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Cohort Profile: The Kaloleni/Rabai Community Health and Demographic Surveillance System

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Why was the cohort set up?

In many resource-constrained settings, availability of reliable vital statistics and health information is limited by lack of proper system for civil registration and health information. This is further limited by the fact that the majority of population health events, such as births, morbidity and mortality, occur outside the reach of these systems. In particular, obtaining credible data from rural and remote geographies can be even more constrained. The development of population-based surveillance systems in resource-constrained countries to monitor demographic and health events in these countries has as its basis the limited capacity of civil registration and health information systems. Locally rooted surveillance systems that are embedded in the nexus of existing community structures and local health systems can serve to address this gap.

In Kilifi county on the coast of Kenya, the Aga Khan University (AKU) and its partners at the Kaloleni and Rabai Sub-County Health Management Offices established a nested surveillance system that captures this information, using the government's community health strategy (CHS). The CHS is a national strategic response of the Kenyan government to the reversal in gains for population health indicators in the 1990s[1] and aims to bridge the gap between communities and the health system. The key innovation of CHS is the development of capacity to deliver basic health services at the community-health facility interface by a cadre of trained community health volunteers (CHVs). The CHVs function within the community level (Tier 1) service delivery structure known as the community health unit (CHU), which comprises on average 1000 households and 5000 people within a geographically defined area, aligned to an administrative sub-location.[1]

The objectives of the Kaloleni/Rabai Community Health and Demographic Surveillance System are to: (i) strengthen the capacity of the local department of health for collection, processing and use of population-level health and vital events data; and (ii) provide a platform serving the University's needs for population-level research and academic programming.

The Kaloleni/Rabai Community Health Surveillance System is centred around Mariakani township and covers

the largely rural sections of Kaloleni and Rabai sub-counties (Figure 1). The two sub-counties formed the Kaloleni district before the devolution of governance in 2013.[2]

The site lies between latitudes 3° 38' and 3° 59' south and longitudes 39° 21' and 39° 39' east. Kaloleni/Rabai sub-counties are among the poorest regions of Kenya[3] and were selected as the AKU field sites in consultation with the county government, due to unavailability of population-level health data and suspected poor population health indicators relative to other parts of Kilifi county[4]

The sub-counties cover an area of approximately 909 km^2 and have a population of about 352 175 people living in about 47 000 households.[5] There are few health indicator data specific to this area, and thus the larger Kilifi county estimates are usually presented to describe the health profile of this area. The study area has three administrative divisions (Rabai, Mariakani and Kaloleni) which are sub-divided into 12 locations and 34 sub-locations. Forty health facilities serve these sub-counties: 20 public health facilities, three faith-based facilities, three non-governmental organization (NGO) dispensaries and 14 privately owned dispensaries.[6]

Of the population, 40% are Christian, 40% are Muslim, 12% do not subscribe to any religion and the rest are traditionalists.[7] Approximately 70% of the population live below the poverty line and 81% rely on subsistence agriculture, crafts, casual labour and petty trading for their livelihoods. Maternal, neonatal and child health indicators are poorer than the national averages.[8,9]

The initial approval for this work was granted by the Aga Khan University (Kenya) Research Ethics Committee. This approval is renewed annually upon re-application and provision of written project updates.

Who is in the cohort and how often are they followed up?

The surveillance system links individual information longitudinally using unique identification numbers, and follows up all residents of 112 villages in the 10 CHUs (each CHU is made up of several villages). The system was established as a 6-monthly surveillance cycle in line with the CHS schedule. Baseline data were collected between February and June 2017, during which the CHVs registered a total of 78 183 residents whose demographic, health and vital

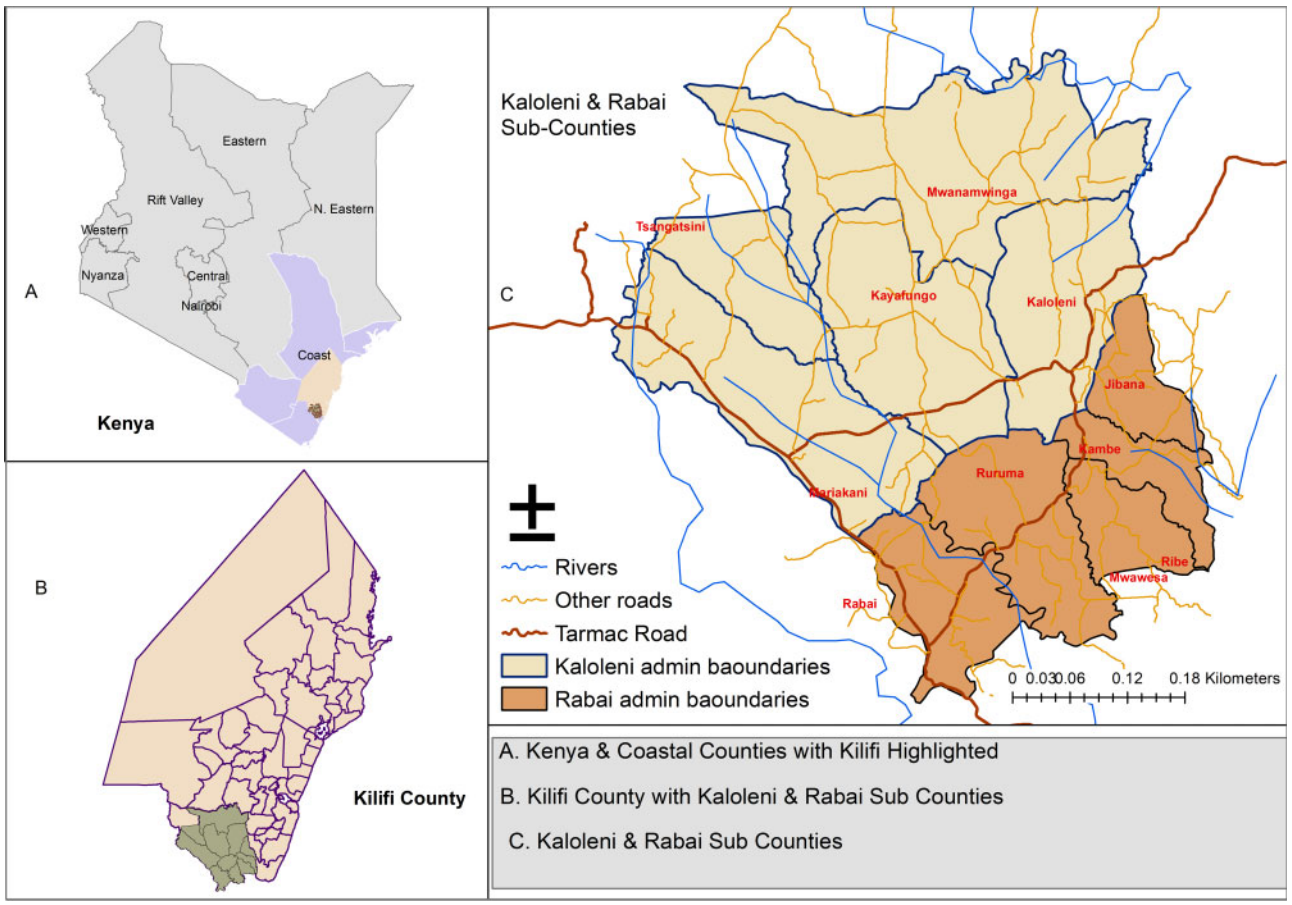

Figure 1. Map of the Kaloleni/Rabai Community Health and Demographic Surveillance site.

status and migration have been followed up in the ensuing biannual rounds. All households are interviewed and each CHV is allocated between 30 and 60 households, according to their village of residence and approximate distance between households. After the training, the CHVs visit each household where they interview the most senior female resident (usually the spouse of the head of the household). In the subsequent surveillance cycles, all in-migrants and births have been added to the system and all deaths and out-migrations occurring in the preceding round have been excluded. A resident is defined as one who has lived in the surveillance area since the previous round or for new residents, one who intends to live in the area for a similar period or longer. During the second, third and fourth rounds the surveillance population increased to 81 329, 85 987 and 87 897 residents, respectively, mainly on account of high net migration into the area (Table 1).

During the first four rounds, the number of households covered increased from 13 778, to 14 992, to 16 094 and to 17 199 in the first to fourth rounds, respectively. In December 2018 (round 4), the median [interquartile range (IQR)] number of people per household was 5 (3–7), women made up 51% of the population ($n = 44\ 775$), 13.9% ($n = 12\ 212$) were children <5 years of age, 2.6% ($n = 2102$) were below 1 year of age, women of reproductive age (15–49 years) made up 23.0% ($n = 19\ 688$) and adults (18 years and older) constituted 52.0% ($n = 44\ 575$) of the total population (Figure 2). Participation rate is high: only 51 households have declined to participate since the cohort was set up.

What has been measured?

During each round, the CHVs record household details and the demographic information for each member, including birth registration, pregnancy, deaths and migration status. Information is also collected on orphanhood and school attendance among children <18 years of age. A range of Reproductive Maternal Neonatal and Child Health and Nutrition (RMNCH and N) indicator data, including other data on use of long-lasting insecticide treated nets (LLINs) and water, sanitation and hygiene (WASH) indicators, are collected (Table 2). At present, no biological samples are taken.

Table 1. Demographic parameters of the surveillance population as at December 2018

Parameter	Estimate
Crude birth rate (per 1000/year)	19.63
Crude death rate (per 1000/year)	4.50
In-migration rate (per 1000/year)	162.53
Out-migration rate (per 1000/year)	93.70
Net migration rate (per 1000/year)	63.83
Not found/attrition rate (per 1000/year)	6.43
Baseline population (n)[a]	78 183
Current population (n)	87 897
Male:female ratio	96: 100
Population growth rate (per 1000/year)	61.00

[a]in March 2017.

These data are analysed to produce reports of estimates and trends of key indicators at the levels of both the individual and the household. Crude birth, death and in- and out-migration rates have been estimated for each round (Table 1). Aggregate data are shared with the health system management for decision making and updating the health information system, and data disaggregated by CHU are shared with CHVs and community health officers for community-level feedback and activity planning.

What has it found? Key findings and publications

Under the decentralized system of governance that took effect in Kenya in 2013, health services were devolved to the newly created counties under the county departments of health.[2] In this context, information on access to and use of health services and their determinants was needed to inform the allocation of resources. The surveillance system, in its pilot phase, was used to host a study to explore the use of health services and the associated factors in this area.[7] This study found that 19% of the respondents reported an illness in the preceding month, of whom 77% sought health care in a health facility. The majority (94%) of the respondents visited dispensary-level facilities. Of those who did not seek health services, 43% self-medicated, 20% indicated that the health services were too costly and for 10% the illness was not serious. Relationship to the head of household was associated with use of health services, with relatives other than the nuclear family of the head of household being less likely to seek medical services. These data enrich the perspective of the local health management to better plan the allocation of health care resources and also to identify extended families as an interest group for health education.[7]

The surveillance system also provided a sampling frame and participant-tracking platform for a study to determine breast health care knowledge, perceptions and practices among women as well as to elucidate the role of male heads of households in a woman's breast health care seeking behaviour. This study showed that more than 80% of respondents had heard of breast cancer, but only 10% knew at least two of its risk factors. The majority (85%) perceived breast cancer as a serious illness and >90%

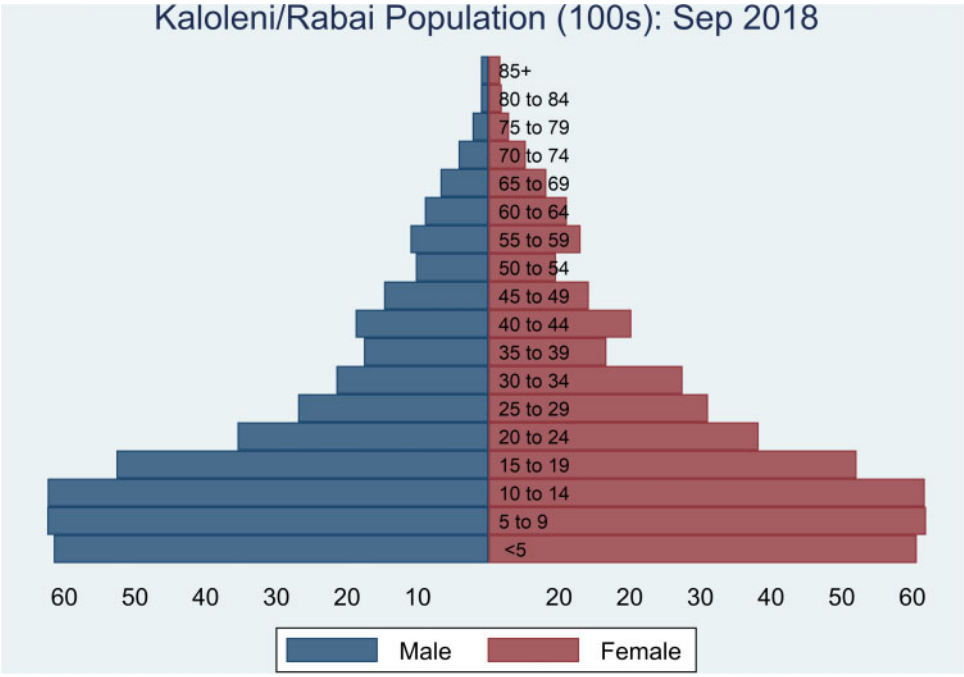

Figure 2. Population pyramid of the surveillance population between June and December 2018.

Table 2. Information collected at each data collection round

Subject	Information collected
Village	Village ID, village name
Household	GPS coordinates, household ID, name of household head, access to safe water, usage of treated water, ownership of hand-washing facilities, ownership of a functional latrine, ownership of a refuse disposal facility
Individual	Individual ID, names,[3] sex, date of birth, age cohort, relationship to head of household, birth registration, use of LLIN, known disability, known chronic illness, persistent cough (for 2 or more weeks). By age/specific cohort: 0–6 months (exclusive breastfeeding). 0–11 months (mother attended antenatal care >=4 times during pregnancy), delivered by skilled birth attendant, Penta 1 and 3 immunization). 9–18 months (measles vaccination) 0–59 months (issued a mother and child health booklet) 6–23 months (complementary feeding) 6–59 months (severely malnourished, moderately malnourished, vitamin A supplementation) 0–18 years (orphanhood) 6–18 years (school enrolment) Female, 12–49 years (pregnant) Pregnant female (issued mother and child booklet) Female, 15–49 years (use of family planning) 6+ years (knowledge of HIV status tested in the past 6 months)
Residency/vital status	Resident, newborn, died, in-migrated, out-migrated
Birth	Date of birth
Death	Date of death

indicated they would screen suspicious breast masses. Variable recognition of signs of breast cancer, limited decision-autonomy for women, lack of trust in the health care system and inadequate access to early detection services were the key themes in the study. This study provided a glimpse into the perceptions of gender roles in health care seeking for breast cancer, and knowledge of and perceived barriers to accessing breast health care, which can inform the development of locally relevant intervention programmes.[10]

Future analysis plans

Using data from at least five surveillance cycles, the team will analyse demographic and vital events and migration trends, trends in the uptake/coverage of approximately 15 key Reproductive Maternal Neonatal and Child Health and Nutrition and WASH indicators, and will perform internal validation of the data. Geographic Information System (GIS) data will be used to generate maps of intervention coverage and vital events, to supplement the trends analyses. Additional contextual data will be used to explain the determinants of observed trends in ecological analyses.

Nationally, data from the Civil Registration and Vital Statistics (CRVS) unit of the Ministry of Health (MoH) indicate that only 7.4% of home deliveries were registered in 2017. Our surveillance data also show low levels of birth registration, with only 17% of the population having a birth certificate. The estimate is as low as 11% for children under 5 years and 7% for children below 1 year of age. We plan to conduct implementation research on linkage of community-generated CRVS to the national-level CRVS system. Additionally, the CRVS unit data also show that only 24% of all deaths occurred in health facilities and only 44% of the total deaths were reported to the CRVS unit in 2017, leading to low penetration of death certification or any form of probable causes of death (CoD) diagnosis. We plan to initiate the tracking of CoDs through verbal autopsies embedded into the system.

The surveillance system also provides up-to-date denominator data as a sampling frame for nested research studies. Since the data are archived electronically and individual information linked longitudinally on unique identification numbers, the system presents a basis for individual tracking over time e.g. in cohort studies or both individual and cluster randomized controlled trials (RCTs). To enhance the sustainability of the system, we plan to conduct studies that will test the effectiveness of economic empowerment models (identified in formative work in the area) on the motivation and retention of CHVs in community health programmes.

Main strengths and weaknesses

A key strength of the Kaloleni/Rabai Community Health and Demographic Surveillance System is the fact that it is nested in local community health structures that are part of government's CHS. A network of community resource persons (i.e. CHVs) collect the surveillance data while performing their health promotion, education and preventive services in the households. Alongside the CHV, the local MoH personnel (supported by AKU surveillance personnel) are actively involved in the training and supportive supervision of the CHVs as they perform these tasks in the community. The CHVs and the MoH personnel involved in the project also contribute to data interpretation meetings, which precede each data collection round. Since these health workers are more knowledgeable of the context and the community, they provide locally relevant explanations of observed indicator trends, enhancing the utility of the data for planning and decision making at the local level. Additionally, the CHVs conduct regular community dialogues in which the data are shared and discussed with community members. A confluence of these factors has ensured close to 100% participation from households in the surveillance area.

The local MoH also uses the data collected on the surveillance system to plan activities such as outreach to and health action days for communities showing poor indicators, enhancing evidence-informed decision making. Furthermore, these data are used to update the local community health information system. Working through, and with, the MoH community health structures and personnel also enhances official buy-in and ownership, since the programme directly supports the CHS and builds the capacity of the local MoH for household level-data collection, interpretation and use. Acceptance by both the officialdom and the community ensures the requisite goodwill, which is important for sustainability of the surveillance system in this locality.

The CHS prescribes criteria for selection of CHVs, among them the ability to read and write.[1] Oftentimes the community overrides these requirements and chooses, for instance, semi-illiterate CHVs based on individual attributes such as good standing in the community or outstanding contribution in community affairs. Approximately 5% of CHVs involved in the surveillance project are semi-illiterate and require additional support to collect data by, for example, more regular supervisory contact, designating a literate assistant or working with other CHVs. Additionally, it is difficult to offer personalized supportive supervision to the large numbers of CHVs, which confers difficulties in field-level data quality control (e.g. regular checking of each CHV's data before uploading to the server). However, the use of mobile data collection devices pre-programmed with appropriate filters and validation rules, and real-time checking of data in the web system with prompt feedback to field supervisors, have enhanced data quality and the efficiency of supervision.

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

Primarily, the synthesized Kaloleni/Rabai Community Health and Demographic Surveillance data are fed back to

local community through the CHVs working with the project. The data are also shared on a quarterly basis with the local Department of Health officials who use them to inform planning as well as to update the community health information system. Other important consumers of the surveillance data include the AKU departments (and their partners) implementing Reproductive Maternal Neonatal and Child Health and Nutrition programmes which use the data to track the impact of their interventions on relevant indicators.

Data summaries are available on request, and de-identified individual-level data can be shared upon completing the relevant application forms with a proposal for collaboration and approval by the data sharing committee. The project management also welcomes proposals for collaborative research that enhance the utility of the surveillance system. For example: cohort studies evaluating the impact of economic incentives for CHVs which are included in the Community Health Policy proposals currently being reviewed by the County government; or randomized trials of public health innovations to improve WASH (specifically unsafe water, hygiene and hand washing); which are some of the key drivers of poor health in the area; are needed.[11] Data requests and enquiries for collaboration should be communicated to the corresponding author.

Profile in a nutshell

- The Kaloleni/Rabai Community Health and Demographic Surveillance System is a population-wide demographic and health registry nested in the community health structures, and was set up to strengthen the capacity of the local department of health for collection and use of population-level health and vital events, and to provide a platform serving the University's needs for population-level research.
- The entire population of a geographically and administratively defined area of Kaloleni and Rabai Sub-counties on the coast of Kenya was registered and enumerated and their health and demographic status recorded between February and June 2017. The baseline population comprised 78 183 residents.
- This population is followed up biannually and four rounds of data collection have been completed so far. An attrition rate of 6.4/1000 persons per year has been estimated, and 87 897 residents remain in the cohort.
- During each round, household details, demographic information for each member and vital events data are collected. Information is also collected on orphanhood and school attendance among children. A range of social determinants of disease and Reproductive Maternal Neonatal and Child Health and Nutrition indicator data are also collected.
- Data summaries, de-identified individual-level data and enquiries for collaborative research can be communicated to: [anthony.ngugi@aku.edu].

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Conflict of interest: None.

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