

Using Health Committees to Promote Community Participation as a Social Determinant of the Right to Health: Lessons from Uganda and South Africa

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Abstract

Community participation is not only a human right in itself but an essential underlying determinant for realizing the right to health, since it enables communities to be active and informed participants in the creation of a responsive health system that serves them efficiently. As acknowledged by the Rio Political Declaration on Social Determinants of Health, participatory processes are important in policymaking and in the implementation of laws relating to health. Collective deliberation improves both community development and health system governance, resulting in more reasoned, informed, and public-oriented decisions. More recently, attention has focused on the elements of health system governance that enable greater responsiveness to community needs. However, there is relatively little by way of interventions linking human rights approaches to governance in ways that recognize participation as a critical social determinant of the right to health. This paper provides perspectives from a three-year intervention whose general objective was to develop and test models of good practice for health committees in South Africa and Uganda. It describes the aspects that we found critical for enhancing the potential of such committees in driving community participation as a social determinant of the right to health.

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Introduction

With consensus being established that community participation is essential for the development, monitoring, and delivery of health services, there is a need for credible platforms through which communities can participate in health decision making to move beyond being passive recipients of health care to actively and effectively participating in health decision making.² These platforms, which transform community participation from a mere civil right to a social determinant of health, increase communities' engagement in accountability and monitoring processes that are able to raise priorities and concerns, and they facilitate the implementation of actions that support the achievement of better health outcomes.³

The international human rights framework is instructive on the right to participation. For example, article 21 of the Universal Declaration of Human Rights guarantees everyone's right to participate in the governance of their country, and article 25 of the International Covenant on Civil and Political Rights enshrines people's right to participate in the conduct of public affairs and to have access to public service.4 The Human Rights Committee, in its General Comment 25, further sheds light on the right to participate in the conduct of public affairs, explaining that article 25 of the International Covenant on Civil and Political Rights requires states to adopt legislative and other measures to ensure that citizens have an effective opportunity to realize this right.5 Meanwhile, General Comment 14 of the Committee on Economic, Social and Cultural Rights—which further interprets the right to health as laid out in the International Covenant on Economic, Social and Cultural Rights-notes that realizing the right to health requires that both individuals and groups be entitled to participation in all government decisions affecting their health, including agenda setting, accountability, and decision making.6 These rights and obligations are similarly reflected in the African Charter on Human and Peoples' Rights, especially article 13, which guarantees everyone's rights to participate in governance and to have equal access to the public service of their country.7

In the context of primary health care, the 2018 Declaration of Astana underscores the importance of supporting the involvement of individuals, families, communities, and civil society in the development and implementation of policies and plans that have an impact on health.8 The declaration outlines countries' commitment to "increase community ownership and contribute to the accountability of the public and private sectors for more people to live healthier lives in enabling and health-conducive environments."9 It builds on the 1978 Declaration of Alma-Ata, which emphasizes people's "right and duty to participate individually and collectively in the planning and implementation of their health care" and requires the state to facilitate the participation of communities and individuals in the "planning, organization, operation and control of primary health care," including educating communities about their right to participate.10 These declarations provide an opportunity to consider community participation not only as an underlying determinant of health but also as a social justice mechanism through which groups can take part in issues affecting them beyond health services.

Partly on account of these international human rights instruments that recognize a right to participate, a community participation movement that places value on involving communities in the provision of public health services has grown. This movement argues that community participation in the provision of health services increases a sense of responsibility and conscientiousness among the public, given a perceived increase in skills, information, and control over health resources.11 The organization and delivery of health services also benefit from community participation due to a better determination of the need for health facilities, their ideal location and size, the number and types of health workers required, employment practices, and health worker policies.12 Ana Ruano et al., in presenting findings from the research consortium Goals and Governance for Global Health, have also argued that through meaningful participation and community engagement, a more horizontal and inclusive approach replaces the top-down process of decision making.13

To fully realize the value of community participation, there is a need for credible platforms that allow communities to effectively participate in the provision of health care services. Following the Declaration of Alma-Ata, health committees have been considered an effective mechanism to achieve this. However, constraints such as the failure to integrate these workers into national programs, socioeconomic and political barriers, bureaucracies, and a lack of support from health professionals at other levels have inhibited the ability of community health workers to effectively facilitate the participation of communities in health service provision.¹⁴

Interventions

Our interventions—one in South Africa and another in Uganda—aimed to enhance the potential of health committees (also known as health unit management committees) to drive community participation as a social determinant of the right to health. In both countries, such committees have been established as participatory structures to represent community interests in relation to the health system.

In South Africa, we had two intervention sites: one in the Eastern Cape (Nelson Mandela Bay Metro) and one in the Western Cape (Cape Metro). We chose these sites based on an audit of health committees in the Cape Metro that identified a number of key challenges facing effective health committee functioning.15 A training guide and an instructor manual were developed, and trainings were conducted with 405 committee members from seven of the eight subdistricts in the Western Cape and 202 participants from 47 clinics in three subdistricts in the Eastern Cape.16 Additionally, intensive mentoring was used in both sites. In the Western Cape, learning circles were set up to provide ongoing support for 92 participants, who in turn provided support to a further 300 health committee members. In the Eastern Cape, 474 health committee members were reached through a more intensive mentoring process involving 41 mentoring and 32 follow-up sessions at 10 facilities over 24 months. We relied heavily on experiential learning, with interactive activities and

group work generating energetic discussions among health committee members that allowed them to learn both from their own experiences and from the experiences of others.

In Uganda, we also had two intervention sites: Kiboga and Kyankwanzi districts. At the start of the intervention, many health committees in these districts were reported to be inactive or, at best, partially active. The role of the committees was sometimes performed by just one or two committee members, who were called on about once every two months, in accordance with National Medical Stores' delivery cycle, to witness the delivery of medicines to health facilities. Our preliminary research also showed that committees were partially constituted, did not hold regular meetings, and did not keep records of their deliberations.

Our trainings of health committee members in Uganda were guided by findings from earlier capacity assessments, Ministry of Health Guidelines for health committees, a gender and human rights mainstreaming manual for health professionals, and training materials for health committees developed by the Learning Network for Health and Human Rights of the University of Cape Town.¹⁷ Like the trainings in South Africa, our trainings in Uganda explored the concept of community participation in health, the right to health, the role of health committees, and strategies for creating partnerships with stakeholders. As a result of these trainings, two health facilities in Kiboga and Kyankwanzi-which had previously been dormant and whose former roles consisted largely of the ceremonial witnessing of medicine delivery to health facilities—were provided with the capacity to undertake their functions.

Our interventions sought to assess and enhance the ability of health committees to serve as a platform for communities to participate in health service provision at their local health facilities. Specific activities included training and capacity building for health committee members, engaging with health officials and policy makers, building civil society networks, training health workers, and producing and distributing educational materials that followed a human rights-based approach. The

relevance and impacts of these interventions were identified through a community mapping process.

Our interventions also involved two exchange visits in which health committee members and health workers from Uganda visited South Africa, and vice versa. Despite the contextual differences between the sites, the visits provided an opportunity for sharing learning and best practices. During these visits, for example, local leaders had the opportunity to share their experiences with members of the visiting delegations regarding how they thought health committees could work better. The health worker from Uganda who was part of the team that traveled to Cape Town described her experience in Cape Town as an eye-opener, especially concerning how to deal with tensions between committee members and health workers. Moreover, the local political leaders in Uganda were surprised that health committees were not unique to their districts and were a best practice across the region.

The resource-constrained nature of health systems in both Uganda and South Africa created a vital space for civil society organizations to facilitate the performance of health committees within the health system. In Uganda, a community-based organization in Kyankwanzi district (Action for Rural Women Empowerment) played an instrumental role, through the provision of technical and financial resources, in building the capacities of health committees, other health professionals, and women's groups to advocate for improved maternal health service delivery. In South Africa, the Learning Network for Health and Human Rights partnered with the People's Health Movement, another active civil society organization in health, to develop training materials and run workshops for the committees on national health policies (such as the introduction of a national health insurance scheme). These investments represented significant resources that would ordinarily have been unavailable to build the capacity of health committees.

Critical features

We found that several aspects of our interventions were critical for enhancing the potential of health committees to drive community participation as a social determinant of the right to health.

The human rights-based approach

In the Cape Metro, training grounded in a human rights-based approach helped revitalize flagging or defunct committees and gave trainees a sense of empowerment and agency to undertake various social and advocacy actions. This is reflected in many trainees' comments and in postgraduate students' evaluations that were done as part of our research process prior to the intervention. For example, committees were empowered to advocate for better-quality services and to raise questions around the conditions of treatment and respect for patients' rights, such as the right to privacy for HIV and tuberculosis patients. Similarly, in Uganda, the rights-based nature of the intervention enabled health committees to demand their right to health by challenging health worker shortages and the lack of water. In Kyankwanzi, for instance, the committee was able to petition the district health officer concerning the absence of water and a poor sanitation environment, which the community had raised as a key concern in a dialogue with committee members.

In both countries, health committees' increased assertiveness—as seen through the active and informed participation of empowered committee members—also elicited an unexpected backlash from service providers when they were confronted with committee members who were unafraid to insist on patients' rights and state obligations. In one instance in Cape Town, this nearly led the clinic manager to dissolve the committee. However, due to the responsiveness of upper-level management and facilitation from the Learning Network for Health and Human Rights, that conflict was turned into a learning opportunity. The network was asked to mediate between the committee and the facility manager, which resulted in a better mutual understanding of the situations and interests of health committees and facility managers. This strengthened and increased accountability between duty-bearers (and their agents) and rights-holders.

The notion of committees as part of the heath system

Our interventions also showed that health committees' integration into the wider health system has a positive impact on advancing community participation as an underlying determinant of the right to health. For instance, while the committees had been formally provided for in all four intervention sites, communities had not been participating through these committees prior to our involvement because they did not view health committees as part of the wider health system. The fact that our interventions approached health committees as part of the health system opened the doors for communities and local leaders alike to exploit committees as a community participatory structure.

In both countries, the health committees were designed to promote participation and accountability in the provision of health services and to create a platform for community members to directly contribute to the planning, design, and delivery of health services at their local health facilities. However, in all four sites, we identified structural and operational barriers standing in the way of this role, including ignorance of the roles of the committees, limited opportunities for communities to engage with the committees, and socioeconomic and cultural barriers that undermined the committees' abilities to facilitate community participation.

One of the key lessons from our interventions is that confining community participation to the lowest rung of the health system is manifestly disabling to community agency, since at the clinic level there is little scope for changing health system determinants. It is also a flawed view of health rights to imagine participation as located only at the local level, without integration upstream.

Committees bring social knowledge, experience, views on health problems, and solutions to health system plans and budgets at the primary care and community levels. This role in governance gives health committees the information, authority, and motivation to facilitate dialogue and consultation with communities; to mobilize social action; to build constructive partnerships and facilitate dialogue with different actors to ensure that prob-

lems are addressed; and to implement services and health actions. This, in turn, raises their oversight capacity.

Health committees need to be mainstreamed within the conceptualization of a health system. Their work should be seen as broad, including not just actions aimed at addressing health care quality and equity but also actions centered on the social determinants of health, many of which lie outside the health system. Central governments should therefore construe committees as being organized intersectorally in ways that can effectively mobilize resources and political will when required to address health systems issues, including social determinants. Our interventions underscore the need for central governments to incorporate health committees into their health systems in a way that maintains their role as autonomous agents for participatory democratic governance.

Support from civil society networks and partnerships

The sharing of experiences between South African and Ugandan committee members and civil society activists helped strengthen community leadership. The exchange visits and the cross-sharing of training materials enabled participants in our interventions to see that their challenges are shared across very different contexts and that the solutions to these challenges are not entirely dissimilar. Since our interventions, committee members have expressed openly the value of networking across the region and sharing best practices.

Partnerships have been found to add significant value to the capacity of health committees to engage with communities and duty-bearers alike. Exchanges at the grassroots level between committees from different facilities go beyond the exchange of knowledge and skills to create solidarity among agents of change who are generally highly isolated. This ensures that there is a shared diagnosis of existing problems and corresponding action plans, which improves cooperation and coordination among agencies and sectors. It also helps committees ensure that action plans and strategies are economically and physically accessible, as

well as acceptable (that is, socially and culturally appropriate), to communities. Therefore, enabling committees to build a movement may be the most important bottom-up strategy to pursue.

Our interventions revealed the importance of building knowledge networks related to health committees, expanding the scope of health committees into subnational and national levels through mobilization and resource pooling, and establishing regional linkages on best practices for community participation through the sharing of information and experiences. While building knowledge networks supports access to relevant information that committees need to effectively perform their roles, pooling resources contributes to making resources available to support the work of committees, an essential facet of the progressive realization of the right to health.

The legal and policy framework

It can be drawn from the research that prior to the formation of health committees, there is a need for a strong legal and policy framework that provides a solid foundation for duty-bearers to act on. In South Africa, the lack of a policy framework for committees meant that health facility managers did not feel compelled to involve committees in the handling of complaints. This was addressed through a series of public dialogues hosted by the Cape Metro District Health Council to ventilate concerns and expectations regarding health committee roles. Partly as a result of community pressure, a draft bill on health committees was introduced for public debate in the Western Cape, and national guidelines were issued by the National Department of Health that recognize the key role of health committees in South Africa. In Uganda, existing health committee guidelines provided some clarity on the roles of committees. While these guidelines lack legal force, they indicate a commitment from the Ministry of Health in terms of committees' integration into the health system.

For policy makers to be compelled to consider committees as community participation instruments, it is essential to have a clear regulatory framework that defines the roles and powers that committees have in their communities and how they feed into national processes. Legislation also contributes to the sustainability of committees within the health system. The survival of committees also calls for legal requirements on continued capacity building and empowerment, system design, community empowerment, health worker reorientation, and an appropriate policy framework.

The existence of a clear legal and policy framework ensures that state commitments are framed as actionable legal obligations on which rights holders can frame their demands. Such a legal and policy foundation can also be utilized to ensure that community participation is not contrary to existing legal frameworks and can address critical issues such as representation, committee tenure, and allocation of responsibilities, among others. This helps transform community participation through committees from just a social determinant to a legally enforceable value within the health system.

Such a legal and policy framework should require that committees be constituted in ways that make them credible to the communities they represent—for example, through elections or representative appointments in genuinely democratic spaces. Mechanisms for the representation and protection of marginalized and vulnerable groups should be incorporated into their setup as well.

Conclusion

Our interventions in South Africa and Uganda indicate that community participation is not only a human right in itself but an essential social determinant of the right to health. It is clear from our interventions that health committees provide a mechanism that enables communities to be active and informed participants in the creation of a responsive health system that serves them efficiently. The results confirm the effectiveness of rights-based trainings and exchanges in strengthening committee members' sense of agency, their capacity to engage the health system, and their ability to exercise claims to health rights. They also contribute evidence of health committees' potential to play a critical role in advancing community participa-

tion as a social determinant of the right to health. These participatory spaces bridge the gap between communities and health facilities, making services responsive to community needs and contributing to the realization of health as a human right.

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