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Establishing a Human Development and Demographic Surveillance System in Butaro, Rwanda: A protocol paper

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ABSTRACT

INTRODUCTION: This protocol outlines the establishment and implementation o f a Human Development and Demographic Surveillance System (HD²SS) in Butaro, Rwanda. The HD²SS will facilitate prospective, continuous monitoring of th e population, tra cking vital statistics, social events, and key health and demographic indicators in a defined population. Th e system will enable accurate and validated assessment of the impact of health and related population-level interventions, s upporting evidence-based de cision-making and data-driven improvements in healthcare and socioeconomic outcomes at a population level.

METHODS: The HD²SS will be implemented in the Butaro sector, home to 38,013 individuals across 68 villages. The Butaro sector was purposively selected due to the existence of the University of Global Health Equity and Partners In Health-supported Butaro healthcare delivery. Data, including location, demographic, socioeconomic, and health-related variables, will be collected using the annual household census and stored using the Survey Solutions system for real-time electronic data capture, ensuring data quality, security, and confidentiality. Data analysis wi ll en able the identification of emerging trends, the development of interventions, and the evaluation of related policies and programs.

CONCLUSION: The HD²SS will provide currently limited but much-needed data to inform improvements in public health programming and socioeconomic development and strengthen local health research capacity. Regular dissemination of findings will ensure stakeholders, including local health authorities and development partners, are informed and able to use the results to improve health and social development outcomes in Rwanda.

Keywords: Human Development and Demographic Surveillance System, population health, wellbeing, health data, Rwanda

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INTRODUCTION

Health and Demographic Surveillance Systems (HDSS) have been established over the past decades in different low- and middle-income countries (LMICs), in response to a paucity of validated population-level health, location, socioeconomic, and vital statistics [1–4]. The goal of HDSS is to collect high-quality information to ultimately enhance the health and wellbeing of populations. The implementation of HDSS across Africa has provided significant insights into population health, informing public health interventions [5–9], building robust infrastructure for research, and enhancing research capacity building [1]. HDSS have embraced standardized methodologies and data structures, made possible through the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH Network) [10].

HDSS are essential to study and track patterns of diseases and exposures, measure epidemiological and socio-demographic impacts of infectious and non-infectious diseases, and serve as a sampling frame and field innovation for population-based studies. While most HDSS have been restricted to health and demographic measurement, a Human Development and Demographic Surveillance System (HD^{2}SS) amplifies the scope of work kickstarted by HDSS, shifting the focus from a methodological, measurement, and thematic orientation mainly focused on health and vital events to one that takes a broader view of the wellbeing of the population. HD^{2}SS themes include assessing and improving health service access and quality, promoting social development, engaging with gender and empowerment, and considering wellbeing and mental health as key dimensions of socioeconomic development. This is especially valuable in a country such as Rwanda, which already tracks vital events of its population.

Accurate and timely data provide the foundation for identifying key health and human development priorities, understanding existing disparities, and tailoring interventions to meet the specific needs of the population. Establishing a system that longitudinally tracks high-quality data enables policymakers and healthcare and social service providers to make informed decisions aimed at optimizing resource allocation and ensuring interventions have the desired impact. Collecting timely data on a regular basis also helps proactively address current and emerging public health issues. This ongoing monitoring, as well as the shift from health to a broader conceptualisation of wellbeing and human development, aligns with global health and development priorities, including the Sustainable Development Goals (SDGs), and ensures that national policies remain responsive to changing sociodemographic and health profiles.

This protocol marks the establishment of an HD^{2}SS in the Butaro sector of the Burera District, to collaborate with the government in its continued efforts to invest in the country's poor and remote districts. This will be the first site of its kind in Rwand and will play a critical role as a population health and development research site for Rwanda and the region. The Butaro HD^{2}SS will provide a robust platform for evaluating interventions and programs tied to social development and wellbeing. It will centre health at its core, while expanding the definition of human development to its manifold ramifications intersecting agency, empowerment, nutrition, wellbeing, equity, and human security – hence the extension from "health" to "human development." Regular data collection will facilitate the assessment of program effectiveness, efficiency, and equity, offering valuable insights into what works and what needs support and/or improvement. Program evaluations will be critical for optimizing existing health interventions, designing new initiatives, and ensuring accountability in health service delivery. The Butaro HD^{2}SS will also serve as a catalytic field research site for our ongoing collaborative research program globally, promoting and supporting the engagement of multidisciplinary research teams across a range of projects and significantly expanding opportunities for collaboration with other health and demographic surveillance sites in the region. The established HD^{2}SS will integrate population and health facility data systems linking demographic, social, epidemiological, mortality, morbidity, clinical, laboratory, household, environmental, health systems, and other contextual data, with a unique participant identification system throughout. The HD^{2}SS surveillance work and evidence generation will have a broad impact across Rwanda, in the sub-Saharan African region, and beyond.

Our long-term goal is to design and test locally relevant interventions to improve the critical

health and human development challenges that Rwanda is facing. In the short term, we prioritise the following objectives, which are linked to SDGs 3, 5, and 10 [11]: establish and maintain a demographic surveillance system that monitors population dynamics in the Butaro sector; collect and analyse data on vital events, including births, deaths, marriages, and migration within the Butaro sector; track and monitor life-course events such as teenage pregnancy, union formation, and child wellbeing; assess the burden and trends of diseases, both infectious and non-communicable, within the population; and track key social development and wellbeing indicators and outcomes in the population, including mental health, life satisfaction, and vulnerability.

METHODS

Study Design

The Butaro HD^{2}SS will employ a prospective longitudinal open cohort design with continuous monitoring of demographic and health events to capture demographic changes and health trends of the Butaro population, beginning in 2025.

Study Setting and Population

The HD^{2}SS will be established and implemented in the Butaro sector, located in the Burera District in the northern region of Rwanda. The Butaro sector was purposively selected due to the existence of the University of Global Health Equity (UGHE) and Partners In Health-supported Butaro healthcare delivery. Burera District consists of 17 sectors and has a total population of 387,729 residents. The Butaro sector is the second most populated sector in the Burera District, with a population of 38,013 individuals. The majority (99.8%) of the population are Rwandans, while only 70 individuals (0.2%) are foreigners [12].

The Butaro sector is made up of 5 cells, constituting 68 villages with an average household size of 4.3 individuals. Households in Butaro are predominantly headed by males (6,633) compared to 2,094 households headed by females. Housing distribution in the Butaro sector consists of 81.3% planned rural settlements organised into villages, locally known as umudugudu; 11.5% dispersed housing, 4.2% old settlements, 1.4% spontaneous/squatter housing, 1.0% comprises integrated model villages, and 0.7% includes other types of housing [12]. For education, 59.3% of Butaro residents have completed primary school; 19.3% reported no formal school attendance, 8.4% have a lower secondary level of education, 6% have an upper secondary level, 4.4% have completed nursery school, and 2.7% have a tertiary education level, and [12].

Butaro faces significant health conditions, including malaria, acute respiratory infections, HIV/AIDS, diarrhoea, premature births, cerebrovascular diseases, tuberculosis, malnutrition, and physical

Table 1: Population residency requirements

Requirements	Definition
Household membership	A household is defined as a group of individuals who reside together in a single housing unit and share common living arrangements, resources, or decision-making. It also includes all individuals considered permanent or semi-permanent members of the household, including family members, domestic workers, and other dependents.
Residency criteria	To be included in the study population, individuals must meet the residency criteria, which require a continuous residence of at least three months within the HD^{2}SS area. Exceptions to this criterion include newborns within the area or individuals returning after temporary absences who maintain their primary residence within the defined boundaries.
Migration status	In-migration includes individuals who move into the HD^{2}SS area to establish residency, such as those joining a household, relocating to the area for work or other reasons, or transitioning from temporary to permanent residence. Out-migration refers to residents who leave the HD^{2}SS area and are absent for more than three months, indicating a change in primary residence or a long-term relocation outside the surveillance area.

trauma. Various factors contribute to the high morbidity and mortality, and low levels of human development, in the Butaro sector. Many of these conditions are exacerbated by high poverty levels, lack of education, and inadequate water, sanitation, and hygiene systems [12]. Only 13% of households in Butaro have at least one member with access to the internet, while the majority (86.9%) do not have any household members with internet access. Just over 80% of households in the Butaro sector engage in agriculture, 56.7% are engaged in livestock farming, and 8.1% are involved in crop farming [12].

The study population for the HD^{2}SS will include all individuals residing within the defined surveillance area who meet the specified residency criteria (Table 1).

Study thematic areas

The Butaro HD^{2}SS is designed to generate high-quality, longitudinal data across multiple thematic areas:

Thematic area 1: Demographic measurement and household dynamics

Enumerating household size and composition is the steppingstone of any HDSS work as it provides basic information on the number of individuals in the households, roles and responsibilities (e.g., household head), and key linkages between household members that enable scholars and policymakers to track movements in and out of the household, "new" household members (e.g., through fertility or in-migration), or reductions in household size (e.g., through mortality or out-migration). Mapping household complexity is also fundamental, considering recent social transformations that see the family system at the core of global changes such as declines in fertility, nuclearisation of households, broader and diversified kinship systems, etc., including in low-income societies such as Rwanda [13, 14]. Table 2 shows related research questions for each thematic area.

Thematic area 2: Gender, empowerment, and maternal and child health

Gender equality and the empowerment of women and girls are central to achieving the SDGs. Yet, despite global efforts to achieve these goals, gender inequalities continue to impede progress [15, 16]. Key challenges include inadequate sexual and reproductive healthcare, a high prevalence of violence against women and girls, and entrenched societal norms that continue to disadvantage women and girls. Addressing gender disparities in health and social development is crucial for fostering inclusive and sustainable growth [17]. The HD^{2}SS will facilitate the collection and presentation of data on gender and household dynamics within the rural community.

Thematic area 3: Non-communicable disease, injury, and health systems

The increasing burden of non-communicable diseases (NCDs) presents a significant challenge to African development; they are projected to surpass infectious diseases as the leading cause of adult mortality in Africa by 2030 [18, 19]. However, reliable data on the prevalence of and unmet need for care for NCDs in Africa remain scarce, as most studies have been hospital-based, small-scale, and have lacked clear participant selection criteria. Injuries are a significant public health challenge in Africa, including Rwanda, where they contribute substantially to morbidity, mortality, and disability [20–23]. To gain deeper insights into the burden, risk factors, and health system-related characteristics of NCDs and injury in Rwanda, we will leverage the Butaro HD^{2}SS to include one of the largest NCD- and health service delivery-focused research efforts in the country.

Thematic area 4: Wellbeing, healthy ageing, and mental health

The HD^{2}SS platform embraces a conceptualisation of development and wellbeing that goes far beyond health. We see this as fundamental from a development perspective, given the multiple challenges and vulnerabilities that individuals and families in Butaro face [24, 25]. This builds on our current work on healthy ageing and multimorbidity in Rwanda, including in Burera District [26]. This shift is also consistent with development priorities and policy programming aligned with development agencies and, more broadly, the SDG agenda, which often sees health as just one component of overall wellbeing. We will collect several key wellbeing measures as part of the baseline household roster, including standardised life satisfaction and wellbeing measures adapted from the Organisation for Economic Co-operation and Development Better Life Index [27].

Table 2: Research questions by thematic areas

Thematic area	Future research questions
(1) Demographic measurement and household dynamics	What do families look like in Butaro? Is there any meaningful way of mapping the complexity of different household structures in this community (e.g., what is the prevalence of multi-generational households?) What does the broader kinship system look like (e.g., horizontal, vertical, lateral)?
	What are the implications of changes in household structure and composition (including divorce, separation, remarriage, in-migration, and out-migration) for children's health and wellbeing throughout the life-course?
	What are the implications of experiencing violence within the family for household stability and girls' life-course trajectories?
	Is migration a risk factor or a "protective" factor (e.g., an escape strategy) to deal with sudden household shocks such as the death of a family member? Is it an escape strategy when dealing with instances of family violence?
(2) Gender, empowerment, and maternal and child health	What is the prevalence and what are causes/correlates of teenage pregnancies, including factors such as child marriage, violence against women and girls, and access to healthcare?
	How does adolescent pregnancy affect maternal and child health?
	What is the prevalence and what are causes/correlates of sexual, psychological, physical, and economic violence against women and girls?
	How do gender norms affect girls' reproductive health, maternal/child health, and violence?
(3) Non-communicable disease, injury, and health systems	How do NCDs emerge and progress, and what are key local risk factors driving these NCD dynamics? How are the natural course and risk factors for NCDs in Butaro different from what has been found in other global contexts?
	Guided by the "Three-Delays Model," what are the relationships between the following and unmet need for care? (Mis)beliefs about care and trust in health systems; Travel times and access and unmet need for care; Cost of care seeking (incl. insurance) and unmet need for care.
	How can we design new models of care that address key gaps in health service use and delivery and improve NCD outcomes? And injury outcomes?
	How might the community respond to health promotion interventions aimed at addressing behavioural risks factors for NCDS in Butaro?
	Linking with other work packages, how are NCDs influenced by individual, household, community, and social forces, and what is the relationship between NCDs and overall wellbeing?
	How do injuries impact individual, household, and community health, and what is the relationship between injuries and overall wellbeing?
(4) Wellbeing, healthy ageing, and mental health	How do we conceptualise, measure, and track wellbeing in Butaro? This will include both adapting measures used in other contexts and potentially developing new, context-specific measures.
	Guided by the WHO definition, understand meaning at the household and community level
	Stigma, recognition, and dealing with mental health in the community
	Pathways to seeking mental healthcare and coping strategies
	What is the impact of the following on wellbeing? Teen pregnancy; Adverse physical health events or deteriorations in health; Economic shocks and livelihood instability (e.g., food insecurity, agricultural shocks)
	How are the different dimensions of wellbeing interrelated (e.g. the implications of poor physical and/or mental health on livelihood stability)?
	How does economic migration impact family and community cohesion and wellbeing?
	How have histories of trauma and genocide shaped wellbeing?
	How do changes in an individual's wellbeing cascade through their broader kinship and social network and ultimately affect community wellbeing?
	What are factors affecting the demand for mental and psychological health services?
	What are the social and clinical factors contributing to healthy ageing and wellbeing in Butaro district?
(5) One Health	What are the primary drivers of zoonotic disease transmission in the Butaro region, and how can they be mitigated?
	How do environmental changes (e.g., deforestation, agriculture) impact health outcomes in humans and animals?
	What are the socioeconomic benefits of integrating One Health practices into rural livelihoods?
	How can community-level interventions improve compliance with environmental conservation and public health initiatives?

Thematic area 5: One Health

The HD²SS offers a vital platform to generate data, implement interventions, and evaluate outcomes using a One Health framework. This approach will enhance our understanding of the interplay between ecosystem services, zoonotic diseases, and community health outcomes [28,29]. Climate change is altering disease transmission patterns, increasing the risk of zoonotic spillovers and the spread of vector-borne diseases. Strengthening epidemic and pandemic preparedness requires climate-sensitive surveillance systems that integrate human, animal, and environmental health data. We will work closely with the Rwanda Biomedical Center Public Health Surveillance and Emergency Preparedness & Response Division to enhance coordination, data sharing, and rapid response to emerging health threats. This collaboration will facilitate the timely detection of disease outbreaks, improve real-time regular surveillance, and strengthen public health emergency preparedness at the district level.

By integrating these thematic areas, the HD²SS will provide a comprehensive understanding of health, social, and environmental determinants, informing policies and interventions to improve wellbeing in Butaro and beyond.

Data Collection Procedures

In this HD²SS we will use routine systematic data collection, starting with an initial census and followed by regular update rounds to collect timely and accurate demographic, health, and social development information. Furthermore, it will serve as a platform for additional modules and studies, leveraging the existing cohorts to address specific research questions and public health and development priorities. We will also attempt to link data from the Butaro HD²SS with health facilities in later rounds.

Initial census: The initial census will involve listing and mapping all households within the HD²SS area to establish a comprehensive framework for data collection (Table 3). Data collectors will be trained to properly list and enumerate the households in each village in the sector. After completing the household listing and enumeration, baseline demographic data will be collected for all regular residents, including essential information such as age, gender, and relationship to the household head. Each household and individual will be assigned unique identifiers to ensure accurate tracking and linkage of data over time. Additionally, the data collected during the initial census will provide a foundation for future studies, enabling researchers to use the existing cohorts for in-depth analyses and to address emerging public health challenges.

Regular update rounds: Data collectors will conduct household visits as part of regular update rounds, which will be carried out annually to ensure the accuracy and completeness of the data. During these update rounds, the household roster will be updated and vital events such as births, deaths, and marriages will be recorded, along with any migrations in or out of the HD²SS area. Additionally, health indicators will be collected to monitor changes in population health and assess the impact of health interventions. However, some vital events, such as births, deaths, in-migrations, and out-migrations, may occur between follow-up visits. To ensure that such events are promptly captured, the HD²SS will rely on community health workers or locally employed data collectors, who will be responsible for recording these events as they occur and reporting them to the data collector assigned to the respective village. This community-centred approach will ensure the collection of comprehensive and accurate data on births, deaths, and in-and out-migrations, limiting recall bias.

Data Management

Effective data management is essential for ensuring the accuracy, security, and usability of the data collected through the HD²SS To achieve this, we will deploy an electronic data capture system with robust data quality control measures, stringent data security, and confidentiality protocols, and efficient database management practices.

Data collection: The HD²SS will utilise Survey Solutions, an advanced electronic data capture system, to streamline the data collection process, reduce errors, and enhance overall efficiency. Survey Solutions will facilitate real-time entry and transmission of data from field sites to central servers, ensuring immediate availability for analysis. The web-based application will be designed to handle large volumes of demographic, social, and health data, while its user-friendliness

Table 3: Core data elements

Thematic area	Variables and measures
1. Demographic measurement and household dynamics	Questions on household members, including: Names, Sex, Age, Relationship with household head, Presence of biological mother/father in the household, Marital status, Education, Enrolment in school, Occupation, Presence of the household member in the same household for specific amounts of time in the past, Household assets
	Number of household members
	Births in the past 1 year (with precise timing); Official registration of births (if available)
	Deaths in the past 1 year (with precise timing); Official registration of deaths (if available)
	Marriages in the past 1 year (with precise timing); Presence of marriage certificate (if available)
	In-migration and/or out-migration in the past 1 year
	Divorce, separation, remarriage, or widowhood in the past 1 year
2. Gender, empowerment, and maternal and child health	Prevalence of teenage pregnancies
	Causes/correlates of teenage pregnancies (child marriage, interpersonal violence, non-partner sexual violence, region, education, school dropout etc.) access to sexual and reproductive health services (including access to/use of modern contraceptive/youth-friendly services)
	What kind of (sexual) partners girls have (partners' age, husband or boyfriends, transactional relationships, etc.)
	Access to and utilisation of youth-friendly sexual and reproductive health services, including HIV/sexually transmitted infection prevention, testing, access to contraceptives, reproductive health decisions
	Prevalence of gender-based violence by type of violence – physical, psychological, sexual, economic, economic abuse by family members/household members
	Perpetrator types/patterns for gender-based violence (family, intimate partner, stranger, others)
	Incidence reporting and help-seeking behaviour among survivors of violence, including use and accessibility of gender-based violence prevention and response services
3. Non-communicable disease, injury, and health services	Blood pressure/blood glucose measured in the past year
	Screening for any form of cancer in the previous year
	Visit to a health centre or hospital in the past 3 months/1 year
	Length of time for a household member to reach the nearest health facility
	Whether any member of the household has a chronic condition or disability
	Whether any member of the household had an injury requiring medical attention in the past 1 year, and if it resulted in hospitalisation, absence from school or work, and/or permanent disability
	Specific type and extent of injury-related disability
	Injury-related access to care
4. Wellbeing, healthy ageing, and mental health	We will measure wellbeing across 10 dimensions based on the OECD How's Life/Better Life Index. This will include questions assessing : Housing Quality*; Income and consumption*; Occupation*; Community engagement; Education*; Environmental quality; Engagement in civic activities; Health*; Life satisfaction; Perceptions of safety and stability; Healthy ageing, frailty and multimorbidity (questions collected as part of other thematic areas are marked with a *).
	We will also assess mental health using the Center for Epidemiologic Studies Depression Scale (CES-D).
5. One Health	The leading zoonotic diseases and the primary drivers of their transmission in the Butaro district
	Impact of environmental changes (e.g., deforestation, agriculture) on health outcomes in humans and animals in the region
	Potential socioeconomic benefits of integrating One Health practices into rural livelihoods
	What community-level interventions improve compliance with environmental conservation and public health initiatives

will ensure smooth adoption by data collectors. It will include built-in validation checks such as branching logic, pre-defined text validation, and custom error messages to ensure that data entered meets predefined criteria, flag any inconsistencies or errors for review and reduce the risk of data entry mistakes.

Data quality assurance: To ensure the reliability and accuracy of the data, rigorous data quality control measures will be implemented throughout the data collection process. This will include regular training for data collectors to standardise data collection procedures and ensure clarity in following the guidelines. Supervisors will conduct periodic spot checks and data reviews to ensure adherence to quality standards. In addition, Survey Solutions will feature automated data validation checks that will flag inconsistencies and errors during data entry. Regular data cleaning procedures will be conducted to identify and correct missing values, duplicates, or inconsistencies before data analysis.

Data security and confidentiality: All data captured through Survey Solutions, secured with two-factor authentication, will be stored in encrypted databases accessible only to authorised personnel. Personally Identifiable Information (PII), including names, national IDs, home addresses, and phone numbers, will be maintained separately, in a password-protected dataset accessible only to UGHE's Data Manager. Research data will be linked to PII using unique codes to protect sensitive details. Regular audits and monitoring will ensure compliance, track data access and usage, and prevent unauthorised breaches. All data management practices in the HD²SS will adhere to the regulations of the Rwanda National Ethics Committee and the Rwanda personal data protection law [30].

Data storage: Survey Solutions will organise, store, and manage the large volumes of data collected through the HD²SS. The secure web application will be optimised to allow easy retrieval, analysis, and reporting of data, ensuring that data integrity is maintained. Regular backup procedures will be carried out to safeguard against data loss, and the platform will be scaled to accommodate future data growth using the embedded longitudinal study features. Data will be indexed and catalogued for efficient querying, and periodic system updates will ensure that the database remains effective in managing evolving data needs.

Data analysis: Data collected through the Butaro HD²SS will undergo data cleaning to identify and address missing or inconsistent values and data coding to standardise variable definitions (e.g., age groups, disease classifications). Given the longitudinal nature of the HD²SS, individual and household records will be structured to allow for trend analysis over time. Descriptive analyses will be conducted to summarise key demographic and health indicators. Population characteristics, including age and sex distribution, births, deaths, migration patterns, and fertility rates, will be analysed. Social and health indicators such as the prevalence of chronic and communicable conditions, maternal and child health outcomes, nutritional status, changes in family composition, and wellbeing will also be examined. These results will be presented using summary statistics (frequencies, proportions, means, medians, and standard deviations) alongside visualisations such as tables, charts, and maps. Longitudinal and trend analyses will be conducted to examine changes in demographic, social, and health variables across multiple rounds of data collection. Cohort analysis will be used to track individuals and assess changes in health conditions, while time series analysis will examine trends in outcomes such as mortality and morbidity, helping to identify emerging health and social issues and evaluate the effectiveness of health and human development interventions. Survival analysis will estimate time-to-event outcomes such as infant mortality or disease progression. Multivariable regression models will be used to assess associations between key exposures (e.g., socioeconomic status, healthcare access) and health outcomes (e.g., mortality, disease burden). Multilevel modelling will account for clustering effects within households and villages, ensuring robust estimations of risk factors. Additionally, spatial analysis using Geographic Information Systems will be conducted to map disease distribution where required.

Roles and responsibilities: The HD²SS program will be led by epidemiologists and global health experts from the UGHE Center for Population Health, Technical University of Munich, and New York University Abu Dhabi, who will provide strategic oversight and technical guidance. An on-site research scientist will serve as the project

lead, managing the HD²SS cohort in Butaro and coordinating day-to-day operations. This individual will be supported by a dedicated data manager responsible for maintaining the Survey Solutions platform, ensuring robust data security protocols locally, managing backups, regulating user access permissions, and performing regular data analysis. A research coordinator will collaborate closely with the team and with full-time data collectors recruited and based in Butaro to facilitate seamless data collection and fieldwork. Together, this multidisciplinary team will ensure rigorous implementation, data integrity, and adherence to ethical and operational standards throughout the project.

Ethics: The Butaro HD²SS team has received approval from the Rwanda National Ethics Committee and will seek further approval from additional relevant national authorities. The team will engage in transparent communication with the community to promote community awareness and understanding of the study, fostering a sense of partnership and shared responsibility. Prior to data collection, participants will be provided with clear and culturally sensitive information about the study's purpose, procedures, potential risks, and benefits. Following this, both written and verbal informed consent and assent will be obtained. In cases where applicable, informed consent will be sought subsequently in future studies, depending on the characteristics of the study participants. Privacy and confidentiality will be sustained to safeguard participants' identities and sensitive health information. We will ensure that all future studies receive ethical approval from the relevant institutions before implementation. Feedback from participants and community members will be received through direct communication, including through phone numbers and email addresses shared in the consent forms, and directly to the study team.

Dissemination: The HD²SS will be a vital system for strengthening public health and social development by generating high-quality data that informs the development of interventions and provides policymakers with critical insights for optimizing resource allocation and service delivery. The dissemination strategy for the HD²SS will ensure that key findings are regularly shared with relevant stakeholders and the broader community to inform timely decision-making, improve health and development outcomes, and guide health policies and programs at local, provincial, and national levels. Interactive data dashboards will be developed to provide real-time access to key indicators. Regular reports will be generated and shared with stakeholders, including local health authorities, policymakers, and development partners, providing updates on demographic, social, and health trends. Through policy briefs, research publications, and stakeholder meetings, data will be made accessible for decision-making and strategic planning. Scientific publications will be produced to share research findings with the global academic and public health community, contributing to the broader evidence base. Feedback will be provided to the community through informational presentations as well as information feedback through community health workers, ensuring that participants are informed about the study's progress and outcomes, fostering transparency and engagement. Additionally, data will be shared with national health information systems, ensuring integration with existing health data frameworks and supporting the development of evidence-based health policies at the national level.

Limitations: Despite its valuable contributions to global health and epidemiological research, the Butaro HD2SS research program has some limitations. Our HD²SS system is in a rural sector, and this population may not fully reflect the broader demographic and socioeconomic diversity of the country, which limits the generalizability of the findings. Information related to birth and death records may not always be readily available during data collection, leading to increased reliance on self-reported data, which may be subject to recall bias or inaccuracies. HD²SS requires long-term funding and trained personnel to ensure quality longitudinal data capture. Participants may experience survey fatigue, potentially leading to information bias. And finally, despite this information being crucial, integrating HD²SS data with national health information systems can be challenging.

CONCLUSION

We believe this first-of-its-kind HD²SS will make a significant contribution to Rwanda's national health and social information systems by enhancing the completeness and accuracy of health and social

statistics at the national level, and fostering dialogue, data exchange, and transparency across different layers of government and policymaking. Integration of data from the Butaro HD²SS into the broader national health information system will improve the quality of health planning, response, and reporting locally. These studies will draw in multiple collaborators who will bring scientific rigor, encourage innovation, and strengthen the overall management of health and demographic information, creating a more responsive and resilient healthcare and social service framework for Rwanda, ultimately resulting in better population health and wellbeing.

REFERENCES

1. Herbst, K.; Juvekar, S.; Jasseh, M.; Berhane, Y.; Chuc, N.T.K.; Seeley, J.; Sankoh, O.; Clark, S.J.; Collinson, M.A. Health and demographic surveillance systems in low- and middle-income countries: history, state of the art and future prospects. Glob Health Action 2021, 14, sup1, 1974676, DOI: 10.1080/16549716.2021.1974676.
2. Foster, G.M.; Scudder, T.; Colson, E. Long-term field research in social anthropology. New York: Academic Press, https://www.uky.edu/~cligget/docs/Scudder%20Colson%20Long%20Term%20book%20chap.pdf (2002, accessed 10 February 2025).
3. Delaunay, V.; Douillot, L.; Diallo, A.; Dione, D.; Trape, J.F.; Medianikov, O.; Raoult, D.; Sokhna, C. Profile: The Niakhar Health and Demographic Surveillance System. Int J Epidemiol 2013, 42, 1002–1011, DOI: 10.1093/ije/dyt100.
4. Berhane, Y.; Wall, S.; Kebede, D.; Emmelin, A.; Enqueselassie, F.; Byass, P.; Muhe, L.; Andersson, T.; Deyessa, N.; Hogberg, U.; Gossaye, Y.; Alem, A. Establishing an epidemiological field laboratory in rural areas -- potentials for public health research and interventions. The Butajira Rural Health Programme 1987-1999. Ethiopian Journal of Health Development, 1999, 13.
5. Samb, B.; Aaby, P.; Whittle, H.; Seck, A.M.; Simondon, F. Protective efficacy of high-titre measles vaccines administered from the age of five months: a community study in rural Senegal. Trans R Soc Trop Med Hyg 1993, 87, 697–701, DOI: 10.1016/0035-9203(93)90301-6.
6. Simondon F.; Preziosi MP.; Yam A.; Kane, C.T.; Chabirand, L.; Iteman, I.; Sanden, G.; Mboup, S.; Hoffenbach, A.; Knudsen, K.; Guiso, N.; Wassilak, S.; Cadoz, M. A randomized double-blind trial comparing a two-component acellular to a whole-cell pertussis vaccine in Senegal. Vaccine 1997, 15, 1606–1612, DOI: 10.1016/s0264-410x(97)00100-x
7. Binka, F.N.; Bawah, A.A.; Phillips, J.F.; Hodgson, A.; Adjuik, M.; MacLeod, B. Rapid achievement of the child survival millennium development goal: Evidence from the Navrongo experiment in Northern Ghana. Tropical Medicine and International Health 2007, 12, 578–593, DOI: 10.1111/j.1365-3156.2007.01826.x.
8. Yeboah-afari, A. When South meets South. How Navrongo learnt from Matlab. People Planet 1997, 6, 25–26.
9. Jasseh, M.; Gomez, P.; Greenwood, B.M.; Howie, S.R.; Scott, S.; Snell, P.C.; Bojang, K.; Cham, M.; Corrah, T.; D'Alessandro, U. Health & Demographic Surveillance System Profile: Farafenni Health and Demographic Surveillance System in The Gambia. Int J Epidemiol 2015, 44, 837–847, DOI: 10.1093/ije/dyv049.
10. INDEPTH Network. Population, Health, and Survival at INDEPTH sites; International Development Research Centre; Ottowa, Canada, 2002.
11. The Global Health Observatory: The Global Health Observatory: Monitoring Health for the Sustainable Development Goals. World Health Organization, https://www.who.int/data/gho/data/themes/sustainable-development-goals (2024, accessed 18 January 2025).
12. National Institute of Statistics Rwanda. Fifth population and housing census, Rwanda, 2022: final results main indicators report. Kigali, 2022.
13. Pesando, L.M.; GFC Team. Global Family Change: Persistent Diversity with Development. Popul Dev Rev 2019, 45, 133–168, DOI: 10.1111/padr.12209.
14. Yu, S.T.; Houle, B.; Schatz, E.; Angotti, N.; Kabudula, C.W.; Gómez-Olivé, F.X.; Clark, S.J.; Menken, J.; Mojola, S.A. Understanding Household Dynamics From the Ground Up: A Longitudinal Study From a Rural South African Setting. Demography 2024, 61, 31–57, DOI: 10.1215/00703370-11146140.
15. Bitty-Anderson, A.M.; Gbeasor-Komlanvi, F.A.; Bakoubayi, A.W.; Tchankoni, M.K.; Sadio, A.J.; Salou, M.; Dagnra, C.A.; Ekouevi, D.K.; Coffie, P.A. High burden of self-reported sexually transmitted infections among female sex workers in Togo in 2021. Front Public Health, 2022, 10, 915029, DOI: 10.3389/FPUBH.2022.915029.
16. Ndayishimiye, P.; Uwase, R.; Kubwimana, I.; Niyonzima, J.C.; Dzekem Dine, R.; Nyandwi, J.B.;

Ntokamunda Kadima, J. Availability, accessibility, and quality of adolescent Sexual and Reproductive Health (SRH) services in urban health facilities of Rwanda: a survey among social and healthcare providers. BMC Health Serv Res, 2020, 20, 697, DOI: 10.1186/S12913-020-05556-0.
17. Arthur, S.; Bangha, M.; Sankoh, O. Review of contributions from HDSSs to research in sexual and reproductive health in low- and middle-income countries. Trop Med Int Health 2013, 18, 1463–1487, DOI: 10.1111/tmi.12209.
18. Bigna, J.J.; Noubiap, J.J. The rising burden of non-communicable diseases in sub-Saharan Africa. Lancet Glob Health 2019, 7, e1295–e1296, DOI: 10.1016/S2214-109X(19)30370-5.
19. Boah, M.; Cyuzuzo, C.; Uwinkindi, F.; Kalinda, C.; Yohannes, T.; Isano, S.; Greig, C.; Davies, J.; Hirschhorn, L.R.; Amberbir, A. Health and well-being of older adults in rural and urban Rwanda: epidemiological findings from a population based cross-sectional study. J Glob Health 2025, 15, 04108, doi: 10.7189/jogh.15.04108.
20. World Health Organization. Status report on road safety in the WHO African Region, 2023. Geneva, https://iris.who.int/handle/10665/378194 (2024, accessed 10 January 2025).
21. World Health Organization. Injuries and violence: the facts 2014. Geneva, https://iris.who.int/handle/10665/149798 (2014, accessed 10 January 2025).
22. Petroze, R.T.; Martin, A.N.; Ntaganda, E.; Kyamanywa, P.; St-Louis, E.; Rasmussen, S.K.; Calland, J.F.; Byiringiro, J.C. Epidemiology of paediatric injuries in Rwanda using a prospective trauma registry. BJS Open 2020, 4, 78–85, doi: 10.1002/bjs5.50222.
23. Ingabire, J.C.A.; Stewart, A.; Sagahutu, J.B.; Urimubenshi, G.; Bucyibaruta, G.; Pilusa, S.; Uwakunda, C.; Mugisha, D.; Ingabire, L.; Tumusiime, D. Prevalence and levels of disability post road traffic orthopaedic injuries in Rwanda. Afr J Disabil 2024, 13, 1251, DOI: 10.4102/AJOD.V13I0.1251.
24. Kayiteshonga, Y.; Sezibera, V.; Mugabo, L.; Iyamuremye, J.D. Prevalence of mental disorders, associated co-morbidities, health care knowledge and service utilization in Rwanda - towards a blueprint for promoting mental health care services in low- and middle-income countries? BMC Public Health 2022, 22, 1858, DOI: 10.1186/S12889-022-14165-X.
25. Neugebauer, R.; Fisher, P.W.; Turner, J.B.; Yamabe, S.; Sarsfield, J.A.; Stehling-Ariza, T. Post-traumatic stress reactions among Rwandan children and adolescents in the early aftermath of genocide. Int J Epidemiol 2009, 38, 1033–1045, doi:10.1093/ije/dyn375.
26. Amberbir, A.; Cyuzuzo, C.; Boah, M.; Uwinkindi, F.; Kalinda, C.; Yohannes, T.; Isano, S.; Ojiambo, R.; Greig, C.A.; Davies, J.; Hirschhorn, L.R. Understanding needs and solutions to promote healthy ageing and reduce multimorbidity in Rwanda: A protocol paper for a mixed methods, stepwise research study. BMJ Open 2025, 15, e089344, doi: 10.1136/bmjopen-2024-089344.
27. Organization for Economic Cooperation and Development. The OECD Better Life Index, https://www.oecdbetterlifeindex.org/ (accessed 10 January 2025).
28. Igihozo, G.; Henley, P.; Ruckert, A.; Karangwa, C.; Habimana, R.; Manishimwe, R.; Ishema, L.; Carabin, H.; Wiktorowicz, M.E.; Labonté, R. An environmental scan of one health preparedness and response: the case of the Covid-19 pandemic in Rwanda. One Health Outlook 2022, 4, 2, DOI: 10.1186/s42522-021-00059-2.
29. Zhang, X.X.; Lederman, Z.; Han, L.F.; Schurer, J.M.; Xiao, L.H.; Zhang, Z.B.; Chen, Q.L.; Pfeiffer, D.; Ward, M.P.; Sripa, B.; Gabriël, S.; Dhama, K.; Acharya, K.P.; Robertson, L.J.; Deem, S.L.; Aenishaenslin, C.; Dantas-Torres, F.; Otranto, D.; Grace, D.; Wang, Y.; Li, P.; Fu, C.; Poeta, P.; Md Tanvir Rahman; Kassegne, K.; Zhu, Y.Z.; Yin, K.; Liu, J.; Wang, Z.J.; Guo, X.K.; Gong, W.F.; Schwartländer, B.; Ren, M.H.; Zhou, X.N. Towards an actionable One Health approach. Infect Dis Poverty 2024, 13, 28, doi: 10.1186/s40249-024-01198-0.
30. Republic of Rwanda. Data Protection and Privacy Law. Law No 058/2021, https://www.risa.gov.rw/data-protection-and-privacy-law (2021, accessed 28 February 2025).