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HEALTH AND DEMOGRAPHIC SURVEILLANCE SYSTEM PROFILE

Profile: The Kilifi Health and Demographic Surveillance System (KHDSS)

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Summary The Kilifi Health and Demographic Surveillance System (KHDSS), located on the Indian Ocean coast of Kenya, was established in 2000 as a record of births, pregnancies, migration events and deaths and is maintained by 4-monthly household visits. The study area was selected to capture the majority of patients admitted to Kilifi District Hospital. The KHDSS has 260 000 residents and the hospital admits 4400 paediatric patients and 3400 adult patients per year. At the hospital, morbidity events are linked in real time by a computer search of the population register. Linked surveillance was extended to KHDSS vaccine clinics in 2008.

KHDSS data have been used to define the incidence of hospital presentation with childhood infectious diseases (e.g. rotavirus diarrhoea, pneumococcal disease), to test the association between genetic risk factors (e.g. thalassaemia and sickle cell disease) and infectious diseases, to define the community prevalence of chronic diseases (e.g. epilepsy), to evaluate access to health care and to calculate the operational effectiveness of major public health interventions (e.g. conjugate *Haemophilus influenzae* type b vaccine). Rapport with residents is maintained through an active programme of community engagement. A system of collaborative engagement exists for sharing data on survival, morbidity, socio-economic status and vaccine coverage.

Keywords Disease burden, invasive bacterial diseases, haemoglobinopathies, vaccine effectiveness, child mortality, demography

Why was the HDSS set up?

The Kilifi Health and Demographic Surveillance System (KHDSS) is nested in the KEMRI-Wellcome Trust Research Programme in Kilifi, on the Indian Ocean coast of Kenya. The research programme was established in 1989, as a partnership between the Kenya Medical Research Institute, the Wellcome Trust and the University of Oxford, to conduct medical research on infectious diseases of children. During the 1990s, the programme developed longitudinal clinical surveillance in the paediatric wards of Kilifi District Hospital (KDH) and evaluated the impact of insecticide-treated bednets on malaria morbidity and mortality in the surrounding community.[1,2] This involved establishing temporary demographic surveillance for a population of 56 000

people. The idea of the KHDSS was conceived in 2000 to create a longitudinal community-based study linked, at inception, to hospital morbidity surveillance by integrating the existing clinical and field-based research infrastructure.

The rationale for the project was (i) to define the incidence and prevalence of significant local diseases of childhood; (ii) to evaluate the impact of new community-based interventions against infectious diseases; and (iii) to provide an epidemiological sampling frame for cross-sectional surveys and case–control studies at the research programme. Although it was established as a framework for epidemiological studies, it also functions as a demographic surveillance system and was affiliated to The INDEPTH network (http://www.indepth-network.org/) in August 2005.

What does it cover now?

At the outset, the project aimed to define rates of mortality, migration and fertility in a setting that lacked formal vital registration systems; to estimate the incidence of major infectious diseases (invasive bacterial infections and malaria) in children; to test the association between genetic risk factors (especially haemoglobinopathies) and infectious diseases in childhood; to calculate the operational effectiveness of a new conjugate vaccine against invasive *H. influenzae* type b disease; and to define the prevalence and incidence of epilepsy in the community.

Additional objectives studied subsequently include: defining vaccine coverage for routine childhood immunizations and estimating the impact of access to hospital care and vaccines on morbidity and mortality; calculating the excess mortality among children discharged from hospital; defining the incidence of potentially vaccine-preventable viral infections of childhood including rotavirus and respiratory syncytial virus and estimating the direct and indirect effects of routine immunization with pneumococcal conjugate vaccine.

Where is the HDSS area?

As the underlying rationale for the study was to create a community-based surveillance system linked to hospital-based disease surveillance, we set the geographical boundaries of the KHDSS with reference to the area served by KDH. An area of 891 km^2 was selected (Figure 1) as the smallest number of administrative sublocations that collectively included the stated sublocation of residence of at least 80% of paediatric inpatients in the preceding 3 years (1998–2000). KDH is located in Kilifi town, 3° south of the equator and KHDSS extends up and down the coastal strip for 35 km from Kilifi. KDH is the only inpatient facility offering paediatric services in the KHDSS area. The local economy is based on subsistence farming of maize, cassava, cashew nuts and coconuts as well as goats and dairy cows. Two large agricultural estates, two research institutes and several tourist hotels contribute to local employment.

In 2001, the area was mapped using ArcGIS Desktop software (ESRI, Redlands, CA) by surveyors using

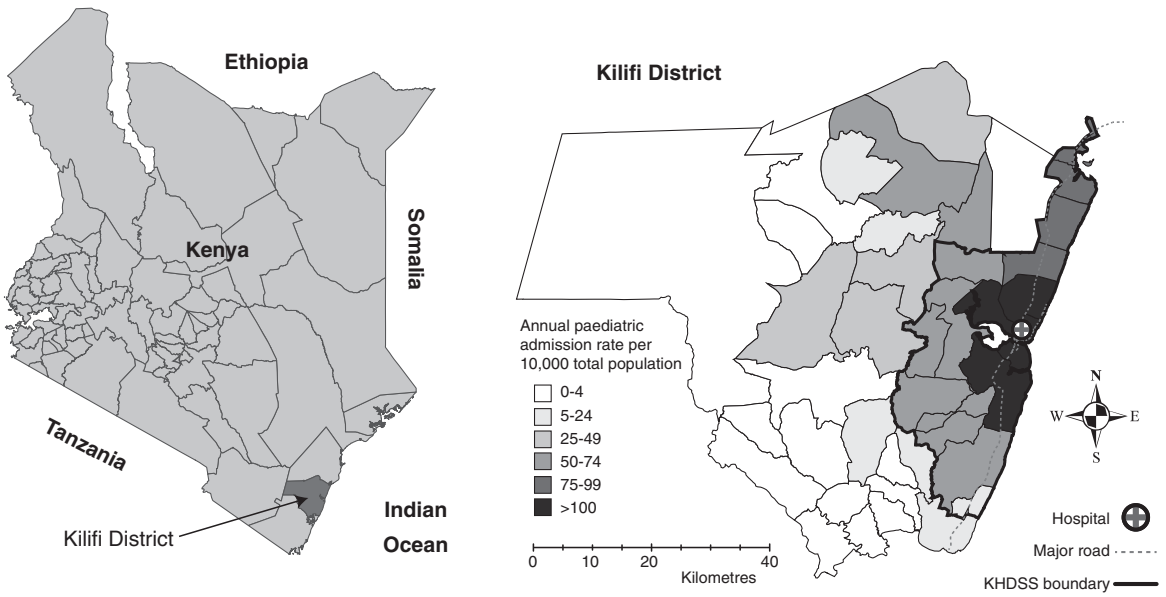

Figure 1 Situation of Kilifi District in Kenya and map of Kilifi District showing the rate of paediatric admissions to Kilifi District Hospital by administrative sublocation and the boundary of the KHDSS. Data are taken from reported sublocations of children aged <5 years admitted to hospital during 1998–2000. The district and sublocation boundaries are those relevant to 2001. In 2009, the Government of Kenya subdivided the district into three new districts but the KHDSS boundaries have remained constant

handheld GPS receivers. The area, which consists of 40 administrative sublocations in 15 administrative locations, was subdivided into 186 enumeration zones each with approximately 135 households. Community interviewers visited every household when the residents were at home, explained the work of the research programme and requested their verbal consent to participate in a continuous demographic surveillance system. A census of all residents was taken between September 2000 and October 2001 defining a population of 198 063. Of these, 24 700 lived in Kilifi town and the remainder lived in rural dwellings.

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

In addition to these original residents all subsequent in-migrants have been invited to participate. A resident is defined as a person who has stayed or intends to stay in a study area household for $\geqslant 3$ months and who has spent $\geqslant 1$ night in the household. To 'stay' means that the individual sleeps, on average, four or more nights per week at this household. In rural areas, a household is a contiguous cluster of dwellings identified by a single name (often that of a household head, either living or deceased). In most cases, a household consists of 2–6 buildings each accommodating related nuclear families. In urban areas, a household is a compound or plot of land owned by a single individual or institution containing one or more dwelling or apartment.

In March 2011, there were 29 970 households with 261 919 residents under surveillance; 49% of these were aged <15 years and 18% were aged <5 years (Figure 2). The male:female ratio was 88:100. The demographic structure of the population varies markedly by administrative location (Figure 3). Rural areas have relatively few adults whereas the urban or semi-urban areas have a more balanced population structure.

Between September 2000 and September 2011, the population was enumerated 24 times. Residents are followed up by community interviewers administering a standard questionnaire at household visits (Figure 4). Prior to each re-enumeration, the household building structures are carefully resurveyed and mapped. The household questionnaires (available at http://www.kemri-wellcome.org/khdss) determine the vital status of each resident and, since March 2003, the pregnancy status of each female resident aged 13–55 years. Paper-based questionnaire data are manually checked on the day of collection, then double-entered and validated on a relational database within 48 h of collection to maintain a live population register.

In the initial census, 10 (0.04%) households refused to participate in the surveillance system. In May 2011, the number of non-participating households was 130 (0.43%). The communications team at the research programme visit all households who withdraw from the study to ascertain the reason for withdrawal and to try to resolve any issues that may have arisen. They also maintain a series of regular channels of communication with community members, including (i) KEMRI Community Representatives—groups of volunteers, organized by administrative location, who are elected by local communities to meet on a quarterly basis with research staff to discuss community views and concerns and (ii) Community Leaders—meetings are arranged every 1–2 years and provide a forum for recognized community elders and representatives to hear about and comment on the plans and activities of the research programme.

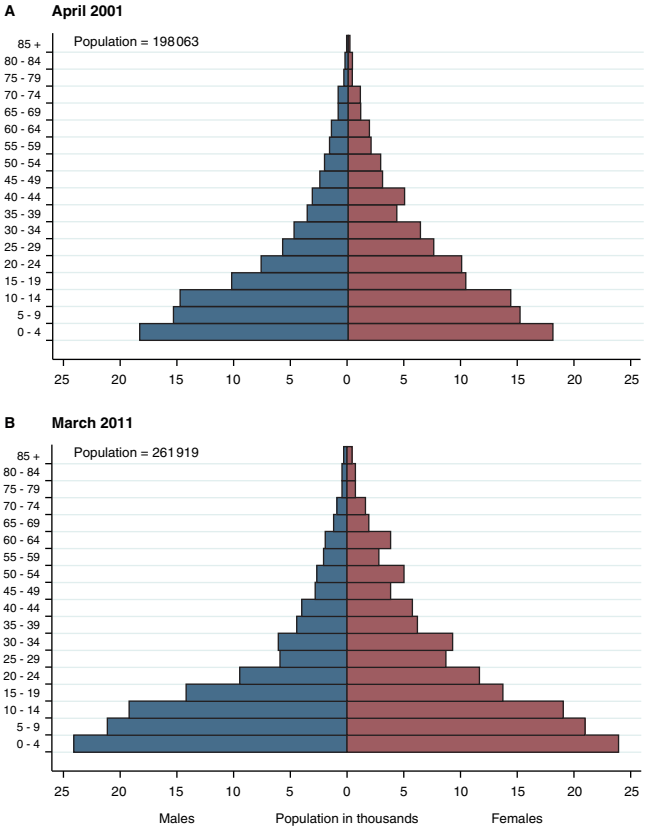

Figure 2 The population pyramid of the KHDSS in 2001 and in 2011. Data are taken from the initial census (date of median observation: 27 April 2001) and from the 23rd enumeration round (date of median observation: 18 March 2011)

What has been measured and how have the HDSS databases been constructed?

Different measurements have been made at four points of contact.

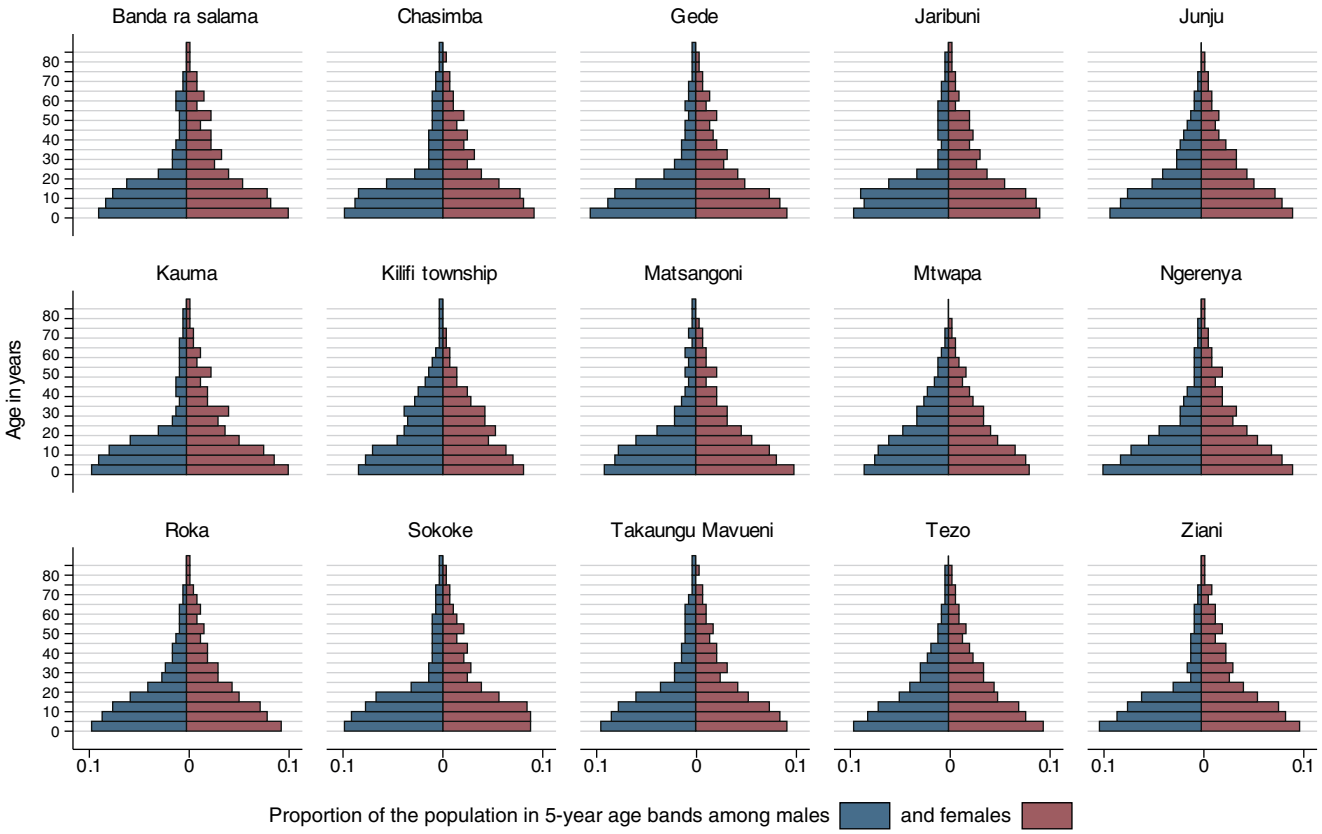

Figure 3 Population pyramids of the 15 administrative locations within the KHDSS. Data are taken from the 23rd enumeration round (date of median observation: 18 March 2011). Predominantly rural environments (the majority) show a marked attenuation of adult residents especially evident among males. Urban (Kilifi Township) and peri-urban areas (Mtwapa, Tezo) show a more gradual attenuation of the population with age, and a more even sex ratio

Figure 4 A census interview underway in a homestead within the KHDSS area

(i) At re-enumeration, community interviewers navigate to a household using GIS-derived maps and ask a single respondent to update the KHDSS information on each resident in turn (Table 1). The survey instrument is pre-printed from the population register and generates specific questions about pregnancy status among women of childbearing age and about National Identity Card (NIDC) information from adults whose data are not yet registered. The interviewers then invite respondents to identify all resident individuals not listed on the KHDSS record, newly born children and in-migrants. They ask the respondent to recall children who were born since the last enumeration round but have died subsequently. Finally, the interviewer requests an update on the status or outcome of pregnancy among female residents previously recorded as pregnant. In each re-enumeration round, a small number of additional questions is asked, unique to that round. These also cover information on educational achievement, socio-economic status, religion, water sources and bednet ownership and use.

(ii) At KDH, medical staff enter the findings of the history and clinical examination directly onto a computer admission record linked to the resident's unique identity number. All patients are investigated with a standard set of laboratory tests including a full blood count, malaria

slide and blood culture and all laboratory or radiographic investigations are linked to the patient's identity in the population register.

(iii) At KDH maternity department, ward clerks record the antenatal clinic attendance, health-seeking behaviour and complications and outcome of delivery directly onto a computer (Table 1).

Table 1 Information collected at each re-enumeration round of the KHDSS

Subject	Information
Homestead	Latitude, longitude
	Number of building units, number of storeys
	Building and roof materials and category (town house, courtyard house, apartment, institution and rural house)
Household	Household name
	Household head
Individuals	Names (3), sex, date of birth, ethnic group
Residents	Update of residency status (resident, died, out-migrated)
	Update pregnancy status for women aged 13–55 years
	Capture any new ID number (e.g. National ID card)
Births	Date and place of birth
	Names (3) and sex of child
	Mother's personal identity number (link)
Deaths	Date of death
	Place of death
In-migration	Date of in-migration
	Names (3), sex and date of birth of migrant
	Family relations between mother migrants and children
	Origin of migration episode
	Previous residence within the KHDSS
Out-migration	Date of out-migration
	Destination of migration episode
Pregnancy	Outcome of existing pregnancy records in the community
	LMP, number of previous pregnancies and ANC attendance record—for new pregnancies recorded in the community
	In maternity department, additional data on pregnancies includes: time of delivery, number of babies, stillborn, live-born child, maternal outcome (death) or complications

In all instances the source, place and date of the information are also recorded.

(iv) In 22 vaccine clinics around the KHDSS area, administrative staff record information onto laptop computers including the date and time of the visit and all vaccines administered.

All the data entry systems link to a central server and the data system is specified in FileMaker Pro v11 in a relational database model with 51 data tables organized around objects, events and episodes. The system is hosted in FileMaker Server Advanced v11 on Windows 2003 Server with mirrored hardware servers.

Matching of patients to the population register was established at the maternity and paediatric wards of KDH in April 2002 and extended to the adult wards in 2008 and to vaccine clinics in 2009 (Figure 5). At each setting, all patients are linked to the population register in real time. At the hospital, all links are made directly with the master database of the KHDSS; at the vaccine clinics, laptop computers, pre-populated with the population register, are used to link immunization data, and these are two-way synchronized with the master database once a week.

Individuals are matched to the population register on five criteria: names, sex, date of birth, place of residence and household characteristics (including the names, sex and ages of co-residents). As children are not formally named for several weeks after birth, it is more efficient to search on the mother's identity and use internal links in the database to navigate to the relevant child. A bespoke database query programme was designed to create and filter potential matches and link the unique personal identity to clinical episodes. The programme can also match patients on a variety of different identity numbers that have been pre-populated in the population register, including NIDC number, Mother and Child Booklet number, hospital admission

Figure 5 Mothers with their children queue for immunization services in a health facility within the KHDSS area during the World Pneumonia Day celebrations (12 November 2011)

number from previous hospital admissions or study number from up to 20 different studies.

Key findings and publications

The demographic indices of the KHDSS are summarized in Table 2.

We first used the passive disease surveillance system of the KHDSS to estimate the incidence of invasive bacterial infections in children aged <5 years (505/100 000/year).[3] The incidence of vaccine preventable diseases caused by *S. pneumoniae* and *H. influenzae* was 111 and 60/100 000/year, respectively. Ascertaining cases at the outpatient clinic, rather than the inpatient ward, the estimate for the incidence of *S. pneumoniae* bacteraemia was five times greater (597/100 000/year) and cases treated as outpatients were frequently severe.[4] Introduction of conjugate vaccine against *H. influenzae* type b (Hib) reduced the incidence of invasive Hib disease in children <5 years of age by 88% within 3 years.[5] In anticipation of rotavirus vaccine introduction, we measured the incidence of admission to hospital with diarrhoea and rotavirus infection in children (478/100 000/year) and characterized the mortality and the epidemiological pattern of presentation.[6] We used the KHDSS to examine the interactions between significant infectious pathogens demonstrating, for example, that over half of all invasive bacterial disease was attributable to prior exposure to *P. falciparum* infection.[7]

Using household surveys of symptoms of seizures, we described the prevalence of epilepsy in the KHDSS population (2.9/1000 residents) and highlighted the high proportion (70%) of epilepsy patients who are not on treatment.[8] Other chronic diseases characterized in the KHDSS include sickle cell disease and thalassaemias.[9,10]

A potential limitation of the KHDSS in measuring disease burden is that it fails to account for illness episodes that present to hospitals outside the study area or, more probably, that do not present to health services at all. For example, among KHDSS residents aged 1–59 months who died between the years 2006 and 2010, only 36% (1419/3917) died at Kilifi District Hospital. We investigated geographical access to health care for pneumonia and meningitis as measures of health equity. Although mortality in children varied 2-fold by geographical sublocation, there was no association between mortality rates and travel times to peripheral health centres or to KDH.[11] Immunization coverage for three doses of diphtheria–pertussis–tetanus vaccine in infancy was 95% and did not vary significantly by sublocation across the KHDSS area.[12] The incidence of admission to hospital with meningitis, but more especially with pneumonia, fell with increasing travel time to hospital, and we used the distance decay function to estimate the proportion of children with pneumonia and meningitis who fail to attend the hospital at 42% and 30%, respectively.[13] Children discharged from hospital have an 8-fold increase in mortality when compared with other children in the KHDSS and this is sustained for up to 2 years post-discharge.[14]

HIV prevalence has not been measured systematically in KHDSS but was recorded as 4.9% in routine antenatal screening at KDH between August 2004 and December 2007 with no evidence of a temporal trend.[7]

Table 2 Demographic characteristics of the KHDSS

Index	Result
Total resident population[a]	261 919
Male:female ratio[a]	88:100
Population density[a] (per km^2)	294
Population growth/100 pyo (%)	2.79
Crude birth rate/1000 pyo	34.7
Crude death rate/1000 pyo	5.85
Crude out-migration rate/1000 pyo	88.5
Crude in-migration rate/1000 pyo	89.3
Crude trans-migration rate/1000 pyo[b]	87.9
Total fertility rate	4.73
Neonatal mortality ratio/1000 live births	17.1
Infant mortality ratio/1000 live births	28.2
Under-5 mortality ratio/1000 live births	41.0
Life expectancy at birth (males) (years)	69.5
Life expectancy at birth (females) (years)	75.4

All figures are averages for the period January 2006 to December 2010 except those marked [a]which are taken from the 23rd enumeration round with a mid-point date of 18 March 2011.
[b]The transmigration rate is the rate of moving residence where the starting residence and the finishing residence are both households within KHDSS.

Future analysis plans?

In collaboration with the Kenya Ministry of Public Health and Sanitation, current fieldwork is supporting a cohort analysis of the direct and indirect effects of 10-valent pneumococcal conjugate vaccine introduced through the routine infant immunization programme. Providing data to the ministry for decision making is an important priority for the KHDSS. For example, we also plan to monitor morbidity and mortality trends associated with the introduction of rotavirus vaccine into the Kenyan immunization system. Within KHDSS, we have a subcohort study of the genetic determinants of childhood infectious diseases, which is examining the clinical and public health impact of haemoglobinopathies, especially sickle cell disease, and has also provided controls for a genome-wide association study of invasive bacterial disease.

We also plan to characterize fertility trends, analyse the association between migration and childhood morbidity/mortality and examine trends in maternal mortality and its determinants. We have established systems to describe the incidence of important diseases of adults including tuberculosis, stroke and meningitis. In the longer term, the KHDSS will explore the role of genetic risk factors, intra-uterine development, complications of childbirth and episodes of severe childhood infectious diseases on the morbidity and mortality experience of adults.

What are the main strengths and weaknesses?

The key strength of the system, and the feature which distinguishes it from most other demographic surveillance studies, is the continuous real-time linkage of morbidity events to our population register; however, this also has significant limitations. Matching of individuals at points of health contact relies on five self-reported characteristics. The most frequent full name in KHDSS is shared by 954 residents, and formal names, used for official records and certificates, are often replaced with informal names in common usage leading to confusion in matching. Most children aged $\geqslant$10 years do not recall their exact date of birth and middle-aged and elderly adults frequently recall only the approximate year of birth. As households are not clustered into villages, the resolution of residence 'addresses' is also relatively coarse. This means that linking individuals at household visits is generally quick and reliable but matching at wards and clinics requires the clerk to verify a match on the characteristics of other household members, which is time consuming.

At several points, we have considered introducing more rapid and reliable personal identifiers, such as fingerprinting, face recognition or study-specific ID cards. However, community feedback has suggested that these would change the tone of the KHDSS and diminish trust between the community and the investigators. NIDCs provide an attractive existing alternative and we have catalogued the NIDC numbers of 49% of adult residents. By the age of 40 years, almost all adults have obtained an NIDC but among young women aged $<$30 years, only 24% possess an NIDC.

The residence definition was focused on the stable population in whom longitudinal epidemiological studies would be most efficient. However, recurrent migration in a significant minority of the population tests the utility of the definition. Many men live and work outside the KHDSS, particularly in the nearby city of Mombasa. As they maintain their family in rural Kilifi District they consider themselves 'resident' there too.[15] Some mothers move frequently with their children between the homes of their husbands and parents and do not therefore fall within the classification of a resident. Although the study area was selected to represent the reported residences of 80% of the paediatric inpatients, with close matching on the population register it was ~65%, and furthermore, over a decade, this has reduced in practice to 55%.

We use trained, programme-based community interviewers for re-enumeration rounds. This means that their work and data can be closely supervised and quickly entered. In addition, because a community interviewer rarely visits the same household twice in consecutive rounds, the validity of every observation is tested directly in the next round. An alternative model, using village-based reporters who are retained to report births, deaths and migration events over a specific small area, allows for more timely event-reporting but is harder to supervise. The fact that the rural population in Kilifi District is not organized into clear village structures argues against this model, but the fact that vital events are currently reported only at 4–6 monthly rounds introduces problems with event recall that are especially evident when reconciling the dates of in- and out-migration within the KHDSS area.

Community-based mortality surveillance in Kilifi has been constrained by the lack of data from verbal autopsies, which have only recently been introduced. Cause of death can be determined for children who die in hospital and a previous validation of verbal autopsy in the study area has highlighted the significant constraints of interpreting this type of data.[16]

Data sharing and collaboration

Basic descriptive data, questionnaires and maps are available on the Research Programme website (www.kemri-wellcome.org/khdss). Anonymous, individual record-level data are also available, subject to ethical committee review, by contacting the KHDSS management committee with a proposal for collaboration. Proposals for new analyses or data use, including an analysis plan, should be specified in a standard data request form that is available at the website and submitted to the KHDSS management committee (hdss_data@kilifi.kemri-wellcome.org).

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Conflict of interest: None declared

KEY MESSAGES

- Kilifi DHSS is the largest population (260 000) under surveillance in tropical Africa for births, deaths, pregnancy and migration.
- The unique feature of KHDSS is that it was designed from the outset to link with morbidity surveillance at a district hospital/clinical research centre.
- The focus of research work has been on the incidence of infectious diseases in children, defining risk factors including genetic risks, and interventions to prevent infectious diseases—particularly vaccines.

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