Contextual Documentation for the Shared ALPHA Data Kisesa

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Quick links

1. What is the Kisesa study data catalogue link?
   Kisesa data catalogue is not available online
2. What is the reference/ citation to the Kisesa study cohort profile?
   https://pubmed.ncbi.nlm.nih.gov/26403815/ (Kishamawe et al. 2015)
3. Where are questionnaires available?

Questionnaires are available on request

Study Background

Study description

The Kisesa open HIV cohort study is in north-western Tanzania close to Lake Victoria and 20 kilometres from Tanzania's second city Mwanza. The study is described in detail here https://pubmed.ncbi.nlm.nih.gov/26403815/

Study area

It is in the Kisesa Ward of the Magu district in the Mwanza administrative region of Tanzania. Kisesa is one of the 31 wards of the Magu district. The study covers all residents of the Kisesa ward.

Study eligibility

Health and Demographic Surveillance in the Kisesa study covers all residents of the Kisesa Ward. The serological surveys done at about three-year intervals cover resident adults aged 15 years and above. See (Kishamawe et al. 2015) for more details.

Study process

The Kisesa HDSS and serological survey study processes are described in the following papers: (Kishamawe et al. 2015; Wambura et al. 2007). A brief overview is provided here.

HDSS Baseline census

The baseline census for the HDSS was done in 1994. It included the registration of all individuals and their households in the geographically demarcated area.

HDSS Follow up updates

Follow up updates of the data are done through household visits by enumerators.
During a visit, the demographic events – births, deaths and migration are listed. In addition, date of birth, date of death and the date that a member moved out of a household are recorded. A new arrival may be a new birth to a resident mother, a returning previously resident member or a new inmigrant. A new inmigrant is recorded as a household member if they stayed or intend to stay for at least three months. Those who left a household and are expected not to return are considered outmigrants. The Kisesa study performs approximately two HDSS rounds per year. A member of the household, usually the household head or a well-informed household member responds on behalf of all members, otherwise known as proxy reporting. Among the recorded details are residency status for each member, vital status, whether each member is still in the household or has moved, new and returning members, pregnancy, parent-child links, births, deaths, education status. In addition, special modules such as disability module have been added to some HDSS rounds.

HIV data

The study conducts regular serological surveys to collect information relevant to HIV and to test particpants for HIV infection. All adults aged 15 and over who were residents during the demographic surveillance round preceding the serological survey round are eligible for the sero-survey. This survey is done roughly at three years intervals. It includes HIV testing and a questionnaire on socio-demographic questions and sexual behaviour, knowledge of HIV and ART and use of health services. The research testing protocol has been based on informed consent without disclosure of results. However, VCT has been offered to study participants interested in knowing their status since the third sero-survey round (1999/2000). Participants have been offered a separate Voluntary Counselling and Testing service if they wished to learn their HIV status. Rapid HIV tests became available by the fifth round (2006/ 2007) enabling results to be provided within 15 minutes of testing. VCT services also became available at a clinic in the health centre since 2005. Referral to zonal hospital have also been done since 2005 for ART. Decentralisation of referrals in 2008 to enable HIV positive participants to access ART from Kisesa Health Centre. Unique identifiers are used to link between sero surveys and HDSS data
Temporary mobile clinics are setup during sero survey and adults aged 15 and above are interviewed and invited for HIV testing.

Timings and scope of study rounds

There were 31 rounds of HDSS data collection between 1994 and 2016 which collected demographic information from a household respondent. There were 8 serological survey rounds over the same period which consisted of interview and HIV testing for resident adults aged 15 and over.

Data collection and management

HDSS - Data collection during the baseline enumeration and update visits was done using paper-based forms until 2011. Electronic data collection through Personal Digital Assistants (PDAs) was introduced in 2012 (Kishamawe et al. 2015).

Serological surveys were carried out on paper until sero 6 and electronic data collection has been used since then.

Residency and household definitions

In the Kisesa study, a household is defined as a group of people living together in the same compound and who regularly eat together from the same pot (Kishamawe et al. 2015)
If previously registered in the HDSS any household member who is present in the household during a particular data collection round is counted as a resident. New residents are: new births to a resident mother, in migrants who have stayed, or intend to stay, for at least three months and a previously resident member who has returned after an absence and stayed or intends to stay for at least three months
Dates for moving out and coming in are recorded when reported by the household respondent. Incomplete dates are set at the 15th of the month. If only year is reported, the date is taken to be half way between 1st January of that year and the date of interview. If no date is reported the midpoint between the previous round interview date and the current round is used.

Migration

The serological survey processes are the main mechanism for migration reconciliation. Serological survey study identifiers are used for linking across survey rounds and HDSS data. Those who previously attended a serological survey are invited to attend the next round. The invitation mechanism identifies those who have moved and reconciles their information through a unique identification number. This does not cater for those who have not participated in the serological survey (all residents are invited to attend regardless of previous participation).
A significant number of residents are not reconciled when they migrate between households.

Date imputation, including right censoring

Right censoring

People who remain resident at the last HDSS round have their follow-up time censored at the date of that last round.

Imputation of missing dates of migration to/from households

If dates of in or outmigration are missing the date of interview in which the in or out migration was first reported are used instead.

Imputation of missing dates of birth (DoB)

Dates of birth are captured in the HDSS and in each sero-survey. Incomplete dates of birth are set at the 15th of the month. If only year of birth is reported, date of birth is taken to be half way between 1st January of that year and the date of interview. If no date of birth is ever reported the date of birth is imputed as half way between the previous date the household was visited and the current date.

Inconsistently reported dates of birth are reconciled as follows: the serosurvey date is preferred to the HDSS date, after that, the most commonly reported year and month are used. If a day of birth is reported that is used instead of the 15th of the month.

Data quality checks

Household census: what is done with previously enumerated individuals for whom there is no data in current round

Inconsistencies in the static variables such as sex

If the recorded sex differs between the serosurvey and HDSS data then the serosurvey record is used. If different information was given on multiple occasions, the most commonly reported information is used.

Inconsistencies in the reported order of key events

Recording of deaths- are there any other sources of data on deaths?

All death data is based on information reported during the census. Each HDSS round begins with a pre-populated household listing based on the previous round and individuals previously interviewed. The household proxy is asked what has happened to any individuals who are listed but no longer present and deaths are captured in this process.
Verbal autopsy interview visit follows report of a death in the household. The date of death information updated based on VA interview. This is usually after the death has been confirmed by the remaining household members (if the household still exists in the area).

Other data recorded outside census rounds

- None

Cross-round linking and harmonisation

Linking of individuals across rounds

Serological survey identification numbers are used to link between HDSS and serological survey and also across serological survey round.
HDSS identifiers are specific to location of residency, they change when individuals and or households move. They can link across HDSS rounds for those who do not move. Serosurvey invitation slips contain HDSS identifiers, and serosurvey staff have HDSS listings to identify survey participants who arrive without their invitations.

Linking of HIV test results to individuals

Samples taken for HIV testing have the individual's serosurvey identification number attached and this is used to link the test results to the individual interview data.

Data harmonisation

Data for each survey and HDSS round are stored in separate tables, and collated for analysis or when developing specifications. All data are stored in the same database on the project's servers.

HIV testing protocol

The first round of sero serological survey collected venous blood. The subsequent rounds collected dry blood spot on filter paper through a finger prick sample.

Serosurvey	First test	Confirmatory test	Tie-break
1	Vironostika HIV-MIXT	Enzygnost HIV1/HIV2	Western blot
2	Vironostika HIV-MIXT	Enzygnost HIV1/HIV2	ELISAs repeated
3	Vironostika HIV-MIXT	Enzygnost HIV1/HIV2	ELISAs repeated
4	Uniform II	Enzygnost HIV1/HIV2	ELISAs repeated
5	Uniform II	Enzygnost HIV1/HIV2	ELISAs repeated
6	4th Generation Vironostika HIV Uni-Form II Ag/Ab assay	Enzygnost HIV ELISA test Enzygnost Anti HIV ½ Plus kit ref OQFK2	ELISAs repeated
7	Uniform II	Enzygnost HIV1/HIV2	ELISAs repeated
8	Determine (RDT)	Unigold (RDT)	

Are self-reported test results included

No self-reported HIV test results are included.

Reconciliation of discrepant HIV test results across rounds (retroconvertors/seroreversion)

If an individual who as tested positive for HIV at a previous serosurvey subsequently tests negative the test result and identification for this and previous rounds are reviewed to ensure that the correct results have been assigned to the person and that the records all correspond to the same person

Glossary

Residency episode: A period of time when an individual is continuously living in a household defined by the start and end dates of that period. Studies can vary in how they define households, and what constitutes a period of continuous residence. Variations usually reflect local differences in residency patterns, and allow capture of data on, for example, capture seasonal labour migrations where relevant.

Internal migration: A change of residence within the study area. These can be challenging to capture correctly in the data. The exit from the original household and entry into the new household is straightforward because they are reported as exiting/entering at the next data collection round. However it is challenging to identify the person in the new household as the same person who has left the old household unless enough information on the person has been collected in both households to unambiguously identify the individual. Dates of birth are not always well known or accurately reported by proxy respondents and names may change (for example upon marriage or the birth of a child) or be spelled in a variety of ways. National identity documents are not univeral and where held, are not necessarily available to proxy respondents.

Migration reconciliation: The process of identifying the same individual across periods of residence in different households. This may be done by fieldworkers, at the data processing stage or using a combination of both approaches.

Date imputation: Dates may not be completely reported or accurately recorded (particularly when using paper forms). Construction of the datasets requires a date and so a missing or imcomplete date must be replaced with a complete data. The rules used to impute the date depend on the event for which the date is being imputed and the study procedures.

Right censoring: Data are right-censored if the subject under study has not yet experienced the event which ends their period of follow up. In these open-cohorts, follow-up ends when the individual dies. Most of the cohort is alive throughout the study period and is resident at the most recent survey round. Their data are incomplete, and are described as right-censored.

Residency gaps: When an individual leaves the study area their follow up is paused (potentially indefinitely) and their residency episode ends at the date of out-migration. If the person rejoins the study they begin a new residency episode upon their return and there is a gap in their follow up time which corresponds to the period when they lived outside the study area.

Seroconversion: For HIV, seroconversion refers to infection with HIV and the subsequent production of detectable antibodies to HIV. Although this is a process which takes a number of weeks, we assign a single date for this which we use as a proxy for the point of acquisition of HIV.

retroconvertor: In the uncommon setting of a longitudinal population-based study on HIV, participants are regularly and repeatedly tested for HIV following the prevailing diagnostic testing algorithms. In many survey, rounds people living with HIV are retested, alongside HIV-negative participants. In some instances, tests on people who have previously tested positive, perhaps on multiple occasions, return a negative result. Testing of samples is blind to the previous results of the individuals. When this happens we refer to these individuals as retroconvertors.