



# Revisiting the role of civil society in responses to infectious disease outbreaks: a proposed framework and lessons from a COVID-19 vaccine equity coalition in Uganda

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## INTRODUCTION

Civil society organisations (CSOs)—a diverse set of non-governmental, advocacy and community-based groups<sup>1</sup>—have historically played transformative roles in advancing health equity. In perhaps the best-known example, CSO campaigns, policy advocacy and scientific partnerships have proven crucial in accelerating the development and global accessibility of treatments for HIV, altering the course of HIV infection programmes and contributing to millions of lives being saved.<sup>2</sup> As public health researchers and advocates focused on infectious diseases in Uganda, we have seen how ongoing action from CSOs—such as The AIDS Support Organization, which cares for 100 000 Ugandans living with HIV while leading additional testing, counselling and public awareness efforts<sup>3</sup>—has brought the country within the reach of achieving the UNAIDS 95-95-95 targets.<sup>4</sup> Thanks to their established relationships with constituents and proximate understandings of local realities, CSOs are uniquely positioned to mobilise communities behind evidence-based public health recommendations, including in settings where more distal governmental and academic institutions may struggle to make an impact.<sup>5 6</sup>

Despite the potential benefits and history of success, governments, local authorities, donors and international development organisations often do not meaningfully involve civil society in initial responses to disease outbreaks.<sup>7 8</sup> This missed opportunity for advancing health equity has been sharply

## SUMMARY BOX

- ⇒ Despite their long history of advancing health equity, civil society organisations are often overlooked by traditional public health institutions—governments, donors, international development organisations and others—during responses to infectious disease outbreaks, most recently COVID-19.
- ⇒ Excluding civil society from outbreak responses decreases the ability of authorities to anticipate and respond to delivery challenges, diminishes healthcare advocacy efforts and sidelines organisations crucial to ensuring community-level trust.
- ⇒ The Vaccine Advocacy Accelerator—which brought together civil society organisations and other stakeholders to promote COVID-19 vaccination in Uganda—offers examples of the unique roles civil society can play in community mobilisation and empowerment, service delivery and advocacy to advance COVID-19 vaccine equity which are also applicable to other outbreak responses.
- ⇒ Based on our experience, outbreak-focused collaborations can be made more effective by ensuring civil society representation in decision-making platforms, equipping civil society organisations with resources needed to support public health responses and jointly setting specific and measurable goals for civil society partnerships.

illustrated by the COVID-19 pandemic. Early in the pandemic, Rajan *et al* analysed national COVID-19 task forces and found, among other deficiencies, that CSOs were ‘hardly involved in national government decision-making nor its response efforts’.<sup>9</sup> An Office of the United Nations High Commissioner for Human Rights report 2 years later concluded ‘few, and in most cases no, participatory mechanisms

were established for discussion and decision-making' between CSOs and other COVID-19 stakeholders.<sup>10</sup> Lack of meaningful engagement with CSOs weakens public health, decreasing the ability of authorities to anticipate and respond to delivery challenges and sidelining organisations with established community trust.<sup>8</sup>

Finding a gap in civil society involvement in the COVID-19 response in Uganda, in September 2021, we formed the Vaccine Advocacy Accelerator—Uganda (VAX-Uganda): a coalition of CSOs, health workers and academics working to increase access to and uptake of COVID-19 vaccination throughout Uganda, where, at the time, less than 1% of the population had completed a primary vaccination series.<sup>11</sup> Inspired by the impact of Ugandan CSOs on the HIV pandemic, we aimed to equip Ugandan CSOs with funding and training to similarly support community-level COVID-19 responses and facilitate knowledge exchange between community-based CSOs, academic partners and national and international stakeholders.

Here, we share experience from the first 21 months of the VAX-Uganda CSO coalition, supplemented with findings from a brief literature review of civil society involvement in public health initiatives with an emphasis on resource-limited settings. We offer a framework and some pragmatic lessons on engaging civil society to advance COVID-19 vaccine equity which are also applicable to other emerging and long-standing health threats.

### CREATING A COVID-19 VACCINATION CIVIL SOCIETY COALITION

VAX-Uganda was conceptualised by the Coalition for Health Promotion and Social Development (HEPS-Uganda), a Ugandan CSO advocating for various health and human rights causes, and the Global Health Collaborative, an academic partnership between Mbarara University of Science and Technology (in Uganda) and Massachusetts General Hospital (in the USA) overseeing multiple research, clinical and educational initiatives in Uganda. HEPS-Uganda, with decades of experience organising around access to essential medicines, agreed to mobilise other Ugandan CSOs into a new civil society coalition focused on advancing COVID-19 vaccination. The Global Health Collaborative, which had supported COVID-19 treatment and vaccination efforts in western Uganda since the start of the pandemic, would serve as a scientific resource for the VAX-Uganda coalition, ensuring CSO-led activities and demands were in line with the most up-to-date evidence around the disease.

VAX-Uganda first mapped out CSOs across Uganda interested in advancing COVID-19 vaccination and inquired about challenges limiting their involvement. The mapping exercise revealed widespread interest in supporting vaccine equity efforts, but many organisations lacked prior experience working with vaccine-specific causes and the necessary funding to engage in meaningful advocacy. The coalition worked to address these gaps: securing grants from a US-based philanthropic

organisation to finance a multiyear CSO-led COVID-19 response, and organising a 4-day workshop in April 2022 reviewing basic vaccine science for 40 CSOs. The workshop featured multiple invited speakers from the Ministry of Health, who reviewed the state of COVID-19 vaccination in Uganda and its challenges, to spark dialogue and future opportunities for COVID-19-focused collaboration between CSOs and the government.

### ROLES FOR CIVIL SOCIETY IN OUTBREAK RESPONSE

Following the April 2022 workshop, the number of CSOs in the VAX-Uganda coalition has increased to 60, representing organisations with expertise in health activism (particularly related to HIV), health communications, intellectual property rights and other areas, all committed to responding to COVID-19 in Uganda. Members of the coalition and other partner CSOs have supported equitable access to vaccinations in three key, replicable ways: community mobilisation and empowerment, service delivery and advocacy (table 1).

#### Community mobilisation and empowerment

Ugandan CSOs have spearheaded efforts to educate and mobilise communities around COVID-19 vaccination. For example, with VAX-Uganda's support, HEPS-Uganda hosted 24 town hall discussions across the country in 2022 to address questions and concerns about COVID-19 vaccination, an essential intervention for improving local trust in vaccination. These discussions, led by HEPS-Uganda staff with experience moderating similar community events, involved presentations on the science and safety behind COVID-19 vaccines, as well as on local and global challenges influencing vaccine access and potential solutions to these. Many participants highlighted their willingness to follow HEPS-Uganda's guidance given the organisation's decades of providing accurate information about HIV in the same locations. In an effort to reach additional audiences with the same messages, staff from HEPS-Uganda also participated in multiple television talk shows and Twitter spaces encouraging people to get vaccinated.

CSOs have also supported the COVID-19 community mobilisation activities of other public health institutions. In August 2022, for example, our coalition organised a meeting between CSOs and multiple Ugandan government branches—including the Ministries of Health, Finance, and Education and Sports—on improving coordination of COVID-19 responses led by these partners. Participating CSOs shared verbal feedback and written guidance on how the ministries could best work with parents and schools to launch a successful COVID-19 vaccination campaign among schoolchildren. Although Uganda's outbreak of Ebola virus disease in late 2022 shifted national attention away from COVID-19, the continuous rapport between VAX-Uganda CSOs and government officials, stemming from these earlier consultations, allowed for some COVID-19 vaccination

**Table 1** Framework for civil society involvement in response to infectious disease outbreaks

Major areas of civil society contributions during infectious outbreaks	Examples of civil society activities during past outbreaks	Examples of Ugandan civil society activities during the COVID-19 pandemic
1. Community mobilisation and empowerment	<p>CSO volunteers in Nigeria used community dialogues and house-to-house mobilisation to build community trust in a polio programme, leading to 73% of local caregivers identifying the volunteer mobilisers as their primary source of polio information.<sup>12</sup></p> <p>During the 2015 Ebola outbreak in Sierra Leone, the SEND Foundation of West Africa assembled community health workers, faith-based groups, women's groups and others to provide medical supplies, particularly to hard-to-reach areas.<sup>13</sup></p>	<p>HEPS-Uganda convened 24 town hall discussions across Uganda in 2022 to hear community concerns, provide education and fight disinformation about COVID-19 vaccine safety. VAX-Uganda CSOs shared ideas with Ugandan government ministries on how to most effectively engage parents and schools during a COVID-19 vaccination campaign for schoolchildren.</p>
2. Service delivery	<p>The AIDS Support Organization in Uganda cares for 100 000 people living with HIV and offers testing and counselling services.<sup>3</sup></p> <p>The Botswana Retired Nurses Society provided comprehensive, palliative and home-based treatment for individuals living with HIV, reaching underserved communities in need.<sup>3</sup></p> <p>BRAC Bangladesh coordinated community health workers who offered directly observed therapy for tuberculosis and connected patients with health providers.<sup>14</sup></p>	<p>The Uganda Red Cross Society provided volunteers for understaffed vaccination sites in five districts in western Uganda.</p>
3. Advocacy	<p>CSO campaigns and policy advocacy accelerated the development and global accessibility of antiretroviral drugs for HIV.<sup>2</sup></p> <p>An El Salvadoran CSO brought a case of reproductive rights violation to the state constitutional court, defending a 17-year-old living with HIV who experienced forced sterilisation after giving birth.<sup>15</sup></p>	<p>VAX-Uganda CSOs influenced the inclusion of COVID-19 diagnostics, vaccines and therapeutics in the 2022 Uganda Clinical Guidelines and Essential Medicines and Health Supplies List of Uganda.</p> <p>Following a request from VAX-Uganda CSOs, the Ministry of Health's Director of Public Health published clear public guidance on heterologous COVID-19 vaccination schedules and instructed radio stations to stop playing outdated messages about the practice.</p>

CSO, civil society organisation; HEPS-Uganda, Coalition for Health Promotion and Social Development; VAX-Uganda, The Vaccine Advocacy Accelerator—Uganda.

mobilisation activities to continue even as the country worked to contain a simultaneous infectious threat.

In multiple prior outbreaks, CSOs have similarly mobilised communities to aid in health equity efforts, with several examples provided in [table 1](#).<sup>12 13</sup>

### Service delivery

Service delivery is a crucial sphere of civil society activities, as evidenced by efforts against HIV and tuberculosis ([table 1](#)),<sup>3 14</sup> and Ugandan CSOs have acted similarly to support COVID-19 vaccine delivery. After receiving basic training from the Ministry of Health, which provided background on COVID-19 vaccine science and on the national COVID-19 vaccination registration system, the Uganda Red Cross Society deployed volunteers to support understaffed COVID-19 vaccination teams in five districts in western Uganda. These volunteers helped to keep vaccination centres functional by registering patients, managing queues sometimes filled with hundreds of people and answering questions that overwhelmed health workers may not have had time to address. When local

demand for vaccination surged to even higher levels, the Uganda Red Cross Society responded by having existing volunteers train new volunteers, increasing the number of people who were able to assist at vaccination sites.

### Advocacy

Building on its established history of using influence for advocacy and human rights ([table 1](#)),<sup>2 13 15</sup> civil society has played a central role throughout the pandemic in demanding an end to COVID-19-related inequities. Ugandan CSOs in the VAX-Uganda coalition—in addition to CSOs around the world and US-based partners in the coalition—have used open letters, public demonstrations and other strategies to raise public awareness of ‘vaccine nationalism’ and convince wealthy nations, pharmaceutical companies and others to make COVID-19 vaccines more available in low-income settings.<sup>16–21</sup> One such open letter, signed by 32 VAX-Uganda CSOs in response to concerns around the accurate reporting of vaccination rates, resulted in CSOs being invited to join weekly COVID-19 Incident Management Team meetings

in Uganda, a standing platform to share feedback with the Ministry of Health, US Agency for International Development and other institutions involved with the national COVID-19 vaccination campaign. Similarly, CSO revisions to the 2022 Uganda Clinical Guidelines and Essential Medicines and Health Supplies List of Uganda—feedback which was invited by the Ministry of Health—influenced the ultimate inclusion of COVID-19 diagnostics, vaccines and therapeutics in both policy documents, a crucial step toward improving their availability around the country.

Advocacy can also take the form of simple but firm requests to duty-bearers. During an April 2022 meeting organised by VAX-Uganda between 40 Ugandan CSOs and the Ministry of Health's Director of Public Health, civil society representatives identified widespread confusion in their respective communities around heterogeneous COVID-19 vaccination schedules: receiving a different COVID-19 vaccine brand for one's second versus first vaccination dose. CSO representatives asked the Director to publish clear public guidance on heterogeneous vaccination and instruct radio stations to stop playing outdated messages recommending against the practice; he immediately carried out both requests.

## RECOMMENDATIONS

In the wake of COVID-19 and other recent outbreaks of infectious diseases, public health stakeholders often talk about the role of CSOs in outbreak response.<sup>10 22</sup> Unfortunately, resource holders often fail to give CSOs the platforms and resources needed to enact the health equity work they are acknowledged to be able to do.<sup>23</sup> Lessons learnt from VAX-Uganda may help to avoid these pitfalls, creating more genuine outbreak-focused partnerships that better capitalise on civil society's unique strengths.

### Ensure civil society representation in decision-making platforms

Governments, aid agencies and other institutions should work to include CSOs in discussions around the design, implementation and evaluation of public health programmes and research. VAX-Uganda demonstrates how giving civil society a 'seat at the table' allows initiatives to benefit from CSOs' community-level insights. Importantly, other stakeholders should be mindful of avoiding meetings that performatively have CSOs as attendees—allowing organisers to claim civil society has been represented—but fail to produce concrete commitments or empower CSOs to take on new responsibilities.<sup>10</sup> We recommend including CSOs in decision-making platforms at baseline, and not just during active outbreaks of infectious disease, so that existing partnerships can be relied on whenever health emergencies arise.

### Equip civil society with resources needed to support outbreak responses

As we were reminded during VAX-Uganda's initial mapping exercise, public health collaborations that

hope to involve CSOs should also have a plan for identifying and meeting their needs. Our experience highlights multiple forms of resources that governments, academia and others can provide for CSOs: funding to organise public health activities, connections to advocacy platforms, such as media interviews and testimony invitations, and training on the science underlying vaccines and other life-saving interventions.

### Set specific and measurable goals with civil society partners

The nature of VAX-Uganda, featuring a series of diverse activities implemented alongside multiple concurrent public awareness campaigns and supply chain improvements, makes numerically quantifying the contribution of our coalition to Uganda's COVID-19 vaccination rates very challenging especially considering the urgency in which the programme was implemented for action rather than as a research study. However, having concrete targets for each CSO-centric objective—for example, the number of CSO-led advocacy events to be organised in a year—has nonetheless kept meaningful coalition activities on track and reaffirmed a shift away from meetings that are more performative than active engagement. By jointly setting specific and measurable goals with CSO colleagues, public health authorities can reduce ambiguity around these collaborations—what does civil society 'engagement' mean in practice?—and better evaluate which aspects of the partnership can be improved. Alongside the collection of goal-related metrics, future studies can be designed to quantitatively measure the impact of CSO collaborations on infectious disease outbreaks and other health challenges.

## CONCLUSION

Strengthening civil society collaborations requires significant effort. The experiences of coalitions that arose out of the COVID-19 outbreak, such as VAX-Uganda, demonstrate the important roles CSOs can play in advancing health for all during a public health crisis. As we move forward and face future infectious disease threats, CSOs can be an essential component of a successful response especially when governments, donors and others assign effort and resources to include them, ideally before emergencies arise.

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