Social Participation Technical Network

Face-to-Face Meeting to support the development of the Handbook on Social Participation for UHC

22-23 October 2019
Background

As part of the effort to achieve the World Health Organization (WHO)’s Global Programme of Work (GPW) ambition of one billion more people benefiting from UHC by 2030, a recommendation of the report of the WHO Task Team on WHO-Civil Society Engagement was for WHO to specifically emphasize and promote civil society participation in policy processes and provide guidance for Member States to do so.

The WHO Handbook on Social Participation for Universal Health Coverage (UHC) recognizes the importance of the role of civil society and communities, in addition to governments, by responding to this recommendation, and aims to strengthen systematic and meaningful government engagement with populations, communities, and civil society in national policy, planning and review processes. Hence, the Social Participation Technical Network (SPTN) acts as an advisory body for the development of the Handbook.

A second objective of the SPTN is to advocate the importance of social participation for equitable pathways towards UHC, supported by the findings of the Handbook.

The Handbook will be based on country case studies and a research of background documents. Case studies that were finalized by the time of the meeting included: country case studies on wide-scale direct population engagement mechanisms; case studies examining the specific role of civil society organizations and communities in sector-wide policy-making and an extensive and comprehensive literature review covering the 5 topical areas of social participation (see below for details)

Following the 1st SPTN face-to-face meeting (April 2019) in Geneva, Switzerland and numerous phone conferences among SPTN members, the objectives of the 2nd SPTN face-to-face meeting (October 2019) were (i) to present country case study results and discuss findings, (ii) to present and discuss findings from the literature review, (iii) to validate identified patterns and lessons learned and receive feedback and guidance from the SPTN in order to steer the finalization of the Handbook.

Timelines and next steps

- Civil society online consultation from December 12, 2019 until the beginning of April to gather feedback from civil society and communities regarding draft chapters of the Handbook.
- Distribution of chapters to SPTN between January and March to gather SPTN feedback
- Revision of draft chapters from mid-January onwards by Handbook team.
- Peer review of chapters after finalizing the feedback from SPTN / online consultation.
- Launch of the Handbook during the 73rd session of the World Health Assembly in May 2020.
WHO published a global monitoring report in collaboration with OECD, indicating that there has been a lot of progress made towards Universal Health Coverage (UHC); nevertheless, half of the world’s population still does not have access. If this tendency keeps going until 2030, five billion people will live without access to healthcare.

The adoption of the high-level United Nations Political Declaration on UHC in New York in September 2019 is the most comprehensive set of health commitments ever adopted at this level.

Social participation is one of the key components of goal 16 of the Sustainable Development Goals (SDG), good governance to “promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels.” Social participation can be a means to include population, community, and civil society organization (CSO) inputs into discussions. Further, it is essential for and mobilizing resources towards achieving UHC.

The Social Participation Technical Network (SPTN) has a unique opportunity to build bridges for effective and efficient social participation by providing the latest knowledge how to successfully engage with the population for policy-making.

Important questions to consider in the (near) future: What is next after the launch of the Handbook? How do we move social participation forward? How can we collectively create and develop our network for social participation post-SPTN? Three areas were suggested by Agnes Soucat that might need further attention during the next steps of handbook development:

1. The handbook should not be a stand-alone product
2. Advocacy in countries is important to convey the importance of social participation
3. Particular attention to marginalized groups

Session 1: Handbook on Social Participation: Update on Progress

Given the push for WHO to engage more pro-actively with civil society, the WHO-Civil Society Task Team was established in January 2018. In the wake of their report of *Together For The Triple Billion* that came out at the end of 2018, the concept of the *Handbook on Social Participation for Universal Health Coverage* started being discussed.

Considering the clear consensus on the gaps/niches for governments how to properly engage with civil society, while civil society has had guidance for engagement with governments, the target audience of the *Handbook* is Member State governments. The goal is to get to collaborative policy dialogue, national health planning, and policy- and decision-making between stakeholders through direct engagement with populations, population engagement through civil society, and population engagement through communities.

There are four areas for evidence generation for the *Handbook* - these areas complement each other.
9 WHO case studies that aimed to cover as many geographical regions as possible and to be as diverse as possible in regard to the modalities of engagement (community, civil society organization or population-wide)

- Literature reviews:
  - Literature reviews were conducted to understand definitions and theoretical concepts of social participation as well as to get to the basics of the topical areas, as identified during the first face-to-face SPTN meeting

- Insights from SPTN face-to-face meetings:
  - Experiential knowledge from 1/3 Civil society, 1/3 Member State governments, and 1/3 Academia

- Insights from WHO internal group meetings
  - Experiential knowledge from WHO colleagues working closely with communities

Session 2: Population engagement and decision-making: the deliberation-to-policy-gap

Handbook team presentation:

- The results of the literature review on the ‘deliberation-to-policy’ gap were presented in this session. The topical analysis findings suggest that the literature generally acknowledges that public participation initiatives have little influence on decision-making. Whilst a culture of participation increases the likelihood of public participation input translating into policy, it requires institutional structures that are open to change and legal frameworks that can support public participation. There is an intrinsic relationship between social participation and investments in health. Political will and decision-maker commitment increase the integration of public voice into policies.
- One can distinguish between 2 different approaches of decision-makers to participation and participatory process: a) one which has the primary objective of improving health service delivery, increasing health facility utilization rates, and augmenting service coverage; and b) one which has the principal purpose of ensuring good governance of the health sector, which focuses more on listening and capturing people’s voice to establish a responsive health system.
- The format and design of participatory process should match context and policy-related needs. Target end points could be increased trust and revision of policies. Capacity aspects (people’s- and government capacities), which are pertinent for decision-making influence, need to be considered.

Case Study

- In Burkina Faso, the involvement of CSO engagement during the health financing strategy process was analyzed. While during the elaboration of the strategy CSOs lamented that they were only invited to provide inputs at a very late stage of the process, resulting in marginal options to influence, CSOs were able to play a key role and influence decision-making processes when it came to rather operational
questions, for example related to the ‘Gratuité des soins’ policy for pregnant women and children under five years.

Plenary discussion:

- Topics recommended for further exploration towards improving population engagement in health include:
  - Improving transparency in population engagement activities
  - Increasing democratic space for population engagement

Session 3: Representation in participation

Handbook team presentation:

- There is no single best method for the selection process of representatives, however, there are certain aspects to consider.
- Policy-makers should be aware of the multiple publics and groups within society (e.g. lay people, community representatives, patients, civil society organizations, lobby groups etc.) who can take on various roles and also represent potentially conflicting interests for health decision-making.
- Finding the ‘right’ representatives infers many challenges. Due to willingness, time, resources, and capacities, participation is often skewed towards the elite and well-educated class. Strategies are needed to balance out groups who can dominate civic space and crowd out other voices. Otherwise, representation risks to further widen inequities. A particular focus is needed to study who is not participating and subsequently reaching out to marginalized groups.
- A combination of mix methods is seen to strike the balance between statistical (i.e. a selection process based on demographic characteristics such as age, ethnicity, education, and income) and qualitative representations of certain groups to ensure divergent perspectives are represented during debates.
- Ensuring a high level of transparency throughout the process, providing balanced factual information, defining clear roles and responsibilities of representatives, balancing out power relations between stakeholders, and creating free and open spaces for discussions are among the key facilitators for the effective participation of representatives.

Case Study:

- The Health Council in Portugal has been legally framed since 1990; however, it took 26 years to formulize. It started its activities and has been functioning for 2 years since 2017, aiming at involving citizens and users in policy making process at the national level. Civil society representatives account for 1/5 of the Council, and are appointed by the Parliament, resulting in potential biases during the selection process. Lack of CSO capacities, both in terms of technical and financial resources, has been acknowledged.
- In France’s *Democratie Sanitaire*, the doors are open to the public, and everyone is welcome to contribute in person or online. A variety of methods, such as an online consultation webpage, citizen juries and open hearings provide citizens the possibility
to address issues and provide inputs. Having young people to participate is a priority in France, with having them 1/3 in the debate. Yet, open questions remain as to the effective representation of all population groups, in particular with regards to involving poorer population segments and marginalized groups.

Plenary Discussion:

- The inclusion of all relevant stakeholders during participatory processes has been stressed by a variety of discussants. Country examples from the SPTN members demonstrated that often times the affected people are not at the table. Ensuring that marginalized groups are represented in the process is critically important, which might mean applying different methods and techniques to ensure that the various target groups (youth, elderly, indigenous groups etc.) are getting involved.
- *Capacity building* of public representatives has been further pointed out. Capacity building initiatives are important for civil society representatives and community members, to not only gain a good technical expertise of the topic but also to transcend their own individual experiences into a ‘common good’ perspectives. To this effect, issues around power relations between stakeholders (in particular experts vs. non-experts) have been widely acknowledged.
- Lending legitimacy to the results is crucial for the effectiveness of representation. A country example from Zimbabwe, civil society representatives getting their mandate from the community instead of being selected by ministers, displays how legitimacy can be attainable.
- Due to the possibility that policy-makers can misuse their power for their own interests, a high level of transparency throughout the whole process of selecting representatives is critical. Having oversight bodies to ensure public accountability or outsourcing the selection process to an independent market research institution are possible means to hold against this risk of manipulation and power abuses.

**DAY 2**

Session 4: Necessary capacities for mutually beneficial government engagement with populations, communities, and civil society

Handbook team presentation:

- Capacities are necessary for (i) civil society to be able to interact with governments on an equal level, and (ii) governments to understand the necessity of engaging in social participation and strengthening civil society capacity to interact with governments on an equal level. Civic and managerial empowerment of community and civil society stakeholders is thus essential.
- Three dimensions of capacities were identified through case studies and literature reviews that need to be strengthened to achieve empowerment:
  - Abilities related to *Recognition*
  - Abilities related to *Communication*
  - Technical Skills
Case Study:

- In India, the National Rural Health Mission (NHRM) was launched to provide accessible, affordable and quality healthcare to rural populations. The capacity development framework consists of strengthening institutional capacity (structure, adaptability, course correction, minimizing duplication), strengthening resources capacity (human and financial resources), and strengthening knowledge sharing mechanism (inclusive partnerships, platforms, sustainability). More than a decade after its installation, the need for capacity building at all levels has become evident, as well as effective knowledge sharing mechanisms to ensure sustainability in capacity development.

- In Madagascar, there are four levels representing the health system: community, district, regional, and central. The community level is characterized by the lack of motivation, visibility, and capacity due to linguistic and educational barriers. The district and regional level health workers’ role is to transmit the plans of the central level model and apply it at the community level; in other words, it is made by central level instead of the community. While civil society organizations are the ‘speakers’ of the community level, they lack communication and financial capacities. Recommendations to resolve the lack of capacity at all levels and in rural areas include decentralization for more power, resources, capacity at lower levels, more civil society involvement in central level meetings, and community needs to be considered at the central level.

Plenary Discussion:

- One question was whether capacity building is a political issue. Capacity usually gets swept under the political agenda given the misconception and intention of the central level. Thus, misconceptions about true capacity building must be addressed, and political will is essential if governments want to be determined to meaningfully strengthen stakeholders in all areas. The political elite seems comfortable with the current situation, which is why the benefit of participation needs to be highlighted by the Handbook, along with recommendations for governments. The reluctance of the central government to build capacity for the lower levels may be coming from their mistrust whether the lower levels could use capacity properly; however, building trust between stakeholders is fundamental. At times, cooperation between the civil society and central authorities may be difficult due to the reluctance of the governments and aggressiveness of civil society; nevertheless, governments need to reach out to understand what is happening on the ground to actively open public spaces, maintain them, and constantly broaden them. Lastly, the political context should be considered prior to implementing decentralization laws, because it does not automatically grant more authority to the community.

- Additional topics during the plenary session included calling for capacity building for people with disabilities, educational obstacles, and information technology as a new capacity barrier. The distinct but important roles of the media, multisectoral committees, and private sector also came up to be considered given the major role they could play.
Session 5: Legal frameworks for participation

Handbook team presentation:

- Results of the literature review on legal frameworks for social participation in health, as well case studies on environmental impact assessments providing an overview on the potential impact of laws for social participation, as well as the barriers and facilitators, were presented during this session.
- 7 examples demonstrating some of the challenges and including capacity to enforce the laws and potential for laws to be adapted and evolve: Factors including the cultural context; readiness; capacity at all levels; available resources; and political will need to be considered.

Case Studies:

- A case study of the process of drafting the Thailand National Health Act and mechanisms for inclusion of the civil society was presented. This included the formation of a National Health Commission with a structure that comprises the population, academia and the Government. This has the ability to bring issues forward to parliament when obstructed/delayed by cabinet.
- This was followed by the Mexico case study, on sexual and reproductive health (SRH). This demonstrated the need for capacity building for knowledge awareness and creating partnerships with other groups. The legal tools utilized and the preconditions necessary for legal frameworks and reforms to be instituted were also discussed.

Discussion:

- Discussion points included the need to build a consensus within the constituency where the law is being developed. The need for social participation in order to catalyze the development of these legal frameworks and reforms has been emphasized. Examples included Zimbabwe’s Public Health Act development and a few other from South America (Uruguay, Argentina, Peru, and El Salvador).
- ‘Public accountability’ and ‘collective action’ literature could be visited towards filling in the gap in legal and regulatory frameworks.

Session 6: Sustaining participation over time

Handbook team presentation:

- The four illustrative case studies (Alberta, Canada; Iran, Cambodia; El Triunfo, Guatemala) from the literature review highlight (i) decentralization can be used as an opportunity to formalize and increase participation in health; (ii) capitalizing on intrinsic motivation to participate; (iii) the advantages to cooperate with locally respected and trusted community representatives and leaders; (iv) to leverage existing structures; (v) the pros and cons to be considered when funding for local
community organizations or NGOs; and (vi) the role of national governments in ensuring high capacity of community groups and civil society.

Case Studies:

- In Tunisia, the launch of the Societal Dialogue for Health led to civil society having a particular role and opportunity to share their visions and experiences, because citizens are in the heart of this dynamic. This is the basis of the engagement, however, the will to participate is needed in the future in order to maintain this momentum. The valorization of citizen participation means the balance between expectations and needs of stakeholders, creation of new interactions, ownership, motivation and accountability, and having the opportunity to influence the context and the Societal Dialogue.

Discussion:

- The discussion yielded that instead of the maintenance of social participation, the evolution of social participation needs to be emphasized. The landscape of countries is ever-changing, and only an advanced type of social participation would be able to manage the changes, the radical transformations, and challenges. By the proper evolution of social participation, the reconfiguration of the process is possible.
- Champion will is needed when political will is not there.
- The soft skills of central authorities were brought to light in the face of maintaining social participation. Building trust and accountability can only happen through persevered work of government officials by considering and responding to the needs of the population. Once the population’s role is acknowledged and recognized by a responsive central authority, the public’s motivation is amplified by knowing that their input can make a difference. Moreover, close collaboration between stakeholders over a sustained amount of time is the only way to gain trust of the public, which must be kept and be the base of future work. One wrongdoing can strike out years or decades worth of work, thus governance accountability and power-sharing must be foremost.
- While it is essential to rely on stakeholders with altruistic motives, funding issues often come up as a key barrier to maintain participation, shedding the light on financial motivation. Leveraging resources from private sector, using technology to help facilitate civil society participation, and the instrumentalization of local nongovernmental organizations (NGOs) by international NGOs were amongst the key suggestions how to combine extrinsic resources with intrinsic structures. However, it is crucial for local structures to avoid dependence on external resources, because that could also undermine the long-term sustainability of participation.
- Finally, the linkages between service delivery and governance were briefly discussed how the two processes are mutually beneficial and interdependent. The primary data indicated challenges in this area that need to be addressed and strengthened.
• UHC Day Coordination Group, supported by UHC2030, is offering a limited number of micro-grants to support civil society-led campaigns for 12 December 2019.
• Suggested approach for the campaign application included reviewing the UHC Advocacy Guide/Online Training to learn about the UHC approach, identifying target audiences, and preparing strategic advocacy messages, as well as last year’s UHC Day 2018 Campaigns to get inspiration for the campaign plan.
• UHC Day micro-grant application deadline is 11:59pm ET on Thursday, 31 October 2019.

General take-aways of the meeting across topics:

• Need for an ongoing social participation network beyond the finalization of the handbook.
• Learning from previous health movements (e.g. the HIV/AIDS movement) on how to put health issues and challenges on the agenda to be highlighted in the handbook.
• “Everything is connected”: Process and design elements need to be addressed in the Handbook.
• Special emphasis on those that are “left behind”: Handbook to take into consideration how to involved marginalized population groups.
• Consensus was stated on the Handbook’s chapter outline and its general content.
• SPTN validated the lessons learned, and recommendations developed (based on case studies and literature reviews).
• SPTN agreed on the next steps for the finalization of the Handbook.
• SPTN agreed on advocacy strategy both on international and country-level.