

Social Participation Technical Network

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

16-17 April 2019, Geneva, Switzerland

MEETING REPORT



The Social Participation Technical Network (SPTN) is a network within UHC2030 and the Health Systems Governance Collaborative. It responds to the network's objectives to bring together a range of stakeholders, catalyse strategic thinking, and influencing best practices by informing WHO guidance.

The Network main 2019 deliverable is the WHO Handbook on Social Participation for UHC. This deliverable recognizes the importance of the role of populations, communities and civil society, in addition to governments, in achieving WHO's Global Programme of Work ambition of one billion more people benefitting from universal health coverage (UHC) by 2030.

The objectives of the SPTN are:

1. To inform the development of the WHO Handbook on Social Participation for UHC.
2. To advance learning on the agenda of Member State governments more meaningfully engaging with civil society, communities, and its populations for health-related matters, including exploration of selected politically sensitive challenges¹, and facilitation of peer exchange.
3. To advocate the importance of social participation for equitable pathways towards UHC.

The **first face to face meeting** in April aimed to inform the development of the WHO Handbook on Social Participation for UHC. The SPTN, which includes civil society, academia, and government representatives, together with WHO colleagues, discussed preliminary results of a literature review on concepts and definitions around social participation as well as reviewed a generic and several context-specific country case study methodologies in order to advance learning on large-scale population engagement platforms, civil society involvement and community engagement in national health policy-making.

A key outcome of the SPTN was to agree on the work plan proposed by the WHO team, including the scope of work and the on-going collection and analysis of primary and secondary data to derive evidence-informed recommendations for members states for improved participatory health governance for UHC.

The main messages from this meeting are:

- **Health systems governance, or the lack thereof, can make or break UHC reforms.** A critical dimension of governance is participation. Engaging populations, communities and civil society in the planning and implementation of national health policies, strategies and plans provide a critical source of information for governments to draft people-centred and responsive policies, which are, in turn, more likely to be accepted and implemented by stakeholders. Health governance anchored in the principle of participation empowers communities and helps hold governments accountable for their commitments, driving progress in improving equity, social justice and rights, and ensuring that the most vulnerable and marginalized groups are not left behind.
- The Handbook is **targeted at member states** because there is need for guidance documents to address decision-makers on how best to leverage population, civil society, and community input for more responsive policy-making. Government cadres often acknowledge the value-add of participatory processes but face challenges in translating people's voice into implementable health policies. We thus aim to provide member states with best practice examples on how to engage; the

¹ Such as enabling representative participation of civil society and managing vested interests, and power dynamics and the scope for civil society participation to influence decision-making.

handbook will be as concrete as possible by outlining a set of mechanisms which work, making it clear in which contexts and under which conditions. We hope to make the case that investments in participatory governance can reap results when undertaken with the sincere aim of addressing people's health needs and expectations.

- Recognizing that we work in dynamic contexts, the Handbook should not be a one-off exercise, but rather be integrated into a series of **multiple products** to promote social participation for UHC. Other options (derived products) shall be explored which bring in more dynamic and interactive elements. This includes the promotion of mutual learning through peer exchange and South-South collaboration.

Introduction and opening remarks

- **Current commitments and momentum on UHC** at country and global levels (Astana Declaration, WHA72, UN General Assembly 2019, PMAC 2020) offer a huge opportunity to advance the meaningful participation of populations, communities and civil society in national health planning processes.
- Social participation is of particular importance in order to advance **social inclusion, equity** and **'leaving no one behind'** in health care, underpinned by the **right to health**.
- UHC is a **political choice** which requires participatory health governance as a foundation. Social participation and issues around inclusion/exclusion are usually reflective of the broader context beyond the health sector.
- At the same time, the **mutual responsibility** for effective participation was stressed:
 - **Creating a conducive environment.** It's not the responsibility of governments to organize civil society, but to ensure they have the capacities and means to do so themselves, and that they are empowered to participate meaningfully in decision-making processes.
 - **Participation brings responsibilities.** For participation at all levels, i.e. at local, regional and national level, it is important to clearly state that there are roles and responsibilities to each actor that raise expectations.
 - **Active voices are limited.** Improvements in coordination and organization among civil society organizations (CSOs) should be facilitated. Mechanisms need to be established to find ways to include the voices that remain often unheard (and to explore why they remain unheard). In addition, the role of media needs to be considered in order to convey messages to the general public and for them to build trust in the process.

Session 1: Handbook on Social Participation – Update on progress

- The Handbook is **targeted at member states** because of the gap in guidance documents addressing policy makers and the challenges they face. As a WHO product, this document can be used: by policy makers to be inspired and inform potential forms of engagement, by WHO country offices to raise awareness of the topic with their counterparts, and by CSOs and communities to advocate for as well as 'use and shape' their engagement with policy-makers on health sector reforms for UHC.
- **Building capacities** on both sides are essential for meaningful engagement. Both capacities of CSOs to influence processes (i.e. advocacy) are critical but also the capacities of government to understand why social participation is important and how it can be supported or enabled.
- The importance of **entering into collaborative and equal partnerships** was further pointed out as the ultimate end goal of good health governance. However, saying so frankly might block efforts to bring in participatory approaches in health, and be perceived as an encroachment into stakeholder power space. To avoid this, it is important to approach participatory governance in increments, keeping the end goal (entering into a true and equal partnership between stakeholders) in mind.

Session 2: Concepts and definitions - findings from a literature review

- There is need for clarity around definitions, terms and concepts, as terms are often used interchangeably and interpreted in different ways. To this effect, it may be better to talk about

'characteristics' instead of 'definitions' as the latter is more rigid and may be misleading. Nevertheless, the handbook team is not undertaking glossary/definition work per se (see next point).

- Rather, this work aims to mainly understand where we are coming from, what we are talking about, and definitions and terms shall serve us as a basis for a **common ground for joint understanding of the concepts that will be used in the Handbook**. Thereby, it is important to carefully consider 'common' language as they are relevant for the handbook. A case in point is to use the term 'citizen' more carefully as it may exclude marginalized groups (e.g. refugees) which voices remain often unheard.
- Participants agreed to apply the trifold distinction between **'state, civil society and market'** which excludes for-profit private organizations from CSOs as they are conceptually part of the market pillar (acknowledging that other actors, like Global Fund, do in fact include private sector in their ideas around civil society). The diversity among CSOs was recognized, also with regard to their ability to access spaces and resources needed for participation.
- Out of the discussion it was felt that two terms / concepts define best what we are aiming for:
 - **Social Participation:** *Social actors group their collective potential to achieve a collective good:* a term rarely used in the literature on civil society and health (at least in the English literature) but was considered very relevant for the Handbook and the contribution that this Handbook might provide to planning and policy-making for UHC.
 - **Deliberativeness:** *Provision of factual, balanced information, aiming at a fair process, which yields public decisions which all will view as legitimate; main criterion is equality, where each participant's input is weighted the same.* Deliberativeness is linked to the idea of governments being responsible for creating dialogue spaces for populations, communities and civil society to engage in decision-making. This term is common in the research community and rather unknown to policy makers.
- The literature search is currently limited to English; it was suggested to expand the search by including French and Spanish reviews (e.g. a lot of literature in Spanish for social participation available, given the vast Latin American context). Resources and time limitations however need to be considered, especially given that definitions will not be the main focus of the handbook. In addition to language, it was stressed that the topic around social participation is not specific to health but goes far beyond, and therefore a search in the social science literature on key frameworks and concepts might be advisable.

Sessions 3 and 4 : Civil society/community participation case studies

- In terms of the methodology, the following **key questions were asked that hinted towards understanding enabling/hindering factors, mechanisms, as well as outcomes yielded from participation in influencing policy and their implementation.**
 - Who participates, who does not participate, and why? What are their characteristics? And to what extent can they influence policy?
 - How does Ministry of Health identify marginalized populations, how do they bring them to the table (or go to communities themselves), and how do they sustain engagement? A focus on marginalized groups was stressed in order for the Handbook to add value and be

- transformative to 'leave no one behind' in UHC. Those who usually participate are privileged, and a focus on the status quo may exacerbate exclusion.
- What are the technical and financial capacities that enable civil society to have agency and engage meaningfully? How can they acquire these?
 - Typology and functions of civil society?
 - Overlap between community and CSO vs artificial distinction between the two?
 - Willingness for engagement and scope of involvement to enable effective participation (e.g. availability of a contact for CSOs at governmental level)?
 - How much does participation impact policy decisions and ultimately implementation?
- The idea to emphasize **country characteristics** (e.g. aid dependent environment, decentralized settings, fragile context) was welcomed.
 - **Case studies** presented in Burkina Faso, India, El Salvador, Mexico and Madagascar thus provide the opportunity to analyze roles and capacities of CSOs and communities through an in-depth view into participation processes *within the political and social context in which they are taking place* (e.g. *El Salvador's case study on maternal and child health in the context of the country's strict abortion law*). Ultimately, case study findings should guide the development of recommendations and lessons learned on meaningful engagement.
 - Country specific case study methodologies have unveiled the often-prevailing **overlaps between communities and civil societies**. Also, case studies' country-specific methodology development has required more Secretariat input than expected. There has been confusion on where the boundaries are between case-study specific results which are borne out of a specific context, and more generalizable, cross-cutting lessons. In addition, the object of study is sometimes a programmatic approach which can be research-based, further causing confusion. (for example, in Madagascar, the district strengthening programme supported by 'Action Contre la Faim' is the object of study for the handbook) Compounding this are the specific policy-focused research questions applying to the Handbook is usually not the emphasis given to many of the community-based approaches.
 - It was further pointed out that less successful case studies could be included, which are also valuable for learning.
 - In terms of the descriptive qualitative study, **faith-based or faith-inspired organizations** shall be recognized as a player in health due to their ability to often reach a broad range of communities. There is a need to distinguish between various roles these organizations take at international/national and regional/local level. Also, controversies in areas such as sexual and reproductive health need to be carefully considered. Concerns were expressed that for the Handbook work, FBOs should be seen as one of several stakeholders, with no greater weighting than any other; more acceptance was sought to explore inter-faith dialogue platforms/councils.

Session 5: Large scale population engagement mechanisms (Thailand, France, Tunisia, Iran)

- **Participatory governance mechanisms such as large scale population consultations remain under-utilised** in most countries independent of their income level.
- **Common issues**, such as identifying entry points/windows of opportunities and change agents to drive the process, building capacities for policy dialogues, raising awareness of the process, as well

institutionalizing the process and upholding participation over time were expressed. To encourage participation, governments shall 'go to the people'; the burden to travel from rural areas to the capital should not be placed on vulnerable groups for them to be able to engage. Also, there is often need to involve other parts of government, beyond the Ministry of Health, including higher levels of the executive and legislative.

- With reference to the Thai triangle (people's, knowledge and government sector), the importance of having evidence generators (**academia, think tanks, etc**) at the table was highlighted in order to stimulate evidence-informed policy dialogue and decision making.

Sessions 6 and 7: Issues to consider in engaging populations, communities and civil society

- During a brainstorming discussion, the following six themes emerged to be discussed in group work to guide the second round of the literature review:
 - *(i) outcomes and rational:* investment case for why social participation is important, theory of change to overcome limitations of attribution to health outcomes
 - *(ii) funding:* better understanding who is funding social participation in health
 - *(iii) Institutionalization, sustainability and participatory governance:* identifying conditions and requirements for institutionalization but also understanding risks and barriers
 - *(iv) representation:* understanding who determines who is invited from CSOs, close link to accountability, also in the regard how does civil society hold themselves accountable as representatives of communities.
 - *(v) equity and leaving no one behind:* how to go from exclusion to inclusion, i.e. representation/agency/empowerment/influence
 - *(vi) tools, processes, institutional capacity, mechanisms:* understanding the role ICT play in social participation, capacity building for both government and civil society
- Four main research areas emerged that was felt needed more in depth exploration in the literature: (a) representativeness of constituencies, (b) capacity building for policy dialogue for both civil society and governments, (c) exploration of how decisions are taken after public consultation process (e.g. through experts and policy-makers, consensus-building etc.) as well as (d) maintaining engagement over time.

Session 8: Advocacy strategy

- The Network has a role beyond the development of the Handbook, to mobilise political support for social participation in global commitments and country governance mechanisms. This may extend the mandate of the Network into 2020, with an **updated advocacy strategy** to drive change at country level.
- There is need for focused **advocacy** in anticipation of the Handbook and in support of its roll-out to mobilise political support for this agenda and improve practice at country level. Identifying and harnessing 'champion will' may be important for this, as well as wider country engagement in the Network.
- **Briefing notes** should be developed that entail key messages that can be disseminated at important events such as UNGA, UHC Day, PMAC, WHO regional committee meetings.

- Along those lines, the **organization of consultative meetings**, potentially at regional level, to promote the topic of social participation and participatory governance mechanisms with policy-makers and sensitise them about the upcoming Handbook was proposed.
- **WHO country offices** are an important target, too. The WHO Representative can play a key role in order to initiate and continue discussion around this topic with Ministry of Health representatives.
- Recognizing that we work in very dynamic contexts, it was stressed that the Handbook should not be a one off exercise, but rather be integrated into a series of **multiple products** to promote social participation. **Creating interactive platforms** for communication and knowledge sharing across countries ('community of practice', e.g. through the Health Systems Governance Collaborative) were welcomed.

Conclusions

- The **Handbook is not an end in itself**; rather, it serves as one of various tools/guidance in a long journey, to move from top-down to participatory mechanisms so that populations, communities and civil society can contribute to strategies that in turn are more responsive to their needs and expectations.
- In addition to the rather conservative format of a handbook (for some the title seemed too 'static'), it was stressed that other options shall be explored that bring in more **dynamic and interactive** elements. This includes the promotion of mutual learning including peer-exchange and South-South collaboration.
- Last but not least, it was stressed to **keep language simple** in the Handbook, and be precise, concise and bold in naming key challenges and why desired outcomes of participation have not been met yet in many countries to accelerate progress towards universal health coverage.

Action points

- Update terms of reference for the social participation technical network including potentially a new name/acronym for the SPTN (suggestions welcome).
- Conduct the second round of literature reviews and consult with the SPTN for input via a teleconference.
- Follow up on case studies and advance data collection and analysis.
- Update advocacy strategy, including the launch and dissemination plans for the Handbook and ongoing advocacy.
- Follow up on the next face to face of the SPTN which will likely be hosted in Paris, soon after the summer.

Annex: Agenda

Day 1: 16 April 2019

Moderator: Godelieve van Heteren

08:45 – 09:15	Registration
09:15 – 09:30	Welcome <i>Marjolaine Nicod, Joint Lead, UHC2030 Core Team</i>
09:30 – 09:50	Opening remarks Social Participation Technical Network Co-Chairs <i>Jean-Francois Delfraissy, President, National Bioethics Council, France</i> <i>Justin Koonin, President, Acon/Civil Society Engagement Mechanism Representative</i> <i>Mette Kinoti, Chief Programmes Officer, Amref Health Africa</i>
09:50 – 10:30	Session 1 Handbook on Social Participation: Update on progress <i>Dheepa Rajan</i> <i>This first part of this presentation will briefly go over the handbook work plan and timelines, remind the SPTN of its objectives and explain the agenda for this 2-day meeting. The second part will explain progress on the work plan content, focusing on the different types of population engagement modalities and the current way of organizing the thinking around the evidence generation for the handbook.</i>
10:30 – 10:45	Coffee Break
10:45 – 12:00	Session 2 Concepts and definitions: findings from a literature review <i>Dheepa Rajan</i> <i>A literature review has begun to inform the handbook, with the first analysis of documents focused on definitions and concepts. The objective of this session is to present preliminary findings of this initial analysis, explain how the draft definition suggestions were arrived at, and have an initial debate on pertinence and utility of these definitions for purposes of the handbook. These concepts and definitions will then be revisited in session 7 on day 2.</i>
12:00 – 13:30	Lunchbreak
13:30 – 15:00	Session 3 Civil society/community participation case studies a) Research methodology and study selection <i>Katja Rohrer</i> <ul style="list-style-type: none"> • Presentation of community and CSO generic case study methodology • Overview of case study proposals and selection criteria • Q&A, discussion b) Descriptive qualitative study on faith-inspired organizations <i>Kira Koch</i> <i>Discussant: Jean-Francois de Lavison</i> <ul style="list-style-type: none"> • Presentation of an on-going descriptive mapping study in partnership with Ahimsa on faith-inspired organizations and their role in the health sector and UHC • Q&A, discussion
15:00 – 15:15	Coffee Break
15:15 – 16:30	Session 4 Civil society/community case study round table Panel with CSO and community case study leads <i>Sylvie Zongo, Benoit van Maele, Kira Koch, Laura Malajovich, Angela Chaudhuri</i> <i>Brief presentations on country-specific case study methodologies examining civil society or community participation efforts linked to national health policy dialogue: Burkina Faso, Madagascar, El Salvador, Mexico, India. This session aims to feed into the country-specific case study methodology reflections and shape the context-specific data collection and analysis. Sufficient time will be provided to ask questions and discuss each case study methodology.</i>
16:30 – 17:00	Wrap-up and outlook for day 2

Day 2: 17 April 2019

Moderator: Godelieve van Heteren (except session 6 and 8)

09:00 – 09:30	Reflection on Day 1 and outlook for Day 2
09:30 – 11:30	Session 5 Platforms to engage populations in policy-making processes a) Cross-cutting lessons from 3 case studies (Iran, Tunisia, Thailand) <i>Dheepa Rajan</i> <i>This presentation will focus on cross-cutting lessons and insights from the 3 case studies including initial thoughts on the following questions:</i> <ul style="list-style-type: none">• What were the main challenges when introducing the population engagement platform?• What were the main lessons learned? <i>A round of exchange with the plenary following the presentation will help shape the cross-cutting analysis of the population engagement case studies.</i> b) France: <i>Democratie sanitaire</i> and public participation in health sector decision-making <i>Michel Wakim and Anais Ronchin</i> <i>Discussant : Jean-Francois Delfraissy</i> <i>Sciences Po Paris will present the methodology and analytic framework for the France case study. Since data collection is still on-going, meeting participants' input into this presentation will be useful to shape further data collection and analysis.</i>
11:00 – 11:15	Coffee Break
11:15 – 12:00	Session 6 Issues to consider in engaging populations, communities, and civil society <i>Justin Koonin</i> <i>This session will present topics drawn from document and literature reviews, as well as the discussions during previous sessions of this meeting, to be covered in the handbook. This session aims to identify and prioritise broad themes and topics that should be taken back to a 2nd stage literature review and included in upcoming research, which will inform the structure of the Handbook</i>
12:00 -13:00	Lunch
13:00 – 15:00	Session 7 Introduction to group work <i>Justin Koonin</i> <i>Groups will be formed according to topics discussed in sessions 2-6 with specific questions to help the handbook team prioritize topics to include in the 2nd stage literature review and the handbook structure overall. This session can be seen as a continuation of session 6.</i> Coffee Break included
15:00 – 16:30	Session 8 Advocacy strategy <i>Lara Brearley</i> <i>Moderated by Githinji Gitahi</i> <i>This session will update the SPTN on implementation of the social participation advocacy strategy. A facilitated discussion will then help the group come to an agreement on how to advance the advocacy objective on country mobilisation</i>
16:30 – 17:00	Next steps <i>Dheepa Rajan</i>
17:00 – 17:15	Concluding remarks <i>Gerard Schmets</i>

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