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Cohort Profile

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Cohort Profile: The Iganga-Mayuge Health and Demographic Surveillance Site, Uganda (IMHDSS, Uganda)

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Why was the IMHDSS set up?

The Iganga Mayuge Health and Demographic Surveillance Site (IMHDSS) was set up in 2004 to provide a platform for community-based epidemiological research and research training. Seed funding was provided by the Swedish International Development Agency (SIDA) as part of the Karolinska Institutet, Sweden and Makerere University–Sweden bilateral research collaboration. The specific objectives at inception were to (i) register and monitor health and demographic events (births, deaths, migration) and dynamics in a population and serve as a resource of information for decision making, providing an environment for several community-based projects in single-/multi-disciplinary research and research training; (ii) provide unique, essential, household-level information individually tailored for policy, planning and research needs; (iii) provide a platform for training in applied field research and practical health, socioeconomic and demographic survey methods to students, staff and researchers; and (iv) provide a platform for high-quality household survey data for operational field trials that measures interventions including but not limited to, monitoring trends in communicable and non-communicable diseases (NCDs), clinical and vaccine trials and other surveillance activities.

Where is the IMHDSS area?

The IMHDSS operates in Iganga and Mayuge districts, located in Eastern Uganda, ~120 km east of the capital city Kampala along the Uganda–Kenya highway (Figure 1). The IMHDSS covers an area of 155 km^2 made up of 65 villages in seven sub-counties under the leadership of the two districts. The infrastructure is under-developed with poor sanitation and hygiene coupled with low levels of protected water sources. There is a primary school in every parish in

this area. Sixty percent of the demographic surveillance area is rural while the rest is either urban or peri-urban.

The population is predominantly of Muslim religion (53%). The main source of income for the rural population is farming/agriculture (51%) whereas it is shop/business for the peri-urban population. The IMHDSS community is served by 16 community-based lower-level health centres (HC) (HC III and HC II) and two hospitals (one district referral public hospital in Iganga and one faith-based hospital in Mayuge district). HC IIIs provide basic preventive, promotive and curative care including laboratory services for diagnosis, maternity care and first referral cover for the sub-county. HC IIs provide outpatient care and community outreach services and represent the first level of care. A network of Village Health Teams (VHT) established by the ministry of health facilitates health promotion e.g. for immunization, service delivery, community participation and empowerment in access to and utilization of health services.

Figure 1. The shaded area shows the districts where Iganga Mayuge Health and Demographic Surveillance Site (IMHDSS) is located.

What is IMHDSS and what is done at the site?

The IMHDSS is managed by Makerere University Center for Health and Population Research (MUCHAP)—a not-for-profit, semi-autonomous organ of Makerere University. The site is an active member of the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) (www.indepth-network.org). The IMHDSS routinely collects data on core demographic events of births, deaths and migrations.

The IMHDSS enhanced morbidity surveillance by setting up of an electronic health records (EHR) system at one health facility in the demographic surveillance area (DSA) in 2017. Other facilities still use only paper-based systems. This system links the IMHDSS members' community data with their health facility visits information to better understand the disease patterns, morbidity levels, pharmacovigilance, diagnosis and treatment practices, determinants of health and treatment outcomes in the rural population. It is expected that the system will enable surveillance of antimicrobial resistance, drug utilization and safety monitoring, and facilitate quick turnaround of health information. This system will also facilitate monitoring the progress of national interventions indicators and those of sustainable development goals (SDGs) and universal health coverage (UHC).

Who is covered by the IMHDSS and how often have they been followed up?

The IMHDSS is an open population cohort collecting basic demographic data (births, in- and out-migration, marriage status) of all residents in the area under surveillance since 2005 (Table 1). A total of 21 bi-annual census rounds have been conducted. Other data collected are global positioning system (GPS) coordinates and description of key features like schools, health centres, water sources, road junctions, churches and mosques. Bi-annual census rounds are conducted to update data. For all deaths, we use three World Health Organization (WHO) verbal and social autopsy tools (version 2009) for neonates (0–28 days), children (29 days to 14 years) and adults (≥15 years). Information about education of all household members and the household's socioeconomic status is collected once every 2 years.

The IMHDSS population has been growing annually at an average rate of 4.8% since 2005. Currently (2017), there are 94 568 individuals living in 18 634 active households (Figure 2). The average size of a typical household is five individuals in rural and four in urban/peri-urban areas. The male to female ratio is 96:100. The overall response rate is 75%. Over time, the response rate has been affected by vacant households (10.4%), demolished households (5.8%), changed status of premises (5.5%), not found at home (0.2%) and refusals (0.04%).

Tables 2 and 3 show more specific information on data collected on the core variables and database structure.

The 2017 IMHDSS population pyramid (Figure 2) shows the age–sex distribution of the surveillance population cohort. The majority are young people <15 years old (48% compared with 50% of the national estimate,

Table 1. Selected core demographic indicators in the Iganga Mayuge Health and Demographic Surveillance Site (IMHDSS)

Vital statistics	2016	2017
Crude birth rate (per 1000 residents)	27.7	20.4
Crude death rate (per 1000 residents)	6.2	4.1
Early neonatal mortality rate (1st week of life) per 1000 live births	32.9	22.3
Neonatal mortality rate per 1000 live births	35.5	28.5
Post mortality rate (29 days to <1 year) per 1000 live births	16.6	8.29
Infant mortality rate per 1000 live births	41.8	36.8
<5 Years mortality rate per 1000 live births	78.8	58.6

Uganda Demographic and Health Survey (UDHS) 2016). Adolescents (10–19 years) make up 27% of the population compared with 24% of the national estimate (UDHS 2016). Approximately 51% is dependent population who are aged <15 years and those >65 years, which is comparable with the national estimate of 53% (UDHS 2016).

How have the IMHDSS databases been constructed and what has been measured?

Over time, the HDSS has measured births, deaths, in- and out-migration, marriage status as well as other sociodemographic data as shown in Table 2 for the various data tables and Table 3 for the core variables. Data are collected using the common HDSS software Household Registration System (HRS). The database is stored on a secure server with firewalls for protection from unauthorized external access and using common data linkage and security processes

Verbal and social autopsy data are collected routinely using the WHO tools[2,3] irrespective of the regular update rounds. Two physicians independently review the verbal autopsies (VAs) to assign the cause of death. The social autopsy looks at issues such as health care seeking practices and the cause of death, as understood by the caretaker of the deceased, before the form is reviewed by the physicians. Pregnancies and their outcomes are reported by village-based scouts and registered at the IMHDSS to supplement and improve the bi-annual update rounds data. All operations follow standard INDEPTH definitions and procedures[4].

An in-house Scientific Review Committee reviews all research, followed by an independent ethics committee duly accredited by the national regulator. All studies are registered with the Uganda National Council of Science and Technology (UNCST) before commencement of data collection.

What has it found? Key findings and publications

The IMHDSS has been used intensively for research in maternal and newborn health, NCDs and vaccination.

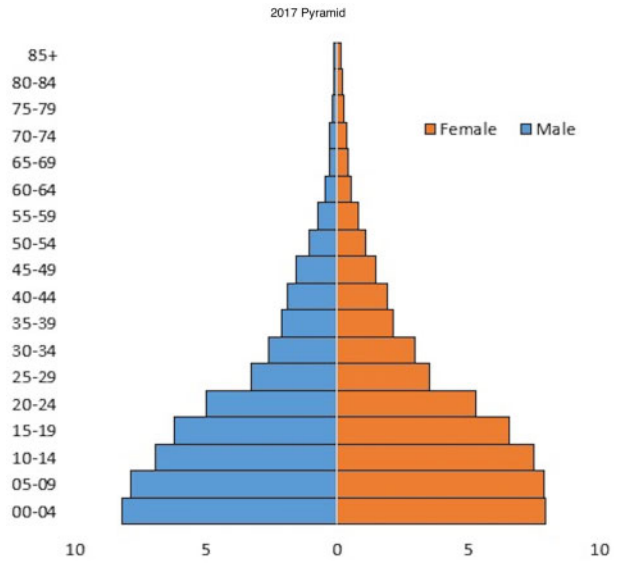

Figure 2. Iganga Mayuge Health and Demographic Surveillance Site (IMHDSS) population 2017 pyramid.

Furthermore, community dialogues to enhance pharmacovigilance by improving patients reporting of adverse drug reactions in collaboration with the National Drug Authority, Uganda, is part of the core activities. The site is a member of the verbal and Social Autopsy Study and the Epilepsy Working Groups of INDEPTH.

Maternal and newborn health

Early studies included a cluster-randomized trial, the Uganda Newborn Study (UNEST), to evaluate community health workers' activities for improved newborn health.[1,5] Results indicated significantly improved essential newborn care practices among mothers in the intervention compared with the control clusters.[1] Home visits were pro-poor, with more women in the poorest quintile visited by community health workers compared with families in the least poor quintile. Care for premature babies, such as Kangaroo Mother Care, was identified as an important intervention that needs to be addressed for further mortality reduction.[6]

Table 2. Information collected at each re-enumeration round of the Iganga Mayuge Health and Demographic Surveillance Site (IMHDSS)

Subject	Information
Household (locationid)	Latitude, longitude coordinates, household head name
Individuals (individid)	Names, sex, date of birth, ethnic group, religion, parental survivorship
Residents	Update of residency status (defined as resident for >4 consecutive months), death, in-migration, out-migration, out residence, entry residence
Pregnancy outcome of existing pregnancy records and births	Mother's id, pregnancy outcome (live birth, stillbirth, abortion, miscarriage), attendance of antenatal care (ANC) during pregnancy, place of delivery, postnatal village health teams (VHT) visit
Deaths	Date of death, place of death, individual name, individual id, cause of death
In-migration	In-migration date, reason for in-migration, name of in-migrant, sex of in-migrant, origin of migration episode
Out-migration	Out-migration date, reason for out-migration, name of out-migrant, sex of out-migrant, destination of out-migration episode
Entry residence	Previous residence within the IMHDSS, moved alone or with whole family, reason for entry
Out residence	Origin of out residence episode, moved alone or with whole family, reason for exit
Individual status	Given to individuals ≥12 years, marital status, highest education level, occupation, religion

Table 3. Variable for the social and demographic characteristics of the population under surveillance

Key social and demographic variables	
Sex	Gender of an individual
Age and date of birth	Data on the age of the population are obtained by asking the day, month and year of birth of an individual at the time of the household visit
Ethnicity	Ethnicity is recorded for all persons aged ≥12 years
Religion	Religion is recorded for all persons aged ≥12 years. The classifications for religion are Catholic, Protestant, Muslim, Pentecostal, Seventh Day Adventist (SDA), other Christian and no religion
Education level (highest level attained)	Education is recorded for all persons aged ≥6 years. The classifications for education are: none, primary, secondary, tertiary and university
Marital status	Marital status is recorded for all persons aged ≥12 years. The classifications for marital status are: married, never married, widowed, separated, divorced, cohabiting and reconciliation
Socioeconomic status	Socioeconomic status index is computed for all households based on household facility and asset ownership
Occupation	Source of income for household members. The classifications are: shop/business, boda boda, professional, agriculture, market vendor, laborer, mechanical work and other
Exit and entry	These are internal movements of individuals within the demographic surveillance area (DSA)
In-migration and out-migration	These are movements of individuals in and out of the demographic surveillance area (DSA)

Other important findings stem from a cluster-randomized controlled trial testing integrated community case management involving community medicine distributors, indicating improved and more rational use of antimalarial drugs and antibiotics for treatment of pneumonia.[7] Current work includes improved measurements for stillbirth and neonatal mortality and the description of neurodevelopmental disabilities[4] including cerebral palsy.[8]

NCDs

Several studies have established the prevalence on NCDs, such as diabetes (7.4%; 95% confidence interval 6.1–8.8 in men and women).[9] Prevalence of overweight was found to be 18% (25.2% of women; 9.7% of men) whereas prevalence of obesity was 5.3% (8.3% of women; 2.2% of men). The prevalence of hypertension was 20.5%.[10] The Centre is working with Makerere University College of

Health Sciences and the Karolinska Institutet to set up a NCDs centre of excellence in Uganda. The site is preparing a population cohort to facilitate long-term studies on risk factors for cardiovascular disease, the Mobile Phone Surveys for Non-Communicable Diseases (NCD) Risk Factors program.[11] The IMHDSS was one of the sites in a study establishing the prevalence of epilepsy in three Africa sites, the Studies of the Epidemiology of Epilepsy in Demographic Sites (SEEDS) project. The overall adjusted prevalence of convulsive status epilepticus among people with active convulsive epilepsy was 2.8 per 1000 population in Iganga.[12,13] Association with antenatal and perinatal events were described.[13,14] In addition, the IMHDSS is used to establish the unmet need for other disease priorities such as estimates of injury and disability,[15] as well as groin hernia surgery.[16]

Vaccine preparedness trials

Among vaccine preparedness studies was a TB Vaccine Trial Site Preparedness study supported by the European Union, which indicated a low prevalence of TB within the target population of adolescents.[17–19] Malaria is highly endemic in the study area according to a study prepared with the support of the African Malaria Network Trust (AMANET).[20]

Mortality data

From the cause of death data collected through VAs, perinatal and neonatal mortality continue to be high. In 2016, the perinatal and neonatal mortality rate was 22 per 1000 pregnancies and there was a substantial number of stillbirth cases. The other main causes of death are birth injury or asphyxia and prematurity, whereas infectious diseases, neonatal tetanus, pneumonia and other febrile illnesses have become rarer.

In the same year, 2016, hypertension was the main cause of death in adults (≥15 years) followed by malaria, diabetes and AIDS. Malaria is still the number one killer for children beyond the neonatal period and is the cause of 59% of deaths. The second most common is malnutrition (15%).

Migration data

The majority of in- and out-migration involves the most productive individuals aged between 20 and 40 years (Figure 3). The youths that migrate into the DSA come with their children, which is not the case for those moving out. There is need for further studies to understand the economic burden such migration patterns place on the elderly, since mobility decreases with increase in age for both males and females.

Future analysis plans and projects

The IMHDSS will continue to provide data on demographic events, education and socioeconomic indicators, showing the trends and patterns. The team will also conduct joint analyses with the other HDSS centres in Uganda to compare the core indicators in different population groups and regions of Uganda and other INDEPTH sites from different regions of the world.

A major future research area identified is describing the burden of NCDs as well as testing innovative interventions to address NCD morbidity and mortality. However, to fully use the opportunities of the IMHDSS, linkages between (i) health facility and (ii) demographic data need to be established—and solutions are at present piloted in the IMHDSS. Currently the Centre is implementing an EHR system in one community-based health facility's outpatient and antenatal clinic. The system has IMHDSS identifiers for community members within the catchment area of that facility. Individuals are advised to carry health cards (with a barcode) whenever they visit the particular health facility. Each household member is identified at the health facility using either their fingerprint biometrics, the barcode or their photograph. The goal is to roll this out in all high caseload community-based health facilities serving at least 60 patients daily.

Other areas of interest are vaccinations, maternal immunization, drug utilization, antimicrobial use and pharmacovigilance or drug safety monitoring at population level, including pharmacoepidemiology, pharmacovigilance, post-marketing surveillance and Phase IV studies for new or old drugs and vaccines in real-life situations.

What are the main strengths and weaknesses?

The IMHDSS has established a good rapport with the communities facilitating access to community study participants. There is a network of public health facilities in the community, both lower level clinics and large hospitals—one in each district where clinical-based studies can be conducted. The population under surveillance provides a robust sampling frame covering all age groups (0–96 years) with diverse demographic characteristics—a key resource for any kind of community, epidemiological or clinical study.

A key strength is the availability of two hospitals—one government district hospital and one faith-based hospital that support special studies. For example the groin hernia

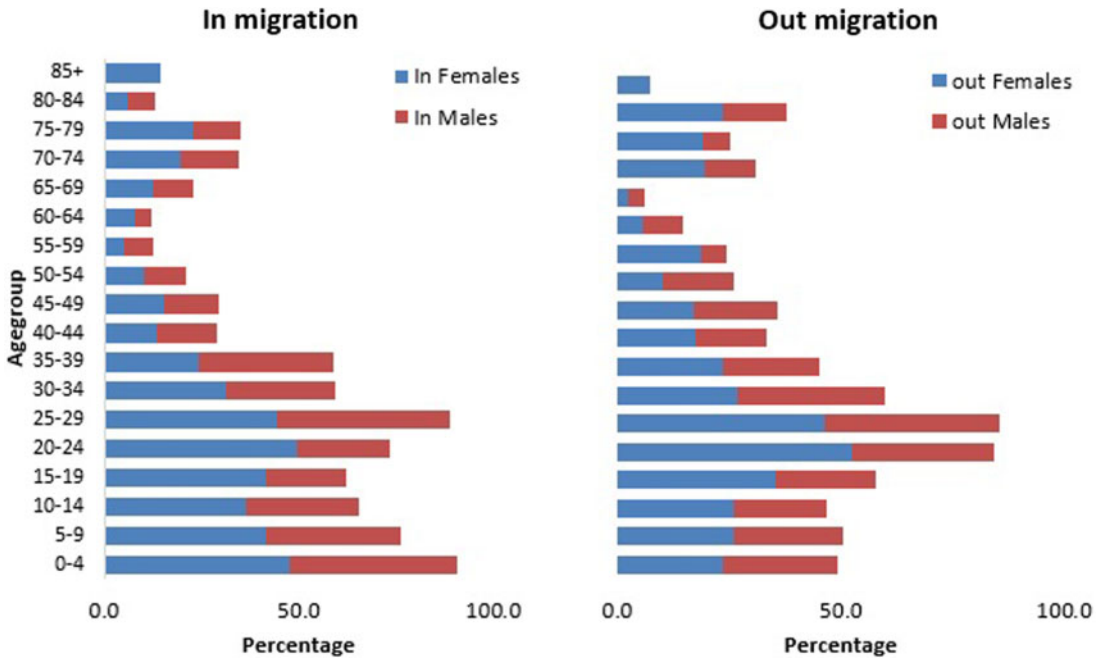

Figure 3. Gender–age distribution among those migrating in and out of the Demographic Surveillance Area (DSA), 2017.

study[16] utilized those facilities to carry out surgeries whereas the cerebral palsy studies set up clinics in Iganga Hospital to manage patients that were screened as positive by the HDSS teams.[8] Other studies like the malaria vaccine trials supported by the European & Developing Countries Clinical Trials Partnership (EDCTP)[20] recruited patients from both community health facilities and Iganga hospital with the clinical trials coordination clinic built in the hospital while recruiting from the HDSS community.

The IMHDSS was set up to support research training for Makerere University faculty and students, a role it has and continues to play effectively because of the close partnership with experts from the university and other collaborating institutions. This has supported several junior researchers to develop their research careers in the form of PhDs and Master's theses thereby contributing to the development of public health research human resources. The Centre is now a fully registered not-for-profit research organization that is a semi-autonomous organ of Makerere University and supports research activities with minimal bureaucratic bottlenecks. The clear organizational framework with experienced leadership and a board of directors composed of seasoned researchers and academicians makes it easy and attractive to conduct research in the platform.

The IMHDSS is now collecting data electronically using the Open Data Kit (ODK) application for most of the studies piggybacked on the 12-year longitudinal population cohort as well as for the core HDSS data collection. This has minimized the cost of data collection, reduced the use of paper (saving the environment), minimized errors and improved data quality as well as made real-time data processing and analysis possible. These are added to the GPS data that has been collected by the IMHDSS since 2010. Coordinates are updated for each household, health facility, school, road and water source twice a year during routine HDSS update rounds and surveys. This enhances spatial analysis and geographical visualization techniques, providing a faster and robust method of understanding disease hotspots, patterns and occurrences for better decision making. Delay in resolving exits and entries has been delaying determination of migration status, which to some extent affects the specific study denominators.

The cause of deaths is still coded by physicians which leads to major delays. We are at present preparing for electronic data capturing and automated coding of VA and hope that this will assist in overcoming the challenges of delays.

Can I get hold of the data? Where can I find out more?

The MUCHAP/IMHDSS welcomes collaborations that are internal as well as external and agrees with the principle of data sharing without compromising the rights and privacy of participants. The standardization of data collection tools in all INDEPTH HDSS sites makes it possible to merge data across sites of differing geographical and epidemiological ecosystems to facilitate multi-centric analysis of

data and comparisons. We have shared our data through the iShare initiative of INDEPTH where core HDSS data are accessible online [http://www.indepth-ishare.org/index.php/catalog/79]. There is a formal data sharing process guided by data sharing standard operating procedures. Data can be requested formally from the IMHDSS leader (info@muchap.mak.ac.ug) who is the point of contact for all data requests. There are more details on the website (www.muchap.mak.ac.ug).

Profile in a nutshell

- The Iganga Mayuge Health and Demographic Surveillance Site is located in the eastern part of Uganda 115 km from the capital city of Kampala. The population under surveillance is 94 568 people (2017 mid-year population), with ~60% living in rural and the rest in peri-urban areas.
- Data for update rounds is collected twice a year, since 2005. A total of 21 bi-annual census rounds have been conducted. The core demographic events covered are migrations, births, deaths including cause of deaths using verbal autopsy methodology. Data are also collected at various times on pregnancy, education, immunization, injury and socio-economic status.
- Core research areas include population demographic surveillance, communicable and non-communicable diseases surveillance, health systems research, implementations science, poverty, agriculture, climate change, environment, technology and social science research.

Funding

The IMHDSS activities have mainly been supported by Makerere University through the framework of a Makerere–Sweden bilateral research collaboration grant from the Swedish International Development Agency (SIDA) since its inception. Grant number Mak:372. Additional funding is raised from the periodic add-on research studies charged as overhead for use of the IMHDSS research platform.

Conflict of interest

None declared.

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