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# WHAT DATA PROVIDE INSIGHTS ON LIFE-COURSE TRAJECTORIES OF DEVELOPMENT AND AGEING IN LMICS?

## An exposition of the LMIC data landscape for potential linkages and investments

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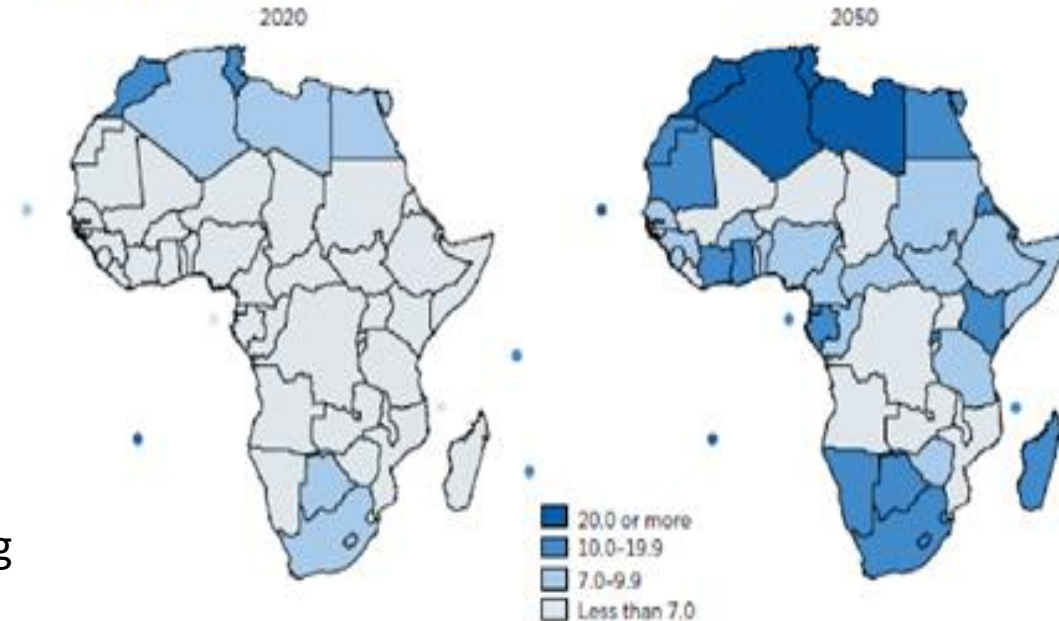
# Outline

- Background/Rationale for studies of ageing in LMICs
- Potential sources of data for ageing studies
- Potential for linkages across databases
- Platforms & surveys that can support cohort studies
- Data sharing landscape

# Background & Rationale

- African population is ageing fast
  - Adults  $\geq 60$  years accounted for 5.6% of population in 2020
  - Projected to increase to  $>15\%$  in 2050
- Kenyan  $\geq 60$  years population expected to grow 4x by 2050
- Scarce population-level data on critical domains of ageing
  - Health, mental health, climate vulnerability, economic wellbeing
- Data needed to inform responses to unique health & socioeconomic challenges
  - Need for data harmonized with other (global) studies

Percentage Aged 60 and Older of Total Population for African Countries:  
2020 and Projected 2050



Source: U.S. Census Bureau, International Data Base, 2019

# Likely sources of data/data platforms in LMICs

1. Health Management Information Systems (HMIS)
2. National or Regional Surveys  
E.g. Census, Demographic & Health Surveys etc.
3. Longitudinal Population Studies (LPS) & Health and Demographic Surveillance Systems (HDSS) platforms
4. Others e.g. Bureaus of Statistics sample frameworks

# 1) Kenya HMIS registers (health facility services)

- 1) Antenatal Care Register: MOH 405, 9, 534
- 2) Child welfare Clinic Register: MOH 511, 11, 643
- 3) Family Planning Services Register: MOH 512, 9, 738
- 4) Inpatient Register: MOH 301, 7, 633
- 5) Laboratory Register: MOH 240, 5, 149
- 6) Maternity Register: MOH 333, 4, 756
- 7) Outpatient (over 5) Register: MOH 204A, 15,029
- 8) Outpatient (under 5) Register: MOH 204B, 16, 136
- 9) Immunization Permanent Register: MOH 510, 12, 756
- 10) Post Natal Care Register: MOH 406, 7, 751
- 11) Radiology (X-RAY) Register: MOH 209, 2,691
- 12) Community Health Worker Household Register: MOH 513, 12,061
- 13) Community Health Worker Service Delivery: Log Book MOH 514, 11,510
- 14) Tuberculosis Register: MOH 4, 500

# The HMIS problem (Kenyan context)

## **Poor availability of Data**

For example, in 2017-2018:

6% of the counties had good reporting ( $\geq 90\%$ ) of deliveries

47% of the counties had good reporting of ANC 1 coverage

51% of the counties had good reporting of DPT 1 vaccination

26% of the counties had good reporting OPD visits

$>90\%$  of health facility births were notified to CRD, but only 7% of home births were

24% of deaths occurred in health facilities, but only 44% of these were reported to CRD

## **Poor data quality**

Low overall quality score ( $<60\%$ )

Poor data availability/completeness

Inconsistencies between related indicators e.g. DPT 1 & DPT 3 vaccination

## **Low capacity for processing & use of data for decision making**

## 2) National (or regional) Surveys

(Conducted by National Bureaus of Statistics & their technical partners)

- 1) National Population & Housing Census Surveys
  - Conducted every 10 years in Kenya
  - Enumerates population + distribution by admin units, age, sex, SES
  - Informs generation of nationally representative sampling framework/clusters
- 2) Demographic & Health Surveys (DHS)
  - Based on nationally representative clusters; Primarily focused on MNCH
  - Only surveys women 15-49 years & men 15-54 years
  - Also includes Housing & SES; KAPS on HIV, AIDS & TB; Malaria; Chronic Diseases/NCDs; WASH; GBV & Social Protection
- 3) Other National Surveys
  - Kenya Integrated Household Budget Surveys (KIHBS)
  - Disease specific e.g. WHO STEPS, AIDS Indicator Surveys, Malaria Indicator Surveys
  - Multiple Cluster Indicator Surveys (regional, by UNCEF, MNCH)

# Other National Surveys

- Kenya Household and Health Expenditure and Utilization Survey (KHHEUS)
- Kenya Continuous Household Surveys (KCHS)
- Other economic surveys (household level)
- National Safety Net Program (social protection in Kenya)
  - Adults >70 years of age
  - Monthly cash transfer (~ 20\$), based on some criteria
  - Registry of beneficiaries (>830,000 in 2020)



### 3) Longitudinal Population Surveys in Africa

- Only 2 on Ageing: HAALSI & LOSHAK
- Kenya Life Panel Survey (KLPS) – implementing HCAP
- Others
  - Network for Analysing Longitudinal Population-based HIV/AIDS data on Africa (ALPHA Network)
  - H3Africa Consortium (Genomics)
    - Human Heredity and Health
  - Etc

# Health & Demographic Surveillance Systems (HDSS)

- Continuously track demographics & health of large well-defined cohorts
  - 80,000+ localized populations
- In several LMICs in Africa and Asia
- Approx 50+ (previously under INDEPTH Network)
- Infrastructure & resources for nesting Longitudinal Population Studies (LPS)
- Not nationally representative
- Potential to change characteristics of population

What potential exists for data linkages  
across sources/dBs?

# Potential for linking datasets

- Limited potential for harmonization
  - No unique IDs across databases (most sources are stand-alone)
- Poor quality (availability, completeness, timeliness & consistency)
  - In particular the HMIS data
- Probabilistic linkage challenging due to non-standard ID information across surveys (in same populations)
  - Names, HH relationships, dates of birth, locality etc

# Current efforts at data harmonization

(LPS and HDSS data)

- African Population Cohort Consortium (APCC)
- <https://wellcome.org/news/African-Population-Cohort-Consortium-data-global-health>
- Implementation Network for Sharing Population Information from Research Entities (INSPIRE Network)
- <https://aphrc.org/inspire/>
- These are regional efforts (forward looking .. to harmonize future data collection)
- Cohorts are not nationally representative

How can we leverage existing data  
platforms/surveys?

# Potential exists to:

- Utilize nationally representative sampling frameworks to mount surveys
  - e.g. National Sample Survey and Evaluation Programme (NASSEP) household master sample frame in Kenya
  - Utilized by other national surveys e.g. Malaria, AIDS, Indicator & WHO-STEPS surveys, DHS
  - LOSHAK plans to use this framework to ID participants in Wave 1
  - Must collaborate with National Bureaus of Statistics!
- Explore add-on limited ageing survey modules to national surveys?
  - E.g. DHS
  - Engage with NBSs & technical partners
- Engaging with budding regional/local data platforms (establish cohorts)
  - E.g. APCC, INSPIRE Network
  - Individual HDSS sites (too localized)

Data sharing considerations



# Shifting data governance landscape

- Several countries have enacted data protection laws
  - E.g. Kenya Data Protection Act (2019)
    - Enhances the Constitutional provisions on right to privacy;
    - Establishes the Office of the Data Protection Commissioner;
    - Regulates the processing of personal data,
    - Provide for the rights of data 'subjects'; and
    - Obligations of data 'controllers' and 'processors'
    - Outlines stiff penalties for non-compliance
  - Many institutions currently establishing frameworks to ensure compliance
  - New data collection initiatives need to complete elaborate "Data Protection & Privacy Impact Assessments" (DPPIA)
  - Research data appear to be exempt from most provisions provided:
    - Specific & adequate consent was sought from data subjects
    - Data are sufficiently anonymized
    - Personal data cannot be transferred outside Kenya (unless there is proof of adequate protection e.g. GPDR compliance, prior consent from participant)
    - DPPIA completed and submitted to the "Office of Data Protection Commissioner"
  - Regulations are restrictive, but not prohibitive
  - Important to work with local stakeholders to help navigate the processes



THANK YOU

