

Digital Innovations for Early Cardiovascular Disease Diagnosis and Heart Failure Prevention in Uganda

Kajol Aggarwal, Zainab Azim, Tracy Dusabimana, Nathan Feltmate, David Li, Hajarah Nakitende, Christinah Nuwahereza, Christine Nalwadda, Cinderella Ngonzi, Isaac Ssinabulya, Godfrey Zziwa Buuka, Sahr Wali, Sarah Haines

The Reach Alliance

The Reach Alliance is a consortium of global universities — with partners in Ghana, South Africa, Mexico, Canada, United Kingdom, Australia, and Singapore — developing the leaders we need to solve urgent local challenges of the hard to reach — those underserved for geographic, administrative, or social reasons. Working in interdisciplinary teams, Reach's globally minded students use rigorous research methods to identify innovative solutions to climate, public health, and economic challenges. The UN's Sustainable Development Goals (SDGs) provide inspiration and a guiding framework. Research is conducted in collaboration with local communities and with guidance from university faculty members, building capacity and skills among Reach's student researchers.

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Note: Authors are listed alphabetically with the faculty mentor listed last.

Cover photo: Masaka Regional Referral Hospital (photo by Tracy Dusabimana, researcher)





Acknowledgements

This research was made possible through the Reach Alliance, a partnership between the University of Toronto's Munk School of Global Affairs & Public Policy and the Mastercard Center for Inclusive Growth. We are deeply thankful and appreciative of everyone we had the privilege of meeting and interviewing for generously sharing their insights with us. We are grateful for the support of Dr. Sahr Wali and the entire Medly Uganda and TRANSFORM HF teams, who supported us through every stage of our research. We also thank all our local Ugandan partners including Dr. Isaac Ssinabulya, Dr. Godfrey Zziwa Buuka, Dr. Christine Nalwadda, and the on-the-ground research assistants Hajara Nakitende and Christinah Nuwahereza. We sincerely thank Dr. Sarah Haines for providing us with countless hours of mentorship and guidance throughout this process.

In health research, there is a growing recognition of the importance of reflexive practices to enhance awareness of a researcher's positionality. This entails examining how personal histories, relationships, and perspectives shape the research process. As authors of this project, we come from diverse professional and cultural backgrounds, each influenced by unique experiences and understandings of global health disparities. While some members of our team are deeply familiar with the Ugandan healthcare landscape through lived experiences or long-standing collaborations, others bring perspectives shaped by work in broader global health contexts. Despite these differences, we are unified in our commitment to valuing the local knowledge, cultural traditions, and lived experiences of Ugandan communities.

This project seeks to reimagine healthcare delivery for heart failure patients, moving away from deficit-based frameworks often prevalent in Western research paradigms. Instead, we aim to build upon the strengths and resilience of individuals and communities, ensuring that Medly Uganda is both relevant and responsive to the cultural and systemic realities of the context. By honouring this richness, we strive to advance equitable, sustainable, and culturally safe solutions for managing cardiovascular disease and heart failure in Uganda.

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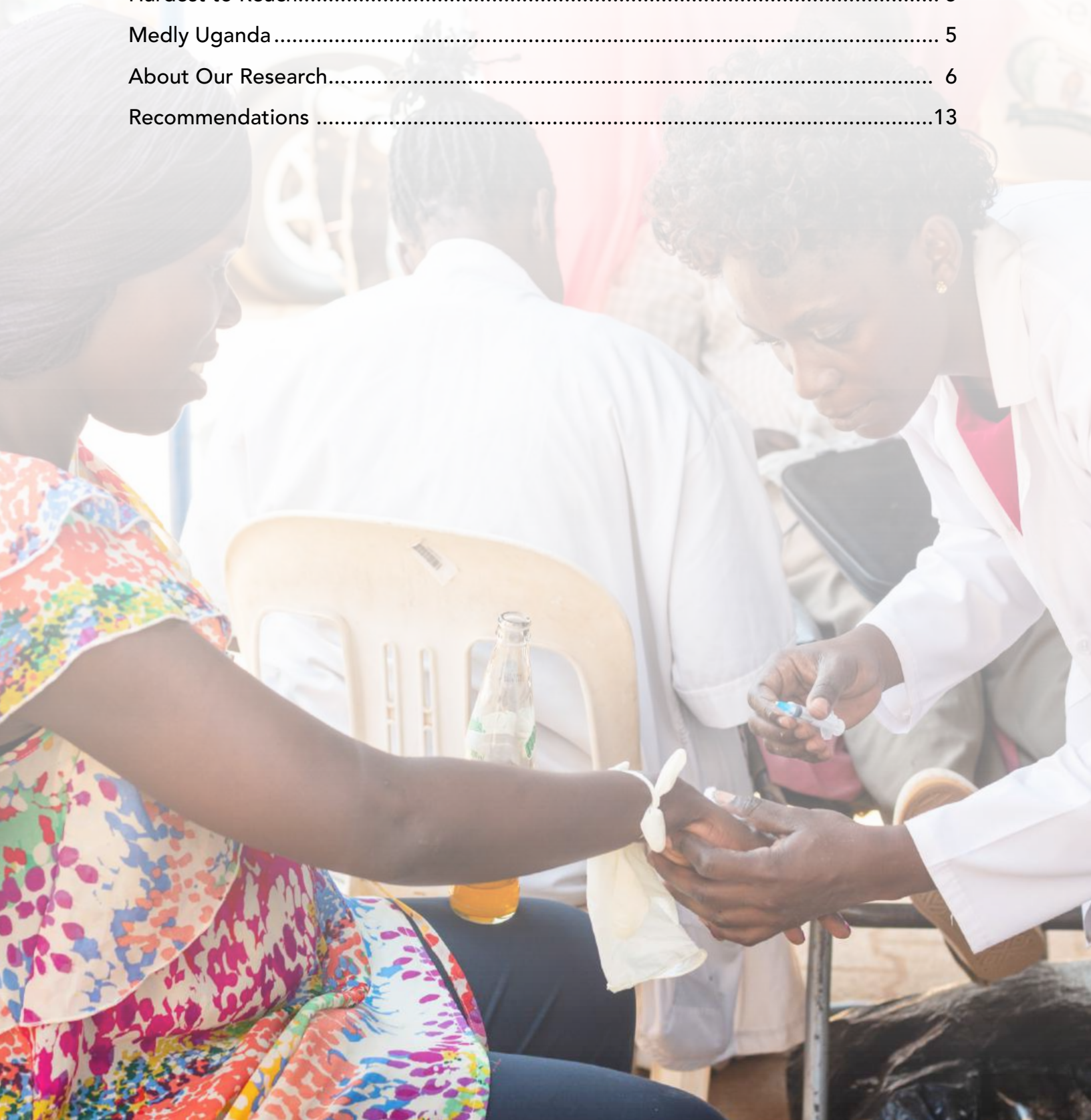




Figure 1. The team at Mulago National Referral Hospital (pictured left to right): Hajara Nakitende, Kajol Aggarwal, Dr. Sarah Haines, Dr. Christine Nalwadda, Zainab Azim, Tracy Dusabimana, Christinah Nuwahereza, Nathan Feltmate

Executive Summary

Cardiovascular disease (CVD) and heart failure (HF) present significant public health challenges to Uganda. Medly Uganda, a digital health intervention, seeks to address these issues by enhancing self-care for HF patients through mobile-based telemonitoring. Early results from Medly Uganda indicate its potential to improve patient outcomes, increase adherence to treatment, and reduce hospitalizations.¹ This project, Digital Innovations for Early Cardiovascular Disease Diagnosis and Heart Failure Prevention in Uganda, aims to evaluate Medly and the broader healthcare system's response to CVD and HF in Uganda, highlighting broader applications and future directions. We employ a mixed-methods approach to generate actionable insights focused on strengthening the uptake of Medly Uganda among HF patients. We critically examine the challenges faced by

patients and healthcare professionals at various stages of the healthcare system that hinder early diagnosis and effective treatment of CVD and HF. Through qualitative and quantitative data collection, our study identifies key barriers, including limited health literacy, inadequate training of healthcare workers, and systemic inefficiencies within the healthcare infrastructure.

The findings underscore the necessity for a multifaceted strategy to enhance the response to heart failure in Uganda. This includes a series of recommendations directed toward policymakers, international organizations, and healthcare professionals committed to improving healthcare delivery in the country. The recommendations emphasize leveraging existing disease management infrastructures, empowering healthcare providers through targeted training and resources, and fostering community engagement. By adopting these strategies,

1 Jeremy Schwartz, Sahr Wali, Martha Nabadda, et al., "Patient Facing mHealth Application Improves Self-care and Symptoms of Heart Failure in Uganda," *Journal of the American College of Cardiology* 79, no. 9 (Supplement 2022): 1820; Sahr Wali, Jeremy Schwartz, Joseph Cafazzo, Heather Ross, et al., "Empowering Heart Failure Self-care Through the Use of a Patient-centered mHealth Application," *Cardiovascular Journal of Africa*, Proceedings of the 15th PASCAR Congress in association with Kenya Cardiac Society (2021): 30–31. [🔗](#)

stakeholders can work together to enhance health outcomes and create a sustainable framework for managing cardiovascular conditions in Uganda.

Context: Cardiovascular Disease in Uganda

Cardiovascular disease (CVD) is a noncommunicable disease (NCD) that accounts for 10 per cent of all deaths in Uganda.² Heart failure (HF) is a structural and hemodynamic complication of CVD, responsible for 30 per cent of all NCD-related deaths and 7 per cent of hospital admissions in the region of Sub-Saharan Africa.³ The development of CVD and HF is partly a result of the high rate of hypertension in Uganda where one in four adults report elevated blood pressure.⁴ Furthermore, only 7.7 per cent of hypertension patients are aware of their condition, leaving most patients undiagnosed and increasing their risk for HF.⁵

In the case of chronic HF, patients require complex care including access to specific medications. However, because most healthcare options in Uganda are in urban areas, access to quality care can be challenging, especially for rural communities where over 84 per cent of the population live. This, in combination with the lack of healthcare sensitization and education for NCDs like CVD, poses a significant risk for delayed diagnosis that can lead to the development of late-stage complications like HF.

HF affects patients with debilitating symptoms and contributes to increased rates of hospitalization that can overwhelm healthcare systems. But when

they are equipped with the right tools for self-care, patients can often manage HF symptoms themselves, thereby reducing the overall healthcare load. Early and long-term management of CVD can reduce the likelihood of HF altogether, which reduces mortality rates and enhances patients' quality of life. This management may be introduced either with or without healthcare workers, the latter being considered "self-care" when families, communities, or individuals themselves maintain their health and well-being. Recognizing and treating symptoms like shortness of breath, as well as controlling sodium consumption in diets, are considered self-care in the context of HF.

With compelling evidence for its success, especially in low-resource settings, the World Health Organization (WHO) endorses self-care as a critical intervention for chronic conditions, including NCDs. Self-care can benefit both patients as well as the healthcare system by empowering patients to perform fundamental care tasks. However, despite its advantages, self-care for HF remains underused especially in low to middle-income countries (LMICs), including in Uganda.

Village Health Teams in Uganda's Healthcare System

The Ugandan Ministry of Health (MOH) has developed an innovative strategy to address the national shortages of healthcare workers. The Village Health Team (VHT) program draws inspiration from existing HIV patient care delivery

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- 2 Jason Hearn, Sahr Wali, Patience Birungi, et al., "A Digital Self-care Intervention for Ugandan Patients with Heart Failure and Their Clinicians: User-centred Design and Usability Study," *Digital Health* 8 (2022): [🔗](#).
 - 3 Albertino Damasceno, Gad Cotter, Anastase Dzudie, et al., "Heart Failure in Sub-Saharan Africa: Time for Action," *Journal of the American College of Cardiology* 50, no. 17 (2007): 1688–93; Hisham Dokainish, Koon Teo, Jun Zhu, et al., "Global Mortality Variations in Patients with Heart Failure: Results from the International Congestive Heart Failure (INTER-CHF) Prospective Cohort Study," *The Lancet Global Health* 5, no. 7 (2017): e665–e672.
 - 4 Emmy Okello, John Omagino, Jean M Fourie, et al., "Uganda Country Report" *Cardiovascular Journal of Africa* 31, no. S42 (2020).
 - 5 Emmy Okello et al., "Uganda Country Report."



Figure 2. A view of Kampala (left); The Uganda Heart Institute with (left to right) Tracy Dusabimana and Kajol Aggarwal

strategies that use “expert patients” or clients as accessible, trusted links between healthcare facilities and local communities. Similarly, the VHT program positions community volunteers within each village to provide direct, familiar, and easily reachable support for basic health services, namely infectious disease care, as well as maternal and early childcare.

VHT members are community-elected volunteers trained to deliver basic health interventions in their communities. Although they receive no financial compensation for their services, their primary role is crucial: engaging communities to improve access to healthcare services, particularly in areas where these services are not easily accessible. By bridging the gap between communities and healthcare facilities, VHT members play a vital role in enhancing health service delivery in Uganda.

VHTs serve as the first point of contact for a community within the national healthcare system, ensuring that even those who cannot afford care — even subsidized care — can access a basic level of free care within their local community. Members conduct home visits; manage malaria, diarrhea, and pneumonia in children under five; distribute basic essential medicines; and make referrals to healthcare facilities.

Community outreach services also include hosting community dialogues for health education and sharing informational posters to increase health awareness, effectively funnelling information from the MOH to even the most remote communities. Always readily available to provide services, VHTs have bridged healthcare service gaps. Since VHT members are elected by the communities they serve, they are given a unique level of trust.

Despite the proven benefits of the VHT model, VHTs are grossly understaffed and underresourced. With only two VHT members assigned to each village (which are on average around 120,000 people), it is difficult to provide thorough and wide-reaching facilitation and education because VHTs cannot reach most households. This challenge is further exacerbated by national drug shortages and the consequent unreliable and infrequent access VHTs have to the basic medications necessary for community care, despite the MOH's duty to supply them. Although VHTs are only a small part of the broader national healthcare system, they play an integral role in connecting hard-to-reach, particularly rural, populations with access to basic healthcare services.

VHTs are expected to report to a local health facility where a healthcare worker oversees their activities. A parish coordinator typically supports all VHTs within a parish (also known as a village), while the district health educator is responsible for overseeing VHT operations at the district level. However, given limited funding and human resource constraints, supervision of VHTs is often irregular and inconsistent. Since the VHT program is volunteer based, most VHT members conduct these activities alongside full-time jobs. Due to the gaps in access to local care, VHT members often find themselves performing duties outside their purview, using their own funds to provide services with little external support from the MOH. For instance, some VHTs shared that they transport patients to the nearest health facility using their own vehicles without compensation for fuel, and other similar costs. These expenses place a huge burden on volunteers who already have limited resources for themselves.

Additionally, most VHT members have volunteered since the program's inception in 2001. As this population of volunteers ages, these issues are further exacerbated. Even so, community members frequently rely on these

volunteers, often under the misconception that VHTs receive government funding. Community members may even show up at VHT members' workplaces seeking care and advice. While the community's trust and familiarity with VHT volunteers are key to the program's success, their overreliance because of limited access to care facilities, coupled with inadequate funding, places significant strain on the VHTs.

All VHT volunteers receive initial training and refresher courses provided by the MOH and other partner organizations as needed, but these sessions are often irregular and lack standardization. VHTs are taught how to screen for blood pressure and to detect signs and symptoms of communicable diseases, particularly malaria, tuberculosis, and HIV. However, training on how to screen for noncommunicable diseases, particularly CVD, is non-existent, despite its prevalence within communities. VHTs report that their training focuses on managing communicable diseases, facilitating maternal and infant health, and community mobilization during outbreaks. Consequently, VHTs' health education and sensitization efforts follow the same curriculum.

As the first point of contact with the healthcare system, and sometimes the only point of contact for those who cannot afford subsidized care or who live in remote areas, VHTs play a critical role, particularly during outbreaks. However, this model is proving to be grossly unsustainable. VHTs receive little support from the government, despite it being a government-mandated program, and volunteers are increasingly finding themselves personally funding program operations. In terms of technical challenges, VHTs are ill-equipped to address the twenty-first-century public health challenges facing their communities, namely the rising prevalence of CVD and HF.

Hardest to Reach

Patient self-care as an intervention is still underutilized in Sub-Saharan Africa (SSA). A study conducted in Uganda investigated the needs and perceptions of heart failure (HF) care from the perspective of patients and healthcare professionals. Through longitudinal qualitative interviews, the researchers identified that both patients and healthcare professionals had related categories of needs including physical, informational, social, and spiritual needs. Patients expressed their core need to return to work and seek cures to control symptoms that impede their ability to work. The study also demonstrated that the current treatment approach for HF in Uganda emphasizes biomedical care that prioritizes the management of physical needs, which was insufficient to meet the multidimensional needs of HF patients.⁶

Given the challenges in the current model of management within the overburdened and inaccessible health care system, it is imperative to understand how self-care strategies can be more effectively utilized by HF patients and those at risk of HF. Because HF has high morbidity and mortality in SSA, interventions that support diagnostic, prevention, and symptom-management efforts are critical for patient well-being. This is especially important given that (1) communicable diseases are prioritized in SSA compared to NCDs; (2) patients often prioritize income generation instead of seeking quality care; and (3) there is an overall poor health literacy for conditions such as HF. Self-care is a WHO-endorsed strategy for HF, but low health literacy levels and disparities in various social determinants of health impede the uptake of these strategies in LMICs. Given

that younger patients are often arriving in hospital with advanced HF symptoms, there is a significant need to explore how communities can be empowered to support more preventative approaches to manage their heart health.

Medly Uganda

Medly Uganda is a digital health intervention developed to improve self-care among HF patients in Uganda. The original program, known as Medly, was first developed and tested in Toronto, Canada, by the University Health Network (UHN). The software-as-a-medical-device allows patients to use a smartphone, weigh scale, and blood pressure cuff to facilitate patient self-care and mitigate the burden of HF on clinics while improving patient experience. The program enables patients to report their daily HF symptoms, receive tailored treatment advice, and connect with a clinician when showing signs of deterioration. It also provides care instructions and alerts clinicians when there are changes in the patient's health status.

The program started in 2016 when the Uganda Heart Institute (UHI) — which is affiliated with Yale University through Uganda Initiative for Integrated Management of NCDs (UINCD) — and UHN had begun collaborating to initiate a mixed-methods study focused on adapting the system to the local environment. Given that in Uganda, home-based telemonitoring is not an option due to resource limitations, the Medly Uganda program was designed based on initial proof-of-concept studies that demonstrated patients' and providers' comfort with mobile health applications using unstructured supplementary service data (USSD) and short messaging service


6 Jason Hearn, Sahr Wali, Patience Birungi, et al., "Bridging Community and Clinic Through Digital Health: Community-based Adaptation of a Mobile Phone-based Heart Failure Program for Remote Communities in Uganda," *BMC Digital Health* 1 (2023). 

Table 1. Distribution of interviewees

| Category | | Number |
|-------------|--------------------------------------|--------|
| Focus Group | Village Health Team Members | 4 |
| Interviews | Nurses and Healthcare Workers | 5 |
| | Doctors and Cardiac Care Specialists | 8 |
| | Public Servants and Officials | 4 |
| | Civic Organizations | 1 |

(SMS) for program access.⁷ This strategy was developed to allow for automated simple tasks with minimal oversight from overburdened clinical staff — it could algorithmically triage patients to optimize resource allocation. There was also precedence for mobile health tools in Uganda such as FamilyConnect which was a hybrid USSD/SMS application that provided health education and self-care recommendations to pregnant and postpartum women.

Medly Uganda currently targets patients in more chronic stages of HF to address their complex treatment plans requiring medications, lifestyle recommendations, self-care instructions, and follow-up appointments with nurses and clinicians. A pilot clinical trial conducted by the UHI demonstrated promising preliminary results. Of the 66 participants (92%) who completed evaluations in their sixth month of using the app, there were significant improvements in all Self-Care in Heart Failure Index (SCHFI) domains compared to baseline measurements. Recent hospitalizations had also significantly decreased and people who used the application regularly reported significantly higher confidence in self-care as well as medication adherence.

These results supported the rationale for further evaluating Medly Uganda through a more sophisticated and ongoing clinical trial.

About Our Research

We were interested in strengthening heart failure patients' uptake of Medly Uganda so we explored the factors contributing to cardiovascular disease (CVD) risk at the individual, family, and community level, and what interventions (e.g., clinical, technological, community-led) would be most effective in improving the early diagnosis of CVD and the prevention of heart failure in Uganda.

Mixed-Methods: Focus Groups, Qualitative Interviews, Quantitative Analysis

For key informant interviews we recruited participants through snowball sampling, leveraging the existing network to access experts. Together with our partners at Medly Uganda and Makerere University School of Public Health,

7 Hearn, et al., "A Digital Self-care Intervention;" Jason Hearn, Quynh Pham, Jeremy I. Schwartz, et al., "Lived Experiences and Technological Literacy of Heart Failure Patients and Clinicians at a Cardiac Care Centre in Uganda," *Annals of Global Health* 86, no. 1 (2020): 85. [🔗](#)

Table 2. Thematic codes used for qualitative analysis

| | |
|-----------------------------------|---------------------------------------|
| Early Diagnosis | Referral Process |
| Education | Patient/Practitioner Communication |
| Health Centres | Prevention |
| Infectious Disease Infrastructure | Self Care |
| Medly and Technology | Policy and General Challenges to Care |
| Health Workers | VHTs |

we interviewed a total of 22 participants, from doctors, cardiac care specialists, and nurses, to healthcare workers, village health teams (VHTs), and public officials (Table 1). We selected each participant to provide insight regarding each level of the healthcare system to gain a comprehensive understanding of challenges and opportunities for different stakeholders. We visited all levels of the Uganda health system: the “first contact” with village health teams, and community spaces located in districts of Kampala and Masaka, as well as the different levels of health centres—level 2 (local clinics), level 3 (regional referral hospital), and level 4 (national hospital) (see Figure 3). Table 1 shows the number of interviewees by their role in the healthcare system. We conducted both in-person semi-structured interviews and a focus group with the village health team workers. Our local research partners supported with Luganda-English translation when needed.

Qualitative data analysis. First, we transcribed interviews using Otter.ai and uploaded clean versions to a qualitative data analysis software (Dedoose). Then we familiarized ourselves with the data and developed initial codes (categories) with clear definitions. Third, we inductively and deductively coded the transcribed data, adding and adjusting categories as needed while

discussing any divergences in applying codes. Next, we examined and synthesized the coded data into memos to identify broader themes, linking each piece of extracted data to a memo for later sourcing. Finally, we selected key findings based on frequency of occurrence and relevance. Medly Uganda provided contextual insight throughout the process, from interview design to analysis. Table 2 shows themes from the data.

Challenges in the Patient Experience and the Referral Process

All participants pointed to inefficiencies in the referral process as a major factor in the late diagnosis of CVDs like heart failure in Uganda. When symptoms first appear, patients do not always seek treatment and often attribute their condition to overworking. As one cardiologist noted, “the first symptom is like difficulty in breathing, and when it starts some of them first ignore [it] and maybe think they are overworked and then they try to decrease their workload.” When patients do seek support, they often first engage VHTs in the community (health centre level 1). However, there are two challenges to this process. Although VHTs receive training by the

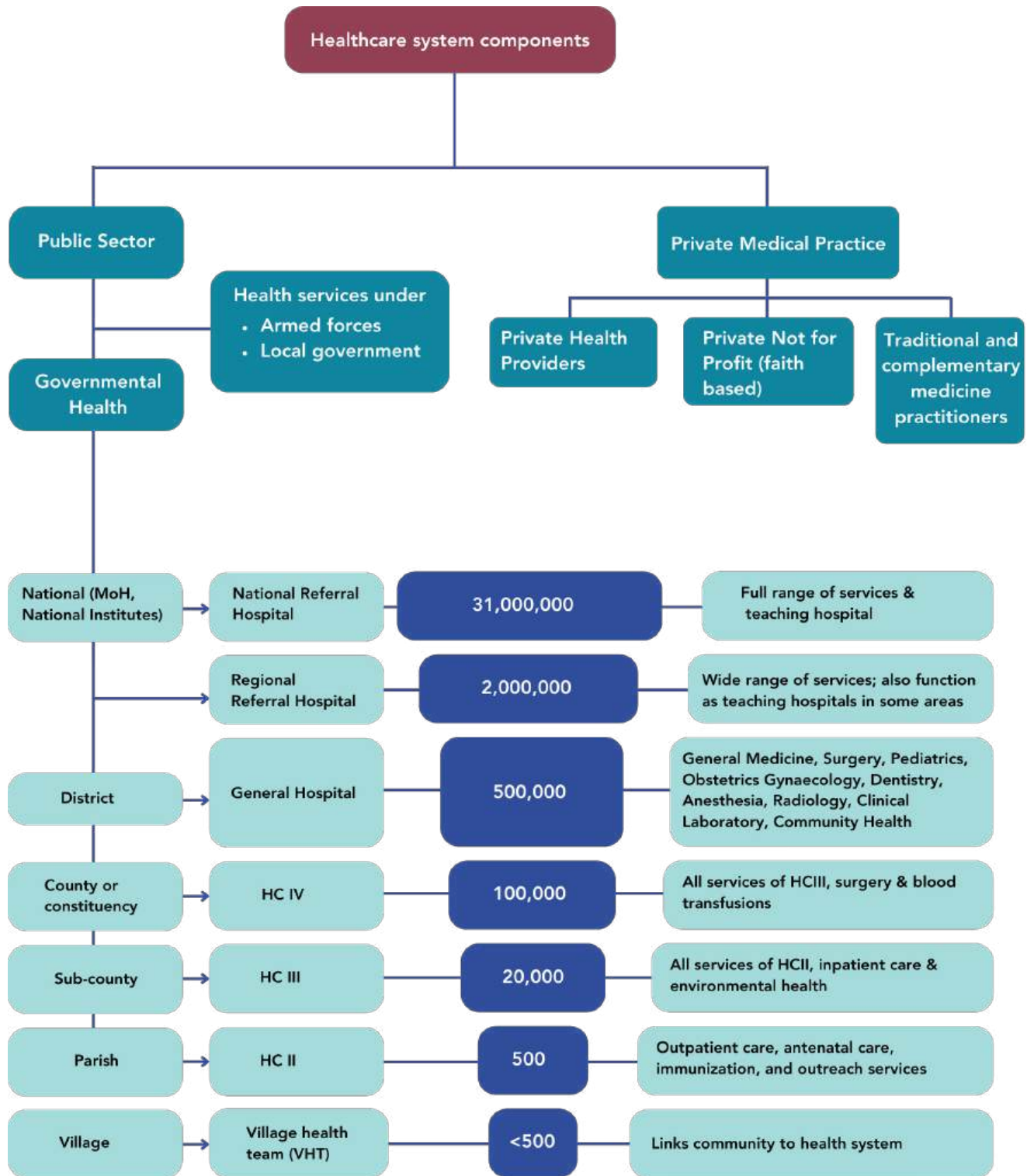


Figure 3. Structure of the Ugandan healthcare system

District Health Office, and are highly committed and trusted in their communities, they are not medical professionals. They often mistakenly attribute symptoms of HF to other conditions like asthma. Based on such “advice,” and to avoid a costly visit to the doctor, many patients then go directly to the pharmacy to self-medicate and treat their symptoms. The medications that the pharmacy provides for asthma can temporarily alleviate symptoms, leading patients to unknowingly allow their condition to worsen. One interviewee highlighted this reality, stating, “So she went to the pharmacy, and they told her that I think you have asthma, and somehow for the first time, someone prescribed a steroid dexamethasone, so when she goes back home, she felt some relief in the symptoms.” This type of result may also occur when patients avoid talking to VHTs or healthcare professionals altogether and instead either go straight to the pharmacy or consult traditional healers.

Health Centre 2

According to government policy, each parish is supposed to have a health centre 2 to provide basic services to a few hundred people. However, in reality, many parishes do not have such health centres and the nearest one may be as far as 40 kilometres away, making the journey prohibitively expensive, both in terms of travel costs and lost workdays.

That difficulty is further compounded by the fact that, in Uganda, requesting a sick day can result in job termination. When patients do arrive at these centres, nurses typically conduct

the general screenings. However, because the nurses have only general training, they may not run comprehensive tests for blood pressure or other CVDs. These healthcare workers often do not have the training to identify CVD symptoms to be able to refer them to the next health centre level (3) where they can see a doctor and receive a diagnosis. Their tools may also be old, overused, or inaccurate — a reality we witnessed when stepping onto a scale at a hospital in Masaka. This can lead to further misdiagnosis that leaves patients travelling to health centres and pharmacies without gaining further clarity on their condition. They may continue to seek treatment which leads to low morale, motivation, and trust in the system. During this process, many patients become frustrated by what they perceive as an endless ordeal.

The journey to receive adequate care is, for many patients, an overwhelming cycle of obstacles that extends far beyond their initial diagnosis.

Health Centres 3 and 4

Once symptoms become severe and are hard to ignore as anything other than CVD, patients are referred to a health centre 3 to

receive a diagnosis. If these facilities do not have a specialist or sufficient capacity, they are referred to a regional referral hospital with a specialist or a level 4 centre. During our time in Uganda, we witnessed the significant difference between health centre 2 and these higher levels in terms of both the training and capacity of the practitioners. However, being sent to these facilities presents its own difficulties because they are only in certain communities, meaning that for many patients they are hundreds of kilometres away. Thus, the difficulties with the cost of travel are further compounded at this stage.

If they do reach a level 3 or 4 health centre, patients are entered into the system and triaged

by a nurse or outpatient doctor to determine their condition before their vitals are taken. They then can receive an official diagnosis and a treatment plan, including medication and lifestyle changes. However, many are extremely sick at this stage. As one doctor told us, “[We get] most of our patients when it is late. Yes. And it’s really painful ... if we could have been able to get them early, we could at least do something for them.”

The challenges of patient expenses continue at this stage. For instance, patients may be unable to return for follow-up appointments or afford their full prescriptions, forcing doctors to devise treatment plans based on what the patient can afford. Even when patients receive the proper medication, it can be difficult for them to follow the prescribed treatment because many are illiterate and struggle to differentiate medicines and read instructions. The journey to receive adequate care is, for many patients, an overwhelming cycle of obstacles that extends far beyond their initial diagnosis.

Practitioners’ Experience

Given the chronic nature of their heart condition, many patients require regular follow-up care but cannot afford the time and cost associated with transportation to the hospital. To address this issue, some healthcare professionals share their contact information with their patients to answer any questions or concerns and refer them to a nearby facility for a checkup, if necessary, thus facilitating timely communication and follow-up. However, this places an additional burden on healthcare professionals, requiring them to address numerous patient inquiries throughout the day and after hours. Cardiac care specialists also oversee a large number of patients so may not have enough time to provide patients with the necessary health education regarding symptoms, prevention, and treatment.

A high burden of HF patients demonstrates a lack of early diagnoses at initial stages of the condition, lack of education on signs, symptoms, prevention, and management, and a shortage of cardiac care specialists. This underscores the need to raise awareness and empower village health teams in the communities, as well as health workers in all health centres and hospitals, to educate patients on heart health to promote earlier diagnosis and better health outcomes.

Infectious diseases such as HIV, AIDS, and malaria are currently more common than HF and other NCDs in Uganda and the rest of Sub-Saharan Africa, so they are the focus of health education and treatment. As a result, health workers are often less empowered to educate the community on heart health, which creates challenges in symptom recognition, early diagnosis, and treatment of HF patients. To complicate matters, clinicians have found that many people with HIV who survive into adulthood later experience heart disease symptoms. One clinician told us that, “The patients are no longer dying from HIV — they’re dying of heart disease.” Given this intersection between HIV and CVD, it is crucial for HIV specialists to be equipped to educate patients on preventing HF and recognizing its symptoms. However, the lack of education among HIV specialists and other infectious disease professionals regarding the risks of heart disease, along with insufficient patient awareness about HF prevention and symptoms, pose a significant challenge.

A shortage of cardiac care specialists, minimal access to doctors below the level of health centre 3, and an insufficient number of doctors in tertiary health centres significantly contribute to limited access to care, delayed diagnoses, and an overburdened healthcare workforce. A subsequent lack of effective policies to support care in lower-level health centres and collaboration between levels 1 to 3 centres further limits access to necessary care for local



Figure 4. Masaka National Referral Hospital (pictured: Kajol Aggarwal, Zainab Azim, Christinah Nuwahereza)

communities while hindering doctor-patient communication and timely diagnosis. The general training received by nurses and healthcare staff in lower-level health centres does not adequately educate and prepare them to recognize and screen for CVD signs and symptoms, further delaying diagnosis. These factors collectively highlight the critical gaps in Uganda's current healthcare system, underscoring the urgent need for systemic reforms to improve access to a clinician, enhance training for healthcare staff, and increase collaboration to support early diagnosis and better patient outcomes across all levels of care.

Use of Technology

Despite technology and mobile phones enabling stronger patient communication, there are still challenges that prevent the widespread adoption

of technology across the patient experience with the healthcare system. First, although clinicians and health workers already communicate with patients through mobile phones, this system is not structured or centralized and depends on personal preference. A more effective system would require the systematic adoption of technology use from both the healthcare and the patient side. Second, there is a general lack of understanding of HF as a condition, its associated symptoms, and ways to manage the disease. Thus, even though mobile phones can bridge the communication gap, they don't address the lack of knowledge in disease management.

For technology to make a meaningful impact, there needs to be a push toward patient education and empowerment, so that critical information can be communicated to patients who understand how

to act upon it. Finally, although most of the population in Uganda from both urban and rural regions has access to mobile phones, the older population that makes up a larger proportion of HF patients often requires family members to help them effectively use mobile devices. It is common for an entire family to share one or a few mobile phones among all the members. Therefore, technology applications need to be scaled in a way that enables patients' family members to be a part of the disease-management experience.

The relationship between patients and clinicians is often close-knit, sometimes extending beyond traditional boundaries when clinicians provide after-hours contact information for ongoing support.

Patient and Practitioner Communication

The existing support group infrastructure for communicable diseases plays a vital role in community health, with various groups dedicated to specific issues like HIV and disability. For example, existing HIV patient communication strategies involve "expert clients" who serve as accessible, trusted links between healthcare facilities and their local communities. However, HF has not received the same attention, so there's a significant gap in HF-specific support groups. This lack of visibility and prioritization means that many HF patients often turn to clinicians for advice that could be provided by VHTs. Recognizing this need, some patients with rheumatic heart disease, who have undergone valve interventions, have taken proactive steps to form support groups. With the support of clinicians, these groups work to raise awareness, reduce stigma, and foster positive perceptions of life after treatment, sharing their journeys within

the community to emphasize that heart disease is not a death sentence.

The relationship between patients and clinicians is often close-knit, sometimes extending beyond traditional boundaries when clinicians provide after-hours contact information for ongoing support. This frequent communication allows patients to update clinicians on their symptoms and progress after diagnosis, ensuring they receive timely advice. In emergencies, patients can reach out directly, and clinicians, often preferring WhatsApp for non-urgent matters, can respond when it's convenient. However, this reliance on clinicians highlights the absence of well-established HF support networks, where trained community health workers or VHTs could handle many of these inquiries.

Partnerships

There are many opportunities within these challenges that participants identified for partnerships, Medly, and other technologies which are already being used in more informal ways. In terms of partnerships, there are already satellite clinics acting as extensions of the national hospital. They train health workers to diagnose and manage patient care because not all patients can come to Kampala or Masaka, nor can those hospitals handle that influx. There are also outreach efforts currently aimed at improving public understanding of heart health. These initiatives are primarily led by the Ministry of Health and District Health Offices, in partnership with private and nonprofit organizations. They often focus on educating communities where they are, with recent initiatives including community

dialogues and health education sessions at local healthcare centres. However, these efforts remain limited and inconsistent across the country.

Recommendations

Uganda would benefit from using existing infrastructure to facilitate collaboration between cardiac and infectious disease specialists. Infectious diseases are more common than noncommunicable diseases (NCDs) in Uganda and have received greater attention in terms of domestic and international funding. Therefore, Uganda should build on the success of HIV interventions by using its existing infrastructure to address NCDs and cardiovascular diseases (CVDs). An example of this collaboration could be the integration of CVD screenings with infectious disease screenings so that people can be examined for both in one trip to the hospital. This would be highly impactful: it would reduce the cost and time of being screened, increase the number of people screened, and improve earlier diagnoses of CVD, especially since many patients diagnosed with infectious diseases later experience heart disease.

Healthcare workers need to be further trained to identify the signs and symptoms of CVD. VHTs in health centre level 1 and nurses in health centre level 2 currently receive minimal training or education on recognizing and screening for CVD, contributing to symptoms being overlooked or misdiagnosed in the case of nurses. Therefore, improved CVD education should occur at all levels of the healthcare system and be completed through collaboration among all four levels of healthcare centres. Education should also differ for different types of healthcare workers. For instance, the lower levels of the healthcare system, including VHTs and healthcare workers in level 2 centres, may benefit from resources such as information packages and checklists that give

them practical tools to conduct CVD screenings and refer patients to higher levels of care if necessary.

The creation of community support groups for CVDs, organized through healthcare providers, is a critical next step to improving care. These groups already exist on an ad hoc basis, organized by certain doctors for their patients, with considerable success. Their expansion and streamlining would be greatly beneficial. These groups can provide both mental health support for patients and cross-patient education.

While most people recognize the importance of infectious diseases, they lack a similar understanding of the prevention, diagnosis, and management of CVD. Consequently, it is crucial to empower and educate the local population to adopt healthy lifestyles and enable them to recognize and prevent CVD signs and symptoms. Public education should cover topics such as diet, exercise, and common symptoms of CVD. This education should include in-person health-education sessions and the development of informational resources, such as infographics and information pamphlets, distributed in public places. Informational resources could be displayed in pharmacies, marketplaces, and religious centres while health education sessions could occur in community venues like religious buildings and healthcare facilities. This education could empower families to conduct screening by educating young people to notice signs and symptoms in their older relatives. And by engaging with community leaders in trusted community spaces (like religious institutions) healthcare workers may be able to overcome some of the reluctance people often have to seek care.

Expanding Medly to include patient education on heart health is crucial in empowering individuals to take control of their well-being. By providing accessible and understandable information about cardiovascular health, Medly can help patients

recognize ongoing signs and symptoms, as well as encourage lifestyle changes that improve CVD management and prognosis. Accessing short videos, audios, and interactive learning modules in local languages can help patients understand CVD risks, symptoms, management strategies, and the importance of medication adherence. Medly could also implement a feature that sends push notifications with daily or weekly heart health tips, reminders to take medications, and prompts for healthy behaviours such as regular exercise or healthy eating.

Enabling doctors to maintain regular virtual contact with their patients and log symptoms within Medly will enhance continuous care and monitoring. Currently, there are inconsistencies in the way that doctors in level 3 and 4 health centres communicate with their patients. While some doctors maintain contact with their patients through WhatsApp, this is not standardized, and the only way patients can get in touch with clinicians is through in-person visits. Medly's expansion to include virtual contact between patients and physicians will allow healthcare providers to track patient progress more closely, respond to emerging concerns promptly, and make timely adjustments to treatment plans, ultimately improving patient outcomes and reducing the burden on healthcare facilities.

Research Team



Kajol Aggarwal is a second year master's student studying laboratory medicine and pathobiology at the University of Toronto. She has a bachelor of health sciences degree from McMaster University. She has extensive interdisciplinary research experience in conducting literature and systematic reviews in the fields of infectious disease epidemiology, psychiatry, and environmental sciences, and has previously worked with local organizations to promote health education and network with stakeholders for the implementation of environmentally sustainable practices.



Zainab Azim is a master's student at Harvard University studying education policy and analysis. She completed her honours bachelor of science degree in neuroscience, public policy, and education studies at the University of Toronto. She is dedicated to advancing the SDGs through her personal and professional endeavours, with a focus on quality education as co-founder of GIVE, researcher at the National Education Policy Centre, former lead research assistant at OISE's Emotions and Learning Optimization Lab, and ambassador with the UN Office of Outer Space Affairs. She holds an IRB Human Subjects Certification in the social sciences and has research training from the Canadian Centre for Diversity and Inclusion.



Tracy Dusabimana is a fourth-year undergraduate student at the University of Toronto's Munk School of Global Affairs & Public Policy, and a research analyst at Momentus Global Development. She has extensive research experience across the energy, health, and climate adaptation sectors in Africa and Asia. Tracy's work in social impact assessment and measurement complements her strong foundation in international affairs and development. Her expertise lies in advancing sustainable development and fostering inclusive growth in Africa, with a particular focus on promoting peace, justice, and resilient institutions.



Nathan Feltmate is a fourth-year undergraduate student at the University of Toronto double majoring in peace, conflict, and justice studies and international relations. He is a research assistant at the Munk School of Global Affairs & Public Policy where he supports the World Education Reform Database. Nathan has served as a student consultant with the World Bank's Africa Gender Innovation Lab and is a Jackman Scholar.



David Li is a PhD candidate in the Institute of Biomedical Engineering at the University of Toronto. He also holds a bachelor's degree in civil engineering from the University of Alberta. His research focuses on developing novel therapeutics for tackling neurological disorders. He has also worked on community projects investigating problems in the City of Edmonton's responses to encampments by interviewing individuals from the city's response initiatives and social agencies. His unique background gives him valuable insights when working on interdisciplinary projects like Medly.



Hajarah Nakitende is a research fellow in the Department of Community Health and Behavioral Sciences at the School of Public Health, Makerere University, Uganda. She holds a bachelor of science degree in human nutrition and a master's in public health nutrition from Makerere University. As a published early career researcher she has done work on nutrition, food security, climate change, CVDs, and health systems in displaced populations. Hajarah is a member of the Climate Change Research Program (CARP) funded by USAID, and the Disaster, Migration and Refugee Center of excellence at Makerere University School of Public Health. Her research interests traverse from nutrition-related issues of public health concern, food security, climate change, disasters, health systems, and refugee health and livelihoods.



Christinah Nuwahereza is a committed public health nutritionist with strong academic and professional backgrounds in nutritional sciences. She earned her bachelor's degree in science and technology biology from Kyambogo University and a master's in public health nutrition from Makerere University, both in Uganda. With over eight years of experience in nutrition assessments, surveys, and health-related research, Christinah has contributed to enhancing nutritional outcomes in various communities. She currently serves as a research associate in the Department of Community and Behavioral Sciences at the School of Public Health, Makerere University, and holds the position of assistant lecturer in Food and Nutrition at Bugema University.



Christine K. Nalwadda is a PhD graduate in public health from Karolinska Institute, Sweden. She is a senior lecturer and chair of the Department of Community Health and Behavioral Sciences, School of Public Health, College of Health Sciences Makerere University. She is involved in teaching, research, and supervision of graduate students. She has mentored and supported inter-university training of students under various university collaborations such as the university of Toronto, Yale, and Oxford. Her research areas of interest include maternal and newborn health, community health, and noncommunicable diseases with an orientation to using qualitative research approaches.



Cinderella Muhangi Ngonzi is a health services researcher with over seven years of experience in health systems strengthening and noncommunicable diseases. She currently coordinates an mHealth research project (MEDLY Uganda) focused on enhancing self-care for heart failure patients across six regional referral hospitals in Uganda. She leads the monitoring and evaluation of the PEN-Plus project, a WHO-AFRO strategy addressing severe noncommunicable diseases at first-level referral health facilities under the Uganda Initiative for Integrated Management of Non-Communicable Diseases (UINCD). Cinderella has served as a co-investigator, consultant, and research fellow on studies spanning HIV, noncommunicable diseases, maternal and child health, and sexual and reproductive health.



Isaac Ssinabulya, MBChB, MMed, is a consultant cardiologist at the Uganda Heart Institute in Kampala, Uganda. He is a lecturer with the Department of Internal Medicine at Makerere University. He is also the co-director of the Uganda Initiative for Integrated Management of Non-Communicable Diseases (UNICD) in Kampala, Uganda.



Godfrey Zziwa Buuka is a consultant physician and head of the department of internal medicine at Masaka Regional Referral Hospital in Uganda. He is also the regional adult cardiologist. He completed his residence training from Makerere University. He further did a fellowship in adult cardiology at the Uganda Heart Institute in Mulago. His area of interest is non-interventional cardiac diagnostics and heart failure care. He undertook super-specialized training in advanced heart failure and transplant science at Toronto General Hospital, Canada, with a biased interest on how to maximize non-invasive options for improved outcomes for patients with heart failure. Dr. Godfrey is a member of the Uganda Heart association. He is also a member of Medly Uganda, a group that is pioneering the integration of smart telephone usage in heart failure care.



Sahr Wali is a scientific associate at the Ted Rogers Centre for Heart Research, University Health Network, and researcher at TRANSFORM HF. As a digital health services researcher, she is committed to bridging the values from culture and innovation to advance the equitable provision of health interventions. Dr. Wali currently leads a portfolio of research in partnership with communities in Northern Ontario and Uganda to support a community-first, digitally enabled avenue for cardiac care. Her collaborative research seeks to challenge the traditional approaches to digital health innovation by incorporating sources of Indigenous methodologies and graphic medicine within the user-centred design process.



Sarah Haines is an assistant professor in civil and mineral engineering at the University of Toronto. She is currently leading multiple interdisciplinary research projects working with marginalized communities in Northern Canada. Dr. Haines also has previous experience managing sensitive individual housing information for over 20 residential homes. She is currently working with seven First Nations communities throughout Saskatchewan and Manitoba to establish appropriate drinking water quality guidelines and establish pathways for housing self-sufficiency, elucidating potential reciprocal relationships between water quality and indoor environmental quality as well as their implications for occupant health. Additionally, she has participated as the faculty mentor for Team Philippines through the Reach Alliance and has experience visiting communities, conducting interviews, and collecting data.



TRANSFORM HF is an Institutional Strategic Initiative created in joint support and partnership with the University of Toronto and the Ted Rogers Centre for Heart Research. TRANSFORM HF's mission is to enable patients to become more active in their own health and increase equitable access to specialized cardiac care by uniting a team of experts, patients, and communities in the development of innovative technologies and co-creation of proactive, personalized, and decentralized models of heart failure care.

<https://transformhf.ca>



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Published by the Reach Alliance, January 2025
Munk School of Global Affairs and Public Policy | University of Toronto

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