

# Realising the right to participate in pandemic prevention, preparedness and response and beyond

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As the WHO discusses the possibility of adopting the Pandemic Accord under Article 19 of the WHO Constitution, there is a fundamental need to prioritise social and political participation in health and public health-related decision-making processes at all levels of governance globally.

The conceptual zero draft of November 2022 (the draft), prepared for the Inter-governmental Negotiating Body meetings, demonstrates a commitment to transformative change by recognising equity and universal health coverage (UHC) as core principles, emphasising the need for innovative finance mechanisms and recognising the crucial role of community engagement in strengthening future pandemic response. Nonetheless, embedding these provisions into the global governance of infectious disease control through incentivising and facilitating meaningful and effective public participation at the local, national, regional and international levels could engender long-lasting positive changes.

If adopted without realising the right to participate, the draft may inadvertently reinforce a state-centric approach to infectious disease control and fail to address existing power imbalances in governance and global healthcare. Such a paradigm can perpetuate the marginalisation of vulnerable and marginalised populations by inadequately reflecting their needs.<sup>1</sup> In other words, without broadening political participation at the WHO and domestic levels, the draft may be ineffective in encouraging a society-wide approach towards pandemic preparedness and response, and as a result may limit opportunities to detect the specific needs of these social groups.

The draft provisions and meaningful participation are mutually dependent; the successful implementation of one requires the inclusion of the other. For instance,

## SUMMARY BOX

- ⇒ The draft Accord on pandemic prevention, preparedness and response by the WHO and member states may inadvertently reinforce a state-centric infectious disease paradigm without substantively changing the governance structure wherein global health policies and decisions are made.
- ⇒ Participation in decision-making processes at all levels of global governance for health can also help mediate and re-establish trust in science and political institutions.
- ⇒ Decisions about pandemic response and preparedness determine the allocation of health resources, where inputs from diverse stakeholders can mitigate the complex vulnerabilities embedded in social and institutional structures.
- ⇒ The right to participate is the 'right of rights'; democratising health through participatory decision-making at all levels of governance is vital to reduce health gaps.

political participation is essential to realising the right to health, wherein UHC is the bedrock for political participation and civic engagement in processes and decisions that affect health.<sup>2</sup> Therefore, including UHC as part of the draft is a positive step towards democratising health. To that end, engaging relevant stakeholders in defining the scope and dissemination of healthcare services as well as their design, implementation, evaluation and monitoring is critical to ensure that all voices and concerns are heard, addressed and represented.

To assess national health emergency preparedness capacities and gaps at the local, national, regional and global levels, the WHO is considering the establishment of a voluntary 'global peer review mechanism'.<sup>3</sup> This is a welcome approach. Extending peer review processes beyond state actors would harness and create new avenues for monitoring and implementing inclusive and participatory health policies.



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Enabling non-state actors to participate in the process would create an additional layer of oversight and generate accountability for governments.

Furthermore, involving stakeholders in decision-making processes at all levels of global governance for health can also help re-establish trust in science and political institutions. The rights-based approach used in the HIV/AIDS movement in the 1990s<sup>4</sup>—‘nothing about us without us’ exemplifies how participation can empower communities and drive lasting social change.

Engaging the public through political participation in healthcare decision-making enhances transparency in power and resource distribution and reinforces accountability. Empirical studies have shown that social, political and economic environments influence population health outcomes, underscoring the need for inclusive participation where policy-making reflects various vested interests. The benefits of participation extend beyond equitable resource allocation and includes, for instance, increasing life expectancy for the population through greater representation of women in parliament.<sup>5</sup>

During the COVID-19 pandemic, countries with deliberative decision-making processes were associated with fewer mortalities as compared with those countries without,<sup>6</sup> thus providing a unique opportunity to ensure inclusive participation at all levels of global health governance.

Decisions affecting pandemic response and preparedness also determine the allocation of health resources, whereas inputs from diverse stakeholders can mitigate the complex vulnerabilities embedded in social and institutional structures. Effective and efficient pandemic response and preparedness must address the various vulnerabilities that stem from structural causes. As evidenced by a growing body of research, the pandemic disproportionately affected vulnerable and marginalised populations<sup>7</sup> and accelerated and exacerbated existing health disparities within and across countries. Unprecedented socioeconomic disruptions resulted from the pandemic. By engaging in and broadening political and social participation in health and health-related decisions at local, national and international levels, opportunities for exercising an individual’s agency can be created.<sup>8</sup>

Thus, regardless of the form and contents of the final text adopted by the WHO, international human rights law, ratified by most countries in the world, provides legal basis for an individual to participate at all levels of global governance.<sup>9</sup> Article 4 of the 1978 Declaration of Alma-Ata on primary healthcare states that ‘people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare’.<sup>10</sup> Furthermore, the right to participate extends beyond the healthcare sector. Specifically, Article 25(1) of the International Covenant on Civil and Political Rights provides that ‘Every citizen shall have the right and the opportunity...[t]

o take part in the conduct of public affairs, directly or through freely chosen representatives’.<sup>11</sup> The right to participate is also reiterated in the Convention on the Elimination of All Forms of Discrimination Against Women<sup>12</sup> and the Convention on the Rights of Persons with Disabilities.<sup>13</sup> Moreover, as the pandemic spread, the UN resolution also recognised the need for effective implementation of the right to participate in public affairs.<sup>14</sup> Given that the pandemic has penetrated all aspects of social, economic and public life, an effective pandemic response requires a collective approach that supports the right to participate.

Given that the right to participation is the ‘right of rights’,<sup>15</sup> ensuring meaningful and effective participation in health decision-making at all levels of governance is vital for reducing health disparities and rebuilding a world of solidarity during and after public health.

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