dialogue and coalition building.

We can also learn from France’s approach to the États Généraux de la Bioéthique (General States of Bioethics, EGB) (see Box 3), a large-scale consultation on topics of bioethical relevance which happens every seven years and feeds into the renewal of the Bioethics Law. It fits into a participatory culture in health progressively developed for three decades in France with other platforms – one such being the National Health Conference as featured in Box 3. During the EGB consultations, the French government dedicated efforts to demystify complex health topics, transforming them into understandable content to ensure all citizens could participate meaningfully. Overlooking this commitment to clarity because of the time and resources it requires would bear the risk of undermining the relevance and potential outcomes of policy decisions. These examples show how and why specific and targeted communications skills in government cadres and/or participatory space organisers are absolutely crucial for a sound participatory process.

Offer solutions to the barriers people face to engage meaningfully in participatory spaces

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.

First, socio-economic disparities can significantly restrict the capacity of individuals from lower socio-economic backgrounds to engage in participatory activities due to limited time and financial resources to be devoted to the process.
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Box 3: France’s ‘health democracy’: the Etats Généraux de la Bioéthique and National Health Conference platforms

The 2018 Etats Généraux de la Bioéthique (EGB) in France exemplifies the government’s efforts to engage citizens in significant health and bioethical debates through a diverse communication channels and participatory spaces. This included events with over 21,000 participants, online consultations, civil society hearings, and a citizen jury, demonstrating a commitment to inclusive dialogue. These efforts have been tailored to reach diverse audiences and overcome participation barriers. The mixed-method approach of the EGB mobilised French residents across generations, indicating broad interest in health topics. The government’s strategic media engagement also allowed informing the public about participatory opportunities, amplifying citizen voices in the health decision-making process.

Despite these advancements, the EGB faced challenges. Experiential knowledge wasn’t valued enough compared to technical expertise in debates, suggesting an excessive influence of experts, well-resourced NGOs and lobby groups. Marginalised and vulnerable groups weren’t adequately represented, and unstable financial support hindered civil participation. The three capacity dimensions discussed need to build capacity for participation are interconnected.

To mitigate these inequalities, proactive governmental measures are essential. In Sweden, the government has implemented policies that lower barriers to political participation by subsidising expenses that could otherwise restrain the population’s involvement, such as transportation and childcare costs. This strategy facilitates a more level playing field, allowing individuals from varied socio-economic statuses to contribute to political and societal discourse.

Sustaining those resources is a second challenge. Here also, Sweden’s commitment extends beyond short-term measures to sustained and long-term investment in capacity building and population engagement. This perspective is crucial as it acknowledges that developing a robust participatory culture is an ongoing process that demands consistent support rather than sporadic funding.

It also implies some level of institutional transformation to ensure social participation isn’t transient but becomes ingrained and persistent (see article by Rao et al. in this issue). Pre-existing hierarchical structures and institutional cultures can significantly reduce the population’s trust in participatory processes. Government entities must translate their willingness for change in governance practices to dismantle existing power imbalances, engage with civil society in the long run, and develop a shared culture of participation.

Lastly, a truly enabling environment for social participation is contingent upon the government’s ability to align capacity-building initiatives with the population’s specific needs (see article by Nambiar et al. in this issue). This encompasses leveraging community networks, addressing literacy barriers, and recognising that capacity-building transcends mere knowledge transfer; it requires a shift towards empowerment and a change in power dynamics. By tackling these challenges head-on, governments can foster a robust framework for social participation, ensuring that every voice has the potential to be heard and to influence the fabric of society.

The three skills which governments need to build capacity for participation are interdependent.

Sources: 4 6
Since the late 1990s, the United Kingdom has aimed to enhance social participation in health governance by establishing structured participation channels to feed into health service design. Initiatives like the experience-based co-design (EBCD) by the King's Fund and the NHS Design Principles promote human-centred design, which seeks to improve the quality and effectiveness of health services by weaving together the lived experiences of patients and the professional insights of healthcare workers to co-create services. EBCD has facilitated various objectives, including creating empathetic communication materials addressing chronic patients’ concerns and emotions; redesign patient pathways based on personal patient journeys and determinants of health; creating more welcoming hospital environments; adapting health programs to cultural sensitivities or specific health areas; or streamlining discharge processes, thereby reducing readmissions, and enhancing patient recovery post-hospitalisation.

These successful experiences have shaped a culture of participation in the United Kingdom, strongly supported by the government, and paved the way for other participatory, human-centred approaches. This is evident in the ten NHS Design Principles (like put people at the heart of everything you do, design for the outcome, be inclusive, design for context, design for trust) and a number of government-supported preconditions such as transparent communication, cultural competency, resource allocation, accessibility, evaluation, and supportive policy frameworks to enhance health service design.

The United Kingdom’s commitment to creating a people-centred, inclusive and participatory healthcare system has been underpinned by strong social participation capacities and is now considered as a benchmark for health governance, covering all three capacities. All stakeholders now benefit from a comprehensive set of technical frameworks, methods and tools to develop meaningful participatory processes. The long experience of open dialogue and partnership exemplified by the EBCD approach, has championed a new paradigm of communication based on empathy and inclusivity, encouraging the exchange of ideas across a diverse range of stakeholders, and accountability through various communication channels and feedback mechanisms. As a result, health services reflect patient experiences and preferences, providing evidence-based care tailored to individual needs.

Sources: [1–3]

**Box 4: Investing in participatory processes in the United Kingdom**

Since the late 1990s, the United Kingdom has aimed to enhance social participation in health governance by establishing structured participation channels to feed into health service design. Initiatives like the experience-based co-design (EBCD) by the King’s Fund and the NHS Design Principles promote human-centred design, which seeks to improve the quality and effectiveness of health services by weaving together the lived experiences of patients and the professional insights of healthcare workers to co-create services.

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**Active participatory platforms provide regular opportunities for government to build their own capacities through practice**

Developing capacities for social participation is an iterative process. Governments that engage in participatory processes often have opportunities to learn from both the flaws and successes, progressively gaining the technical, recognition, and communication skills (see Box 1) required to effectively facilitate dialogue spaces that elicit meaningful engagement.

The United Kingdom (see Box 4) provides an excellent example of how the motto ‘practice makes perfect’ helped capitalise on lessons learned through decades of investing in participatory processes in health. By iteratively building a culture and appropriate conditions for social participation, the United Kingdom’s health system stewards were able to build operational capacities and integrate participation into comprehensive frameworks after years of practice.

**Conclusion**

In conclusion, the incorporation of people’s voice into policymaking is central to effective health system governance. Despite widespread stakeholder consultation practices, effectively implementing this type of engagement remains a challenge for many governments. Government can play a fundamental role by developing the three essential capacities discussed in this article: technical, recognition, and communication skills. Equipped with these capacities, governments can overcome traditional policymaking paradigms and adopt a more inclusive, equitable, and responsive governance model. Technical capacities empower governments to design and manage participatory spaces effectively, recognition capacities ensure the value of participation is embraced, and communication capacities adapt communication needs to different audiences. These capacities are not standalone; rather, they are synergistic, with advancements in one area amplifying the others, thereby reinforcing the participatory framework.
The insights derived from social participation stories in Ecuador, France, the United Kingdom, and other countries, provide practical examples of how these capacities cultivate participatory mechanisms that genuinely strive to level the playing field between government, civil society, and the community to incorporate all voices into health policymaking. The journey toward embedding meaningful social participation in health governance is iterative and demands a commitment to continuous learning, adaptation, and resource allocation. Much of what these examples demonstrate is that practice and perseverance are key to developing the nuanced understanding and skills required for effective government social participation.

Looking ahead, there is a great deal of room for the role of social participation in health governance to broaden. Governments increasingly recognise the importance of engaging with communities and civil society in the redesign of people-centred health systems. By redefining the True North in the way health governance and decision-making are approached, social participation offers concrete means to foster a shared sense of ownership and trust between governments and populations in the long run, progressing towards more inclusive, efficient and resilient health environments. This article seeks to offer both a roadmap and an inspiration for governments keen on harnessing the power of social participation to improve health outcomes and equity. By embracing the iterative nature of capacity building and leveraging the mosaic of technical, recognition, and communication skills, governments can continue to pave the way for a future where health systems align policy objectives with the needs and realities of all community members.

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Empowering people, communities, and civil society through social participation

STANDING FOR, WITH AND BEHIND EACH OTHER: HOW TO FOSTER CIVIL SOCIETY CAPACITIES FOR SOCIAL PARTICIPATION

By: Devaki Nambiar, Amy Boldosser-Bosch, Caroline Costongs, Milka Sokolović, Manca Kozlovič, Kurt Frieder, Kjeld Hansen, Hamaiyal Sana, Christina Williams, Rispah Walumbe and Lara Brearley

Summary: Civil society and communities are central players in social participation processes for health. Effective civil society engagement in health decision making processes requires specific capacities – including technical, recognition, and communication skills among others. These in turn have pre-requisites, like conducive legal frameworks, and adequate financial and human resources. This article shares examples from the European Union, Argentina, Burkina Faso, and Slovenia that demonstrate the importance of such capacities and how they can be advanced. Drawing from these, it reflects on lessons and recommendations for governments and civil society to stand for, with, and behind communities, especially those in vulnerable and marginalised situations, in social participation efforts.

Keywords: Social Participation, Civil Society, Capacity Building, Human Right to Health, Health Policy Reform

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Introduction

This statement, made by a woman leader in India, alludes to the importance of strengthening the capacities of people, communities, and civil society to foster mutual trust and empowerment, and thereby realise the potential of social participation. It also indicates the need for these capacities to continuously be strengthened in different ways over time. A recent review found that interventions working through civil society groups with a focus on capacity-strengthening for collective action, including groups facing disadvantage,
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may be more effective at improving public good service outcomes than engaging unorganised citizens. As the agenda of social participation advances, we must be mindful that central players in this process – communities and civil society – are both prepared and well equipped to make meaningful use of institutionalised platforms and claim opportunities to shape policy and reform processes for health.

But what do we mean by community? By civil society? In ‘Voice, agency, empowerment – handbook on social participation for universal health coverage’ published by the World Health Organization (WHO) in 2021, civil society is defined as “individuals or groups of individuals who associate together based on shared interests, goals, needs and functions.” Civil society is generally considered independent of the state, the market (and thus distinct from private for profit entities), and the realm of family.

There is great variety in civil society’s actual legal and operational nature across and within countries: civil society entities may be grassroots collectives, organisations, networks, advocacy groups, and even academic institutions. The WHO Handbook defines communities as “a group of individuals that have something in common… an individual can be a member by choice… or by virtue of their characteristics, such as age, ethnicity or residence.” Communities serve as the basis for civil society actors to have legitimacy and thrive.

Civil society and communities are critical to the exercise of ‘diagonal accountability,’ i.e. the contribution of people and non-state actors in holding government to account. Accountability mechanisms nurture and strengthen the social contract, whereby governments are responsible for delivering on the human rights to health and participation.

Social participation can take various forms, responding to and often shaping the political, economic, social, cultural, technological landscape within and across countries (see the article by Koch et al. in this issue). And as Sundaramma stated above, standing before, with and behind communities is a complex process. To identify and seize opportunities to engage with a range of actors across complex and changing power dynamics, to “speak the language” of health policy and to effectively communicate the interests of vulnerable and marginalised groups – all require capacities.

There are specific capacities that enable civil society to meaningfully participate in health decision-making processes: technical skills, recognition (or reflexivity) skills, as well as communication skills (see Figure 1).

* It is also observed that civil society is widely diverse, and that indeed there may be pressure on governments from anti-democratic civil society organisations to advance actions that may violate rights to health and participation (for some).

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**Figure 1: Capacities critical to social participation**

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**Source:**
Box 1: Advocating for core funding for European health civil society to engage with EU policy processes

Like many globally, European (health) civil society organisations (CSOs) face an increasingly shrinking civic space, with barriers in access to funding, as well as challenges to functioning experienced by civil society leaders. In such circumstances, core funding mechanisms are central in enabling CSOs to be independent and enhance their capacities to respond to external developments, such as the growing engagement of civil society in European policy processes.

In recent years, the Operating Grants from the European Commission that have provided much of this stability for members of the EU4Health Civil Society Alliance have declined, undermining the capacity, sustainability, and in some cases, survival of the Alliance’s membership.

In response, CSOs have advocated for the continuation and reinstatement of funding, which itself required a range of capacities. A campaign for multi-year CSO funding – which was done in partnership with representatives from the European Parliament, countries and the media – culminated in the renewal of operating grants in 2023 and the reinstatement of framework partnership agreements for 2025–2026.

The campaign continues to ensure funding is part of the European elections agenda in 2024 and aligns with the next EU strategic agenda (2024–2029), as well as a dedicated EU-wide Civil Society Strategy.

Global evidence regarding capacities

Pre-requisites for strengthened civil society capacities – legal frameworks and financial resources

There are certain pre-requisites in order to strengthen the capacities of civil society and communities for social participation, and these include a conducive legal environment that enables civil society to organise, function and receive funds. Further, sufficient and predictable financial resources for staffing, capacity development and the ability to represent people facing vulnerability and marginalisation, as well as the implementation of activities, are pivotal (see Box 1).

Technical capacities

Health policies, plans and programmes can involve highly technical concepts, such as health financing, as was the case in Burkina Faso (see Box 2). Technical skills can imbue a form of managerial empowerment that allows for engagement on an “equal footing” with experts and powerful players. It is both possible for and in the interest of government actors to ensure funds and tools exist for communities to interpret and influence technical discussions, so that policies can also be validated by communities and civil society for ownership and buy-in.

This requires that civil society and community members are aware of basic technical principles, terms, evidence and guidance, current debates and knowledge gaps, as well as equipped with analytical skills to review and appraise content that may be discussed in a participatory process. To have an informed opinion and meaningfully engage, literacy and numeracy skills are also key. Policy processes involve a lot of reading and analysis to understand what exists, what doesn’t, and the subtext that underpins use of certain phrases, approaches and epistemologies.

In some cases, particularly where governments do not share data transparently, it may be important for civil society to generate, interpret and use evidence on their own accord. This requires familiarity with major data sources and other evidence on the subject that is the focus of the participatory process (e.g. health financing models, the latest developments around a drug, or evidence for the effectiveness of a policy intervention). In Guatemala and India, information and communication technologies (ICT) have facilitated the gathering of data by citizens which enhanced technical competency as well as transparency and sharing of health data.

In other cases, it may not be possible to hold all the technical skills; in such circumstances, social participation requires deep and sustained collaborations and partnerships with technical experts. This was a key feature of the coalition-building efforts in Burkina Faso (see Box 2).

In many contexts, capacities have been acquired through a “learning by doing” model. For instance, through sustained engagement in Thailand’s National Health Assemblies and Portugal’s Health Councils, over time participants have been able to cover a range of formats and topics, learning in the process how social participation platforms – and capacities to meaningfully engage – may be optimised.

Recognition capacities

Recognition skills involve understanding the context, processes and key stakeholders, to identify or claim spaces for participation in the first instance.

In the case of health reforms in India in 2005, civil society actors saw and leveraged the opportunity to formalise community-based and community-driven accountability processes and models that they had thus far been incubating.
In Burkina Faso, CSOs unite under umbrella coalitions such as the National CSO Council (CNOSC), which is for local civil society, and the permanent secretariat of NGOs (SPONG), which includes both local and international civil society organisations (https://spong.bl/). These cohesive platforms have facilitated civil society engagement with policymakers, while fostering internal collaboration among civil society with the aim to consolidate their voices for more effective engagement and policy impact. The formation of such coalitions reflects the recognition skills of Burkinabe civil society in the potential of collective advocacy to influence policy decisions.

These umbrella coalitions offer opportunities for cross-learning to leverage the different technical skills and expertise brought in by different members. For example, SPONG facilitated joint learning and capacity-sharing during the development of the Burkina Faso free healthcare policy for pregnant women and children under-five, making them a valuable partner for the Ministry of Health in different stages of strategy development. They also ensure that a wider group of members have sufficient technical command of various topics so that they are able to step in if and when more specialised civil society organisations cannot participate.

The CNOSC and SPONG have both gained legitimacy as facilitators for engagement with the government as well as development partners, based on their broad civil society membership.

Recognition skills can also help identify limitations in participatory spaces that do exist and bridge them, in which boundary spanning actors, like collectives or civil society groups can play an important role. For instance Apoio in the Netherlands (Kingdom of the) created “hybrid participatory spaces” that were “offering connections to the state but avoiding being dominated by the professional or bureaucratic concerns which usually characterise invited spaces.” These resonated with and reflected the perspectives of group participants from marginalised situations in social participation initiatives, allowing them to have voice despite the powerlessness and marginalisation that may be reinforced in participatory spaces. Indeed, civil society can harness and leverage particular skills across coalitions for the benefit of the many, as has been the case in Argentina (see Box 3).

Recognition skills require a critical understanding of and engagement with the actors and players involved – a kind of political savviness, knowing when to be proactive or responsive – shaped by a strong understanding of power relations at individual, interpersonal, organisational and structural levels. In Tunisia for instance, the context of the revolution made it appropriate and timely for civil society to advance rights-based claims-making, buttressed by government support and a high level of volunteer commitment.

In Slovenia, informal engagement with the government, carried out by high recognition capacity representatives of networks, has convinced government counterparts of the unique perspective youth can bring and the value of their engagement, creating a growing legacy of youth social participation in health policymaking (see Box 4).

**Communication capacities**

A great deal of evidence exists on the need for communication skills for civil society to hold governments accountable as duty bearers, i.e. having the moral and legal responsibilities for the welfare of populations. This may include training on public speaking and advocacy, to
Box 4: Recognition and communication skills to strengthen meaningful youth participation in Slovenia

The youth network No Excuse Slovenia is a national youth organisation which focuses on building the capacities of active young people who are passionate about positive social change in the fields of health, environment and youth participation. A great deal of the emphasis is on enhancing capacity of young people to be part of policy change conversations and campaigns. Since successfully engaging in activism to shape tobacco law reforms in 2007 with a focus on preventing youth use of tobacco, No Excuse has been recognised as a valuable civil society partner and collaborates with the government both formally and informally. Advocacy has resulted in Slovenia establishing legal grounds for youth organisations to ‘have a seat at the table’, as a member of different government consultative bodies such as the Commission of Health and the Expert Group in the Field of Tobacco, as well as attending the Board of Health meetings. No Excuse facilitates sustainable and high-quality cooperation which gives the involved youth a sense of accomplishment, usefulness and hope for change. It also builds awareness of the limitations of one’s contributions to a certain challenge or policy agenda. This formal engagement is underpinned by substantial financial support from the Ministry of Health, which funds the continued development of youth organisations including human resources, activities and research.

Convey points in a convincing way that is tailored to the context and audiences. In some cases, this involves bringing new voices and speakers, especially youth, to existing spaces (see Box 4). In this case, ongoing informal engagement has convinced government about the unique perspective youth can bring and the value of their engagement, which has been pivotal in initiating opportunities for social participation.

In many cases, like in India, Iran and Uganda, by being involved in social participation processes, community members have even become health advocates in their communities, helping to amplify and widen access to messages and content they learn about in decision-making processes, in many cases engaging with the media (which requires its own set of unique skills and tactics).

Another area that is critical in communication is active listening across constituencies – governmental and non-governmental, throughout ensuring that constituencies facing marginalisation are heard. This is reflected in the approach taken in Thailand as part of preparing for the National Health Assembly process where working group meetings across types of stakeholders require extensive preparation, repeated interaction and exposure to each other, which can enhance active listening and engagement with experiential knowledge.

Lessons learned and recommendations

While strengthening the capacities of people, communities and civil society is crucial, they cannot adjust power asymmetries and achieve meaningful social participation without other enabling reforms – as are outlined throughout this issue. Nevertheless, various lessons emerge from the evidence about both the types of capacities required on the part of civil society, and how these can be acquired and supported, including by government actors, in order to enhance social participation processes.

Stand for: No capacities without prerequisite frameworks and resources

Strengthening the capacities of civil society to participate is meaningless in the absence of laws that enable civil society to organise and receive funding, and resources for civil society to be staffed and implement activities. As indicated in the EU4Health and No Excuse cases (see Boxes 1 and 4), making sure capacity-strengthening receives sustained resourcing and political priority is among the world’s greater challenges at present, particularly in the context of shrinking civic space.

Governments should commit to legal frameworks and fund flows for civil society that capacitate meaningful and constructive social participation. Civil society must make appropriate and ethical use of these opportunities and resources.

Stand with: Cross-constituency collaborations, coalitions can learn and grow together

Evidence that several case studies presented points towards cross-constituency engagement, across individual organisations in civil society, between civil society and state actors, as well as between civil society and technical actors, so as to create networks that complement each other, evolve and learn together. All our cases involved large coalitions brought together by boundary spanning individuals and entities – across regions (EU4Health), between technical and advocacy groups (Burkina Faso), between advocates and legal experts (Argentina) and using formal and informal platforms (Slovenia). In each case, these coalitions have set precedents for collaboration on other topics and possibly with other population subgroups.

Governments and civil society leaders alike should encourage diversity and inclusivity of social participation platforms, to bring in multiple perspectives and to work in multi-constituency coalitions to mobilise their respective strengths and streamline engagement.

Stand behind: “Learning by doing” for sustained periods and across generations sustains capacity

In countries where statutory mandates for social participation lead to sustained systematic engagement over time, civil society and communities tend to “learn
by doing”. This ongoing relationship helps to build trust and foster a culture of participation, in which participation may be better able to impact positive change. Bringing youth leaders to the fore to become movement vanguards as seen in Slovenia; keeping memories of movements and social change alive as was done in Argentina – will help to sustain gains in capacities and maintain impact as part of any single campaign or movement.

Governments should plan for long term sustained social participation, that will evolve as capacities do; civil society stakeholders should ensure that capacity strengthening efforts are practical and applied, extend over time, are constantly renewed, and inclusive of future generations.

Listen for change: Document for accountability and to keep learning

Understanding how various capacities were built or strengthened in the past can produce important learnings for sustaining capacities and building new ones. From leveraging peer technical skill strengthening via coalitions in Burkina Faso (see Box 3), to the recognition of systematic formal and informal engagement in Slovenia (see Box 4), careful documentation and dissemination of country experiences are vital to promote learning.

All stakeholders should carefully document and appraise how capacities are being strengthened, where gaps in learning remain and share lessons for continued improvement.

As countries endeavour to advance social participation, strengthening the capacities of people, communities and civil society to meaningfully engage can and must be a priority. Only with capacities in place can communities and civil society co-develop and contribute to formalised social participation mechanisms from national to local level, building and enhancing mutually empowering engagement with governments, with a commitment to ensuring inclusive representation of all population groups’ needs and aspirations. Capacity strengthening efforts need a strong base, wide, long-term and renewing collaboration, with a learning mindset.

All these features heed Sundaramma’s call of standing for, with, and behind community voices for a healthier future.

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ASSESSING PROGRESS: HOW TO MONITOR AND EVALUATE SOCIAL PARTICIPATION FOR LEARNING AND IMPROVEMENT

By: Prateek Gupta, Ernesto Bascolo, Natalia Houghton, Nanoot Mathurapote, Pascal Mélihan-Cheinin, Weerasak Putthasri, Khanitta Seaiew and Benjamin Rouffy-Ly

Summary: Countries can and should monitor and evaluate concepts important for social participation in their context. This article will introduce the themes and concepts associated with social participation that countries can use when developing a monitoring and evaluation system, illustrated by lessons from monitoring efforts from France, Thailand, and across countries of the Pan American Health Organization. The themes for social participation include representativeness, capacities, legal frameworks, sustainability, and policy uptake.

Keywords: Monitoring and Evaluation, Governance, Social Participation

Introduction
Social participation can foster trust, responsiveness, and people-centredness in health systems (see the article by Rajan et al. in this issue). As referenced in the draft resolution on social participation to be presented at the 2024 World Health Assembly, monitoring and evaluation can be a key operational tool to strengthen and sustain social participation.

This article introduces some options for monitoring and evaluating social participation in health systems governance. First, a framework is highlighted that connects social participation – as a sub-function of health system governance – to a health system’s intermediate objectives and final goals. Next, measures used in countries for monitoring and evaluating social participation are summarised.

Case studies from France, Thailand, and work led by the Pan American Health Organization (PAHO) are presented to share information on how they monitor and evaluate social participation and its purpose for decision-making. Some additional considerations for countries in their effort to monitor and evaluate social participation in their national context are also discussed.

There is a need to measure the performance of governance better
In a recent health systems performance assessment (HSPA) framework, the World Health Organization (WHO) highlights how governance can interact with the other three health system functions (resource generation, financing, and service delivery) to affect how health

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systems reach their intermediate objectives (e.g., quality, access) and final goals efficiently and equitably, including people centredness, health improvement, and financial protection. However, while monitoring resource generation, financing, and service delivery is done routinely in most countries, efforts are needed to measure better the performance of governance and its sub-functions, including social participation, which is termed “stakeholder voice” in the HSPA framework. The HSPA framework introduces functions and assessment areas but doesn’t provide measures for which empirical evidence has been collected. Measures for social participation in health systems exist and some can be found in the peer-reviewed literature. The intention of this article is to provide options to measure themes and concepts that stakeholders can use to assess social participation in health system governance in their context.

**Identifying the themes and concepts of social participation in health system governance**

The handbook for social participation describes five themes that are particularly relevant to meaningful social participation. These include representativeness, capacities, legal frameworks, sustainability, and policy uptake.

A recent literature review identified 172 measures used to assess different aspects of social participation mechanisms for decision-making involving the people and policymakers’ spheres. These measures were grouped under 27 concepts linked to the five themes associated with social participation. While each of these measures is context-specific, they offer options on how countries can assess the five themes and 27 concepts of interest in other contexts.

**Table 1** lists the themes, sub-themes, and concepts of social participation as detailed in the handbook and for which empirical measures were identified. Next, the measures identified in the literature review linked to each theme are summarised.

<table>
<thead>
<tr>
<th>Social participation theme</th>
<th>Sub theme</th>
<th>Concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Representativeness</td>
<td>N/A</td>
<td>Diversity</td>
</tr>
<tr>
<td>Representativeness</td>
<td>N/A</td>
<td>Participant perception of clarity of roles</td>
</tr>
<tr>
<td>Representativeness</td>
<td>N/A</td>
<td>Participant perception of the quality of representation</td>
</tr>
<tr>
<td>Representativeness</td>
<td>N/A</td>
<td>Proportion of different stakeholder groups</td>
</tr>
<tr>
<td>Capacities</td>
<td>Government communication skills</td>
<td>Ability to listen</td>
</tr>
<tr>
<td>Capacities</td>
<td>Government communication skills</td>
<td>Ability to negotiate with civil society</td>
</tr>
<tr>
<td>Capacities</td>
<td>Government communication skills</td>
<td>Ability to provide feedback</td>
</tr>
<tr>
<td>Capacities</td>
<td>Government communication skills</td>
<td>Clarity of communication</td>
</tr>
<tr>
<td>Capacities</td>
<td>Government recognition skills</td>
<td>Perceived added value of participation</td>
</tr>
<tr>
<td>Capacities</td>
<td>Government technical skills</td>
<td>Participant perception of facilitation</td>
</tr>
<tr>
<td>Capacities</td>
<td>Government technical skills</td>
<td>Participant perception of space design</td>
</tr>
<tr>
<td>Capacities</td>
<td>Population communication skills</td>
<td>Ability to negotiate</td>
</tr>
<tr>
<td>Capacities</td>
<td>Population communication skills</td>
<td>Ability to speak publicly</td>
</tr>
<tr>
<td>Capacities</td>
<td>Population recognition skills</td>
<td>Perceived usefulness of participation</td>
</tr>
<tr>
<td>Capacities</td>
<td>Population recognition skills</td>
<td>Perception of empowerment</td>
</tr>
<tr>
<td>Capacities</td>
<td>Population technical skills</td>
<td>Capacity to engage</td>
</tr>
<tr>
<td>Capacities</td>
<td>Population technical skills</td>
<td>Technical knowledge of the issue</td>
</tr>
<tr>
<td>Legal framework</td>
<td>N/A</td>
<td>Documented procedures and strategies for participation</td>
</tr>
<tr>
<td>Legal framework</td>
<td>N/A</td>
<td>Participatory spaces delineated in laws and programs</td>
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<tr>
<td>Sustainability</td>
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<td>History of participation</td>
</tr>
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<td>Sustainability</td>
<td>N/A</td>
<td>Political will</td>
</tr>
<tr>
<td>Sustainability</td>
<td>N/A</td>
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<tr>
<td>Sustainability</td>
<td>N/A</td>
<td>Sustained attendance</td>
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<tr>
<td>Policy uptake</td>
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<td>Documented impact on decision-making</td>
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<tr>
<td>Policy uptake</td>
<td>N/A</td>
<td>Link to downstream changes</td>
</tr>
<tr>
<td>Policy uptake</td>
<td>N/A</td>
<td>Perceived impact on decision-making</td>
</tr>
</tbody>
</table>

Source: 2
**Box 1: Integration of social participation monitoring and evaluation in the strengthening processes of health systems based on primary health care – An example of monitoring government capacities**

As a result of the implementation of the Monitoring Framework for Universal Health in the Americas, PAHO identified a group of 16 countries with inclusive dialogue processes for health policy development, including the institutionalisation of social participation in health.

To support Member States in analysing their capacities to promote and ensure social and community participation, PAHO integrated key tools to assess social participation within the evaluation and strengthening processes of the Essential Public Health Functions (EPHF). Among the 15 (out of 16) countries that completed the evaluation by 2023, “Social participation and social mobilisation, inclusion of strategic actors, and transparency”, has been signaled as one in which health authorities have, in general, “limited” capacities. Formal and supervisory capacities have been evaluated as “limited” due to the lack of normative frameworks and monitoring and evaluation of social participation. Meanwhile structural capacities have been reported as “moderate” on average, aligning with the recent development of participation mechanisms in the Region, as mentioned above. Performance capacities have been reported as “initial”, mainly due to the lack of resources to sustain social participation initiatives.

The application of the tool has not only allowed the identification of gaps in the capacities and aspects of social participation but, most importantly, the incorporation of strengthening proposals within action plans and national health plans.

### Representativeness

Looking at the representativeness of participatory spaces, it may be of value to understand which representatives are included in a participatory space, how representatives have been selected, or whether they account for the diversity of the constituency that is being consulted. Several countries have made it a priority to encourage diversity for the purposes of credibility and perceived legitimacy of a participatory process. The issue of representation is specifically discussed in another article (see De Ruysscher, et al. in this issue). The literature review disaggregated the measures for representativeness into four concepts: diversity, participant perception of clarity of roles, participant perception of quality of representation, and the proportion of different stakeholder groups in a participatory space.

### Capacities

Meaningful participation requires that all stakeholders involved can adequately fulfil their roles. Governments can support both population representatives and government officials in acquiring the respective technical, recognition, and communication skills they need to engage on an equal footing in meaningful dialogue spaces, as discussed in the article by Greenley, et al. in this issue, and further explored in the article by Nambiar, et al. on civil society capacities. This division into three skill sets was also used to provide more clarity among the large number of potential measures identified to monitor progress in terms of capacity strengthening.

Government capacities to develop quality participatory spaces are sometimes underestimated. In fact, in a PAHO-led review, all 15 countries selected for their use of inclusive dialogue processes showed limited to moderate capacities in social participation for health (see Box 1). Assessing these capacities and their limitations is a critical first step to designing strengthening activities.

Capacities highlighted for the government were categorised in the following concepts: the ability to listen, the ability to negotiate with civil society, the ability to provide feedback, clarity of communication, public awareness of the participatory space, the perceived added value of the participation, participant perception of facilitation, and participant perception of space design.

The literature review listed 79 measures and associated them with the following concepts: the ability to negotiate, the ability to speak publicly, the perceived usefulness of participation, the perception of empowerment, the capacity to engage, and technical knowledge of the issue. In practice, developing the skills required for meaningful participation is often a challenge in many countries, as illustrated in the cross-country comparison led by PAHO.

### Legal framework

While not necessarily required, a legal framework may encourage social participation (see also the article by Rao, et al. in this issue). The presence, and more importantly, the type of legal framework, may provide evidence of a participatory culture and can be a potent tool for civil society to claim their right to health and participation. The literature review identified seven measures in two concepts linked to the theme of legal frameworks: documented procedures and strategies for participation, and participatory spaces delineated in laws and programs.

### Sustainability

Social participation is ideally an activity sustained over time, indicating long-term motivation, interest, capacity, and funding (see the article by Rao, et al. and Dale, et al. in this issue). The 14 sustainability measures were categorised into four
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Box 2: Assessing regional participatory spaces in France

The National Health Conference (Conférence Nationale de Santé, CNS) in France is the independent consultative body placed within the ministry of health, mandated to organise the public debate in on health. In 2022, it conducted a study of all participatory spaces at the regional level between 2015 and 2019.

Through a mix of document review and semi-directive interviews, the study offers an evaluation of participatory spaces through several dimensions:

- its existence (498 events organised during the time period), output;
- its modalities (e.g. panel presentation and debate, focus groups, round tables), process;
- its target audience (e.g. students, healthcare professionals, user/patient groups), input;
- communication, output;
- reporting, output;
- and policy uptake, outcome.

This exercise provided some key considerations to further strengthen civil society engagement in policy dialogue by identifying gaps. For example, regarding representativeness, attendance mostly comprised experts due to an open-to-all format not targeting specific groups. In terms of government communication, the monitoring found uneven clarity of communication and the ability to provide feedback. Participants noted a lack of clarity from organisers on the different modalities for engagement. Finally, concerning policy uptake, 78% of interviewees indicated a perception that the voice of the public had limited impact.

Policy uptake

Policy uptake is a key outcome of social participation (see the article by Noirhomme et al. in this issue). The 32 policy uptake measures that assess the perceived and documented links between dialogue and decision-making and their direct and distal effects were categorised into three concepts: history of participation, political will, resources for participation, and sustained attendance.

Identifying measures aligned with country goals

Monitoring and evaluation frameworks in health systems usually consist of indicators, metrics, and measures that can broadly be classified into the following categories: inputs, activities or processes, outcomes, and impact.

To strengthen social participation, it may be useful for countries to delineate their ambition and specific goals for social participation in advance to identify appropriate measures. Measurement of social participation can then be included in their broader routine health systems monitoring efforts. In-depth assessments can also be done through ad hoc protocols to assess the government’s ability to leverage citizen input into decision-making and identify areas for improvement. The review conducted in France in 2022 illustrates how a country can compare the initial target audience to the actual stakeholders engaging in participatory spaces and identify areas for improvement to fulfil national goals.

In this section, some of the measures identified in the literature review are highlighted to provide illustrative examples of types of indicators that can be used in routine or ad hoc monitoring efforts. The studies cited in the literature review allowed for the establishment of a repository of measures based on empirical evidence and can guide the data collection methodologies.

Inputs

Regarding the representativeness theme, the following measures collected via surveys or review of attendance lists could be used to determine the diversity concept: ‘number and types of participants’; ‘age of participants’; ‘sex of participants’; ‘ethnic/religious group of participants’; ‘socioeconomic status of participants’. Simply tracking the numbers and types of participants in a participatory space may not be sufficient to determine the representativeness of a participatory space. Several studies used qualitative assessment measures to allow for a more nuanced understanding of what individuals in a participatory space thought of the quality of the participation, possibly focusing on specific groups, e.g., women, minorities, and individuals from different socioeconomic classes.

Activities/processes

Participatory spaces require investment to work effectively. Countries could use quantitative measures such as ‘initiatives to promote greater participation’ to monitor the diversity of mechanisms and bring population representatives into a participatory space. Qualitative interviews with participants can also help to evaluate how interventions are managed to build their capacities.

Outputs

If the existence of a participatory space is a goal in and of itself, then countries could monitor the number of effective committees that are active in each catchment area. In one example, effectiveness was defined as the committee having a prepared action plan.
The evaluation of the participatory space can be quantitative, such as surveying the members about their satisfaction with their role, or a qualitative assessment of the depth of participation.

Outcomes

One goal of a participatory space may be to influence downstream health system activities and results. Countries could track, using quantitative measures, the number or proportion of decisions that reflect public choices. Another option is to quantitatively assess changes in the number of activities endorsed by a participatory space. To evaluate outcomes, investigators could ask questions related to the extent to which the participatory spaces were involved in health-related activities.

In practice, no single measure is recommended to monitor or evaluate social participation in health system governance. Given that social participation approaches must be tailored to their context and the policy issues at stake, outcome measures must also be context specific. This is illustrated by the flexible approach adopted by the National Health Assembly in Thailand to monitor the number of resolutions they passed (see Box 3), including both progress indicators on resolutions being discussed, and implementation indicators through a policy uptake mechanism.

Linking the framework to concepts and measures

The HSPA framework offers a starting point for key stakeholders to consider when developing a monitoring and evaluation framework for their context. The HSPA framework is broad enough to link health system functions to health system outcomes while allowing countries to adapt it to their local context. Therefore, it would be useful to identify which themes and concepts are pertinent for the country to assess for progress and evidence-informed actions. This will require understanding the explicit and implicit goals for developing social participation mechanisms at the country level. Finally, once a country has narrowed its interests to specific themes and concepts based on the local policy and implementation intents, it can identify measures useful to assess progress. The repository of measures available in the systematic literature review may provide some options, but each country can also consider using other frameworks to develop new measures that can more accurately monitor and evaluate the situation in their country.

The selection of measures a country uses will flow from its objectives for social participation in its context. For example, a government may consider representation in social participation a standalone goal; others may want to see changes in policies that result from social participation and thus focus on policy uptake. The three examples showcased in the boxes within this article illustrate how they use monitoring and evaluation to assess aspects of social participation.

Gaps in monitoring and evaluating social participation

There is no unified tool or approach for monitoring and evaluating social participation. The recent literature review did not identify a tool or measure used in a setting other than that of the study, though multiple measures in a concept shared similarities. The measures in the literature review primarily focused on the existence of social participation in health system governance, with relatively fewer measures focused on the quality of social participation. The exact tools used to collect data for the measures were not always available from the study, so additional work will be needed to develop the tools for the measures so they are readily accessible for researchers and program managers. Consistency in measurement approaches may assist with within-country comparisons to identify best practices. Given the literature review’s limitation of searching for documents in the French and English peer-reviewed literature, it has likely missed documents published in other languages or not published in an academic journal. Finally, the measures identified in the literature review were focused on the population-policymaker interface. It would be of value to determine how social participation affects the governance of providers.

Box 3: Monitoring and Evaluation of Policy Uptake in Thailand – An example of monitoring policy uptake

Thailand’s National Health Assembly (NHA) is a national platform that includes representatives from the government sector, civil society, academia, the private sector, and youth. In this participatory space, the representatives develop policy recommendations or resolutions. The National Health Commission formed the NHA follow-up committee in 2010 to undertake the following roles.

1) Strategise and drive the resolutions into action by seeking collaboration with multiple actors;

2) Monitor the policy uptake of the resolutions and report the progress to the NHA and to the National Health Commission;

3) Evaluate the progress of the resolutions for execution.

The Minister of Public Health chairs the NHA follow-up committee with members from different sectors, including civil society. The Committee introduced a roadmap as a tool to assess the outputs and outcomes of each resolution. It monitors the implementation status of the discussed resolution as achieved, ongoing, or needing to be revisited or terminated. Despite this system in place to assess the ongoing policy uptake, the NHA Follow-up Committee has identified some challenges, including the long process of policy uptake, which can take more than ten years. The committee itself is limited to four-year terms.
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Future directions

This article aims to encourage countries to discuss using preexisting frameworks and measures to start developing a monitoring and evaluation plan. The boxed examples share some of the work already underway in this regard.

WHO has an opportunity to play a leadership role in synthesising global evidence for monitoring and evaluating social participation in health system governance to develop measures and tools that could be useful to country-level managers in gathering the data they need for evidence-informed actions. We call on WHO to develop a publicly accessible repository of measures and tools that countries could consider for use in their context.

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SECURING RESOURCES: HOW TO ENSURE ADEQUATE AND PREDICTABLE FINANCING FOR SOCIAL PARTICIPATION

By: Elina Dale, Elizabeth F. Peacocke, Ann Louise Lie and Cathrine M. Lofthus

Summary: Encouraging citizen involvement in health policy decision-making processes can enhance equitable health outcomes, trust in public institutions and support for health reforms. Stable and predictable financing is vital for meaningful social participation that includes transparency, reason-giving, and opportunities to appeal decisions. Some social participation methods cost more and are more demanding to implement. Examples from Brazil, Kenya, Norway, and Thailand, highlight financing considerations in public participation. Importantly, financing for social participation should not compromise investment in health services, especially in health systems that are underfinanced; separate budget streams for participatory policy processes can ensure that resources are not diverted from essential health services.

Keywords: Social Participation, Citizen Engagement, Transparency, Public Reason, Financing

Introduction

Effective social participation requires stable and predictable financing to work. Without dedicated expertise and resources, social participation initiatives become tokenistic and can even undermine the public interest. Offering opportunities for participation alone does not necessarily promote inclusivity without principles for a fair process (see Box 1 and Table 1), the implementation of which require resources. Otherwise, those with more resources, more education, or those better versed in civic procedures, end up participating more than others and wield greater influence on the policy decision. Studies on participatory budgeting highlight that creating conditions for effective engagement with the public requires investments, including training and incentivising participants, dedicating staff to manage the process, and removing financial barriers for participation for the most vulnerable populations. Therefore, it is important to ensure stable public financing for social participation to work.
Differing methods of citizen engagement require differing levels of resources

Local context and historical approaches will influence how governments approach social participation. However, all systems can do something, and cost should not necessarily be a barrier. Opinion polls, for instance, are relatively inexpensive and can be run regularly, providing a straightforward way to gather community opinions on specific issues. Citizen Proposals (see Table 1 and Box 2) offer ongoing grassroots participation outside the bounds of set timelines or policy cycles. Citizens’ Assemblies distinguish themselves from other engagement methods, like referenda, by emphasising a process of learning and dialogue rather than relying on pre-existing policy expertise and judgement. In such assemblies, a variety of representatives can delve into complex topics, facilitated by expert input, aiming to produce policy recommendations. This inclusive approach harnesses diverse perspectives to address entrenched or divisive issues through deliberative discussions. However, they are particularly resource intensive. For example, Climate Assembly UK, a national initiative which consisted of 110 members, had a budget of £520,000 (approximately USD 650,000); on the other hand, assemblies at smaller, local levels may not require as much funding, but still necessitate substantial investments. For instance, Citizens’ Jury on Compulsory Third Party (CTP) insurance in Australia with 56 jurors was AUD 260,000 (approximately USD 170,000); while Citizens’ Jury on integrated care in Ontario, Canada, which involved 24 citizens, cost about CAD 83,000 (approximately USD 61,000). This shows a wide variance in costs, depending on how citizens are selected, length of the preparation process leading up to the actual consultation, and reimbursement levels for participants among other things. Country-specific factors and types of questions influence the affordability and suitability of each method (see Table 1).

Participation may not be necessary for all issues, therefore limited resources should be prioritised for those issues where it is most relevant and will make the most impact

There are reasonable constraints, including costs, on public participation; in these cases, there is an imperative to ensure accuracy of information, transparency, reason-giving (see Box 1), and enable opportunities to appeal the decision.

For example, it might not be a reasonable...
Equality demands that there is equal representation regardless of social status, gender, ethnicity, religion, or power. People should have equal opportunity to access information and articulate their views, and their views should be considered with equal respect.

Reason-giving: Reason-giving involves addressing moral disagreements through public reasoning where reasons are exchanged, listened to, and accepted (or rejected) by free and equal persons.

Box 1: Principles and criteria for a fair process

The value of participatory approaches to decision-making relates to the extent to which they are based on principles and criteria of equality and mutual respect, reason-giving, accuracy of information, transparency and inclusiveness.

Equality: Equality demands that there is equal representation regardless of social status, gender, ethnicity, religion, or power. People should have equal opportunity to access information and articulate their views, and their views should be considered with equal respect.

Reason-giving: Reason-giving involves addressing moral disagreements through public reasoning where reasons are exchanged, listened to, and accepted (or rejected) by free and equal persons.

Accuracy of information: Decisions must be based on accurate information and on high-quality, and informed opinion, representing the full breadth and diversity of views.

Transparency: Transparency is about making information accessible to the public. This includes information on the decision-making process itself, justifications during deliberations on the issue at hand, and reasoning on the decisions taken, as well as the output of the decision itself.

Inclusiveness: Inclusiveness is about the range of views and concerns represented and considered in a decision-making process. It requires mechanisms for bringing in people who typically would not contribute to public policy and decision making. Inclusiveness goes beyond ‘counting heads’ to securing the inclusion of various perspectives and arguments in the process.

Source: 1

Box 2: Social participation in decentralised settings: example of Norway

The Norwegian healthcare system is characterised by semi-decentralisation, where the municipalities are responsible for primary health care services, whereas the four state-owned regional health enterprises have the responsibility for specialist health services. The requirements for social participation are the same for all health service funders (municipality or regional health enterprise) and are specified in the Patient and User Rights Act 1999. Section 3–1 states that the patient or user has the right to participate in the implementation of health and care services. At the municipal level, user participation is a statutory right. Additional mechanisms include Citizen Proposals (not limited to health services), where the municipality is required to take a position on a proposal from the community if at least two percent of residents support it. There is no guidance on individual compensation for user participation at the municipality level, and it is therefore case dependent. For specialist health services, the regional health enterprises have a formalised approach to user representative compensation. This includes remuneration for meetings, travel and subsistence allowance, and compensation for lost earnings and any other legitimate expenses. In terms of financing social participation, the legal obligations for social participation in the municipalities do not have specific earmarked financing (according to the 2022–23 Municipal Plan [Kommuneproposisjonen]). Instead, municipalities have the freedom to allocate finances as they believe will best meet the needs of their community. In the 2022–23 plan, there were no specific measures in any of the municipalities related to social participation, however efforts are being made to strengthen social participation at the municipality level in Norway. In 2023, a two-year pilot was implemented in seven municipalities to contribute to increased knowledge about the importance of participation in the development of local democracy. The financing of social participation at the four regional health enterprises is part of the funding envelope from the government.

The financing of social participation at the four regional health enterprises is part of the funding envelope from the government.

In more decentralised settings, mechanisms for engaging citizens, including financing, can vary by level of government as well as between sub-national units

In Norway, as an example, the requirements for social participation are the same for all health service funders (municipality or regional health enterprise), but there is a significant difference between regional and municipal levels on how users are involved and what costs are covered. For specialised health services managed by regional health enterprises, there is a formalised approach to user representative compensation, while at municipal level, there is no guidance on individual compensation for user participation and it is therefore case dependent (see Box 2). In a very different context, in Kenya, county
governments are mandated to finance public participation forums, which are an integral part of the budgeting processes at sub-national level. In some counties, such as Makuueni, Elgeyo-Marakwet, West Pokot and Bungoma, dedicated budgets for public participation are available, although amounts allocated differ from county to county – including how the various types of activities and associated costs are reflected in the budgets. Therefore, there is room for learning between sub-national units within a country.

In some cases, ensuring special provisions (earmarking) in the budget is important to ensure that citizen engagement happens

In Thailand, perhaps one of the most well-known examples of successful citizen engagement in health, there is earmarked funding for the National Health Security Office (NHSO) – which is mandated to involve ordinary citizens in decisions about health policies, services, and programs. Through these processes, it is also required to pay for the transportation costs for all attendees, thus ensuring that communities from all parts of the country are well represented and costs to that participation do not become a barrier to participation.

In terms of visibility, Kenya presents a good example how financing of participation can be illustrated in county budgets (see Table, Programme 2 of the Department of Devolution, public Participation, County Administration and special Programmes, which aims to promote “Effective and meaningful citizen engagement”). In Brazil, the federal government made specific financial transfers to states and counties for implementation of Health Councils, which played a crucial role in their rapid expansion across the country (see Box 3). A consideration for policy makers in financing of social participation, is that the resources required for citizen engagement mechanisms should not come at the expense of health service delivery.

Conclusion

Social participation in health policy decision-making requires sufficient investment; its financing should also be stable and predictable, allowing for relationships to be built and a culture of participation to be fostered – this does not happen with one-off, ad-hoc participatory events. A significant barrier to meaningful social participation is recognising the time and financial costs for individuals and institutions to engage communities. Drawing from examples across different countries, this article outlined potential strategies and factors to consider in financing social participation initiatives. Effective social participation holds the promise of fostering more equitable health outcomes, enhancing trust in public institutions, and garnering acceptance of and support for health reforms.

Table 2: Example of a county budget from the Country Government of Makuueni, Kenya

<table>
<thead>
<tr>
<th>Sub-Programme 1.1: General administration &amp; planning</th>
<th>Current Expenditure</th>
<th>Compensation to Employees</th>
<th>Use of goods and services</th>
<th>Other Recurrent</th>
<th>Capital Expenditure</th>
<th>Other Development</th>
<th>Total Expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>273,448,388.83</td>
<td>245,949,685.34</td>
<td>258,247,169.61</td>
<td>271,159,528.09</td>
<td>4,251,693.00</td>
<td>3,212,936.80</td>
<td>277,700,081.83</td>
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</table>

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<tr>
<th>Sub-Programme 2: Participatory Development &amp; civic education</th>
<th>Current Expenditure</th>
<th>Compensation to Employees</th>
<th>Use of goods and services</th>
<th>Other Recurrent</th>
<th>Capital Expenditure</th>
<th>Other Development</th>
<th>Total Expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-Programme 2.1: Participatory Development &amp; civic education</td>
<td>17,862,500.00</td>
<td>13,457,797.10</td>
<td>14,130,686.95</td>
<td>14,837,221.30</td>
<td>25,161,696.60</td>
<td>13,457,797.10</td>
<td>28,957,494.00</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Sub-Programme 3: Research, Documentation and Knowledge Management</th>
<th>Current Expenditure</th>
<th>Compensation to Employees</th>
<th>Use of goods and services</th>
<th>Other Recurrent</th>
<th>Capital Expenditure</th>
<th>Other Development</th>
<th>Total Expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-Programme 3.1: Research, Documentation and Knowledge Management</td>
<td>4,500,000.00</td>
<td>4,725,000.00</td>
<td>4,961,250.00</td>
<td>4,961,250.00</td>
<td>4,500,000.00</td>
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<td>4,961,250.00</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Programme 4: Coordination of Service Delivery and Enforcement</th>
<th>Current Expenditure</th>
<th>Compensation to Employees</th>
<th>Use of goods and services</th>
<th>Other Recurrent</th>
<th>Capital Expenditure</th>
<th>Other Development</th>
<th>Total Expenditure</th>
</tr>
</thead>
</table>

Source: Eurohealth — Vol.30 | No.1 | 2024

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Box 3: Financing for social participation in Brazil

The Brazilian Health Reform Movement that championed the democratization and basic human rights in the health sector, is well recognised as a leading example of social participation. In 1986, a significant landmark was achieved in the establishment of the Brazilian Unified Health System (SUS), which aligned with advocates of the participatory democracy movement — incorporating social participation into health decision-making. The Health councils of SUS became not only mandatory, but their establishment was crucially also linked to financial transfers from the federal government to states and counties. Necessary infrastructures identified for these health councils to function were budget allocations for the council, a permanent physical space, and technical support for carrying out activities. To overcome shortfalls in the implementation health councils, a legal resolution establishing full administrative autonomy of health councils — with a requirement for their own budget allocation and fiscal autonomy — was passed by the Brazilian government in 2012. An evaluation of the implementation of this resolution found that the majority are compliant with the resolution, holding monthly meetings. However, gaps in implementation were identified and the research pointed to the necessity for monitoring of councils to reduce the number that are non-compliant.

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Empowering people, communities, and civil society through social participation

SUSTAINING ENGAGEMENT: HOW TO INSTITUTIONALISE SOCIAL PARTICIPATION

By: Neethi Varadaraja Rao, Kira Koch, Joëlle Khoury Auert, Klára Čižková, Julio Cesar Pedroza Toribio, Eliana Bohland, Gonçalo Figueiredo Augusto, Dawda Sowe, Omar Sam and David Clarke

Summary: Sustaining participatory engagement over time is necessary for health system transformation but remains a challenge across the globe. Current efforts lack sustained prioritisation and neglect to systematically incorporate people’s experiences in health decision-making due to power imbalances and socio-economic barriers. The creation and maintenance of meaningful and inter-linked participatory spaces implies institutionalising a participatory governance culture across the policy cycle and at all levels of the system. Drawing from examples from Portugal, Brazil, Czechia and across Member States of the WHO Regional Office for Africa, this article discusses the key drivers of institutionalisation. Governments have a key role and interest in strengthening sustainability by proactively expanding access to information, resources and capacities for participatory engagement.

Keywords: Institutionalisation, Participatory Governance, Social Participation, Legislative Frameworks

Introduction

Sustaining social participation over time poses a significant challenge. Current efforts are often ad-hoc and siloed, failing to consistently integrate people’s voices into decision-making that affect their health and well-being.

Fully embedding social participation in governance actions necessitates a paradigm shift. This entails ensuring, in addition to funding, long-term motivation, interest, and capacity of both government cadres as well as people, communities, and civil society. Sustained political commitment is essential to create and maintain spaces for meaningful participation, involving both formal and informal channels of exchange. Regular exposure to dialogue and ongoing collaboration cultivate trust and improve the quality of engagement for improved decision-making, ultimately fostering a participatory culture grounded in transparency and accountability.

This article aims to address the challenges of ensuring long-term commitment to social participation by outlining key drivers that support sustained participation.
and institutionalisation. Examples from Portugal, Brazil, Czechia as well as study findings on legal provisions from the WHO Regional Office for Africa (AFRO) illustrate countries’ pathways towards institutionalising social participation as a key ingredient of health system governance.

**COVID-19 and the imperative of collective action**

The consequences of not having institutionalised participation were laid bare during the COVID-19 pandemic response when the centralised formal authority of governments was found inadequate. Many countries struggled to balance promptness with sensitivity and responsiveness, leading to an exacerbation of inequities and even human rights violations in some cases. After the first wave of command-and-control-style action, governments began to realise the necessity for a whole-of-society, adaptive emergency response.

Civil society partnerships had to be built on the fly to maintain community trust, support delivery to the marginalised, improve adherence, and overcome hesitancy to infection prevention or control measures. In the absence of prior relationships, these last-minute collaborations were often ridden with inefficiencies and stymied by a lack of mutual trust and understanding. Whether or not participation was meaningful varied greatly depending on local leadership, as the experience from federal polities (like India) especially illustrated.

Trustful, constructive partnerships between governments and civil society are difficult to form in times of emergencies but rather must be built over time, prior to the onset of crises. Developing a participatory health system culture driven by systematic engagement between governments and civil society or communities, is thus key to building preparedness and resilience. In Portugal, for example, leveraging the National Health Council, a multistakeholder platform with fixed seats for service users, proved effective to timely engage with trusted civil society to develop recommendations for the government-led response that incorporated people’s challenges and lived experience (see Box 1).

**Supporting formalised linkages across levels of government and the policy cycle**

An adaptive governance approach that explicitly reflects people’s values in policymaking at all times and, ensures its adequate implementation can only be made possible through formalising social participation such that it reflects across all parts of the health system. Engagement processes at different levels of government may have slightly different strengths and objectives. A cross-country analysis of participatory initiatives in Bangladesh, India and Thailand, for example, found that local mechanisms were much more flexible with a more ready uptake of operational recommendations, whereas national-level participatory forums were more suitable for the development of plans and largescale policy. Leveraging the relative strengths and complementarity of decision-making at different levels of government requires institutionalised feedback and coordination across engagement processes at all these levels. Reforms that embed inclusion and social accountability in health system functions like financing, purchasing and quality of care can similarly augment the overall governance architecture for universal health coverage. Brazil for example,
ensures that public interest influences health policy, planning and review through mutually reinforcing institutionalised mechanisms across all administrative levels (see Box 2). Community feedback from the bottom up, gathered in local and municipal health councils is then fed into national health council discourses and vice versa. Such policy environments in turn allow for a flourishing civil society and can help harmonise formal invited spaces for civic engagement with spaces claimed by grassroots social movements.

Factors supporting institutionalisation and sustained participation

Creating an enabling environment for participation based on fundamental rights, freedoms and duties

When exploring avenues for institutionalising social participation, the emphasis is often placed on identifying legal provisions for creating participatory mechanisms (refer to section below for further details). Yet, the role of laws for social participation extends beyond the mere provision of participatory mechanisms. To be meaningful, efficient, and sustainable, these mechanisms need to operate within a broader system that embodies the goals of inclusiveness, transparency, and accountability. This calls, beyond health-related legislation, for the provision of a set of rights, duties, and freedoms serving as the foundations to enable meaningful participation at various levels (national or local). These include for example the provision in the legal system of the right to participate in policymaking, the freedom of information, the freedom of association, the State’s obligation to disclose a required set of information etc. (see Box 3). These overarching rights, freedoms, and duties allow people to claim decision-making spaces and make their voices heard effectively through free and open access to information, resources and expertise. Further, these rights, freedoms, and duties have the potential to incentivise the establishment of formal participatory mechanisms and support their efficient and effective use.

Equally, removing legal, administrative, or cultural barriers that hinder effective democratic engagement in public policy processes is also important for supporting an enabling environment. Excessive regulation of funding or activities of non-governmental organisations (NGOs), for example, can prove detrimental to their participation.

Institutionalising participatory mechanisms for health through legal frameworks

As mentioned above, legal frameworks can be used to establish participatory mechanisms to systematise regular social participation for health. These frameworks encompass various legal instruments (constitutions, laws, decrees etc.), which countries have employed to institutionalise participation in different ways (see Boxes 1, 2, and 3).

In Thailand, for instance, the 2007 National Health Act was pivotal in laying the ground for a participatory culture as it established the National Health Commission Office mandated to organise yearly National Health Assemblies. Having a legal framework in place made participation more robust against government turmoil and reduced reliance on individual political whims. Tunisia similarly is making efforts to
### Box 3: Legislation to facilitate participation – examples from WHO AFRO countries

A rapid assessment across 47 countries in the WHO AFRO Region examined a broad range of legislation influencing progress towards Universal Health Coverage (UHC), revealing that more than half of the countries legally acknowledge a right to health. These legal frameworks vary in how they ensure the legitimate participation of the population and civil society in public affairs and policymaking. Examples from Algeria, Kenya, and Gambia illustrate diverse approaches to incorporating social participation into governance structures and processes. Algeria’s National Observatory for Civil Society is enshrined in its constitution, whereas Kenya has mandated stakeholder consultations when developing or amending any legislation. The case of Gambia illustrates how different policy and legal instruments come together to support participation. The constitutional principles promote an open and democratic society, fostering transparency and accountability. The institutionalise the societal dialogue process through a legal framework, to sustain participation regardless of fluctuating political interest.

Moreover, legislation holds the potential not only to secure the establishment of participatory mechanisms but also to govern their features and characteristics so that successful enablers for implementation are provided for at the onset – this includes legislation specifying the composition of an established body, giving it normative mandates, addressing financing sources, facilitating civil society capacity building, providing systems to manage conflict of interest etc. Purposefully designing legal frameworks is thus pivotal to ensure meaningful participation and equitable representation, as institutionalised spaces often risk being captured by the elite. Additionally, well-established civil society organisations (CSOs) may also unintentionally limit representation of the lay public. Rotation principles such as in the Portuguese Health Council can help prevent the continual dominance of the same individuals and organisations, allowing for the inclusion of new voices in debates. Regularly re-examining norms is critical to address power imbalances within participatory spaces. This along with the overarching enabling environment mentioned earlier, will facilitate flourishing civil society and grassroots movements to claim new spaces alongside existing institutionalised platforms.

However, legal frameworks do not guarantee meaningful participation per se. In Portugal, the CNS was only established when political commitment was assured, 26 years after the enactment of the Basic Health Law in 1990 (see Box 1). This underscores that while legal provisions lay down a structural foundation, they are one of several components necessary for effective and sustained participation. For long-term meaningful engagement, other factors are equally important as outlined in the following sections.

**Continuous, iterative engagement for building knowledge and relationships**

Whether or not a legal framework is in place (while helpful to have), repeated, iterative and continuous engagement builds trustful relationships across stakeholder groups, and improves the quality of engagement over time. In India, districts with a history of engagement with civil society were more receptive to the inputs from CSOs in their pandemic response measures. Prior experience with participation can help build feedback loops and progressively reinforce the capacities of conveners of participatory spaces to ensure meaningful engagement. In turn, this increases the motivation and interest of people to stay engaged. Czechia (see Box 4) initially started by establishing a Patient Council formed solely by patient organisations and are now considering refining the format and design of this participatory space to include a diversity of voices, as both experiences of the ministry of health working with the Council and demand from other community groups to participate in the Council grows. Repeated exposure of stakeholders to varied perspectives can help break down barriers and build respect for different views. Long-term relationships increase the opportunity to build consensus around pragmatic solutions to challenging policy questions on both normative and operational aspects. In Thailand, civil society actors go beyond airing grievances or complaints to bring viable options, based on a sense of co-ownership of the outcomes of the participatory health assemblies. This in turn makes it more likely that participatory input is taken up by policymakers, creating a virtuous cycle of strengthening communities further reinforcing their capacity to provide meaningful policy input.
Box 4: Patients’ Council and beyond – Czechia’s journey in reinforcing participation for health

The Czech Ministry of Health established the Promotion of Patients’ Rights Unit in 2017, which oversees the Patient Council composed of up to 25 representatives from patient organisations. The Council provides input on legislative and non-legislative documents, and its members participate in ministerial working groups. The Council can also set up working groups with broader representation from civil society and community-based organisations around specific issues. The Council has a four-year term and meets four times per year and their input is integrated into strategic documents like the national strategy “Health 2030” and legislation.

Demonstrating impact through formal M&E as a key element of institutionalising participation

Integrating formal monitoring and evaluation (M&E) of participatory spaces within routine government processes gives weight to sustained participation and helps to consistently refine participatory set-up to improve engagement. As seen in the Czech case (see Box 4), evaluation of who is (not) participating can also help build the case for an expansion of participatory processes to become more encompassing over time. Gupta et al. in this issue reflect in more detail on how measurement can help improve the quality of participation, participatory contributions within their own government to ensure that a participatory approach will also be taken up the next time around. For example, the important role of community engagement in overcoming vaccine hesitancy as part of the global polio programme prompted similar efforts in engaging communities during subsequent immunisation efforts, including most recently for COVID-19. Reflective learning and skill-building for participatory engagement based on the lessons from evaluation, can thus yield more visible, positive outcomes through policy uptake, reinforcing policymakers’ motivations for investing in participatory spaces. Noirhomme et al. in this special issue deliberate in greater detail on how policy uptake can be ensured in different contexts.

Ensuring dedicated, predictable funding for sustainable long-term engagement

To ensure sustained participation, dedicated resources are required both for funding the participatory processes itself as well as building capacities of the participants (see article in this issue by Dale et al.). Mandating an institutionalised participatory space (such as in Brazil, Portugal or Thailand) earmarks funding for participatory engagement and in turn provides the time and space to engage adequately with the full range of stakeholders, including those who are typically marginalised. Funding is also necessary to improve awareness of consultative activities, including their outputs, and build capacities of all participants to meaningfully engage.

Sustainable, institutionalised participation has the promise to yield continued dividends

Sustaining government support for participatory institutions might also depend on demonstrations of impact and measurements of civil society contributions vis-à-vis other actors within policy spaces. It can give policymakers the insights and confidence to highlight civil society and community groups can especially face challenges in obtaining funding and skilled representatives to participate with high-level stakeholders on an equal footing. Czechia (see Box 4) has recognised this and responded with targeted efforts to improve the capacities of patient groups to ensure the sustainability of its participatory processes. Building a sustainable practice of engagement will also likely translate into greater cost-efficiency of participatory processes over time.

Moreover, ministries of health have a pragmatic interest in proactively ensuring sufficient resources for participatory practice to strengthen policy adherence and improved programmatic outcomes. For instance, proactive funding and capacity-building for NGOs through the Slovenian Coalition for Public Health, Environment and Tobacco helped reduce smoking prevalence in Slovenia to below 25% among adults. While external funding can be catalytic, sustained support from local resources which are also often more predictable is essential for better outcomes and sustainability. Well-prioritised health programmes such as against HIV/AIDS and polio have already demonstrated the utility of entrenched social participation in strengthening the fight against these conditions.

Sustainable, institutionalised participation has the promise to yield continued dividends for many more such issues including palliative care and mental health services among others. Benefits of investing in meaningful participation thus
far outweigh the costs associated with implementing meaningful participation across the health system.

**Leveraging technology to strengthen communication and maintain engagement**

Technology can also be leveraged to enhance engagement while helping to sustain processes over time. For instance, Tunisia used a combination of online and offline participatory spaces to maintain exchanges even in times of low political will. Digital communication channels like social media, web-based surveys and other platforms can be used to facilitate feedback and two-way communication between decision-makers and the population. During the COVID-19 pandemic, for example, Thailand’s National and Provincial Health Assemblies were conducted both in-person and virtually, leading to an increase in participation. Additionally, the proceedings were live streamed on Facebook reaching more than 120,000 viewers in 2020 and 160,000 viewers in 2021.

Technology can also enable stakeholders to raise awareness, educate, and inform through dissemination of visual tools like maps, videos, infographics, on social media and websites. This in turn allows participants to familiarise themselves with technical analysis and build coalitions with complementary experiences and expertise to improve the quality of participation over time.

The availability of free or open-source software or tools can further help optimise costs, which maybe especially useful for sustainability in low- and middle-income countries. However, concerns related to privacy and security, inequalities in access to technology and digital literacy have to be accounted for while utilising technology in formalised participatory mechanisms. Technology can be a force-multiplier but cannot supplant in-person engagement. The need to combine different participatory mechanisms arises from the necessity to cater to diverse populations, integrating technology-based approaches with personalised interactions.

**Empowering community health workers and locally trusted community representatives as intermediaries on the road to institutionalisation**

Last but not least, extending the reach of social participation to decentralised communities to consistently integrate local learnings into mainstream policy processes further aids in sustaining engagement over time. This requires intermediaries, who are simultaneously socially and institutionally anchored. Community or voluntary health workers and other frontline personnel play this crucial role in sustaining participatory engagement by facilitating reciprocal relationship building, localised dialogue and outreach, as seen for example in Bangladesh and India. Institutionalised community-based cadres across the globe have already proven to be a valuable health system asset, anticipating community sensitivities and amplifying the needs of marginalised voices. Strengthening these intermediaries through resource provision and capacity building deepens trust and sustains meaningful engagement for the long-term. However, undue reliance on volunteers or community workers without systemic linkages can undermine social participation, leading to public apathy and a failure to realise the full potential of frontline cadres as the embodiment of the shared ownership of health decision-making between governments and the people.

**Conclusion**

This article explores how an ingrained culture of participatory governance can be developed and sustained in order to help achieve health system goals. By embedding it within institutions and functions of the health system, social participation moves beyond transient initiatives into a persistent and organic feature of decision-making across the policy cycle. Recurrent and inter-linked participation at all levels creates and reinforces institutional memory of shared power and accountability across people and governments, ultimately leading to sustainability.

Legislative frameworks that create an enabling environment for participation can often be an important first step for promoting formal and informal collaborative arrangements across population and governments. These processes and structures for engagement and co-ownership can be formalised through legislation establishing and governing participatory mechanisms that are sustained over time. Whether backed by legislation or not, purposeful attention to the design and implementation of participatory mechanisms is necessary to ensure broad and inclusive representation, manage possible conflicts of interest and risk of elite capture. Dedicating resources to building institutional and individual capacities for engagement through iterative learning as well as formal processes of monitoring and evaluation will help improve the quality of participation over time. The use of digital tools, strengthening the role of intermediary cadres who are simultaneously anchored within institutions and communities, and visibly demonstrating the positive impact of participatory input through policy uptake can all synergistically strengthen the foundation of participatory spaces, making them resilient to shocks and sustainable in the long run.

Articles in this Eurohealth issue deep-dive into each of the elements necessary for meaningful social participation, which importantly need to be sustained over time by leveraging the synergistic roles and competencies of civil society and the government towards greater equity, efficiency, effectiveness, and resilience of the health system. Sustained institutionalisation of social participation over the long-term can fundamentally transform systemic inequities by encouraging diversity and empowerment for all.

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Empowering people, communities, and civil society through social participation

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Further reading on social participation

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

The Handbook provides practical guidance on how countries can strengthen and sustain meaningful social participation with the population, communities, and civil society in decision-making for health.

Available at: https://www.who.int/publications/i/item/9789240027794

Social participation for universal health coverage: technical paper

The Technical Paper synthesises key messages from the Handbook and a multi-stakeholder consultation to identify priorities for Member States in institutionalising social participation.

Available at: https://iris.who.int/handle/10665/375276