

# FINDING HUMANITY IN UNCERTAINTY:

PANDEMIC PREPAREDNESS AND RESPONSE IN UGANDA

A CONSENSUS STUDY OF THE UGANDA NATIONAL ACADEMY OF SCIENCES







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The Uganda National Academy of Sciences (UNAS) is an independent, nonpolitical, and nonprofit organization founded in October 2000 to provide evidence-informed policy advice to the government and nation of Uganda.

Finding Humanity in Uncertainty: Pandemic Preparedness and Response in Uganda

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<sup>&</sup>lt;sup>1</sup> Fellow of the Uganda National Academy of Sciences

<sup>&</sup>lt;sup>2</sup> Fellow of the Kenya National Academy of Sciences

<sup>&</sup>lt;sup>3</sup> Fellow of the Nigerian Academy of Science

### INDEPENDENT REVIEWERS

The Academy thanks the following experts, who reviewed the report in draft form, for their *pro bono* service and comments:

- **Dr. Grace Akello**, Associate Professor of Medical Anthropology, Gulu University, Gulu, Uganda
- **Prof. Monica Chibita**, FUNAS,<sup>4</sup> Professor and Dean, Faculty of Journalism, Media & Communication, Uganda Christian University, Mukono, Uganda
- **Mr. Bruce Compton**, Senior Director, Global Health, Catholic Health Association of the United States of America
- **Prof. Seggane Musisi**, FUNAS,<sup>4</sup> Professor of Psychiatry, College of Health Sciences, Makerere University, Kampala, Uganda
- **Prof. Joseph M. Ntayi**, Dean, Faculty of Economics, Energy, and Management Science, Makerere University Business School, Kampala, Uganda
- **Dr. Shailey Prasad**, Executive Director and Carlson Chair, Center for Global Health and Social Responsibility (CGHSR), University of Minnesota
- **Dr. Aloysius Ssenyonjo**, Lecturer, College of Health Sciences, Makerere University, Kampala, Uganda

<sup>&</sup>lt;sup>4</sup> Fellow of the Uganda National Academy of Sciences

### RESPONSE TO REVIEW COMMITTEE

We would also like to extend our thanks to the following professionals who served on the Response to Review Committee:

- **Prof. Charles Rwabukwali**, FUNAS,<sup>5</sup> Professor of Anthropology, Makerere University, Kampala, Uganda
- **Dr. Henry Clarke Kisembo**, Global Chief Managing Partner, Development Associates Link International, Kampala, Uganda
- **Dr. Emilly Comfort Maractho**, Director, Africa Policy Center, and Senior Lecturer, Journalism and Media Studies, Faculty of Journalism, Media & Communication, Uganda Christian University, Mukono, Uganda
- **Dr. Wilber Karugahe**, Lecturer, Department of Mental Health and Community Psychology, School of Psychology, Makerere University

v

<sup>&</sup>lt;sup>5</sup> Fellow of the Uganda National Academy of Sciences

### STUDY STAFF AND SECRETARIAT

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### Introduction

Everybody knows that pestilences have a way of recurring in the world, yet somehow we find it hard to believe in ones that crash down on our heads from a blue sky. There have been as many plagues as wars in history, yet always plagues and wars take people equally by surprise.

—Albert Camus, La Peste ("The Plague")

Infectious diseases and the epidemics they cause are no longer a rare occurrence in human life. Some of the most memorable epidemics in recent history include the human immunodeficiency virus (HIV) and the associated condition acquired immune deficiency syndrome (AIDS); H1N1 in the early 2000s; Middle East respiratory syndrome (MERS) in the 2010s; Ebola in West Africa in 2015–2016; and now SARS-CoV-2, or COVID-19, from 2020 onwards. The issue of infectious diseases and epidemics is not new. For decades, experts have warned of the increasing frequency of epidemics and of their capacity to spread across the globe, thus becoming pandemics (Marani et al. 2021, Morse 1995). Policies, plans, and procedures have been developed nationally, continentally, and globally to prepare for and respond to the crisis that epidemics and infectious diseases present. People have and are trying their best to respond to these epidemics with specificity, care, and dedication.

However, while having similar structures or stages, each epidemic differs in terms of its breadth and depth of impact. As the COVID-19 pandemic has shown, while many African nations have not borne the brunt of globally documented COVID-19 deaths, the impacts on African economies and healthcare systems are and will continue to be enormous. Similarly, the impacts of the HIV/AIDS pandemic continue to reverberate in people's economic, social, and cultural

lives despite the ability now to treat and control the disease. Diseases' ramifications go beyond the human body to influence how human beings live and engage with one another.

The impacts of these epidemics are intimately linked with targets for growth in national, continental, and global development agendas. These agendas include the National Development Plan III and Vision 2040 in Uganda, the Agenda 2063 of the African Union, and the global Sustainable Development Goals of the United Nations, to name but a few. The ability of nations to pursue and sustain the achievement of their development goals must now take into consideration the inevitable crystallization of the risks presented by epidemics and infectious diseases beyond the disease itself.

For this reason, the Uganda National Academy of Sciences, with the support of the National Research Foundation of South Africa, conducted a consensus study exploring the human side of epidemics and pandemics. The amount of time, money, and energy invested nationally, continentally, and globally to address the biomedical aspects of infectious diseases is vast. However, if epidemics are to become a natural and less disruptive part of human life, understanding how to incorporate the human being into preparation for and response to epidemics and pandemics will be key to supporting more holistic, sustainable, and resilient development.

### PROBLEM STATEMENT

The biological basis for the increase in frequency of epidemics and related pandemics is twofold. The emergence of novel epidemics (infectious diseases that are generally unknown before their spread) is primarily a function of increased interaction between animals and humans (Haileamlak 2022). As humans and animals interact more closely, viruses have more opportunities to mutate and cross species. At the same time, human-to-human spread of epidemics from known sources (a previously identified pathogen) is exacerbated by globalization and urbanization. In both cases, human beings have played a major role

in facilitating infectious disease emergence and spread. In other words, while human behaviour does not cause epidemics, it is a major source of fuel for their spread.

Human behaviour, particularly in crisis, is a dynamic and messy affair with various influences that do not adhere to hard and easily applicable rules (Balog-Way and McComas 2020, Birner et al. 2021, Kansiime et al. 2021, Macgregor et al. 2022). Epidemics create uncertainty in the mental, physical, social, and spiritual lives of humans. Every part of a person's life, from their ability to meet their basic needs and those of their families or loved ones, to their ability to engage in leisure and entertainment, or even move around freely, is infused with a previously unexperienced set of demands and risks. Decisions that were formerly routine or mundane require more attention, energy, and discretion, and trade-offs frequently have more significant consequences.

At the same time, an epidemic makes other people both a source of an epidemic's continued existence and the basis of its solution. From healthcare providers (including traditional and nonbiomedical healthcare providers) to policymakers and law enforcers, from rural farmers to educated urban youth, a human-based solution depends on how a person perceives their peers and vice versa (Abdelmagid et al. 2022, Adel and Razek 2022). While everyone is in theory free to pursue their own desires and needs, in a health crisis, people must be willing and able to make decisions that place the interest of their community or group above their own (Gostin and Wiley 2016, Kamweri 2013). While people cannot have an exhaustive appreciation of the dilemmas that their fellow human beings experience, it is possible to design and shape the structures of human society to help them grow in empathy.

In practice, many systems and structures of society are not designed to address this issue explicitly. Much the opposite, many practices, particularly in public health, tend to hinge upon a command-and-control structure (Haldane and Morgan 2021, Merrill et al. 2021). Originally a product of military crisis response systems, a command-and-control structure presupposes a clear and authoritative hierarchy from which high-level decisions are rapidly implemented and acted upon at all levels (CDC 2014, Miller 2015). It is this incongruency in expectations that contributed in part to what some scholars have

labelled the "securitization" of the COVID-19 response (Nkuubi 2020). Some public health experts have argued that strict interventions and loss of life due to reckless enforcement of those interventions may be unfortunate, but necessary, actions to preserve control over spread of the disease (Musisi 2022, Nyamutata 2020). The community is assumed to be a part of this structure of decision-making, in which the enemy is the disease (Ejembi et al. 2022). Where an affected community fails to adhere to this role, they can be perceived as an impediment needing to be actively coerced or forced into behaving in particular ways (Schapper and Jenichen 2020). In almost all cases of health crisis, the resolution of such tensions starts with preparation and early consideration of those difficult questions before a crisis occurs, rather than during it.

The issue to address therefore, is how to promote a society's resilience to the uncertainty an epidemic or pandemic creates, drawing on human beings' abilities to both empathize and act individually and communally to reduce the spread and impact of the disease. The path to that resilience lies at a nexus of multiple structures and systems, from human psychology to economic, legal, social, cultural, and media ecosystems that shape the ways in which human beings see and treat one another. While there are differences in approach and outlook among human beings, it is possible to debate constructively about how to build greater consensus on how to respond together in advance of a crisis, thereby strengthening society's ability to ensure resilient sustainable development.

### A NOTE ON OBJECTIVES AND METHODOLOGY

The objective of this study is to support consensus building among stakeholders and decision-makers from various backgrounds on how structures and systems of society could be designed to be promote resilience to epidemics and pandemics. This study aims to accomplish this objective by providing a broad, accessible, and inclusive description of the challenges and lived experiences of Ugandans in relation to the challenges and uncertainties that epidemics create. This description is

informed primarily by a synthesis of published peer-reviewed literature in disciplines including but not limited to public health, gender and women's studies, economics, legal studies, medical and cultural anthropology, social and cultural psychology, and media studies, among others. That synthesis provides the foundation for diverse opinions and perspectives, in order to understand one another and therefore build more robust and inclusive consensus-driven decision-making.

The choice of Uganda as the case study is a practical one. Uganda has a robust history of controlling epidemics using biomedical technologies and public health strategies. Uganda, like many of its African neighbors, faces great challenges in mobilizing communities in advance of epidemics, and creating consensus on how communities should act before a crisis. In effect, Uganda presents a unique example of a country whose biomedical technical expertise and capacity is robust, but whose ability to move beyond it remains in question. It shows the complexity of epidemic preparedness and response when considered holistically.

However, this study is not intended to be an exhaustive or systematic exploration of the enormous body of literature regarding public health or epidemic preparedness and response. The study is about clarifying the stakes and considerations that different parts of society make during a health crisis. Such an examination requires a more flexible and pragmatic exploration of the evidence, whereby the objective is to reveal insights from various disciplines. Such an approach focuses on promoting interdisciplinary learning and understanding, rather than creating new knowledge.

The selection of issues was informed by an inclusive and broad group of stakeholders from government, the private sector, cultural and religious institutions, civil society, and international development partners. The full set of queries can be found in Annex 1.

### THEORY OF CHANGE

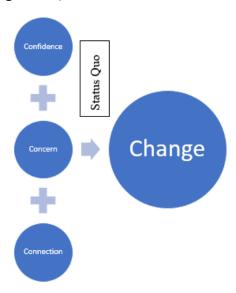
Preparing a society for uncertainty starts with understanding how a society and the individuals in it operate. The status quo or the current situation deeply influences the range of possibilities for change. The process of change, by its very nature, implies uncertainty because those who are changing do not know if the process will work. While change is possible, the range of changes, and the associated difficulty with making those changes, is shaped significantly by history, upbringing, and the reference point from which one is changing.

The range of possibilities and the degree of ease in actualizing those possibilities are reflections of human nature. Human beings have limited windows for substantial change in behaviour and outlook. Most growth and learning take place in early childhood between the ages of 1 and 5 years (Alatorre and Mugumya 2019, McAuliffe et al. 2017). Children grow rapidly in physique and in mental, emotional, and cultural intelligence, establishing the foundations for mindsets that they will use for the rest of their lives (Armstrong et al. 2014, Bwayo 2014). Children are raised to become a part of a society and are inducted into a series of norms and attitudes that are supposed to help them be effective participants in that society's evolution and growth (Boothby et al. 2017).

As children grow into adolescents, their changes are not in outlook or in approaches to life, but in terms of the range of experiences that allow them to hone and improve the foundations already laid for them (Catalano et al. 2019, Namuggala 2018). Adults change similarly: as the rapid hormonal and biological changes associated with early life slow, the sociocultural foundations of living in society are honed and refined in response to life; however, they rarely create substantial shifts in mindset (Elder et al. 2014, Pichon et al. 2022).

This process of learning through experience what is socially appropriate, culturally expected, and effective in achieving one's goals predicts an individual's ability to fit within society (Ejuu 2013). This learning process and its outcomes, when shared by a sufficiently large-enough group, can reduce the costs of human interaction in terms of resources, time, or energy. As a result, attention is paid elsewhere, on areas in which that society has not come to a consensus, and negotiations in those areas attract much of our care and attention.

Crises tend to challenge these paradigms of what has been learnt by a society to be effective or appropriate. In the absence of the threat of death or other catastrophic outcomes, adult behavioural changes occur primarily when presented with new experiences that resonate with existing models of thought (Nocek 2022, Van Den Broucke 2014, Verelst et al. 2016). Human beings do not like to hear dissonant or contradictory information that challenges how they already think or believe (McLeod 2008). Appeals to logic and reason, often used to convince people that their way of behaving does not make sense, frequently fail (Kahneman 2011). Appeals to emotions may be more successful in prompting a change, but they are much more volatile because they can serve to entrench existing behaviours rather than change them (Brinton 1988). Moral or ethical appeals rely upon a shared consensus within a given community as to what is authoritative or credible (Rapp 2022). When in crisis, maxims like "do no harm" can become much more difficult to apply in practice. In most cases, profound and sustained human change is contingent on three interrelated concepts: confidence, concern, and connection (see Figure 1-1).



**Figure 1-1.** Change at any level of inquiry depends on three Cs: *confidence*, *concern*, and *connection*. All three are viewed through the lens of the status quo, which shapes the question of whether change is perceived as realistic.

Source: Generated by the committee.

Human beings have varying inherent capabilities to do different things (Niepoth and Bendesky 2020). Some may be more predisposed to being physically strong; others may more easily perform logic and reasoning tasks; and others may more easily sing, tell compelling stories, or lead with charisma and compassion. But none of these capacities are static. They are moderated by the individual's belief or confidence in their own ability to make changes to those capabilities. For example, a footballer's belief that they can improve may have substantial effects on their persistence in trying to get better, regardless of their natural capabilities.

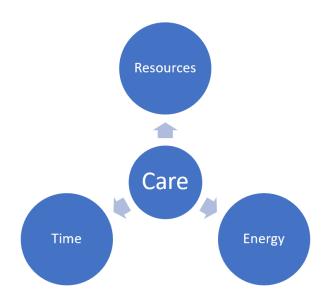
While a person's internal beliefs and confidence can help to overcome challenges in the change process, perceived concern, motivation, and sense of urgency also drive change processes. What individuals care about is a complex nexus of individual needs, social structures, and life stories, to name but a few documented determinants (Rodgers and Loitz 2009). Problems that are considered irrelevant or of low importance therefore attract less attention, energy, and resources, if any at all. In order to change, people need to perceive that an issue has value to them in meeting their basic needs or other desires.

Lastly, human connections to the issue necessitating change determine the sustainability and desirability of that change. In part, the influence of human connections reflects inherent natural tendencies. Human beings do not easily exist in a vacuum, isolated from other human beings (Park and Akello 2017); instead, they change or at least sustain their change processes in a community and with others that they perceive as being connected to them. The strength of those connections varies: they may be family, business, social, or spiritual relationships. Whatever the connection, it provides a means of accountability and solidarity in pursuing change.

### CONCEPTS EXPLORED IN THE STUDY

This study uses several interrelated but discrete concepts in ways that may differ from their conventional understandings. Two important

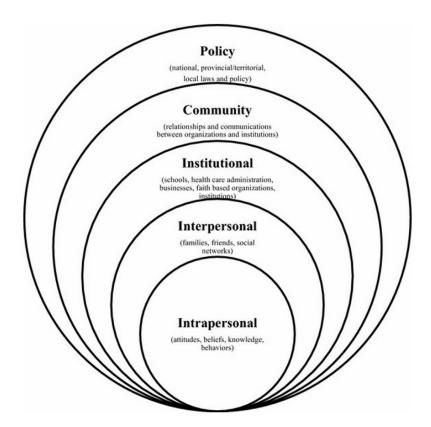
concepts the Committee presents are care and technology. This study defines *care* as the investment of time, resources, and energy by an individual, community, or institution towards achieving a given outcome (see Figure 1-2). Based on this definition, a finite amount of individual care can be exercised. It is possible to invest time, resources, and energy more productively, often through the use of technology. The Committee defines *technology* as practices, tools, skills, and environments that improve human productivity and efficiency of time and energy use (Nightingale 2014). The easier it is for people to navigate daily life, the more responsive they can be when asked to care for other people. In an epidemic, the availability of technology that could potentially eliminate or address points of uncertainty or anxiety in meeting basic needs, such as food, water, and safe social interaction, can reduce the number of dilemmas that people have to experience.<sup>1</sup>



**Figure 1-2.** Care is expressed through use of time, resources, and energy.

Source: Generated by the committee.

<sup>&</sup>lt;sup>1</sup> An example of technology beneficial in addressing epidemic-related concerns is the mobile phone. In the recent case of an Ebola outbreak in 2022 in Mubende District, Uganda, individuals placed in isolation were allowed to maintain access to mobile phones and were given airtime to maintain social contact with family and other social networks.



**Figure 1-3.** Components of human behaviour at different levels adapted from Bronfenbrenner's ecological systems theory.

Source: Guy-Evans (2020).

Care is particularly relevant in public health crises because a crisis fundamentally alters the ability and technologies that people use to exercise care. For example, during the COVID-19 pandemic, the increased risk of being infected with a deadly disease due to physical proximity made public transit incredibly taxing both mentally and physically in new ways. The costs of using public transit immediately increased, and accessibility to all services that required public transit were affected (The Daily Monitor August 3, 2021). The care that is expressed operates under different contexts and conditions depending on the level of inquiry as detailed in Figure 1-3. While care issues at an

intrapersonal level can have impacts further up, aggregate intrapersonal or interpersonal issues may present differently at the macro levels of policy, community, and institutions. Detailing each of those varying ways in which care is affected at different levels can show how crises affect human relationships and the viability and desirability of technologies that were previously in use.

While people may change in response to a crisis, the default or otherwise "normal" behaviour greatly affects the extent of that change. For example, in the context of the COVID-19 pandemic in Uganda, lockdowns majorly disrupted urban dwellers' ability to meet their basic needs. Scholars noted that, for some people, the choice was perceived as risking death by starvation or risking death by COVID-19 infection (Birner et al. 2021). In contrast, rural small-hold farmers, who would only attract meagre financial returns on their local-level farming, saw comparably fewer drastic changes to their behaviour by redirecting their production for personal consumption. This study presents the ways in which people already exercise care—the ways in which they already operate—to reveal the complexities and challenges in encouraging people to change their behaviour.

In this context, one can reconsider the framework from the World Health Organization Commission on the Social Determinants of Health (see Figure 1-4) to consider the status quo for each determinant. For the purposes of this study, the Committee did not examine every determinant exhaustively, but rather highlighted several of the most well-documented issues emphasized in the literature in Uganda.

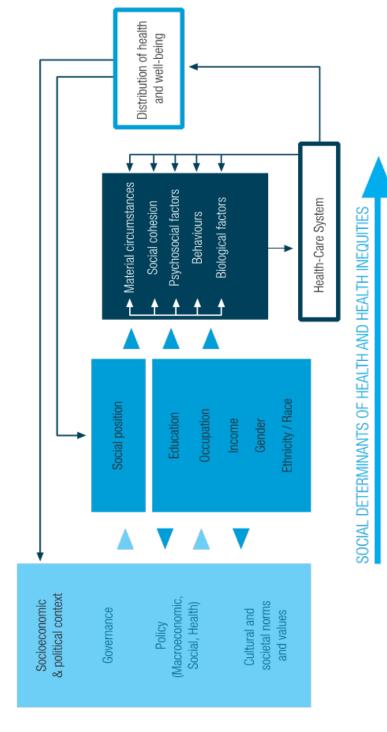


Figure 1-4. Social determinants of health and health inequities.

Source: Adapted from the World Health Organization Commission on the Social Determinants of Health (2008).

### **Uganda in Context**

The following sections present an analysis of Uganda's context. One of the most critical facets of a holistic response to an epidemic lies in understanding how individuals and communities already think and behave. Those individuals and communities operate within broader systems and institutions that shape the range of choices and their relative desirability or viability. Claims are made about each level, from the individual and their relationship to their communities and close social networks, to the broader institutions of service delivery and national policy, based on available peer-reviewed scholarly literature. These findings inform the conclusion at the end of each section, with a series of evidence-informed recommendations from the Committee.

**Finding 2-1:** Ugandan social networks have a profound effect on individual perceptions that shape health decision-making.

Health is a concept that can be interpreted in many ways. While the World Health Organization (WHO) definition<sup>2</sup> is most frequently used, other definitions of *health* include a "state that allows the individual to adequately cope with the demands of daily life" (Sartorius 2006), and a "collective and individual intergenerational continuum, encompassing a holistic perspective incorporating spiritual, intellectual, physical and emotional dimensions" (Bodeker and Kronenberg 2002). Despite the diversity of health definitions, decision-making at an individual level is often not a matter of deliberate philosophical conceptualizations of health. Health decision-making tends to be a nexus of emotional, logical, ethical, and reflexive or unconscious influences that result in a decision.

<sup>&</sup>lt;sup>2</sup> The WHO constitution defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO 1948).

For this reason, health interventions that do not consider social influences tend to have limited impacts. The broader sense of concern regarding a public health problem deeply shapes the desirability and willingness to adhere to or participate in an intervention. For example, mass drug administration efforts in northern Uganda to eliminate schistosomiasis have faced challenges regarding uptake (Allen et al. 2019). The premise was that mass drug administration did not require a major behavioural change (Akurut et al. 2020). The drugs were inexpensive and, in some cases, free, and the impact could be substantial if most of the population adhered to it (Parker et al. 2018). The response surprised many project advocates: local populations argued that the drug was unpleasant to take and complained of a lack of consultation by national health policymakers, and many drug regimens were either not adhered to or used for alternate purposes (Lal et al. 2018). Those who adhered to the drug regimen tended to have social connections or networks that mutually enforced compliance or had connections to those who sought to push the program (Akurut et al. 2020, Allen et al. 2019, Lal et al. 2018). While mass drug administration efforts do not necessarily parallel epidemic responses, they present an example of the complex social determinants of health that shape people's perspectives on receiving treatments administered by a public health program.

Similar results—nonrecipients and lack of adherence to drug regimes—were found in efforts to address malaria and HIV/AIDS. Bakeera et al. (2009) highlighted the extent to which social connections provided critical confidence that treatment was not only necessary but feasible. Women with numerous dependents frequently could not access healthcare facilities without childcare or undertaking highly stressful journeys already with ill health. At the same time, Taremwa et al. (2017) found that many health seekers are not even using the technological materials supposedly beneficial for prevention of malaria. For example, 75% of insecticide-sprayed nets were not being used for the purposes of covering children while sleeping but for other purposes, including fishing, agriculture, and clothing. Namukwaya et al. (2015) argued that these issues in noncompliance with treatment regimes were offset if credible peers or village health teams were there to support the change process.

Other studies have emphasized the fact that these social connections remain of deep intrinsic value in managing and coping with illness. For example, a study by Mattes (2012) examined how people living with HIV/AIDS were not satisfied with simply being on antiretroviral drugs but rather yearned and demanded ways in which to address stigma and the desire to be productive members of society. Solidarity with other people who shared the illness created networks that supported efforts of people living with HIV/AIDS to become productive and active contributors to one another's economic and social growth.

Social networks are critical predictors of public health intervention success because, in the Ugandan context, they provide critical infrastructure to fill in gaps in knowledge and appropriate practices. The quality of those social networks shapes the extent to which the messages that flow through them actually affect behavioural outcomes. These networks can alter the internal motivation, the sense of genuine individual concern, and the sense of solidarity with a group that catalyzes change efforts.

**Finding 2-2:** Ugandan communities have various mechanisms of social protection that historically have provided resilience in times of crisis.

Throughout its history, Uganda has had various mechanisms built around interdependency, founded upon family and clan structures and societal superstructures, such as the *Kabaka* in Buganda, the *Isebantu Kyabazinga* in Busoga, or the *Omukama* in Bunyoro-Kitara, to name a few (Lubwama 2012, Mwakikigile 2009, Sentongo and Bartoli 2012). These various ties, structures, and practices would provide informal means of managing the disruptions that death, illness, or disaster could bring. A broader sense of solidarity and reciprocity informed those structures and practices, ensuring their sustainability in many ways.

The core of interdependency began with families and clan structures. While there was a great deal of variation depending on tribes, in general, families and clan structures provided an immediate means of addressing the basic needs of life. Families, which were often large and inclusive beyond direct blood ties, could occupy large swathes of land

that would inevitably require family labour to maintain (Reid 2016). Community members who occupied a similar geographic space could support other groups, since ownership of land was defined by leaders of various clans or members of a family (Hewlett and Amola 2003). These communities would also take care of those who were orphaned or affected by death or illness in various ways, from the active indication of illness to the provision of time and resources to ill persons (Hewlett and Hewlett 2007).

The superstructures of interdependency could be called upon to provide further support to clans and families during crisis. For example, in the event of a major agricultural disaster, the *kabaka* could distribute grain supplies or other stored agriculture produce (De Coninck and Drani 2009). Other historical examples include the *munno mukabi*, an informal grouping of geographically proximate and loosely related individuals who would provide resources, time, and energy to celebrate or respond to death, illness, or marriage (De Coninck and Drani 2009, Karlström 2004). Such groups were critical for several different reasons, including limited transport infrastructure, low levels of urban concentration, and diffusion of services and power. Services, social networks, and resources depended on those near to you since it was cost prohibitive for most to seek services elsewhere (Médard and Golaz 2013, Reid 2016). For these reasons, such events solidified and strengthened the interdependencies between groups, reducing their vulnerability.

These historical examples and structures through which communities and individuals related to one another provide a reference point from which different generations of Ugandans draw value and importance. While it is debatable whether these structures should still have value today, it is clear that some generations of Ugandans drew great value from them in responding to the challenges of an uncertain world.

**Finding 2-3:** Ugandan communities continue to predominantly use informal mechanisms of social protection to meet daily and urgent needs.

In Ugandan society, the status quo is shaped deeply by the ability to meet daily needs. From a financial standpoint, most statistical snapshots point to positive trends, with those under the national poverty line reducing from almost 40–50% in the early 2000s to 21.4% in 2016 (UBOS 2021, World Bank and Meija-Mantilla 2020). Almost 87.8%, or 34.8 million Ugandans, have reached what is defined as the "upper-middle-income-class poverty line" or 7266.9 UGX per day per person in income (World Bank 2020). These statistics suggest an overall improvement in the financial situation of most Ugandans.

However, raw financial statistics on personal income capture a limited picture regarding the full range of lived experiences at the grass roots, and they do not necessarily account for how funds are spent or the extent to which they are sufficient for meeting people's daily needs. Scholars have sought to interrogate this point more closely. Van Campenhout et al. (2016) point out that the national poverty line is based on a 1993-1994 national food consumption bundle, which identified 28 of the most consumed food items from households below the median income level and converted those findings into an estimate of the cost of a 3,000-calorie food intake for an adult male (Van Campenhout et al. 2016). While this estimate is supplemented with "non-food expenditures" that could account for differences in nutritional preferences across the country, it faces several limitations. For example, the costs of preferred foods can fluctuate quickly and severely across the country in response to varying conditions, including poor growing conditions and inflation, as occurred during the COVID-19 pandemic (Agamile 2022) and in 2008 (Mawejje 2016). Depending on the nutritional preferences of a particular region, these variations can contribute to substantial food security shocks that may thereby limit the extent to which the public can reasonably change their behaviour in response to public health crises.

Considering these monetary constraints, many Ugandans who live in poverty regularly forego various activities that may be beneficial to their health otherwise. For example, a 2022 national survey by Afrobarometer (Kakumba 2022) found the following:

• Nine in 10 Ugandans (89%) say they or a family member went without a cash income at least once during the year

- preceding the survey, including 42% who did so "many times" or "always."
- Three-fourths (74%) went without medical care at least once, while more than half experienced shortages of food (58%), cooking fuel (57%), and clean water (55%).

These statistics correspond to the main areas where Ugandans spend the most time. A Uganda Bureau of Statistics (UBOS) time-usage survey in 2019 suggested that almost 1 hour per day on average was spent searching or procuring cooking fuel, and another hour per week on average was spent trying to access or procure health services (UBOS 2019). The difficulty and amount of time spent in accessing these services reflect the general level of difficulty that a family or individual faces in trying to meet their daily needs.

These difficulties in meeting daily needs suggest that most Ugandans do not and cannot access services without support. For example, UBOS estimates indicate a dependency ratio of 103.3 (based off of the 2014 census), meaning that for every 100 people between the ages of 15 and 65, 103.3 people of ages outside that range (ages 0–14 or 65+) may depend on them for economic support (UBOS 2021). At the same time, most Ugandans are employed informally, with estimates suggesting that anywhere between 60% and 95% of the population is engaged in informal employment (Mugoda et al. 2020). Informal incomes are also highly volatile and are frequently insufficient to meet individuals' needs, requiring many Ugandan families to either depend on others to fill the gap or simply go without.

These gaps are reflected in the explosion of informal social protection systems. For example, Village Savings and Loan Associations (VSLAs); microfinance; and event- or issue-specific savings methods, such as burial groups, have emerged (Kansiime et al. 2021, Musinguzi et al. 2022). These groups depend on social reciprocity and often operate dynamically in response to interpersonal conflicts. For example, in the case of the burial groups examined by Musinguzi et al. (2022), the sharing of responsibilities and duties in response to the death of members was often circumscribed by the extent to which the member was active or caring towards others. Much of the activities of the group were dynamic and fluid, depending on the perceptions of care, ranging from jealousy

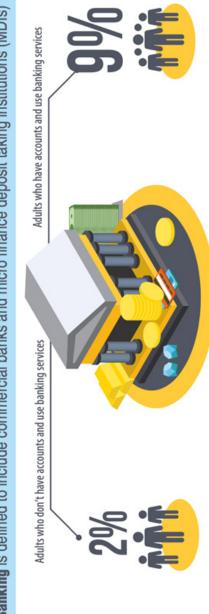
and irritation to generosity and compassion. These structures, while less consistent and even visible from a formal standpoint, were able to evoke intense and meaningful connections between individuals and communities.

Microfinancing institutions are designed to address some of Ugandans' widespread needs. Tarinyeba (2009) noted that while these institutions are presented as powerful tools for remedying financial inaccessibility, many Ugandans do not use them because of the formality of their structures and contracts. Her surveys showed that most Ugandans who would benefit are largely sceptical and wary of the strict terms and conditions required by microfinance institutions to mitigate risk and recoup costs in the case of default (Tarinyeba 2009). More recent studies reflect the persistence of these attitudes and fears: the FINSCOPE survey on financial inclusion of 2018 estimated that only 11% of Uganda's adult population use banking services (see Figure 2-1); of that 11%, 46% live in rural areas and 46% in urban areas (FSDU 2018b).

At the same time, resource distribution programs, such as Emyooga, Entandiikwa, and other public resource mechanisms have appeared to be largely ineffectual, with a survey by Kakumba (2022) indicating that fewer than 15% of Ugandans have been a beneficiary of a public social protection program. Therefore, in a public health crisis, the main mechanisms of distributing resources are largely informal and are ineffective for managing large influxes of funds that may be made available to remedy these issues.

In the event of a health emergency, many families are obliged to depend on social connections to make up for the lost time, money, and energy. These emergencies are costly: estimates indicate about 1% of Ugandans have formal health insurance (FSDU 2018a), and while public healthcare facilities are free in theory, they have many hidden costs in practice (Atake 2018, Kyomugisha et al. 2009), including medicine, out-of-pocket incentives for faster service, implicit costs of time away from earning income or other productive activities, and such explicit costs as childcare (Kiwanuka et al. 2008). Some programs that

# Banking is defined to include commercial banks and micro finance deposit taking institutions (MDIs)



In 2018, 11% of adults used banking services; 9% had accounts, while 2% did not have accounts. Using banking services without having accounts include over the counter (OTC) transactions such as paying school fees and bills and using an account of a relative or friend.

Figure 2-1. Percentage of users of banking services in Uganda who have and do not have accounts: Findings of FINSCOPE survey of 2018.

Source: FSDU (2018b).

have sought to address patients' financial concerns have seen knock-on benefits, such as in the cases of HIV/AIDS treatment adherence and subsequent financial growth (Jennings et al. 2016).

Ugandan families often rely heavily on women, children, and extended family networks to fulfill basic needs of the family at home, such as food preparation, farming, and other activities. Large families often depend on children to leave school prematurely to work at home (Nabugoomu 2019). Women are disproportionately affected, as, in rural settings, almost all these activities are conducted by women, and much of this labor is not reflected as an economic activity in traditional economics literature (Naisiko 2020). As a result, most women and families attempt to make do by developing interdependencies within families or through informal networks.

**Finding 2-4:** Most income earning opportunities in Uganda continue to be produced predominantly through social connections and networks.

Interdependencies emerge again as influential in the area of access to livelihoods, this time primarily through the distribution of jobs and income. Uganda's highly informalized economy tends not to operate through registered institutions nor with employment contracts. As a consequence, markets are largely opaque. It is difficult for Ugandans to compare goods and services and get empirical data on the trustworthiness of any potential business partner or employee. Rather, business relationships and access to opportunities depend on who you know and to what extent their connections to you are sufficiently convincing to warrant investment of resources.

Studies on hiring practices in Uganda emphasize this point. For those institutions that operate within the formal or registered economy, it is possible to engage a wider audience of potential employers and employees with a clearer and more transparent set of obligations regarding remuneration, competitive compensation, and duties (Sendi et al. 2021, Tarinyeba 2009, Waeyenberge and Bargawi 2018). Nonetheless, most studies on the formal sector document widespread preferential treatment and nonmeritocratic hiring—even if formal

processes are used for selection publicly, they are easily co-opted by informal methods of manipulation (Wiegratz 2010).

While studies document that many informal hiring practices are preferential, they also note that hires are often based on social networks and kinship, in which hiring provides a means of connecting and ensuring accountability (Jackson 2012, Therkildsen 2010). Even in informal settings, the lack of ability to manage the costs of public hiring processes are simply too high a barrier to overcome. Almost all these practices operate outside of the view of law enforcement and legal intervention, which can be problematic when dealing with conflicts and lack of adherence to labour laws. Those who are seeking livelihoods are therefore left to the whims of their employers, who may or may not treat their employees with consistency or fairness.

**Finding 2-5:** Ugandan resilience to mental stress is strongly correlated with the effectiveness and resilience of their social networks.

Mental health is shaped by peer and social networks. When a person is faced with a stressor, social networks shape the stressor's impact on the individual. While the interpretation of stressful events may be a distinctly individual act, networks provide feedback mechanisms to support or dissuade an individual's action in response (Amanya et al. 2017, Case et al. 2005). Inevitably, mental health is challenged in a crisis because individuals have less ability to directly control their circumstances (Keister 2009). Unless an individual is adequately prepared both individually and by their networks to adapt, the results can be damaging as people potentially employ negative coping methods to make sense of the problem. When an individual is prepared inadequately, the results are more catastrophic, which can lead to the development of mental illnesses requiring more intense intervention.

This conception of mental health in epidemics and pandemics is well-established in scientific literature. In response to HIV/AIDS, Ebola, and COVID-19, healthcare workers and patients experienced various hardships and found ways to cope in negative and positive ways (Ashaba et al. 2019, Camlin et al. 2020, Haroz et al. 2013, Matua and Van der

Wal 2015, Okello and Neema 2007). Stigmatization of those who are infected is an inevitable response of a society to the uncertainty that the disease presents. Combined with the challenges of cultural explanatory models of mental illness, it can be challenging for individuals to address this stigma independently (Okello and Musisi 2006, Okello and Neema 2007, Seruwagi et al. 2022). The stress that comes with a public health crisis creates a need for individuals to find adequate coping mechanisms for addressing the resulting uncertainty and fear.

Five types of coping are identified as most prominent in the literature (Aldwin and Yancura [2004]):

- Problem-focused coping
- Emotion-focused coping
- Social support
- Religious coping
- Meaning making

Of the qualitative studies conducted in Uganda, most demonstrate that healthcare workers often deploy a combination of the above strategies in order to continue providing care to their patients (Muzyamba, Makova, and Mushibi 2021, Park and Akello 2017). Some scholars have studied the role of religious coping in dealing with the stressors of daily life (Bakibinga, Vinje, and Mittelmark 2013). The prevalence of religious coping is corroborated by national statistics estimating that 85% of Ugandans are Christians, 15% are of the Islamic faith, and a very small subset are nonpracticing or atheist (Ssentongo 2022, UBOS 2021). In almost all studies, individuals use social networks to reinforce and support their coping strategies.

There have been a variety of different programs that have sought to address stigmatization building through social network change. For example, a study by Nalugya et al. (2018) sought to include children in the process of managing HIV/AIDS treatment for parents with HIV/AIDS to promote greater family solidarity. That study suggested positive reinforcement in which children supported their parents' adherence to treatment programs and provided a healthy way to address the stigma

or internalized fear of the disease (Nalugya et al. 2018). Similar studies demonstrate the powers of family participation in addressing stigmatization and sustained resilience to challenges (Haroz et al. 2013), and that such approaches to child-rearing can enable longer-lasting resilience to stressors among parents and families (Amone-P'Olak and Ovuga 2017, Murphy et al. 2017). Studies highlight how uninfected family members can sometimes be the most fearful and potentially damaging to the psyches of those who survive an infectious disease (Hewlett and Hewlett 2007, Matua and Van der Wal 2015, Park and Akello 2017). These findings reflect the value of early intervention in building solidarity within family networks to respond to illness.

# Based on the above findings, the Committee makes the following conclusion:

**Conclusion 2-1:** Ugandans are highly interdependent and rely on social connections and networks for survival and prosperity.

All human societies use social networks and connections to some extent to achieve their goals or meet their needs. However, not all societies use them to the same extent nor are the stakes associated with their usage the same. Ugandan society is highly interdependent, using social networks and connections for survival and growth. Ugandans make decisions that can have substantial impacts on their lives shaped by what their peers or networks think, say, and do. In a crisis, because the structures and systems in place have not adequately addressed in advance people's fears and anxieties, the depths of this interdependency can drive people to make paradoxical choices that are in neither the interests of their social networks nor their self-interest. The implication of this interdependency is that systems may have less credibility and usage because they try to remove the relevance of human relationships in an effort to improve consistency, efficiency, and equity. Systems that address only consistency of outcomes without a commensurate sense of humanity are unsustainable.

### Recommendations

Based on the above findings and conclusion, the Committee recommends the following:

**Recommendation 2-1:** The Government of Uganda should identify the existing structures of grassroots community action and governance. Once they have done that, they should center long-term pandemic preparedness intervention around existing modes of collective action or dialogue, to establish a shared understanding of how to operate in a crisis.

**Recommendation 2-2:** The Ministry of Education and Sports and the Ministry of Health should develop a national program for health education and life skills for primary school learners within the next 5 years to establish societal foundations for family health resilience.

**Recommendation 2-3:** The Ministry of Health should establish a mental health hotline for healthcare workers that can adequately support both mental health crises and the building of effective mental health resilience.

**Recommendation 2-4:** The Ministry of Health should consider supporting the establishment of an independent forum for religious groups and health experts to dialogue on how to prepare and develop guidelines that ensure equitable, inclusive, and meaningful coping when epidemics and pandemics occur.

### **Power and Leadership**

This section presents a series of evidence-based claims regarding the politics and leadership of Uganda and their relevance to epidemic and pandemic preparedness and response. Politics, at its core, is about power. When dealing with a crisis, the range of responses depends on how power is exercised. How that power is exercised, though, is a product of many factors, including history and incentives. The intent in this section is to show how leadership and the politics of Uganda are deeply intertwined with social, financial, cultural, and historical considerations.

**Finding 3-1:** The colonial experience reshaped the content of relationships between leaders and constituents, limiting the trust in systems of service provision that are independent of personal influence and control.

Power and leadership in Uganda face a unique and tense situation. Ideally, leadership provides direction to government systems to distribute resources to constituents. Systems are supposed to maximize the value of limited resources, mobilized through the collection of taxes and other mechanisms. Government systems aggregate resources to make it quicker, easier, and more effective to satisfy a wider array of needs. They are supposed to establish rules that allow people to participate in ways that promote collective well-being and minimize freeloading or exploitation.

The realities of government systems in Uganda are often at odds with this ideal state because of what some scholars call a "hybrid" system of government (Goodfellow and Lindemann 2013, Tripp 2010). Uganda's history has shaped this status quo because of the extent to which the "indirect rule" of the colonial system fundamentally altered the political, cultural, social, financial, and spiritual foundations of

leadership, affecting the accumulation and distribution of resources, as well as accountability. Various parts of Uganda had different precolonial structures of leadership, from councils of elders or clan elders (predominantly in northern Uganda) to monarchies (Buganda Kingdom, Bunyoro-Kitara, Busoga Kingdom) and many versions in between (Mengisteab 2019). The legitimacy of such structures of leadership was drawn from their ability to navigate multiple spheres of power at the same time.

The relationships between constituents and leaders were dynamic and fluid affairs. Constituents could exercise inordinate amounts of influence because their relationships were not solely defined by a financial stake expressed through taxation (Asiimwe 2013, Bukuluki 2013, Komujuni and Büscher 2020). Spiritual, social, and practical ties were of fundamental precedence, whereby it was not necessarily loss of office or position that was at stake, but rather one's power and credibility within society. Leaders could lose constituents, and thereby resources, because constituents could simply exit from the relationship into other groups through intermarriage or migration.

The colonial experience changed the accountability relationship by emphasizing the financial obligations of duty-bearers to the colonial administration. Tribal chiefs or duty holders were often co-opted or sidelined by the colonial system to collect taxes on behalf of the colonial government. Taxes were not unheard of in precolonial Uganda, but taxation was characterized by implicit social and cultural expectations focused on social protections (Mutibwa 2008). For example, granaries of the kabaka held the collected taxes from subjects in Buganda Kingdom that could be redistributed in the case of poor harvests. In contrast, the British Colonial Empire could extract financial benefits from the local population without having to bear the brunt of demands for services or accountability. This strategy was highly effective in redirecting frustrations of Ugandans away from the colonial administration to their intermediaries, evidenced by such rebellions as the Nyangire (Nyangire Abaganda means "I refuse the Baganda") in Bunyoro Kingdom in the early 1900s (Mbatudde 2013). In effect, leaders were expected to provide for their constituents, but had little to no power to do so.

The consolidation and incentive structures that introduced many Ugandan chiefs and their families into the British system created separations in opportunities for those in villages and those who were connected to the system. For example, immediately following independence, most civil servants were family members of tribal chiefs, had been associated with missionary schools, or had participated in other related opportunities for indigenous citizens, despite their marginalization from power and decision-making (Sjögren 2013, Veit et al. 2017). A sizeable contingent of well-trained medical providers of varying backgrounds came from well-known schools predominantly of colonial origin, including St. Mary's College Kitovu, Kisubi Kings' College Buddo, Nyakasura, Lohana Academy, and Ntare School, to name a few. While these schools, which created a generation of welleducated, nationally oriented, and diverse individuals, benefitted from an inequitable system, they were also oriented towards the growth of their society and nation. What these historical inequities show is a source of connection for wealthier and well-connected individuals and disconnection from less wealthy and less well-connected individuals, thus creating a new form of exclusion.

**Finding 3-2:** Political leadership is cost prohibitive for almost all Ugandans without incurring debt, which incentivizes cycles of patronage and recouping of costs when in office through corruption.

Patronage—the personal distribution of resources in exchange for votes, public support, or other benefits—has become a consistent feature of political life in Uganda. Public perceptions on patronage lie at a nexus of multiple personal, cultural, social, and economic needs and fears. There remains a general lack of confidence in the ability of the government to distribute resources nationally adequately and fairly. Given the lack of confidence, political leaders and constituents alike manipulate and exploit political office for personal gain to the detriment of public services and systems.

Part of this cycle lies in the perceptions of patronage. For example, a study by Vokes (2018) examining the primaries for National Resistance

Movement (NRM) candidature in Rwampara County, Mbarara District, in 2015, detailed the ways in which all five candidates frequently made public financial donations to potential voters. Vokes argues that there are socially acceptable ways in which financial resources are distributed in politics, which define the line between corruption and gift giving (Vokes 2018). Similar studies by other scholars have echoed these points: Tripp (2010) notes that many office holders have become critical cogs in the ability of their social networks to survive and thrive, making loss of office no longer a matter of political viability, but of personal survival and significance. Political leaders are beholden to an implicit social expectation that their office confers upon them great financial, social, and political benefits that necessarily should be distributed to their supporters (Asiimwe 2013, Vokes and Mills 2015).

The intertwined nature of these patronage networks has complicated the ways in which power is managed between the executive, legislative, and the judicial branches. In theory, the separation of powers is meant to ensure that no one branch of government can exercise complete control over the other. However, from the very start of Uganda's democracy in 1962, there were challenges in how this separation of powers was expressed. The very roles of prime minister and president were the product of a power-sharing agreement by the Uganda Peoples Congress and Buganda Kingdom at independence. To appease Buganda Royalists under the Kabaka Yekka party and avoid at independence a government led by the Democratic Party, an agreement was made to put the *kabaka* as the president of Uganda and the prime minister as the political leader (Mutibwa 2016). In theory, the president was supposed to collaborate with the prime minister, but in practice, the partnership was fraught with mistrust and efforts to undermine one another.

These tensions remain in place today, whereby the prime minister is the "Leader of Government Business" in Parliament, while the president is head of the executive branch. In the Ugandan context, this mixing between legislative and executive branches has created an advisory relationship, whereby the legislature has limited powers to moderate the power of the executive branch (Tumushabe 2009, Wilkins 2016). In this context, legal frameworks can be circumvented and, in

many ways, directed by the executive branch, rather than as a dialogue between the two.

The inequality in this relationship advantages the executive branch, which—largely unchecked—can call upon legislators to work in the interest of the ruling party to maintain the possibility of access to the executive branch. Legislators, who are primarily assessed on their ability to mobilize their communities, engage in widespread patronage of their communities by paying for constituents' school and medical fees, as well as other daily needs (Wilkins 2016). The costs of political campaigns (including primary campaigns) are estimated to be about 465 million UGX on average for national legislative positions and 237 million UGX for local council five positions (Kayinda and Muguzi 2019, Kitamirike and Kisaakye 2020). There is a gender discrepancy in terms of financing those campaigns, with 81.6% of male respondents having taken out personal loans, whereas only 18.4% of female respondents did the same. These incredibly high costs of political campaigning create a vicious cycle of financially driven politics underpinned by high debt and unsustainable patronage dependent on maintenance of office.

In light of both the tensions between the executive and legislative branches of government and the role of finances in electing leaders, the broader ability to mobilize communities to work in unison in response to an infectious disease is contingent on financial distribution. The policies introduced in response to the COVID-19 pandemic reflect a narrow set of politically driven perspectives, thereby limiting their actual value in responding to the disease (Mukuru et al. 2020). Efforts to remedy these incongruities by philanthropic or external actors become largely inconsequential because they are fundamentally disconnected from the political actions that give political actors power and perceived value to their constituents (Birungi and Colbourn 2019, Kirya and Sekalala 2022). The effectiveness of the governmental response and its ability to lead in a crisis can become highly expensive and may yield limited benefits in terms of actual disease control.

**Finding 3-3:** The lack of devolution of financial power to local governments has created local-level accountability pressures that are out of alignment with a realistic ability to deliver services.

In theory, Uganda's pivot towards greater decentralization starting in the early 1990s would bring services closer to the service seekers. Local governments would build off the existing structure of resistance councils, which were highly effective tools for mobilizing forces against the Obote II regime and were often composed of highly diverse and educated persons. From the construction of health centers to the development of local policies, the central government would take a role of managing national oversight and consistency, while local governments could develop and implement plans at their own discretion, so long as they were compliant with central government standards.

The efforts to decentralize in Uganda, however, were not accompanied with decentralization of financial power. governments, while able to levy taxes, were quite limited in their ability to meet the needs of their constituencies. For example, the Graduated Tax, a flat-rate tax that had colonial antecedents, represented some of local government's largest sources of non-central government financing, with districts having up to 20% of their budgets represented by these taxes (Mushemeza 2019, Musisi and Asiimwe 2007). The tax, which was unpopular because of heavy-handed collection efforts by police forces, was summarily removed by the ruling party in the lead up to the 2006 elections, exacerbating power inequalities between local and central government actors. Most estimates indicate that unconditional grants provide 5-10% of local government funding and central government transfers provide 70-80%, with the remainder coming from various local taxes and funding from international development partner projects (Davies et al. 2021, Sarzin 2007).

Studies have suggested that many funds are distributed inequitably and inconsistently, creating circumstances in which districts are failing to achieve their own targets for health (Nannyonjo and Okot 2013, Zikusooka et al. 2009). Out-of-pocket expenditures continue to be estimated to be almost 40% of national health expenditures, with only 9% contributed by the Government of Uganda. This amount is below the desired 15% for public health expenditures, meaning that the public health services that are supposed to be free continue to incur costs that many of the most vulnerable may simply not be able to afford (Zikusooka et al. 2009). The lack of devolution or ability of local governments

to manage their own financial decisions effectively creates tensions between central and local governments, as local officials are held to account for failures to deliver services, while at the same time being beholden to the central government for the means to do so.

# Based on the above findings, the Committee makes the following conclusion:

**Conclusion 3-1:** There are strong incentives for affluent, socially connected, and politically powerful people to express their interdependency and solidarity with other people through personal patronage.

Those who are in positions of power and political decision-making are shaped by a complex set of incentives. At the apex of multiple pressures and perceptions, those who are financially, socially, or politically powerful are expected to exercise power in ways that benefit those to whom they "belong." This notion of belonging tends to be a dynamic and fuzzy tool for negotiation, rather than an automatic trait that might be reserved to kin or genetic progeny. Powerholders create expectations and deliver or fail to meet those expectations in ways that are not entirely under their control. In the context of material poverty, leadership is less about ideas and more about distribution of resources. The very process of getting to a point in which one can set the rules regarding distribution of resources, however, is incredibly exclusive because of the enormous social and financial costs of pursuing such a position. The demonstration of ability to distribute resources precedes political office, creating spaces in which leadership is tied to personal action. The more special treatment is distributed, the easier it is to claim ownership of its benefits and attempt to demand reciprocity through votes. In this way, personalization of power is a reasonable course of action, even if it is self-defeating in the long term. The deep debt in which many would-be politicians find themselves creates a vicious cycle of attempting to recoup the costs of political campaigns while maintaining the appearance of stability and the ability to distribute

wealth. This cycle contributes to a fundamental mismatch between those who are accountable for the delivery of services and those who have the power to shape service delivery. A public health crisis demands collective action, which individual politicians and powerholders are unable to satisfy. During these moments, collective action serves their self-interest not by responding to a public need inclusively, but rather by preserving the status quo—without considering the consequences.

#### Recommendations

Based on the above findings and conclusion, the Committee recommends the following:

**Recommendation 3-1:** A consortium of civil society organizations, media houses, the Uganda Communications Commission, and the Uganda Electoral Commission should consider piloting public dialogues on the priorities and interests of political aspirants and office holders to reduce the influence of money in the pursuit and control of political office.

**Recommendation 3-2:** The Government of Uganda should strongly promote intragovernmental dialogues inclusive of the executive branch (Office of the President) that establish a clear consensus of key stakeholders on plans, policies, guidelines, and actions to be taken in the event of a pandemic, epidemic, or other health crisis.

**Recommendation 3-3:** The Ministry of Finance, Planning, and Economic Development; the National Planning Authority; and the Ministry of Health should strengthen collaboration with local government planning units to ensure that financial resources are available in the event of a health crisis.

# **Earning Trust and Empathy**

The following section presents a series of evidence-informed claims regarding how healthcare workers and patients interact and engage with one another. It documents some of the major challenges and incentives that shape their behaviours and interactions. The intent is to show that the relationship of care between healthcare workers and their patients is a critical facet in shaping sustainable and meaningful relationships that are resilient to the challenges of a pandemic or epidemic.

**Finding 4-1:** Many Ugandans use the public healthcare system as a last resort because of drug shortages, long wait times, and perceptions of inequitable treatment based on social or economic standing.

The public healthcare system in Uganda is persistently underresourced. Despite resource limitations in drugs, personnel, and systems, Uganda continues to register technical improvements. Yet, even with those improvements, trust and overall appreciation of the public healthcare system appear to be stagnating (Akello and Beisel 2019, Siegrist and Zingg 2013). The delivery of healthcare has become more efficient and effective, but seemingly without a commensurate increase in respect and appreciation for its services. This incongruency is a problem because in a health crisis, public appreciation for healthcare workers relies on an understanding of the challenges healthcare providers face, as well as empathy and a shared orientation towards supporting solutions.

In part, the incongruency between healthcare system improvements and the public's lack of appreciation reflects a general dissatisfaction with the human side of service provision. This generalized dissatisfaction starts with the amount of time spent trying to access services. Despite the fact that almost all Ugandans have access to a hepatitis C vaccine within 5 kilometers of their home (Maina et al. 2019), this service is provided with major inconsistency. Absenteeism of healthcare workers, inconsistent wait times that range from 1 to 3 hours or more, and the implicit costs of simply getting to healthcare facilities contribute to a sense that the public healthcare system is not respectful of its patients (Akello and Beisel 2019, Amin et al. 2007, Odokonyero et al. 2017). Often, patients that use public healthcare facilities are those who cannot afford other options. And yet, because they must work more hours to earn a living wage, patients who have low incomes are especially burdened by long travel and wait times—every financial consideration and moment of their time is imbued with trade-offs.

Those who are most impoverished tend to have the fewest connections to exploit in order to get services faster or more respectfully. For example, a study by Ackers et al. (2018) examined midwifery services in southwestern Uganda and found that in many cases, those who were poorest felt that they were treated with less respect than others and in some cases, were even verbally abused. The respondents witnessed discrepancies in treatment between people that they perceived to be better off or were connected to the midwives providing services. These perceived conflicts of interest contribute to changes in how people access and pursue health services—geographical proximity and even financial cost decrease in importance compared with preference for more considerate service (Sundarajan et al. 2020). In a public health crisis, when transport and livelihoods can become increasingly disrupted, attitudes towards and perceptions of healthcare facilities can mean a difference between seeking and delaying treatment.

**Finding 4-2:** The public healthcare system is overwhelmed and depends heavily on international development aid for most development expenditures.

The public healthcare system of Uganda faces a difficult set of circumstances regarding its financing. It is a well-established fact that Uganda remains below most standards of health financing. With some

of the highest out-of-pocket expenditures for health in Africa, its per capita rate of spending is not in line with World Health Organization (WHO) recommendations, and its ability to take care of nonrecurring expenditures, such as infrastructure or in-service training, depends on international development partners. These financial limitations often collide with the demands placed on the public healthcare system: its intent is to be more equitable, accessible, and effective with such efforts as universal healthcare, which requires intensive investment. The Ministry of Health cannot fund these development expenditures independently, and the longer-term ability of the Government of Uganda to do so will rely upon growth in its domestic revenues, which have not seen commensurate growth (see Figure 4-1) (UNICEF 2020). With limited growth in domestic revenues, enhancements in service delivery will inevitably depend on either public borrowing or international development financing.

These levels of public financing also account for the provision of the minimum healthcare package, in which private and private not-for-profit (PNFP) healthcare providers receive funds to provide frontline healthcare services. Estimates vary, but statistics suggest anywhere between 50% and 75% of all frontline healthcare services are provided by private services, with approximately 42% of those private services provided by PNFPs (Ssennyonjo et al. 2018). At the same time, PNFPs are perceived as more trustworthy and considerate in their provision of services compared with their private or public counterparts (Reinikka and Svensson 2010).

This situation creates numerous perceptual difficulties in understanding who receives how much funding and from whom. For example, many projects in the donor off-budget financing operate on parallel systems and many of the same facilities receiving funding pursue these projects to supplement salaries and bring in much-needed cash flows (Meinert and Whyte 2014). Efforts to mitigate these issues between financing and service delivery have operated on results-based financing models (Ssennyonjo et al. 2021), which sought to create direct incentives for the provision of technical services. The technical accomplishments reflect this financing focus, in which the provision of services was paramount.

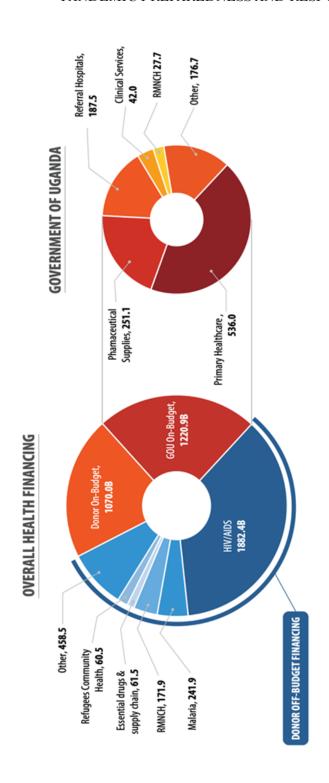


Figure 4-1. Healthcare financing between donors and the Government of Uganda in UGX for the financial year of 2018/2019.

Note: GOU = Government of Uganda; RMNCH = Reproductive, Maternal, Neonatal, and Child Health

Source: UNICEF (2020).

With anticipated reductions in donor funds, the status quo will change inevitably, and potentially in a negative direction. Therefore, the perceptions of care provided in public healthcare facilities will become a critical feature in mobilizing broad-based community support in support of healthcare facilities and workers to overcome systemic barriers.

**Finding 4-3:** Healthcare workers, especially within the public health sector, are often overworked, receive inconsistent pay, and perceive opportunities for growth and learning as preferentially distributed and few.

These tensions most likely reflect the psychological, economic, and social toll of not being able to provide care that corresponds with their personal values. Many healthcare workers have found that crises have cemented their sense of self and professional identity as one in which they provide care where others cannot (Akello and Beisel 2019). However, during infectious disease crises, they also have been those most quickly abandoned and shunned because they are perceived as the most dangerous potential carriers of disease (Kayiga et al. 2021). With some exceptions, crises often deplete the healthcare system of human resources, as the sense of frustration and lack of ability to change the circumstances become more entrenched (Englert et al. 2019).

Since 2000, Uganda has implemented the Integrated Disease Surveillance (IDSR) strategy—introduced by the WHO African Region in 1998 for tackling public health emergencies. A set of revised IDSR guidelines were adopted in 2011. The IDSR was operationalised in Uganda by implementing training programs in order to build a task force and rapid response team of health workers for performing core functions and implementing emergency plans (Kihembo et al. 2018). Lack of sustainable funding of IDSR activities is the major challenge to IDSR implementation in many countries, including Uganda (Kihembo et al. 2018). Research indicates that pandemic and epidemic responses in Uganda are also impacted by the high dependency of the healthcare system on overseas aid, leading to responsiveness to external influences and donor-centric health priorities (Okello et al. 2015). The

response to pandemics in Uganda is also guided by the International Health Regulations (IHR), which require developing core capacities to "prevent, protect against, control and provide a public health response to the international spread of disease" (IHR 2005). This includes legislation, financing, coordination, designating a National IHR focal point, surveillance, having national health emergency framework, and more (Bartolini 2021). For Uganda, the national IHR focal point is located with the National Surveillance Unit in the Ministry of Health. Assessments of IHR obligations reveal the need to review the national legislation in Uganda for public health to aid the attainment of the designated core capacities (Wamala et al. 2010).

Inadequate and untimely access to financial resources for the implementation of obligations under IHR (2005) has been a factor in the WHO African Region as a whole (Talisuna et al. 2019). Additionally, the region shows a general lack of resilient national health systems that can prevent, detect, respond to, and recover from public health emergencies (Talisuna et al. 2019). A survey of preparedness for pandemic influenzas across this region demonstrates general inadequacies in the areas of case investigation, treatment, surveillance, and monitoring (Sambala et al. 2018). And more specifically, Uganda's pandemic preparation plan was evaluated to be limited in the areas of "prevention & containment" and "case investigation & treatment" (Talisuna et al. 2019).

**Finding 4-4:** Ugandans use herbal and traditional remedies because of their reduced cost, greater accessibility, perceived medical superiority, and care exercised by herbal and traditional healthcare providers.

Herbal and traditional medicines are a fundamental and critical part of healthcare services used by the general population. Studies estimate that almost 70% of people seeking treatment for a health issue start with traditional healers or herbal medicines (Atwine et al. 2015, James et al. 2019, Langlois-Klassen et al. 2007, Logiel et al. 2021, Rutebemberwa et al. 2013). Those who seek such treatments cite a variety of different reasons for doing so, including the perceived strength of Western drugs, cost, accessibility (requires little to no travel to find relevant herbs), and

positive experiences with treatment providers. At the same time, studies suggest that many people do not seek medical expertise to moderate their treatment selection, instead directly going to pharmacies. Frequently, pharmacies do not require prescriptions for otherwise controlled substances or substances that could have public health impacts. People who seek treatments for various health conditions enjoy this autonomy afforded, even though it may have less favourable outcomes than treatment overseen by a physician. Cost, accessibility, sense of comfort and familiarity with herbal medicines, and uncertainties about the dangers of Western pharmaceuticals all shape a generalized perception that herbal medicines are preferable.

Those individuals who do use formal systems of healthcare face another set of perceptions and challenges. Various studies have detailed poor treatment by healthcare workers, particularly in public healthcare, where the perception is that even if you go to a healthcare center, you cannot assume you will be treated, despite supposedly "free" nature of its provision (Bahall 2017, Tabuti et al. 2012). Although thoughtful and culturally humble care is both necessary and productive for improving adherence to treatments and usage of services, healthcare workers are frequently exhausted and overworked, and they have little time and energy to provide this level of care. Reports have indicated that healthcare workers are frequently "moonlighting," in part because of income inconsistency and a lack of ownership over system change. At the same time, many health centers operate without a full staff complement. Shortages of drugs and other supplies further contribute to the reputation that public healthcare is not a reliable source of treatment. The combination of these deficiencies creates an adverse working environment, both for patients and healthcare providers, particularly in the public health system.

Studies that have looked in detail at traditional healers note that, while there are concerns over their professionalism and the potential to start combining modern pharmacological advances with more benign or even therapeutic herbal medicines, the practitioners themselves are not averse completely to engaging with biomedical systems of healthcare (Kamatenesi et al. 2011, Mwaka et al. 2021, Tabuti et al. 2012). However, interactions between the two theoretical bases tend

to be antagonistic and adversarial because of concerns over the risks that accompany the lack of systematized or scientifically corroborated use of herbal medicines (Ssempijja et al. 2020). This perceived sense of antagonism between biomedical healthcare providers and herbal or traditional healthcare providers has limited engagements between the two.

Based on the above findings, the Committee makes the following conclusion:

**Conclusion 4-1:** Although technical outcomes have improved, trust in the healthcare system remains low because the improvements have not commensurately addressed people's desire for respect and dignity.

Healthcare systems in Uganda have made significant strides in improving health. Despite those improvements, however, the level of satisfaction and actual trust in the healthcare system have either remained stagnant or deteriorated in some cases. The biomedical underpinnings of these healthcare systems, whether private or public, have tended to ignore considerations regarding a healthy relationship between patient and care provider. With such relationships poorly administered, the ability of public health officials to garner the requisite public interest and concern is limited.

#### Recommendations

Based on the above findings and conclusion, the Committee recommends the following:

**Recommendation 4-1:** Healthcare worker training institutions (universities, medical schools, technical institutes) should incorporate hospitality and cultural humility training into their curriculums.

#### FINDING HUMANITY IN UNCERTAINTY

**Recommendation 4-2:** Healthcare institutions should organize regular community outreaches, particularly around health education and promotion, as a way of identifying community priorities and needs, strengthening bonds of trust, and building long-term foundations for epidemic and pandemic preparedness.

**Recommendation 4-3:** The Ministry of Health should strengthen its partnership with the Uganda Healthcare Federation and private healthcare providers in order to expand healthcare coverage by delegating health campaigns and other responsibilities to them.

**Recommendation 4-4:** The Ministry of Health should provide greater clarity or assurances about the financial obligations of healthcare seekers through a national healthcare scheme that ensures sufficient funding for healthcare workers and sufficient coverage for basic healthcare needs.

**Recommendation 4-5:** An independent forum for dialogue between traditional and biomedical healthcare providers should be established to promote greater appreciation and mutual learning regarding their social and medical benefits.

# The Intricacies of Decision-Making and Conflict Resolution

This section presents evidence-based claims on the challenges of decision-making and conflict management within the government's existing structures. While evidence-informed policymaking has become an increasingly popular tool, there remain deep-seated tensions between political decision-making and the evidence that informs those decisions. Conflict resolution mechanisms, either through the formal judicial system or in the form of law enforcement, have a great deal of existing challenges that health crises exacerbate. The intent of this section is to present the complex needs of both the decision-making system and the system tasked with enforcing and maintaining societal order in response to them. A greater appreciation of those complexities can help to reveal why early preparedness efforts that deal with these difficult questions can potentially reduce conflicts both within government and outside of it.

**Finding 5-1:** The Ugandan technical bureaucracy is not well-supported or insulated by political leadership.

Policymakers in Uganda are increasingly seeking out and creating an evidence base for their decision-making processes in part due to increased interest and demand by international donors to see impact for their investments. This juxtaposition of international monetary incentives and national policymaking has created an explosion in monitoring and evaluation intended to document and reveal ways in which government programs and systems could improve. Nonetheless, decision-making remains with political leadership and the manipulation of evidence has become a barrier in the hands of some and an asset in the

hands of others, particularly when used to justify political expenditures and distribution of resources.

The resolution of these differences is often a matter of perspective and communication. Studies by Henriksson et al. (2017, 2019) and Nabyonga-Orem and Mijumbi (2015) point to similar issues in the incongruency between which evidence policymakers and practitioners use and consider most important in their decision-making. Policymakers tend to focus on what would otherwise have political or directly relevant importance to the decision at hand. In most cases, the producers of the evidence do not necessarily know the specifics of the desired decision, nor its latent importance because transparency between the two is sometimes lacking. While efforts have been made to remedy this issue through different communication and research strategies (Mijumbi-Deve et al. 2017), there are limitations in the ability to speak specifically to the issue in question and give a straightforward answer. In part, because of different standards of evidence and goals between researchers (who may otherwise prioritize rigorous and objective standards of inquiry) compared with practitioners or policymakers (who may prioritize the evidence's ability to support their policy or practical objectives), neither is adequately satisfied no matter how fast, comprehensive, or relevant the advice provided is.

The ability to manage these differences is often the deciding factor in whether institutions are able to function and advise effectively. For example, in the recent establishment of the Uganda National Public Health Institute, Ario et al. (2022) detail the necessity of political buyin and long-term engagement to demonstrate value to political decision-making. Most studies examining effective projects that have been able to sustain value reinforce the necessity of trying to balance political and technical interests in a long-term fashion, whereby persistent negotiation between technical interests and political interests is managed over time in order to build greater bonds of trust that can then facilitate major change actions (Andrews et al. 2013, Leonard et al. 2020, OECD 2014). By focusing on clarifying where there is political interest, technical capability, and broader acceptability in pursuing change agendas, evidence can influence and shape policies more effectively.

Failures in managing politics in technical cadres towards technical objectives often contribute to a persistent perception that politics trumps technical expertise. Examples of what is often described as political interference are plentiful. From water provision in rural areas (Quin et al. 2011), to policymaking at the Uganda Revenue Authority, Kampala Capital City Authority, and Ministry of Health (Katusiimeh 2017), to selection of local-government chief administrative officers and redistricting efforts (Mutebi et al. 2019, Nabaho 2013), publicsector employees are constantly in friction with political cadres for both real and perceived inconsistency and lack of engagement with technical teams. The bureaucracy and the political class become antagonists within the government, limiting the extent to which any policy or practical intervention is supported by a whole-of-government directionality. With little whole-of-government support, a public health crisis like COVID-19, which had implications for multiple aspects of human life and government-line ministries, can create the perception on the part of the public that there is inconsistency in the intent and practice of interventions. With little consistency, the existing fissures in trust in public health can be exacerbated and can be a recipe for disinformation and apathy to creep in.

**Finding 5-2:** The legal system is heavily backlogged, leading to long times for judicial resolution and incentivizing the reliance on informal or personal means of conflict resolution.

The legal framework that enables citizens to claim a right to health tends to operate in parameters distinctly separate from the practical, governmental, and social demands that are placed upon duty-bearers. In the Ugandan legal system, which is based upon the British system of adversarial practice, the ability to access and exercise legal rights depends heavily upon one's financial prowess. Citizens interact with the law primarily through its enforcers—in this case the Uganda Police Force—rather than through courts of law. The importance of the law in shaping behaviours then primarily concerns those within political, policy, and bureaucratic circles because it prescribes sets of rules regarding their ability to meet social, financial, and practical needs.

The primary legislation dealing with pandemic preparedness in Uganda is the Public Health Act Ch. 281 of 1935. In the COVID-19 pandemic, the Ugandan government passed a range of orders authorised under this Act to prevent the spread of the virus. This included restrictions at the border, requirements for notifying COVID-19 infection to authorities, restrictions on public gatherings and mobility, mandatory quarantine, and more. These rules were amended in accordance with the changing situation of the pandemic. Additionally, Uganda's 2010 National Policy for Disaster Preparedness and Management provides for strengthening surveillance and developing appropriate response plans for tackling a pandemic (Directorate of Relief, Disaster Preparedness and Refugees 2010). For epidemics, the policy focuses on improving hygiene and sanitation, ensuring vaccination, increasing surveillance, and staffing health centers. Research indicates that the pandemic policy, along with the rules framed under the Public Health Act, enabled the extended roles and powers of the Uganda Peoples' Defence Forces in the enforcement of pandemic measures, leading to a highly militarised COVID-19 response in Uganda (Nkuubi 2020). The approach of implementing stringent presidential directives by forceful means was met with resistance in many parts of Uganda, with people speculating that the state was using COVID-19 to reinforce its authority (Parker et al. 2020).

During COVID-19, the initial response in Uganda was focused on surveillance at airports and borders. Containment and closers were enforced subsequently, with the government shifting COVID-19 planning to a dedicated national task force situated in the Presidency (Macgregor et al. 2022). Public responses demonstrated a low level of trust in government initiatives and messaging regarding COVID-19 and the concern that important resources were being diverted away from other diseases (Macgregor et al. 2022).

In addition to a lack of trust in the making and enforcing of pandemic mitigation legislation, inefficiencies and distrust in the legal system has exacerbated conflict resolution during the COVID-19 pandemic. This affected those who use the formal legal system as well as those who rely on family members and other third-party mediators. The discrepancy between the "formal" apparatus of justice and "informal" apparati is

most pronounced in how most Ugandans get advice and resolution for their needs. Most Ugandans want faster, more accessible, and simpler means of conflict resolution in part because of the overwhelming frequency of conflicts (Hague Institute for Innovation of Law 2020). A national survey on legal needs by the Hague Institute for Innovation of Law (2020) indicated that, in a 4-year span between 2016 and 2020, 84% of national respondents had a conflict requiring legal intervention. Of those respondents, 70% did not receive a resolution or received a resolution that they considered to be unfair or unsatisfactory. That survey also indicated that this lack of resolution contributed to over 50% of respondents indicating that they experienced stress-related illnesses. These findings may suggest why domestic and intimatepartner violence increased significantly during the pandemic—there were fewer means of resolving these issues among family members or third parties. At the same time, urban centers and wealthier members of society, who primarily use courts for conflict resolution, saw their cases put into limbo (Ainembabazi 2020). The stress and disruption of daily life, particularly in terms of the general eruption of interpersonal conflicts, are exacerbated in a biomedical pandemic, thereby potentially unleashing other epidemics unless carefully managed.

# Based on the above findings, the Committee makes two related conclusions:

Conclusion 5-1: Ugandan governmental systems of policy and decision-making are slow, opaque, and difficult to navigate for both politicians and technical advisors, incentivizing appeals to authority and power.

Conclusion 5-2: The justice, law, and order sector is limited in its ability to respond quickly and consistently during a health crisis because of existing demands that outstrip its capacity.

Conflicts in decision-making are inevitable. In Uganda, basic disputes can require large amounts of time, money, and energy to find and be heard by an adequate judge, whether in the formal courts of law or outside of it. Law enforcement is poorly remunerated and often ill

prepared. At the same time, tensions between technical and political decision-makers can make effective decision-making painstakingly slow and opaque. Decision-makers and duty-bearers, who may be prompted to respond urgently in a crisis, are incentivized to pursue appeals to power and authority as ways of bypassing these tensions. These types of responses can alienate stakeholders, who are critical in meeting the challenges of a health crisis. The value of slow, deliberate decision-making that promotes wider buy-in in the decision made is lost.

## Recommendations

Based on the above findings and conclusions, the Committee recommends the following:

**Recommendation 5-1:** The Government of Uganda should continue to participate in and support existing platforms for dialogue on health crisis planning and policy that promotes community ownership and participation in both the plans and policies developed and the actions that would be taken.

**Recommendation 5-2:** The Uganda Police Force, the Uganda Peoples' Defence Forces, and the Judiciary should establish an independent forum with outside stakeholders for discussions on how to prepare their institutions and personnel to respond humanely but fairly to societal anxieties and needs in a health crisis while ensuring public stability and consistency.

# How Do You Know?: Information Systems in Uganda

**Finding 6-1:** Most Ugandans use radios as their primary source for mass media consumption.

Most Ugandans get their information from radios. Estimates of the percentage of Ugandan households with at least one radio vary from 32% (UBOS 2021) to 65.3% (NITA 2018)—and. even reach 87% (BBC Media Action 2019). Daily listening of the radio among Ugandans is potentially as high as 52% (BBC Media Action 2019). While these statistics vary widely, it is generally accepted that Ugandans use radio as their main form of information, with one potential explanation being the multifunctionality of many mobile phones to be able to operate as televisions or radios (Nassanga 2010). In comparison, fewer than 25% of Ugandan households have a television, with the majority of those being held in urban households (BBC Media Action 2019, NITA 2018, UBOS 2020). While the content of radio programming may draw from print or television media, radio broadcasts have the widest reach and the most diverse audience in Uganda.

The types of radio programming and stations vary widely. Approximately 309 radio stations exist across the country (NITA 2018). Many of these are formally registered under the Uganda Communications Commission—which means the government could retract their ability to broadcast, in theory (Maractho 2015). Informal means of radio programming are also available, including community radio stations, which are small and geographically limited, and whose focus tends to be driven by local interests (Unwanted Witness 2014). The funding for community radio stations contrasts from those of larger commercial players, who often must depend on donor or international funding because of limited or nonexistent advertising revenues (Internews 2021, Unwanted Witness 2014). These funding modalities

create circumstances in which it is difficult to distinguish between independent journalism and development communication, with agendas driven by funder or political interests.

**Finding 6-2:** Most popular mass education campaigns have combined elements of entertainment with education.

Most health education campaigns operate on an underlying assumption that health information is a critical component of health decision-making. If people are given adequate information relevant to their health, they can make the best possible decision for themselves. These campaigns are informed by various health behaviour theories, that focus on knowledge, attitudes, and practices, whereby if an individual has the appropriate knowledge to make the desired decision and a positive attitude towards that decision, their practice will change in response. However, this theory tends to fail in practice, partly because the status quo—or the audience's default set of knowledge, attitudes, and practices—is informed by broader ways of conceptualizing and understanding the world. In public health crises, presenting information that is irrelevant to these ways of understanding the world will be largely ineffective in changing behaviour.

In part, the arts can inhabit these ways of being in the world and therefore tend to be more effective in creating a commensurate change in behaviour. For example, in the case of HIV/AIDS, a study examining a clinic at the Infectious Diseases Institute showed that music, arts, and other forms of creative endeavour provided a means for patients to cope with their disease and increase their confidence (Neema et al. 2012). Similar studies speak to other infectious diseases, where it is the ability to cope with the shock that diseases present during and after their fight with the disease that predicts their future resilience (Akankunda et al. 2022, Sonke and Pesata 2015). Patients' and peers' ability to express themselves is part and parcel of the ability to cope with the struggle that inevitably results from a public health crisis.

Artistic expression in a mass media context can achieve results similar to self-expression in an individual context. Mass health education campaigns can affect knowledge and attitudes towards various forms of treatment or illnesses (Davidson 2017, Dralega and Napakol 2022, Grady et al. 2021). Radio dramas, such as Rock Point 256 (see Box 6-1), combine elements of dramatic expression with health education messaging that meshes well with people's lived experience, while avoiding an explicit or information-exclusive appeal to changing behaviour. Treating audiences with respect and trust, rather than as merely clients or patients needing to make decisions, enables these communicators to create more relevant and resonant messages.

## BOX 6-1 Rock Point 256

Rock Point 256 is a 30-minute radio serial drama for young people in Uganda set in a fishing and farming village in Uganda. It is produced by the Communication for Development Foundation of Uganda under the Young, Empowered, and Healthy program, in partnership with the Uganda AIDS Commission.

The intended audience for the program is young Ugandans, who are presented with characters and ideas that are like their own. The program closely echoes theoretical perspectives on behavioural change, such as the planned behaviour and stages of change models. The program suggests that up to 75% of all listeners have been influenced to take action as a result of listening to the program.

**Finding 6-3:** Platforms for public debate of policy and practice have been shut down because of claims of fomenting insecurity and violence.

Public participation in public policy presents a third avenue in which mass media plays a role in shaping how a public health crisis can deteriorate or become a vehicle for collective action. For decades, mass media has been presented as a means of encouraging greater participation in public affairs. Similarly, the internet, and its various platforms for connecting people socially, has also been presented as such a tool for improving democratic participation. In practice, these aspirations have faced stiff challenges.

Talk shows are one of the main ways mass media facilitates public dialogue and participation. For several years following the liberalization of media in the 1990s, numerous talk and debate shows emerged under a broad genre of talk show colloquially referred to as ekimeeza (ebimeeza in plural), which focused on public policy issues and include such shows as Parliament Yammwe, Hard Talk, and Katuhurirane, to name a few (Nassanga 2008). These platforms were highly popular but often faced scrutiny because of questions over the impartiality and ethics of the journalists who were operating them (Dralega 2010, Nassanga 2008). Their growth in popularity corresponded with increasing regulation and stringency by public-sector actors, culminating in a brief ban of the genre in 2005 (Chibita 2010). For some observers, these actions were reflections of a disruption of the monopoly over media that many powerholders had enjoyed for decades and prompted a response by powerful individuals to co-opt mass media for their own purposes (Mwesige 2009). Its broader implications were a reduction in the ability of average Ugandans to participate meaningfully in a discussion of their own future.

The successes of such approaches have been emulated in parallel by many health projects that sought to promote greater participation of the community in health interventions. For example, a randomized controlled trial that implemented community monitoring of primary healthcare providers observed improvements in community participation and outcomes in primary healthcare (Björkman and Svensson 2009). Other methods have been used such as the *baraza* program, a community monitoring and evaluation methodology led by the Office of the Prime Minister, which has seen similar signs of positive engagement (Van Campenhout et al. 2018). Yet, like the issue highlighted in the broader usage of *ebimeeza*, these interventions have prompted responses from powerholders that can sometimes alter the intended or ideal purposes of these platforms.

In an ideal setting, these interventions would prompt powerholders to be more accountable or responsive to the sentiments and issues expressed in these structures. Most studies suggest that, while the behaviours of powerholders changes, their approach to consolidating and maintaining power does as well. For example, the abovementioned studies on *baraza* observed limitations to its effectiveness; local resident district commissioners, who were supposed to be the representatives of the executive branch, have easily dismissed, or suppressed participation of the community on various occasions (Van Campenhout et al. 2018).

Especially regarding the *ebimeeza*, some have argued that the liberalization of the media space allowed for misinformation and disinformation to proliferate, as media owners used the liberalized space to distribute their own perspectives and interests on a mass scale (Maractho 2015, Mwesige 2009). This dynamism within the media can also be observed through the content presented. During the COVID-19 pandemic, much of the print content framed the issue of coping with the lockdown in ways that corresponded to religious, security, and economic frames (ACME 2021, Maractho and Omland 2022). The wide array of interests, means, and ways of communicating information and engaging participation presents difficulties in both presenting a unified message and assuming that the information presented is relevant and accurate to the people listening or reading.

# Based on the above findings, the Committee makes the following conclusion:

**Conclusion 6-1:** The mass media ecosystem is driven primarily by demand for entertainment, with limited space for public dialogue, education, or holding powerholders to account.

In a society where education has been largely inequitable and unequally distributed across generations and regions, social networks are the main sources of information and knowledge. The mass media ecosystem is often conceptualized as an easy mechanism for distributing information quickly and cheaply because of its immense reach.

Information on its own, though, is insufficient for promoting behaviour change. Most successful programs seeking to change behaviour combine forms of entertainment with education by creating imagined realities that their audiences consider relevant to their own. Using mass media platforms and entertainment to present ideas that are relevant and yet surprising can potentially change perceptions of what is problematic and present solutions that audience members may have the confidence to pursue.

## Recommendations

Based on the above findings and conclusion, the Committee recommends the following:

**Recommendation 6-1:** Community media structures and central government authorities should collaborate together to set out a long-term plan for quality of information and health crisis programming.

**Recommendation 6-2:** Existing reporting structures for abnormal or epidemic-potential events should focus on supporting social networks to participate meaningfully and feel comfortable and valued for their contributions (not necessarily financially).

**Recommendation 6-3:** Health communication campaigners, scientists, and entertainment stakeholders should collaborate to move away from information-exclusive campaigns towards using edutainment or multimedia approaches to communicate information about health issues.

**Recommendation 6-4:** Universities and departments of mass communications should conduct further research on community radios and quantify their presence and value in improving social cohesion and distribution of information.

**Recommendation 6-5:** Small-scale media or local-level media groups should be regulated or guided by local governance systems, rather than national systems, in order to avoid introducing the high costs associated with formalization while retaining and enhancing their value to the local community.

# Case Studies and Concluding Remarks: Contextualizing Change

The situational analysis regarding Uganda has presented the argument that various layers of human life in Uganda have not been adequately resolved by its political, bureaucratic, social, cultural, and financial systems. Whereas historically Ugandan social systems, leadership, and distribution of resources had implicit or informally recognized rules and expectations, civil instability, changes in the structure of leadership and the economy, and the shift to a national government system without a commensurate national identity have all created tensions that make it practically difficult for individuals to change the status quo.

In recognition of this practical difficulty in creating behavioural change that might prepare Uganda for a health crisis in the future, this section examines two case studies, based on evaluations of numerous programs with varying degrees of success in creating behavioural change and improving technical outcomes. Using the findings from the situational analysis, this section contextualizes what these outcomes reflect beyond successful or failed achievement of a desired outcome. Their selection corresponds to three different success stories at social and family levels, within the information system, and in terms of bureaucratic effectiveness.

# THE OBULAMU CAMPAIGN AND COMMUNICATION FOR HEALTHY COMMUNITIES

Communication for Healthy Communities was a 5-year project funded by the United States Agency for International Development

(USAID) and implemented in Uganda through Family Health International (FHI 360) between 2013 and 2018. Its primary project was the Obulamu campaign, an integrated health communication campaign that was intended to change and shape adolescent and adult behaviours regarding HIV/AIDS. Its name is based on the Luganda term *obulamu*, which can be loosely translated as "how's life" but has various implicit meanings in social context.

The Obulamu campaign has been a ubiquitous feature within Uganda, regularly seen for years in health centers at local levels and in national referral hospitals. Various evaluations and research studies have examined in close detail the extent to which it was successful both in building an awareness of HIV/AIDS-related issues and in changing behaviour (Burke et al. 2021). In particular, they found that the campaign was an unparalleled success in terms of the scale of its brand recognition, relative ease of recall, and awarenesss of the health messaging (Nalukwago et al. 2020). Most evaluations also found general knock-on effects in other diseases, such as malaria and tuberculosis, in terms of awareness and general desire to manage those health risks (Kayongo et al. 2019).

However, these evaluations also noted that the Obulamu campaign was inconclusive in its ability to change behaviour and attitudes sustainably. When adolescents sought care, they were confronted with inconsistencies between the messaging and the practical realities—healthcare workers were presenting treatment in ways noncomplementary to that messaging (Burke et al. 2021). Midterm reviews helped highlight the demand and appreciation for local-language messaging that prompted greater investment in translation services. The campaign's effectiveness was deeply intertwined with the realities of the healthcare system itself.

## THE SASA! PROGRAM

The SASA! program is a community mobilization program originally developed by Raising Voices, a Ugandan Civil Society Organization, and originally implemented by the Center for Domestic

Violence Prevention in 2007. Its programmatic intent was to change the norms regarding violence, namely intimate-partner violence, by creating local platforms for open discussions on preventing violence and actively diffusing situations that could lead to it.

The program has been lauded as an example of Uganda's own programmatic creations and is now being used as inspiration for similar social norm change programs in the region, including in Rwanda, Tanzania, and other parts of sub-Saharan Africa (Goldmann et al. 2019). The program may also have knock-on effects for other forms of violence outside of intimate-partner settings, including violence in schools and against children.

Most evaluations and a randomized controlled trial found that the program was incredibly effective in changing people's attitudes and knowledge regarding intimate-partner violence, primarily because it provided a conducive atmosphere for at-risk groups to participate in conversations about healthy relationships without fear of reprisal (Abramsky et al. 2014, Kyegombe et al. 2014, Starmann et al. 2017, 2018). The methodology, in which a local community champion would facilitate discussions, was considered to be robust in its effectiveness. The connection between at-risk populations and a credible figure who was able to facilitate and guide discussions provided outlets for awareness of the problem, a social network, and potential avenues for innovation and thinking of solutions for individual challenges.

Generally, however, efforts to systematize or scale up these types of programs have failed because the program's design attempts to provide a methodology for interrogation of power dynamics, which duty-bearers may have an explicit interest in avoiding (Goldmann et al. 2019). Formalization of these programs therefore depends on the facilitating group, whose functionality depends on their authority, capacity, and acceptance of their role. At the same time, financing dynamics are highly dependent on longevity and sustainability, and many failures of the program have been attributed to changes in donor or financing incentives or objectives.

## **CONCLUDING REMARKS**

Infectious diseases and the epidemics or pandemics they cause are a regular part of human life. Anthropogenically driven changes in interactions between the natural world and humans have created an engine for rapid emergence of new infectious diseases with the potential to destabilize communities and nations. These infectious diseases disrupt human life beyond their physical impacts on human health. Human health is a nexus of multiple forms of health, including mental, social, and spiritual, with interactions between each of them. For decades, most health systems have been designed to focus on the biology of health, neglecting the mental, social, and spiritual realms of health. This focus has left health systems ill prepared to address the ways infectious diseases disrupt the sociocultural and psychological fabric of human life.

This report provides an analysis of Ugandan society as a case study for comparison and reflection on how human beings respond and adapt to the challenges that infectious diseases present. At the same time, it shows the strengths and weaknesses of existing systems of health provision, including linkages to economic, political, and legal aspects of human life. By reconsidering these linkages and the ways in which they both respond and ignore parts of human life in moments of emergency, readers of this report, in their various capacities, are invited to imagine new ways of conducting pandemic preparedness and response nationally, continentally, and globally.

Throughout this study, preparedness has been presented as an opportunity to reduce the future costs and anxieties that give epidemics and pandemics the power to destabilize societies. The argument for preparedness is that difficult discussions that occur today can potentially elicit knock-on benefits when they are executed in a crisis. Societies are highly interdependent; crises challenge their ability to maintain or alter those connections in a positive way. A lack of preparedness invites a crisis to ask individuals to take charge and determine for themselves their own reality.

While such an approach may seem laudable and heroic because of the individual actions of those who meet this challenge, it is unfair to expect that everyone can meet the challenges of such an enormous task. Human beings can be selfish, fearful, and violent; they can also be generous, compassionate, and selfless to the point of giving up their lives for others. Individuals, communities, and nations, and their institutions and systems, will have to recognize both capacities of human beings and explore how to bring out their best. Epidemics and pandemics then, can become challenges that reveal humanity's ability to transcend its present and create a better future.

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#### ANNEX 1

### Statement of Task

## **UNAS Committee on Management of Human Perceptions and Behaviour in Pandemic Preparedness and Response**

Diseases with the potential to become pandemics are increasing in frequency and threat to human life as a result of human interactions with wildlife and other disease vectors. In light of the most recent and still ongoing global pandemic of COVID-19, human perceptions and behaviours have become increasingly visible aspects of effective pandemic management. For that reason, the Uganda National Academy of Sciences (UNAS) is convening a committee of experts to examine three dimensions of human perceptions and behaviours and their relationships with effective pandemic management. They are:

- 1. Mental health and stress during pandemics
- 2. Socio-cultural aspects of disease transmission and response
- 3. Science communication during public health pandemics and emergencies.

The Committee on Management of Human Perceptions and Behaviour in Pandemic Preparedness and Response (HPBPPR) will advise on the following issues:

## Mental health and stress during pandemics

- 1. What should the role of the community be in supporting communal mental health and resilience during pandemics?
  - a. What community structures promote mental resilience in different subpopulations?
- 2. What structures should be in place in public and private service delivery in order to provide effective social protections during pandemics?

- a. What structures should be in place in order to facilitate the quick and effective adoption of low-to-no contact provision of services?
- b. What structures should be in place to ensure the effective provision of services to significantly affected populations in a pandemic? In particular, this question seeks advice on the value or necessity of additional governmental units to manage epidemics and their impact on mental health and families.

## Socio-cultural aspects of disease transmission and response

- 3. What should constitute vulnerability or vulnerable populations in a pandemic? Traditionally defined vulnerable populations shall be included but not limited to People with Disabilities (PWDs), mental health patients, families, women, and children in this question.
- 4. What should the roles of traditional and cultural leaders be in pandemic preparedness and response?
  - a. What mechanisms should be in place to support community and traditional/cultural institutions playing their roles effectively in promoting and ensuring compliance with public health and safety measures during pandemics? This question seeks advice on approaches to socio-cultural events including but not limited to burials, marriages, and funeral rites.

# Science communication during public health pandemics and emergencies

- 5. What should the roles of various communication structures be and what would make them most effective in pandemic situations? Communication structures in this question include but are not limited to religious and traditional institutions, private and public media, community-based organizations, scientists, and information and communication technology platforms.
  - a. What impact do local languages have on health messaging and uptake?
  - b. What methods can be used to combat misinformation? In particular, this question seeks advice on the emerging role of technology and associated mass communication platforms.
  - c. What role should the creative and fine arts play in supporting

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effective public health messaging and communicating policy and practice updates in pandemic management?

d. Which long term communication strategy for mindset shifts promoting public health behaviours should policymakers pursue?

The Committee is requested to consider locally derived and contextually appropriate interventions in responding to these queries. In all questions, the Committee is requested to draw evidence from all disciplines including but not limited to history, sociology, epidemiology, virology, journalism, counselling, therapeutics, linguistics, emergency management, business, anthropology, human and business administration, biomathematics, computer sciences, and fine arts.

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