

Access to COVID-19 Self-Testing:

An Assessment Conducted among
Marginalised Communities in Uganda

November 2023



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About: Innovations for Development

Innovations for Development (I4D) is an indigenous non-governmental organisation (NGO) based in Uganda, dedicated to championing the right to health of all individuals, especially the most marginalised members of society. As a recognised grassroots champion, I4D operates where public health policies & practices interface and interact with communities. I4D's work strives to challenge power systems and structures to deliver equitable, inclusive, and sustainable development to those left behind due to their gender, sex, ethnicity, or socioeconomic realities. I4D employs a multifaceted approach that includes; research-driven strategies, evidence-based advocacy, service delivery and participatory democratic processes to foster innovation, participation, collaboration, and system strengthening.



In communities, I4D operates as a facilitator to enhance leadership and civic competencies of community members and marginalised groups to stewards of change for their communities. Whether as Community Change Agents, Community Health Workers, Expert Clients, Home Care workers or Peace Ambassadors, I4D believes that every community has within its people what it takes to challenge power and work towards inclusive development.

About: Health Poverty Action

Health Poverty Action (HPA) is a UK based, international non-governmental organisation founded in 1984 as “Health Unlimited”, that aims to secure health care access for marginalised communities in developing countries and works with communities and health service providers in remote areas, often to deliver healthcare to women, children, indigenous communities, and the internally displaced. We currently work in 17 countries in Africa, Latin America and Asia. All of our programmes aim to improve the health and livelihoods of those we work with and for.



While its head office is in London and has a US registered office, HPA runs fully-fledged offices managed by national staff in each of the countries it operates in. Besides, the organization also has the Africa Regional Office in Nairobi comprising of a key technical team providing technical back-stopping to the country teams. Many of HPA's programs involve community-based Primary Health and Nutrition Care, WASH, education & training, Social Behavioural Change as well as mass media and outreach health communication approaches, implemented in collaboration with the local government ministries, national NGOs, CBOs, and the local communities.

HPA has programs in six countries in Africa with projects focusing on health systems strengthening, maternal and child health and nutrition, WASH, sexual and reproductive health and rights (SRHR) including prevention and response to sexual and gender-based violence (SGBV), with donors ranging from FCDO, the EU, Irish Aid, GIZ, UN agencies (UNICEF, UNFPA, UNHCR and WFP), FIND, ENABEL and other trusts and foundations. HPA has also led and/or been part of multiple research projects in the global south, in partnership with research and academic institutions.

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Introduction

COVID-19 self-tests were available in many countries in the Global North during the acute phase of the pandemic. In England for example self-tests were made available for free on the NHS and delivered to homes in April 2021¹. Germany approved COVID-19 self-tests earlier still, with tests made available in February 2021². Countries outside the Global North approved self-tests later (e.g., Malaysia in November 2021)³ but with many countries (including most African countries) never rolling self-tests out at all. This may be in part due to the delayed release of WHO guidelines on COVID-19 self-testing in March 2022, meaning that global procurers such as Global Fund and UNICEF were unable to procure for deployment up to that date.⁴

One case study conducted in Nigeria, found that most respondents lacked awareness around self-testing for COVID-19, but that self-testing was 'valued as an approach that would help the public to reduce costs, time, and other resources necessary to access facilities equipped with COVID-19 diagnostics.'⁵ However because these results were released in 2023 as countries were easing out of COVID-19 measures, these may have had limited impact.

In Uganda, COVID-19 self-tests were not available during the acute phase of the pandemic. The country is familiar with the rollout and use of rapid tests more generally given the deployment of malaria RDTs in health facilities across the country – enabling access to malaria testing in remote areas.⁶ Furthermore, the country has an HIV rapid self-testing policy adopted in 2019, and studies showing high acceptability among female university students,⁷ and marginalised communities.⁸ 2018 and 2020 studies found that the use of a peer model to distribute HIV self-test kits in a fishing community reached men who had not previously tested,⁹ and that the use of community-based, trained lay providers, is popular because people can easily obtain kits at their convenience, as the distributors live within the same community as the potential users.¹⁰

However, the use of COVID-19 self-tests have not been widely studied. This study was conducted by Innovations for Development (I4D), a Kampala-based organization, in collaboration with Health Poverty Action, to understand acceptability, feasibility, and barriers to access self-testing, with the objective to provide recommendations both on how to implement COVID-19 self-testing and self-testing for pathogens in future pandemics, as well as which populations are most relevant to target for self-testing.*

** Since the data collection and writing of this report, the Ministry of Health has released National Guidelines for COVID-19 Testing in September 2023 which recommends, inter alia, that COVID-19 self-testing may be conducted when 'an individual experiences COVID-19 like symptoms, when an individual has had exposure to a confirmed COVID-19 patient or suspect; after travelling to a COVID-19 high-risk area, prior to visiting vulnerable and high-risk populations e.g. care homes for elderly, if there is suspected COVID-19 outbreak and on-going community transmission; in cases where it is a requirement prior to a gathering such as a conference, political rally; for self-care and assessment.'*



Figure 1: COVID-19 Self-Testing device
Source: Freepik.com

¹ UK Government, 'Twice weekly rapid testing to be available to everyone in England' (5 April 2021) accessed 26 July 2023

² Reuters, 'Germany approves COVID home tests to ease way out of lockdown' (24 February 2021) accessed 26 July 2023

³ Covid-19 self-test kits now available in Malaysia for as low as S\$1.60 (November 2021) accessed 26 July 2023

⁴ People's Vaccine Alliance, 'Study on the Availability and Affordability of Diagnostics for COVID-19 and MPOX in Low and Middle-Income Countries' (2022)

⁵ Undelikwo VA, Shilton S, Folayan MO, Alaba O, Reipold EI, Martínez-Pérez GZ (2023) COVID-19 self-testing in Nigeria: Stakeholders' opinions and perspectives on its value for case detection. *PLoS ONE* 18(4): e0282570.

⁶ National Malaria Control Program. (2011). *Uganda National Malaria Control Policy*.

⁷ Segawa, I., Bakeera-Kitaka, S., Ssebambulidde, K, et al. Factors associated with HIV self-testing among female university students in Uganda: a cross-sectional study. *AIDS Res Ther* 19, 59 (2022).

⁸ Hensen, B., Schaap, A. J., Mulubwa, C., Floyd, S., Shanaube, K., Phiri, M. M., ... Fidler, S. (2020). Who accepts and who uses community-based secondary distribution HIV self-testing (HIVST) kits? Findings from the intervention arm of a cluster-randomized trial of HIVST distribution nested in four HPTN 071 (PopART) communities in Zambia. *Journal of Acquired Immune Deficiency Syndromes* (1999), 84(4), 355; Matovu, J. K., Nambuusi, A., Wanyenze, R. K., & Serwadda, D. (2021). Peer-leaders' experiences and challenges in distributing HIV self-test kits in a rural fishing community, Rakai, Uganda. *BMC Public Health*, 21, 1-12.

⁹ Choko, A. T., Nanfuka, M., Birungi, J., Taasi, G., Kiseambo, P., & HELLERINGER, S. (2018). A pilot trial of the peer-based distribution of HIV self-test kits among fishermen in Bulisa, Uganda.

¹⁰ Matovu, J. K., Nambuusi, A., Wanyenze, R. K., & Serwadda, D. (2021). Peer-leaders' experiences and challenges in distributing HIV self-test kits in a rural fishing community, Rakai, Uganda. *BMC Public Health*, 21, 1-12.

Methodology

The research utilized a cross-sectional survey design that integrated both quantitative and qualitative data collection techniques. This design allowed for a comprehensive exploration of COVID-19 community & self-testing in three distinct locations in Uganda, and among marginalised communities facing unique challenges in:

Kawempe Division: We engaged individuals considered part of the 'urban poor' in Bwaise III parish which is an informal settlement (slum area). These individuals live in congested and high-density housing, bearing particular COVID-19 risks.

Masaka District: We engaged people with disabilities in Buwunga and Kyanamukaka sub-counties. These communities had vulnerabilities and mobility challenges associated with their disabilities and their living in rural contexts.

Kalangala District: The district has many people engaged in commercial or subsistence fishing activities on and around the islands in Kalangala District. These communities in particular are mobile and migratory depending on fishing seasons, tidal factors, and other related factors.

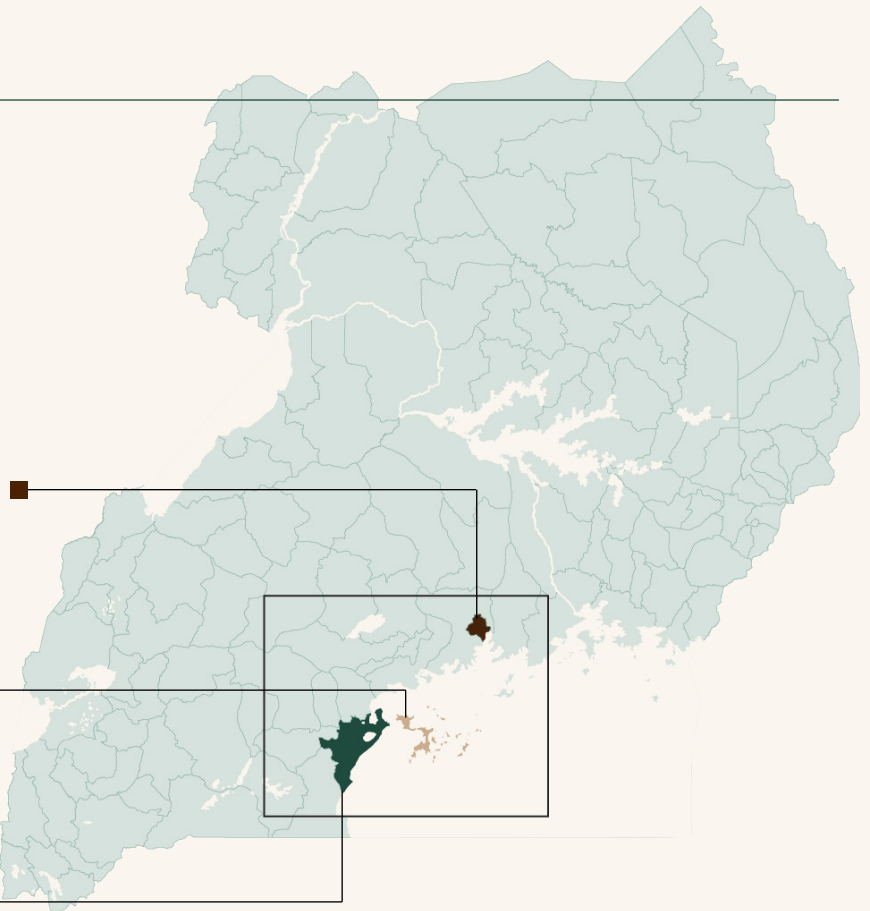


Figure 2: Districts/areas in Uganda where data collection was conducted.

Quantitative data collection was conducted among a total of 64 respondents identified through random sampling from purposively identified community clusters (fishing, PWDs, residents of informal settlements) to answer questions in the survey instrument. The survey included questions such as: "Is COVID-19 still a concern for you?" and "Do you think self-testing for COVID-19 is important for controlling the spread of COVID-19?". A simple random sampling technique was used in each location, supplemented by snowball sampling as respondents referred their colleagues and friends. Selected respondents were sampled from cluster residency lists obtained from their local authorities. These individuals were also asked some qualitative questions, such as "What are your reasons for participating or not participating in self-testing?" and "How can health care workers or the government make it easier/more convenient for you to access testing?"

Additionally, we conducted **Qualitative Data Collection** through Focus Group Discussions (FGDs) of community members and Key Informant Interviews (KIIs) from health workers, and local leaders with background experience in community testing initiatives. Three FGDs were conducted with 10 individuals in Kalangala, 8 individuals in Masaka, and 8 individuals in Bwaise; these individuals were not drawn from the same sample as those who underwent the quantitative survey. These FGDs were conducted specifically to facilitate group interactions and gather insights from community members within each targeted area. The FGDs included participants from different age groups and genders to capture diverse perspectives. KIIs were conducted with local leaders and health workers. Data collection occurred over a five-day period, from 8th to 12th May 2023.

Data Analysis: Quantitative data was analyzed using excel to derive descriptive statistics and identify patterns and perception for community and self-testing for COVID-19 across the three locations. Qualitative data obtained from FGDs and KIIs were transcribed and thematically analyzed to explore nuanced insights and perspectives on the subject matter.

Ethical Considerations: The study ensured adherence to ethical guidelines, including obtaining informed consent from all participants before data collection. Confidentiality and anonymity of participants were maintained during data analysis and reporting.

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Limitations:

- The cross-sectional nature of the study may limit the ability to establish causal relationships between variables.
- The sample size may be relatively small, reducing the generalizability of findings to larger populations.
- The study was conducted during a specific time frame, which may not capture seasonal variations impacts for COVID-19 testing.

Findings

Demographics

Almost 60% were male (N=38), with the remaining being female (N=26). Median age of interviewees was 30.5 years old. Of those interviewed, 15 (23%) were agricultural labourers working either on vegetable or fruit farms, 13 (20%) were fishermen, and 13 (20%) were running small enterprises, such as clothing shops and hair salons. The fishing communities we interviewed predominantly lived on islands and coast areas around Lake Victoria, such as Bubeke, Lwanabatya, Nkese, and Kalangala, whereas those who owned small enterprises lived in and around Kampala, the country's capital city. 45% of respondents had some form of secondary education, followed by 41% with primary education.

Respondents (Disaggregated by Sex)

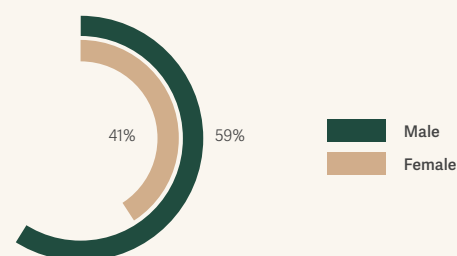


Figure 3: Respondents for Survey (Disaggregated by Sex)

Continuing concern about COVID-19 and other health conditions

Most respondents (69%) stated that COVID-19 was still a concern for them. These were due to multiple reasons including those related to severity ("COVID-19 kills and there is no cure"; "I have had it before, and I know how severe it is") and age. For those who were no longer concerned about COVID-19 (N=20), vaccinations were most frequently cited as the reason for their lack of continuing concern, followed by reduced COVID-19 deaths, and that life/business had moved on.

Why is COVID-19 no longer a concern for you?

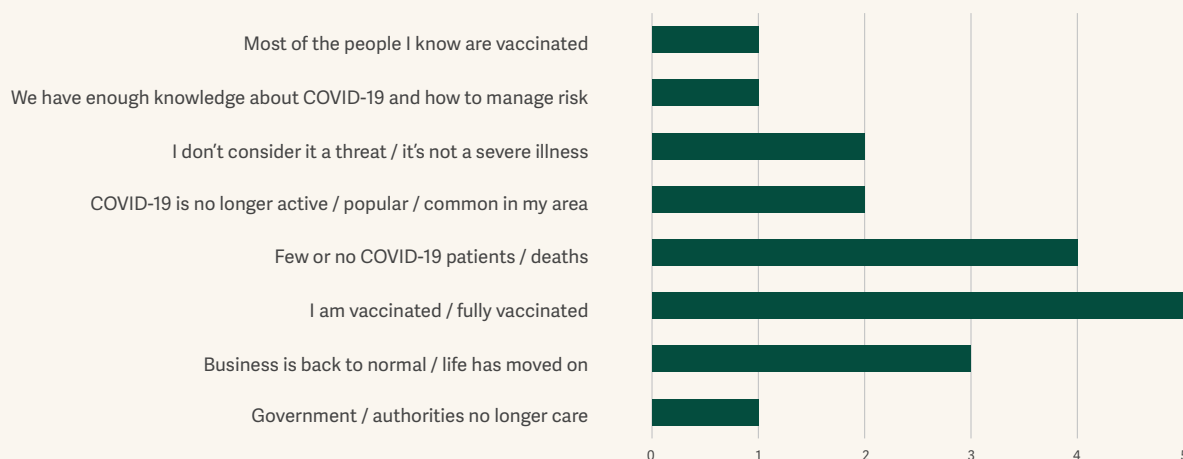


Figure 4: Respondent Feedback: "Why is COVID-19 no longer a concern for you?"

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Continuing concern about COVID-19 and other health conditions (continued)

98% of respondents (63/64) stated that they had higher levels of concern for other diseases or conditions. In response to an open-ended question where respondents could cite multiple diseases, HIV was cited most frequently as the diseases/condition that respondents were most concerned about (43% of the time), followed by malaria (20%), and schistosomiasis (9%). These point to overlapping health concerns, potentially related to sexual health and HIV prevention modalities, access to malaria prevention tools and services, and contact with freshwater bodies such as lakes and rivers, for which individuals would require additional diagnostics services.

Are there any conditions/diseases that you are more concerned about than COVID-19?

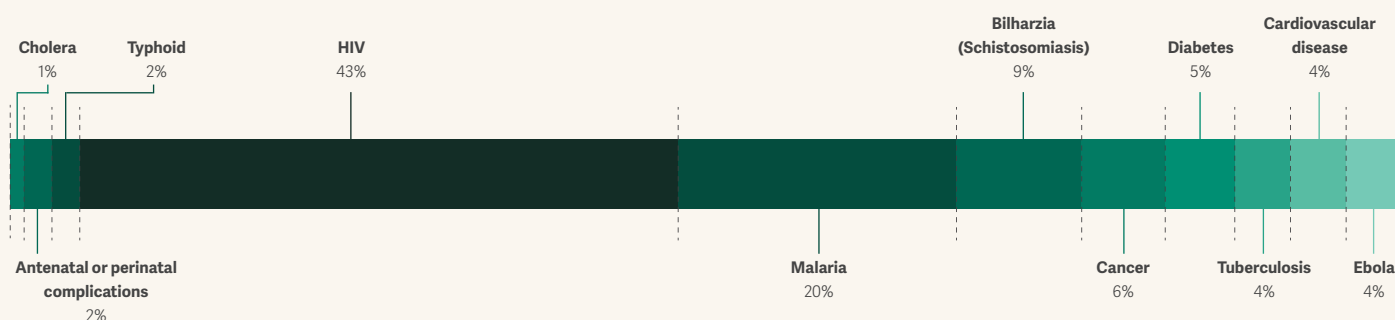


Figure 5: Respondent feedback: "Are there any conditions/diseases that you are more concerned about than COVID-19?"

94% of individuals stated that if they had COVID-19 symptoms, they would want to know what it was. Only 78% of individuals knew where to access COVID-19 testing in their communities.

Knowledge and Preferences on COVID-19 Self-Testing

Only 7 individuals (11%) had ever heard about self-testing for COVID-19. Of these people, none of them knew how to do a COVID-19 self-test. 86% (N=55) of respondents said that they would take a self-test if it was offered in their community, although 46% of total respondents stated that they would also prefer assistance from a healthcare worker in carrying out the test, indicating that at least in the initial stages, healthcare workers should be made available to provide assistance and to support communities with self-testing instructions.

Of the 55 individuals who said they would take/use a self-test, 47% (N=26) of individuals stated that their main reason for participating would be to know their COVID-19 status and avoid transmitting onwards. This response may be underlined by other factors such as convenience and distance to PCR facilities. Indeed, convenience/saving time and money was the second most frequently cited reason for participating in self-testing at 27% (N=15). In their own words:



Figure 6: Mothers waiting for services in a public clinic in Masaka.

Source: Freepik.com

"It makes testing easier and reduces time wasting from going to a facility for testing."

48-year-old male agricultural labourer, Mikoni village, Rakai District, Central Uganda

"Self-testing reduces the need for transport to go to the facility. And I can regularly test."

46-year-old male agricultural labourer, Zzwimwe village, Masaka District, Southern Uganda

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Knowledge and Preferences on COVID-19 Self-Testing (continued)



Figure 7: Respondent Feedback: "What would be your reasons for taking a self-test/participating in self-testing?"

Wroe and colleagues in *The Lancet* in 2022 stated that 'demand (for rapid diagnostic tests and self-testing) will be amplified by the availability of effective treatments.'¹¹ While our sample is limited, treatment was less of a factor for uptake of self-tests compared to the convenience of self-tests and the desire for communities to know their status. This points to, perhaps, the value of amplifying testing as a rights issue, i.e., the right to test as part of the human right to health and the right to benefit from scientific progress.

Where do Communities Currently Access Services?

The majority of respondents (N= 40, 62.5%) reported receiving healthcare from a Health Centre IV facilities, a tier of health facility in the Ugandan health system that serves a county or parliamentary constituency, and should be manned by a senior medical officer, another doctor, and should have a theatre for carrying out emergency operations.¹² Three individuals reported receiving services from a Health Center III. Health Centre III's are usually led by a senior clinical officer, who run a general outpatient clinic and a maternity ward, and should have a functioning laboratory.¹³ 23 respondents reporting receiving healthcare from Kalangala Health Centre IV, with others receiving healthcare at the Kyanamukaka Health Centre IV, Masaka Hospital, Buwunga Health Centre III, and other health facilities.

When asked whether there were any challenges in accessing these facilities, 21 individuals (33%) stated that there were insufficient health workers to meet demand and that there were long lines and waiting times, and 12 individuals (19%) stated that there was poor accessibility to health centres due to poor roads, long distances, or expensive transport costs to get there. Communities suggested several solutions including improving health workers remuneration concerns (low pay, prompt pay, overtime allowances) and welfare to reduce frequent health worker strikes and absenteeism. These issues result in patients having poor experiences with testing services at healthcare centers – and some of this may be ameliorated or alleviated via self-testing or community-based testing. According to one nurse in Kalangala:



Health workers are the most critical pillar of any healthcare system and any health intervention that seeks to reach the unreached must first explore to what extent they have improved the living and working conditions, skills, and knowledge of the health worker, short of that the intention may end in futility. Community testing if it going to add extra workload, stress and anxiety to those doing it, it will eventually cause more attrition, absenteeism and frustration to the already burdened health workers.

– Nurse In-charge, Kalangala Health Centre IV

¹¹ Emily B Wroe and colleagues, 'Test and treat: a missing link in the global fight against COVID-19' (2022) 10(2) *The Lancet Global Health* E181-E182

¹² Richard M Kavuma, 'Uganda's health system explained' *The Guardian* (1 April 2009) accessed 17 August 2023

¹³ Ibid

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Where do Communities Currently Access Services? (continued)

Communities also mentioned the need to hire more health workers to lower workloads, building health facilities closer to where they lived, and more specifically bringing diagnostic services to communities, including self-testing. While addressing staffing levels, low pay, and prompt salary payment is critical to motivate health workers and hence optimise healthcare at facility level, these may not address the issue of long distances and expensive transport needed to reach health centres. Considering these and respondents preferences that they would save time and money, and that they want to know their status and prevent transmission to their families, self-testing and community testing should be recommended where these barriers exist to facilitate timely testing of individuals located far from health centres.

Conclusion

Self-testing for COVID-19 was not available for the majority of Ugandans during the acute phase of the COVID-19 pandemic, despite its convenience and usefulness especially for populations who either are mobile or migratory like fishing communities who do not have regular access to health facilities, people with disabilities who have reduced mobility, and for the urban poor who spend a lot of time in informal employment for subsistence and may not have the time to spend accessing PCR testing.

Challenges to equitable access to testing is multi-layered and includes poor payment to health workers, long distances to health centers, long wait times for health services, and poor confidentiality. Increased accountability through deeper engagement of community groups and civil society groups may center these issues at the national level. Crucially, extensive and comprehensive plans are needed to address testing gaps among particular marginalized communities who have irregular or infrequent access to healthcare due to multiple challenges discussed in this report.

Key Takeaways and Learnings

There were several key takeaways from the study, notably that:

- » **There was low awareness of COVID-19 self-tests and how to use them, but high levels of interest to access them.**
- » **Most people accessed healthcare at Health Centre IV's and reported facing barriers and challenges in accessing healthcare such as staffing shortages and distance. This aligns with benefits of self-testing expressed by respondents, i.e., that they could save time and money if they could test at home, and thereon act to protect their families and communities.**
- » **Strong messaging has emerged in communities we spoke to on how self-tests are critical in helping people know their status. Additionally, communities need help to understand what their symptoms are if they have COVID-19 symptoms.**
- » **Communities expressed being overall more concerned about diseases/conditions such as HIV, malaria, and schistosomiasis (compared to COVID-19), but that they would still like to know their status for COVID-19 so that they could protect their families. This raises questions about the prospects for integrated testing to reduce time and financial cost to communities.**
- » **Each community we examined had specific challenges in accessing healthcare and would benefit from tailored services, including provision of self-tests in their communities. People with disabilities faced mobility barriers in accessing health services. Fisher people spend most of their time fishing at sea/in lakes and need easy access to services.**

As discussed in the introduction of this report, during the COVID-19 pandemic, Global North countries deployed self-testing at much earlier/faster rates than the Global South. Government officials will need to explore alternative stringent regulatory authorities for self-testing guidelines in the next pandemic if WHO guidelines are delayed, to ensure that Ugandans are able to access self-tests at the same time as Global North countries. The African Medicines Agency, a body established on 10 June 2023¹⁴ and mandated by the African Union to ensure that all African people have access to essential Medical Products may play a useful role in addressing these challenges in future pandemics through both regulatory and local manufacturing initiatives.

¹⁴ Treaty for the Establishment of the African Medicines Agency (10 June 2023) accessed 5 September 2023

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Recommendations for Testing Reform (and for the Next Pandemic)

Communities suggested several key reforms to improve their access to testing services. Some pertained to issues of confidentiality and the fear that healthcare workers would 'leak' their results to communities, resulting in a lack of trust of healthcare workers and acting as a deterrent for access to testing. In the words of a 19-year-old O-level student from Kalangana:

"We need more privacy after being tested (rather) than being talked about in the whole community."

- 19-year-old female student, Kalangana

Numerous individuals felt that their rural locations were impediments to accessing health services in general, and that mobile services were necessary for them to have access. One agricultural labourer living with disabilities in Buwunga, a rural subcounty in Masaka district, highlighted that services for persons with disabilities were not available, and that:

"COVID-19 testing outreach should be done in hard-to-reach areas (and) the government should pay health workers to send to us for testing and treatment."

- 48-year-old female agricultural labourer, Buwunga subcounty, Masaka district

As discussed elsewhere in this report, most respondents stated that they would be interested in COVID-19 self-testing, however acknowledged that they needed to be supported in learning how to use the tests. A 36-year-old male individual engaged as a plumber (informal self-employed) in Kalangala stated that "we need more sensitisation about self-testing." Another individual, a 30-year-old male fisherman in Bubeke, stated that "I think self-testing for COVID-19 is good but only if people are educated about it." This was echoed by another 25-year-old male fisherman in Kalangala, stating that self-testing would be "the best" if they had the expertise to use them. Research elsewhere has shown that individuals with low literacy have faced challenges to conduct self-tests and interpret results,¹⁵ thus initial rollout should always be supported by trained community health workers.

Last mile testing initiatives like community and self-testing efforts can enhance equitable access for isolated individuals who are engaged in occupations that require long working hours like the fishing communities of Kalangala. Fishing activities on average requires more than 18 hours of work through night and day. This means for such individuals unless essential testing like for COVID and other health issues is made closer, they often don't have time or interest to use such services.

Communities also mentioned the importance of testing integration, although the notion of testing integration was at no point introduced to them. A 70-year-old agricultural labourer in Butenzi, a village approximately 120 kilometres from the country's capital Kampala, complained of long distances to access testing, and stated that COVID-19 testing should be offered alongside HIV testing. Based on these and other data in this report, we make the following recommendations:

» **Clear vision, processes, and milestones for testing in emergencies and pandemic situations.** The September 2023 National Guidelines on COVID-19 Testing should be operationalised immediately and be used as a model in future pandemics. However, in future pandemics, guidelines on community-based testing must come during or before the acute phase of the pandemic. Comprehensive pandemic preparedness and response plans for communities in rural- and hard-to-reach areas, including self-testing, mobile services, and training and salarizing of community health workers.

Continued on next page

¹⁵ Veronica A Undelikwo and others, 'COVID-19 self-testing in Nigeria: Stakeholders' opinions and perspectives on its value for case detection' (2023) PLOS One

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Recommendations continued

- » **Ensuring community leadership and utilizing community-derived data in testing initiatives.** Testing plans and strategies should explicitly include and be informed by the needs of marginalized communities such as fishing communities, the urban poor, and people with disabilities – including mapping barriers and setting aside resources for mobile and self-testing. Government diagnostics decision-making teams should establish regular discussions with community groups. This could begin with townhall discussions to discuss the findings in this report. Additionally, communities should be actively involved and engaged in the roll-out of testing initiatives for example as mobilisers, promoters, service providers etc. Stakeholders and experts should be cautious and thorough in examining differences in contexts between fishing communities, the urban poor, and persons with disabilities – and systems and capacities should be developed to ensure ability to identify and operationalise the differences.
- » **Mapping and studying the role of the private sector** in self-testing given long distances to public health centres. Islanders in particular rely on drug shops and micro pharmacies to access healthcare commodities and services, therefore having a harmonized policy on testing that is inclusive of the private sector especially at last mile can play a role is important.
- » **Adequate and appropriately allocated financing for testing initiatives.** Communities reported poor staffing causing delays in testing, and that healthcare workers were often not paid on time. Sustainable and adequate financing should be allocated for testing (including healthcare workers responsible for testing) and should be specified in national strategies on diagnostics. It should be noted that financing alone will be insufficient without the whole-of-society approach specified in the following point.
- » **Applying a health equity lens for roll-out, scale-up and sustainability of testing initiatives .** This will enable underserved and marginalised communities to have priority status when initiating nation-wide health interventions like community and self-testing. A health equity approach would entail ensuring optimal human resources, adequate diagnostics and ancillary supplies, robust health information systems for surveillance getting prioritized in hard to reach and underserved communities like the fishing communities of Kalangala islands, informal settlements for the urban poor as well as disability groups.
- » **Promote dialogue on the wider issues relating to public health testing;** engaging in public conversations with wider stakeholders to support and influence investment, public awareness for testing especially for public health crises at all levels.



Figure 8: A rural village in Kyanamuka, Masaka district
(Photo credit: Innovations for Development)