

Participation is The Medicine For AI Healthcare, But It Needs To Be Real

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The World Health Organization is currently drafting its next *Global Strategy on Digital Health (GSDH) 2028-2033*. As a group of public health professionals, AI developers, policymakers, patient advocates, industry representatives, and academics in the social and computer sciences working together in the HealthAI Community of Practice, we have seen that all-too-often visions for digital health miss a key ingredient. For AI to benefit human health and protect population sovereignty, governments and insurance firms need to use their purchasing power and other authority to centre participatory approaches in the design and development, through to deployment and governance of the AI in the health ecosystem. These principles inform a set of action points stated below.

Meaningful participation matters for better AI in health

Participation is a fundamental human right, grounded in rights to freedom of expression, freedom of opinion, sovereignty rights, and in the right to the highest attainable standard of health.

Global AI in healthcare is a booming industry: according to analysis shared by HealthAI, the total number of AI patents granted annually doubled yearly from 2015 to 2022, and the global market compound annual growth rate, US\$16.61 billion in 2024, may go up to US\$421.18 billion in 2032 (Sources: The AI Index 2024 Annual Report; Market Data Forecast).

As AI increasingly shapes the availability, accessibility, acceptability and quality of health information and services, often based on extractive data regimes; and as it increasingly shapes our environment, including underlying environmental determinants of health (such as clean water), it is more crucial than ever that the digital health agenda not be shaped purely by commercial interests far away from the people they impact.

Participation itself functions as a determinant of health. When communities are excluded from AI design, the resulting tools risk reinforcing the very inequities they purport to address, eroding trust, misaligning with local priorities, and producing outcomes that serve the system rather than the population. The GSDH should therefore require that vendors disclose the populations represented in training datasets, document community input on what data is collected and how it is used, and demonstrate how design choices were validated against the contexts in which tools will be deployed. Transparency at the design stage is not a procedural nicety, it is a precondition for health equity.

Meaningful participation enhances social accountability. It ensures AI development, procurement, and use align with local priorities and reflect cultural, operational, and resource contexts that are continually revisited through ongoing engagement with communities and health workers. Applied to AI, participation is required not only in design but across deployment, adaptation, evaluation, governance and harm-reporting processes. Mechanisms for raising concerns, documenting harms, detecting and responding to incidents, requesting remedies, and iteratively adjusting systems are critical for safety and relevance.

Current governance approaches in the health AI space are far from sufficient, dominated by private-sector standards, and often falling between medical and consumer safety review. There is a lack of certainty and clarity, slowing innovation and making it harder to patients and healthcare professionals to trust AI. Whilst demanding developers better explain their products better is important, participatory AI governance models emphasise that transparency alone is insufficient unless communities are empowered to influence procurement, implementation, and evaluation decisions across the AI life cycle.

Structural barriers—such as time, compensation, language access, disability access, digital divides, immigration status, and fear of retaliation—may limit who can participate and require thoughtful preparation. Meaningful involvement requires access to understandable information: what an AI tool does, its limitations, how performance varies across populations, how often it updates, and who is accountable when harm occurs. This implies participation that starts in the design of an AI solution (including the problem definition and intended use), and continues through deployment and use, including local adaptation to cultural, operational and resource

realities, and iterative evaluation that tracks who benefits, who is missed, and what changes are made in response.

Building the conditions for participation

Regulatory capacity is foundational. Many officials want to ensure the safety and effectiveness of AI systems but lack technical skills; long-term, structured training programmes produce more durable capability than one-off workshops. Participation in AI development benefits from early engagement, co-design, transparency about system functionality and data use, interdisciplinary collaboration, and digital literacy initiatives.

A major structural challenge is that key design decisions—data sources, performance thresholds, optimisation targets—are made by global technology companies long before procurement. Thus, meaningful participation requires both local capabilities to interrogate vendor claims and broader governance mechanisms ensuring upstream accountability.

Legal architectures supporting participation—rights to information, to contest automated decisions, and clarity around data governance—need to be developed in many countries. These rights, including access to information about how AI is used in your care, the ability to challenge automated decisions, and clarity on how health data is processed, require a functioning data governance framework as their foundation.

By the time a health ministry is selecting a tool, the design choices that will determine how it performs for their population have already been made, in a different legal and cultural context, without that population in view. Strengthening participation at procurement therefore requires both local capabilities, knowing what questions to ask and what contract conditions to insist on, and upstream accountability mechanisms that reach vendors at the design stage. Procurement conditions on transparency, independent validation, incident reporting, and exit rights are enforceable levers that can move faster than regulatory timelines, particularly in markets where AI legislation is still developing.

Procurement frameworks must also expand how AI health tools are evaluated. Cost savings and efficiency gains are insufficient proxies for health outcomes and can actively conflict with prevention goals. The GSDH should require member states to include upstream value metrics in procurement criteria, prevention rates, reduction in health inequities, and community trust, alongside financial ROI. Tying funding to health-promoting outcomes rather than short-term cost reduction alone shifts incentives toward tools that identify risk early and address root causes that can cut costs in the longer-term, enhancing sustainability and resilience of healthcare systems.

New ways to communicate AI and policy

While often participatory approaches of a variety of stakeholders are foreseen, these processes often tend to be designed in a way that participation is included when decisions are already made.

Meaningful participation in AI governance faces a structural obstacle: although AI policy is a matter of democratic governance, it inherits technical barriers associated from the AI industry.

Dismantling these barriers is essential, both in processes tied to the development and deployment of AI systems and, more broadly, in the democratic processes that will define the rules for AI's development. This requires technical stakeholders to actively reframe their communication to include non-expert participants and level the playing field for them. It also requires building literacy in two directions: public understanding of AI, and public familiarity with how policy processes work. Neither alone is sufficient to enable genuine participation.

If participation is often currently treated as a one-off exercise, the essential next step is to make it truly iterative and embedded in routine structures, rather than just a one-off activity. This continuous approach is what helps us spot problems early and adjust over time as tools are updated or used in new settings. To advance innovation of AI in healthcare, the next WHO Global Strategy on Digital Health must include these points.

1. Shift the discourse where diverse stakeholder **participation is treated as a driver of innovation** in AI healthcare rather than only a regulatory burden.
2. Harmonised and enforceable regulations on AI in healthcare that specify **minimal standards for participation**.
3. **Facilitate communities of engagement between key stakeholders** (e.g. developers, governments, clinicians, patient associations) **early enough to influence design - not only at the procurement stage**.
4. **Mechanisms for assessing impact, monitoring effects, and raising concerns** over AI usage in healthcare should be accessible to local and diverse communities prior to large scale deployment of AI models.
5. **Feedback processes** whereby **documented harms lead to redesign** of AI healthcare technologies.
6. **Regulatory sandboxes on AI healthcare must invite patient associations and other key civil society stakeholders** to evaluate potential risks and identify solutions.

7. **Predictable procurement frameworks that reward responsible and participatory design** rather than lowest cost.
 8. **Governments must support patient associations and related civil associations** in monitoring the effects of AI healthcare on patients.
 9. **Education for developers and healthcare professionals must include Social Science teaching** that places AI in its societal context.
 10. **Public disclosure of training data limitations** of AI tools used in health and healthcare.
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The HealthAI Participatory AI working group includes as members:

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