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Commentary

Community Engagement as a Partnership Is an Essential Element of Evidence Informed Health Policy-Making

Comment on "Civil Society's Evidence-Generating Role for Health Policy Decisions: A Thematic Analysis of a Healthcare Information for All (HIFA) Community Online Discussion"

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Abstract

Recent outbreaks and pandemics coupled with efforts to ensure universal health coverage demonstrate the importance of community engagement in evidence-informed health policy-making. Commenting on Gopinathan and colleagues' thematic analysis of a Healthcare Information for All (HIFA) online discussion, this commentary argues that civil society organizations should be recognized as advocates, generators and interpreters of evidence. The HIFA analysis highlights the diversity of civil society and that meaningful participation requires institutionalized mechanisms where experiential, tacit and local knowledge can complement formal research evidence. It also highlights important constraints, including self-selection, unequal representation and wider political economy factors that shape whether such evidence influences policy. This commentary draws on TDR-supported research to illustrate how communities can help identify research priorities, co-design interventions, generate data, and interpret findings. It concludes: engagement has greatest value when communities are treated as partners in knowledge production and decision-making, rather than as consultees or research participants only.

Keywords: Community Engagement, Social Participation, Evidence-Informed Policy-Making, Implementation Research

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Recent disease outbreaks, including Ebola, Zika, and the COVID-19 pandemic demonstrate the importance of public engagement in responding effectively to these emergencies. There is a vital role for institutionalized mechanisms to foster a dialogue that creates the trust necessary between all parties if a response is to be successful (Figure).[1]

More widely, such dialogue is a central to the approach recommended by the World Health Organization (WHO) in order to achieve universal health coverage. But achieving effective public engagement is challenging. It requires an understanding that power is not evenly distributed and all participants, be they patients or policy-makers, come with their own inherent biases. Participation can be difficult for marginalized sections of the population due to economic status, language, and disabilities.[2] Participation requires a structure and management to support all participants so that it is not only the loudest or most powerful voices that are heard and acted on.[3]

Finally the most important enabler of all is an environment that welcomes public input, little will change if the political economy does not value evidence-informed policy or public discourse.

Gopinathan and colleagues make an important contribution to this area with their thematic analysis of a structured online discussion hosted by Healthcare Information for All (HIFA).[4] Their short communication focuses on civil society organizations and how they have contributed evidence to policy decisions.

The article's central message is that civil society should not be seen only as an advocacy actor or pressure group seeking to influence, but, when managed well, they also serve as a generator and interpreter of evidence.

The participants in the online discussion drew on their own experiences to identify four themes. First, civil society is plural and heterogeneous, encompassing grassroots organizations, professional non-governmental organizations, patient groups, community networks, and advocacy coalitions. Second, meaningful civil society engagement depends on institutional arrangements that create regular and legitimate opportunities for participation. Third, civil society can contribute evidence that can be applied locally or globally and, if that evidence

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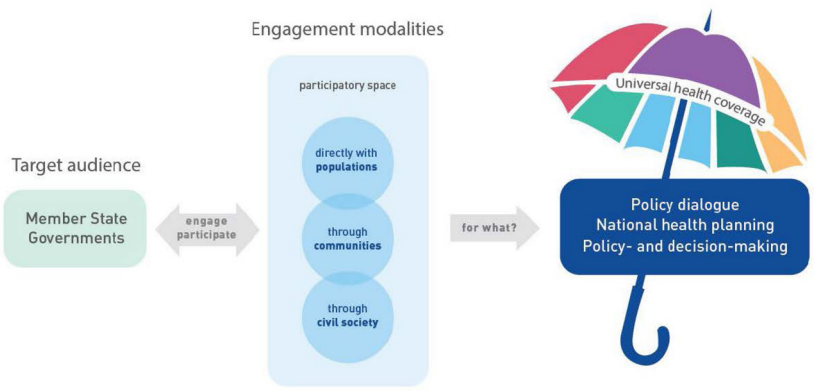


Figure. The World Health Organization Model Promoting Effective Public Engagement as Vital to Achieve Universal Health Coverage. Adapted from World Health Organization,[1] Copyright (2021).

is experiential and tacit, it is valuable and complementary to the evidence generated by formal scientific research. Fourth, the influence of such evidence is shaped by political economy factors, including power asymmetries, professional interests, donor priorities, and commercial pressures. These findings align with current efforts to broaden what counts as relevant evidence in health policy and to make decision-making more democratic, transparent, and responsive.

By using its existing global community of practice HIFA provided access to a geographically diverse and professionally varied network of health workers, researchers, policy actors, and civil society representatives. Although the number of active contributors was modest, at just 14 participants from a membership of 10 000, the discussion generated rich qualitative material.

The article is particularly valuable in challenging what constitutes evidence. Historically within a clinical setting policy was made with a narrow selection of evidence limited to the use of systematic reviews, epidemiological studies, and economic evaluations. For good quality evidence-informed policy decisions the focus will be on effectiveness and value for money but also requires evidence on feasibility, acceptability, equity, implementation barriers, values, and lived experience. Civil society organizations are often well-placed to provide this knowledge because they work close to affected communities. They can aggregate the concerns of larger groups and identify and represent problems that formal systems overlook. Civil society can generate evidence that includes community testimony, service-user experience, monitoring reports, case documentation, participatory research, and accounts of how policies operate in practice. Such knowledge can improve the legitimacy, relevance, and equity of policy decisions when engagement is well-designed and linked to decision-making authority.[1,2]

In the HIFA study we see findings from a small, self-selected sample of stakeholders which means that the findings should be interpreted more as exploratory than representative. Participants in HIFA are likely to value public engagement and may already be sympathetic to civil society engagement. The discussion therefore provides insight into informed perspectives but cannot capture the full diversity of civil society actors, particularly less-resourced community groups, informal networks, or organisations operating in politically constrained environments. The authors recognised these constraints but most notably used the engagement to contribute to the development of a Cochrane protocol that will explore further how civil society does, or does not, influence policy.[5]

Consultation is clearly valuable, but experience show us that participatory evidence generation will have a greater impact and influence policy particularly when the engagement is structured and institutionally connected. A systematic review of community engagement in 2023 highlighted the importance of genuine engagement with communities throughout the whole research cycle, going beyond just consultation and information sharing.[6] TDR, the Special Programme for Research and Training in Tropical Diseases, is the organization where I work and has pioneered this type of community engagement within participatory research for more than two decades.[7]

Research, supported by TDR, has demonstrated that communities can contribute directly to the identification of research questions, the design of interventions, the generation of data, and the interpretation of findings.[8] The examples below illustrate complementary ways in which community engagement has strengthened research on infectious diseases of poverty and health systems in low- and middle-income countries.

The first example comes from the TDR Social Innovation in Health Initiative. Work initiated in 2021 supported ten projects across Africa, Asia, and Latin America to identify, analyse, and document good practices in community engagement related to infectious diseases of poverty and health service delivery.[9] The projects examined how communities participate in implementation research, social innovation initiatives, and health service delivery programmes, with topics ranging from infectious diseases to broader public health challenges. A central objective was to understand how community engagement contributes to the relevance, effectiveness, and uptake of research. Across the portfolio, communities were engaged in defining research priorities, documenting local experiences, identifying barriers to implementation, and co-producing knowledge with researchers. The initiative reinforced the view that community engagement is most

effective when communities participate throughout the research cycle rather than only as respondents or beneficiaries.

Further analysis was undertaken by Ahumuza et al of these and other Social Innovation in Health Initiative projects addressing a range of health issues, including infectious diseases, maternal and child health and access to primary health care, using a global sequential mixed methods analysis.[10] The findings showed the community members were engaged from the earliest stages of the research process, helping to identify health priorities, co-design interventions, implement activities, and assess outcomes. The study found that more than half of the projects involved collaborative or shared leadership with communities. Community engagement was particularly important during problem identification and intervention design, ensuring that solutions reflected local realities and priorities. The study concluded that community engagement increased community ownership, acceptance of interventions, and sustainability while simultaneously contributing to the generation of research findings and locally relevant innovations.

The second example is a TDR-coordinated multi-country study on residual malaria transmission conducted between 2015 and 2019. The programme involved research teams working in ten countries across Africa, the Americas, South-East Asia, and the Western Pacific Region.[11] The objective was to understand why malaria transmission persisted despite widespread use of insecticide-treated nets and indoor residual spraying. Researchers found that human behaviours—including outdoor sleeping, occupational exposure, evening social activities, and population mobility—played a critical role in sustaining transmission. These insights emerged through close engagement with affected communities and analysis of local practices. Community knowledge therefore became a key source of evidence, revealing determinants of malaria transmission that would not have been apparent through entomological or epidemiological data alone. The findings informed recommendations for locally tailored malaria control strategies that better reflected community realities.

This work illustrates that genuine engagement with specific populations can be beneficial in co-developing outputs across the entire research process—from identifying priorities and designing studies to generating data, interpreting evidence, and supporting implementation.

This was particularly true when TDR supported research to better understand how to engage youth within health programmes. Youth-led designathons, crowdsourcing challenges and community-led implementation projects demonstrate that experiential and local knowledge can contribute not only to advocacy but to intervention design, implementation and evaluation.[12] A practical example of how this work can generate outputs was the youth co-created guide that provides comprehensive, evidence-informed guidance on how to design, implement, and sustain youth co-creation processes in diverse settings. These examples broaden the discussion from civil society as commentator to civil society as co-producer of knowledge and innovation.[13]

In each of these examples, community participation improved the relevance and applicability of findings while generating knowledge that would otherwise have remained inaccessible.

In conclusion, Gopinathan and colleagues' article advances an important argument: civil society should be recognised as part of the evidence ecosystem for health policy. Its contribution lies in showing that civil society evidence includes lived experience, contextual knowledge and practical insight into how policies affect people and communities. The research pioneered by TDR shows that for engagement to have an impact on behaviour, decision-making and policy communities, civil society and the broader public have to be seen as partners in the research process and not merely as participants. Civil society engagement should not be treated as an optional add-on to evidence-informed policy-making. When appropriately supported and critically assessed, it will improve the relevance, equity, and legitimacy of health decisions.

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Ethical issues

Not applicable.

Conflicts of interest

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The author alone is responsible for the views expressed in this article and he does not necessarily represent the decisions, policy, or views of the WHO.

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