

Building Cooperative Data Sharing Networks in LMICs: The Case of the **INDEPTH Network**

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Executive Director

On behalf of researchers from 45 Research Centres running 53 HDSS sites in 20 LMICs in Africa, Asia and Oceania

Personalised Medicine and Precision Public Health

Chairs: Bill & Melinda Gates Foundation, European Commission & Institut Pasteur

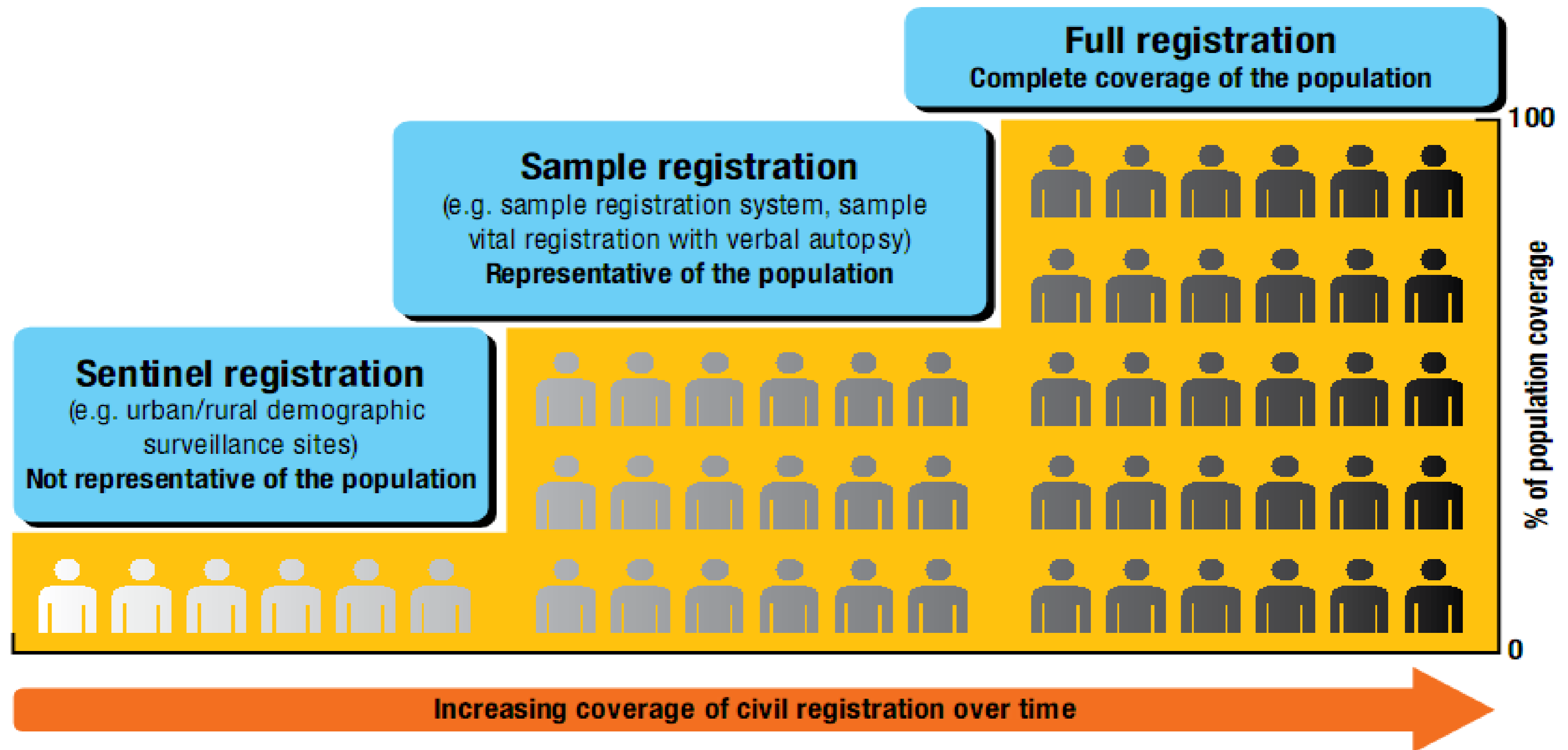
Grand Challenges Annual Meeting 2016, London, UK

24-26 October 2016

The data and scientific capacity challenges in many resource-constrained countries

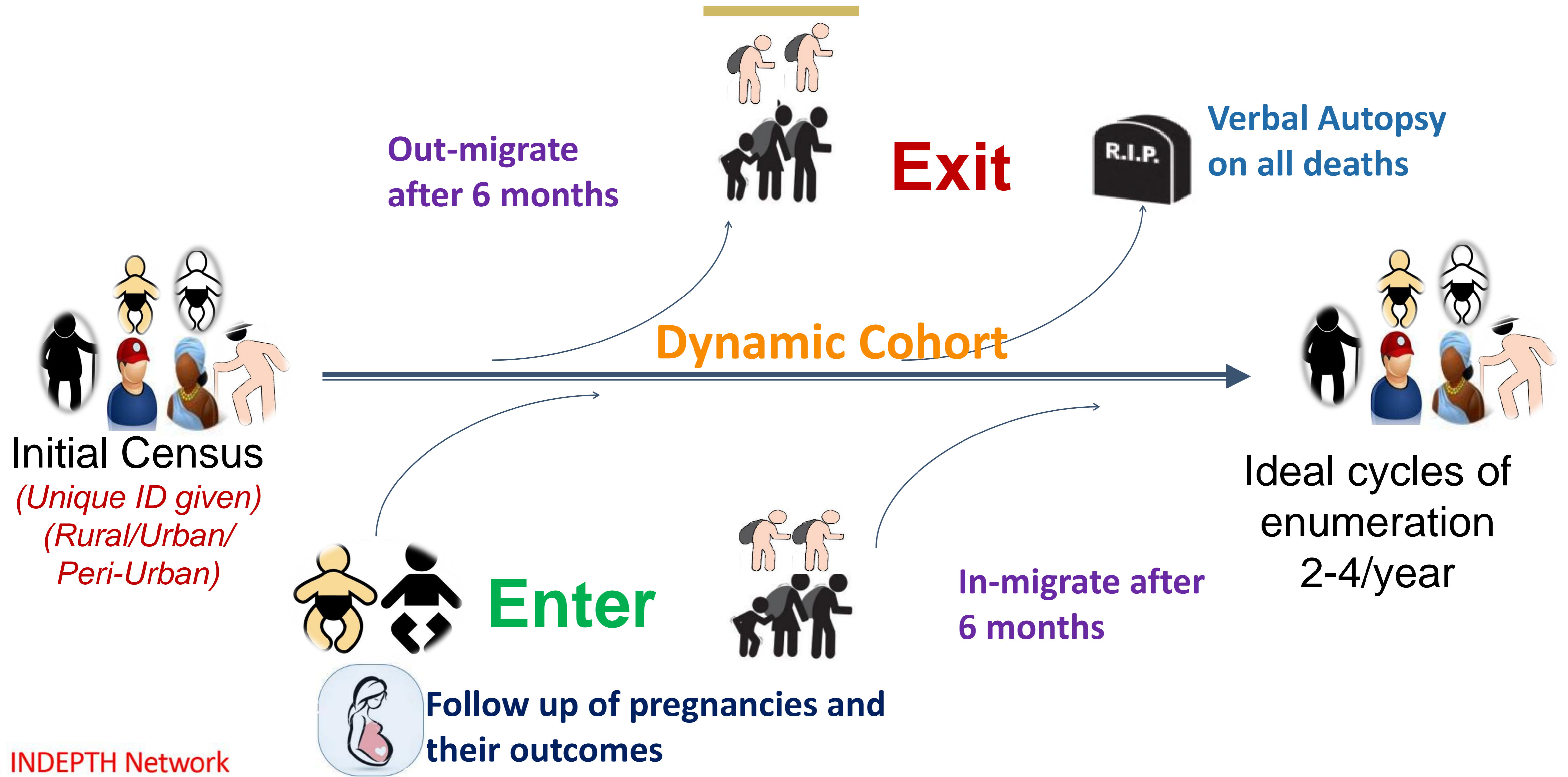
- Reliable demographic and health data lacking in many low- and middle-income countries
- Births, deaths, causes of death not always registered
 - ***Many people are invisible!***
- Health facility data only provide partial picture
- Censuses – conducted mostly every 10 years!
- Policy-makers hence act largely in the dark
- Weak scientific capacity for data generation, quality control and analysis

A country's wish: A functional civil registration with vital statistics system



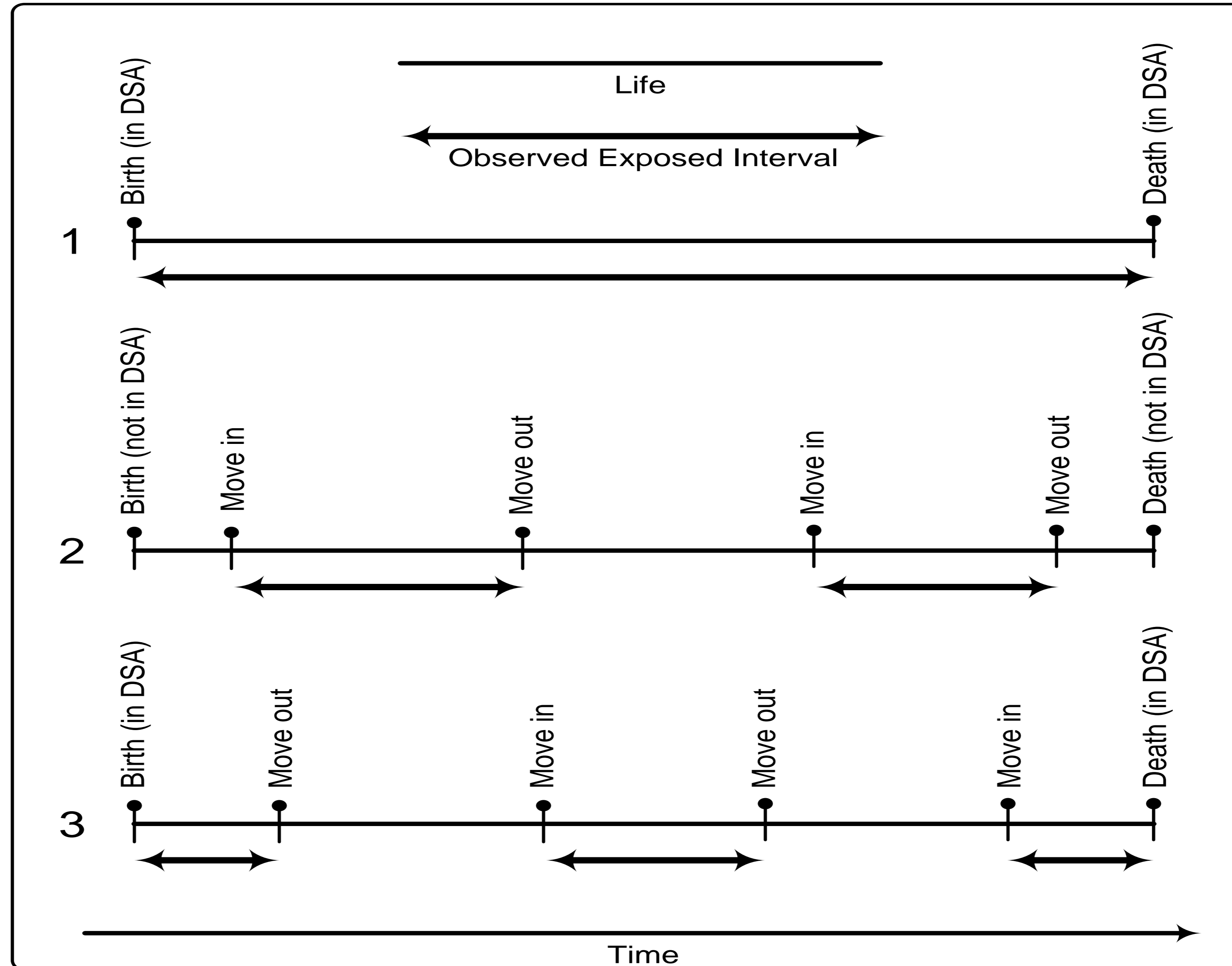
HDSS – A viable solution

- Health and Demographic Surveillance System (HDSS)
– provides a fuller picture
- HDSS collects data from whole communities over time
 - *Monitors new health threats – more accurate reflection of health and population challenges*
 - *Tracks population changes*
 - *Assesses policy interventions*

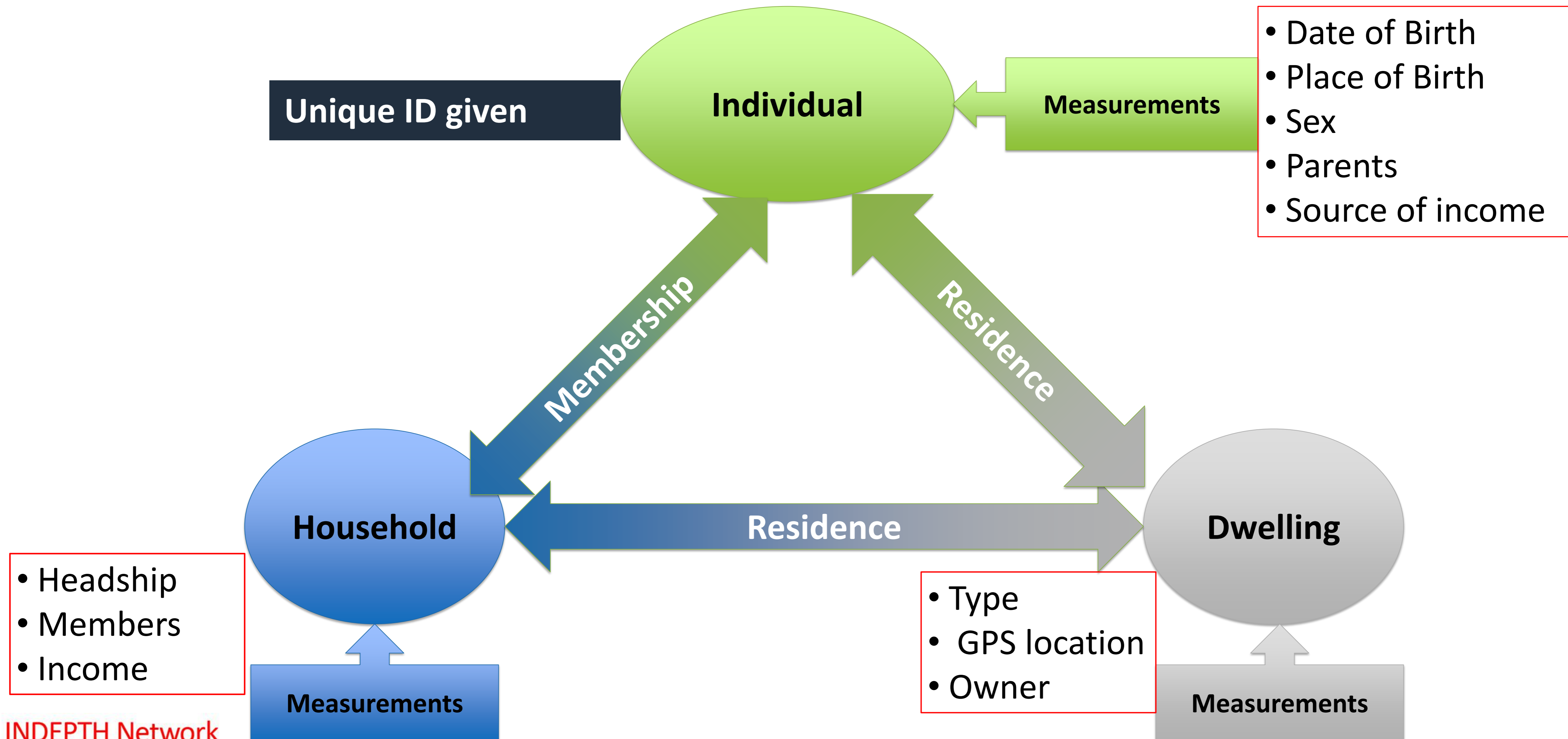


Examples of Observed Exposed Intervals

Follow-up of an individual (Person Years)



Population Data Structure – HDSS Participants

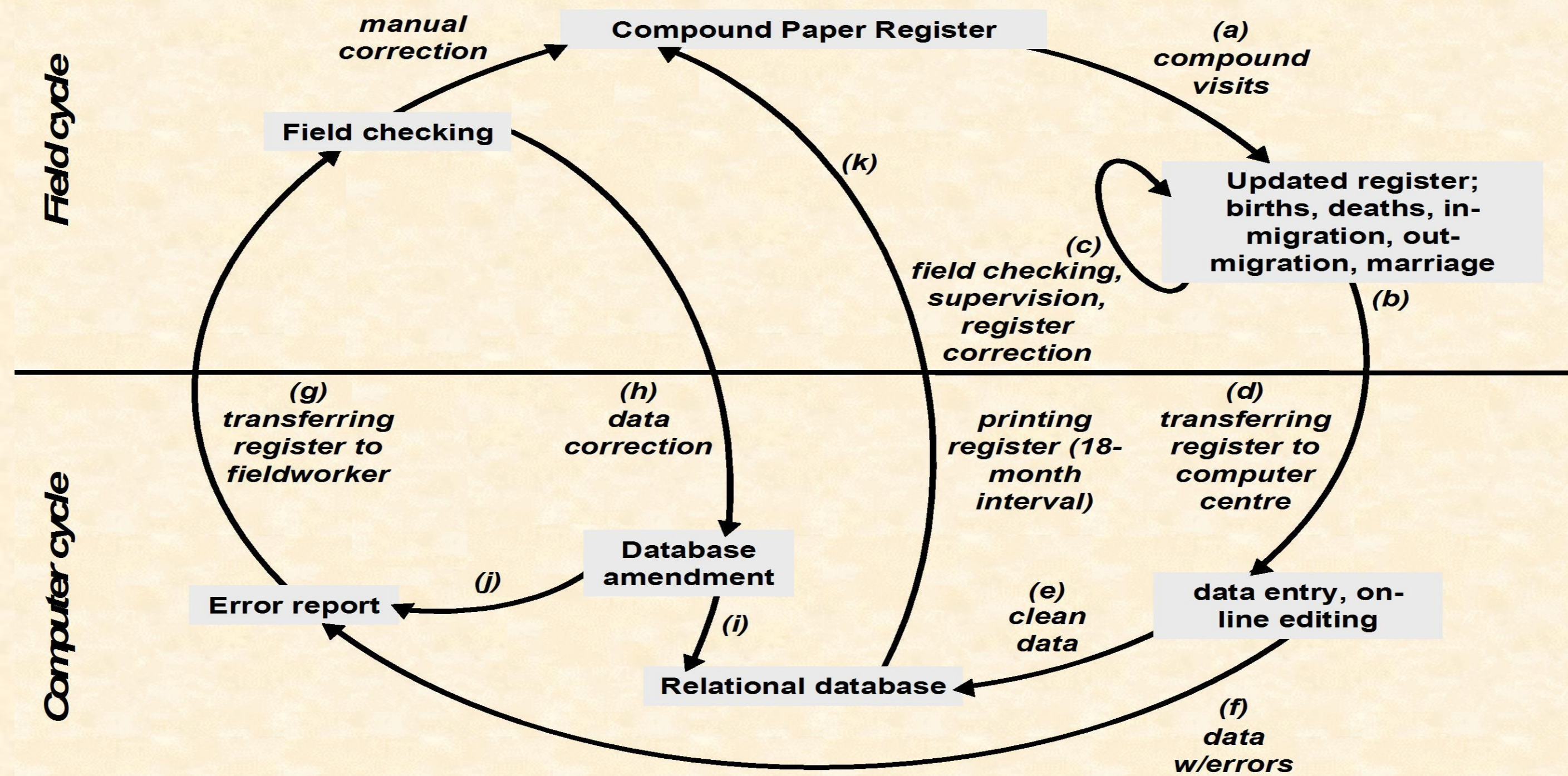


How does a Sentinel HDSS operate?

- | Typical size: > 60-100,000 population, larger if urban
- | Initial census using GPS for households
- | 150 community Key Informants, 25 HDSS professional enumerators, 16 supervisors, 5 data entry clerks, and administrative staff.
- | 3-4 enumeration update rounds per year
- | Events by cause, age, sex all linked to resident population
- | Annual recurrent core costs: ~\$200,000 USD.

HDSS operations: field and computer components

The routine cycle of Health and Demographic Surveillance Systems



Outputs from an HDSS

10

CORE

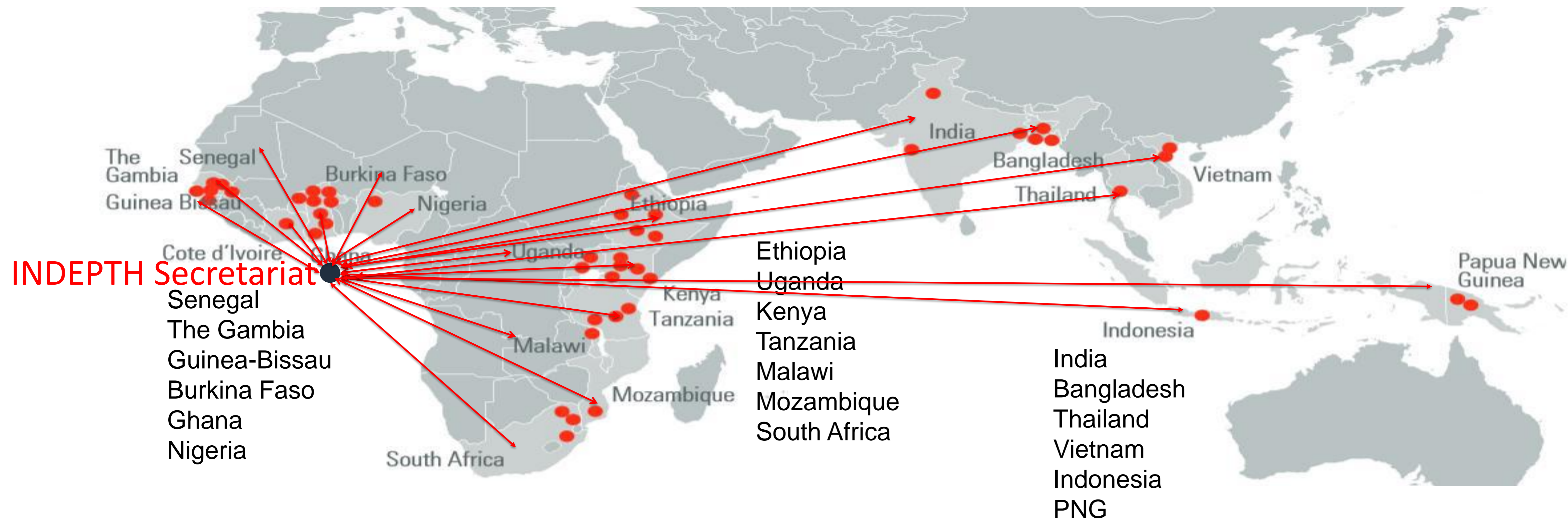
- ✓ All cause mortality rates
- ✓ Cause-specific mortality proportions & rates
- ✓ Life table probabilities
- ✓ Fertility rates
- ✓ Migration rates

ADDITIONAL

- ✓ population characteristics
- ✓ household characteristics, assets and wealth indexing
- ✓ health status / disease burdens
- ✓ access, use and impact of health services
- ✓ health seeking behaviours for severe and fatal conditions
- ✓ environmental contexts, risks, exposures
- ✓ household food security
- ✓ impact of poverty reduction strategies
- ✓ impact of health interventions

INDEPTH Member HDSS Sentinel Surveillance Countries

Over 3,500,000 people under continuous surveillance in INDEPTH Network



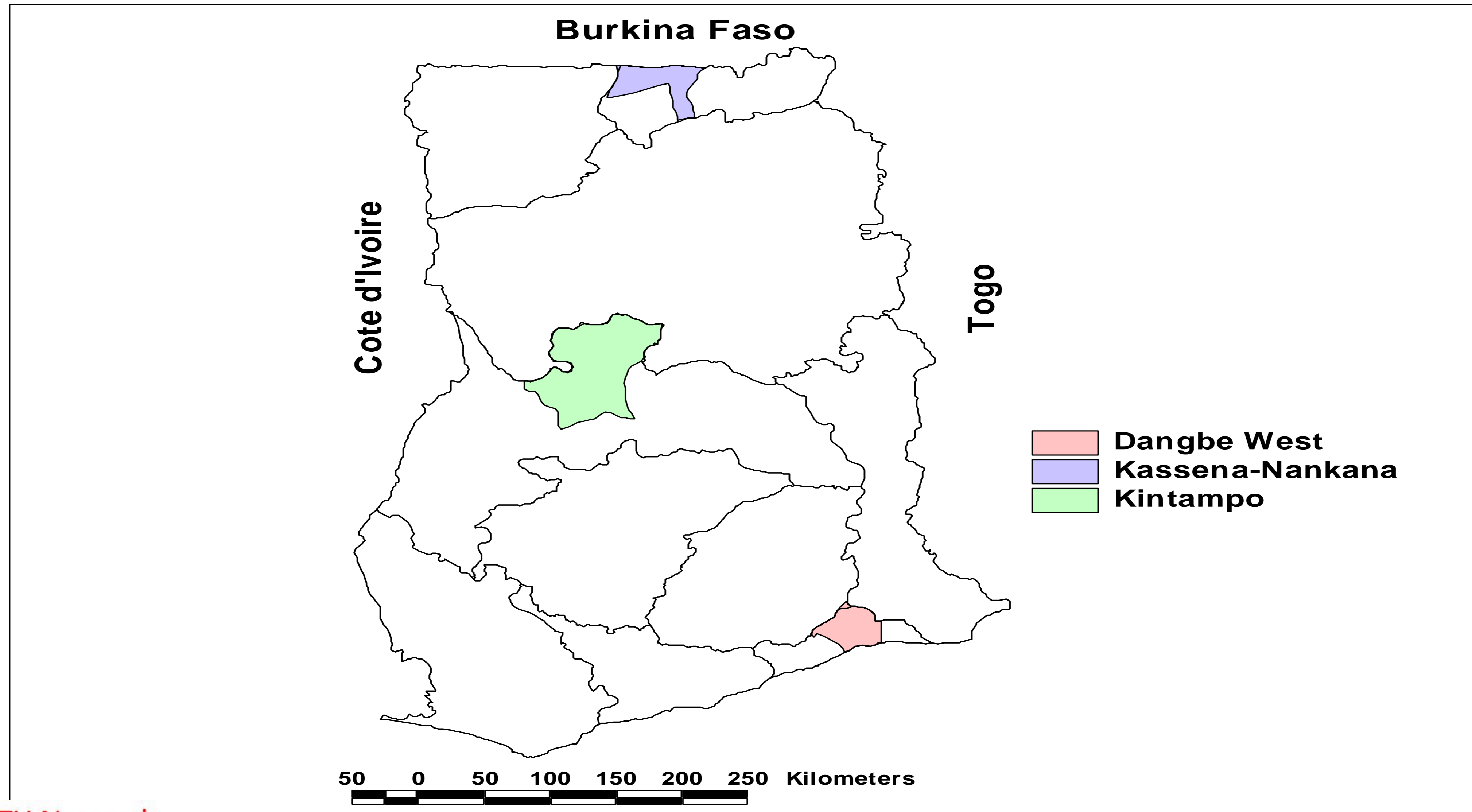
Through INDEPTH to diverse countries and continents

www.indepth-network.org : 1st July 2016 – New datasets on the Repository

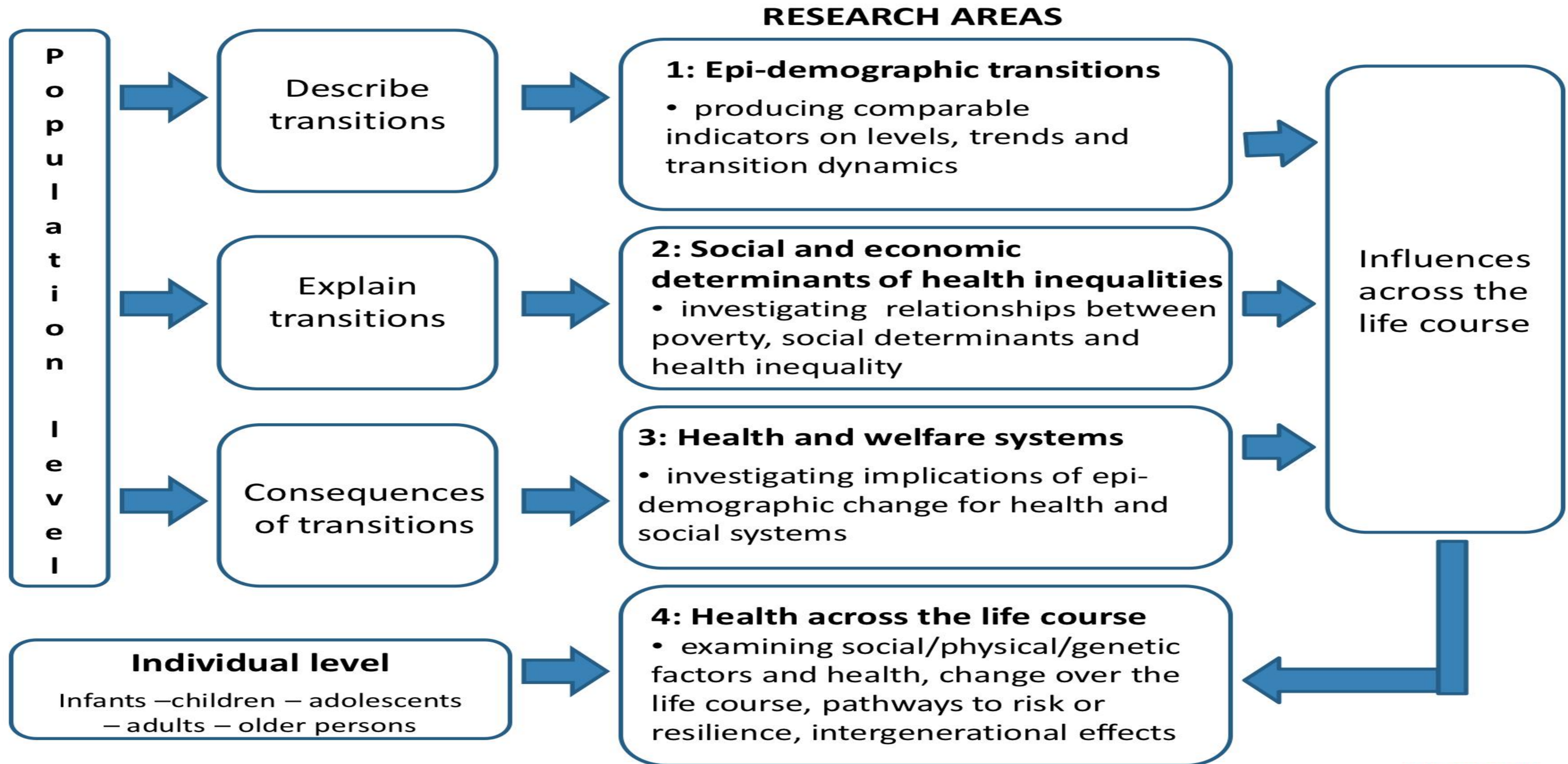


INDEPTH Network
Better Health Information for Better Health Policy

Ghana Health Service Health Research Centres Navrongo, Kintampo & Dodowa (HDSS sites)



Research Framework



Structuring the Science

Observational work: denominators, vital events and contextual variables inherent in HDSSs

Development of sub-cohorts (e.g. adult, adolescent or household cohorts)

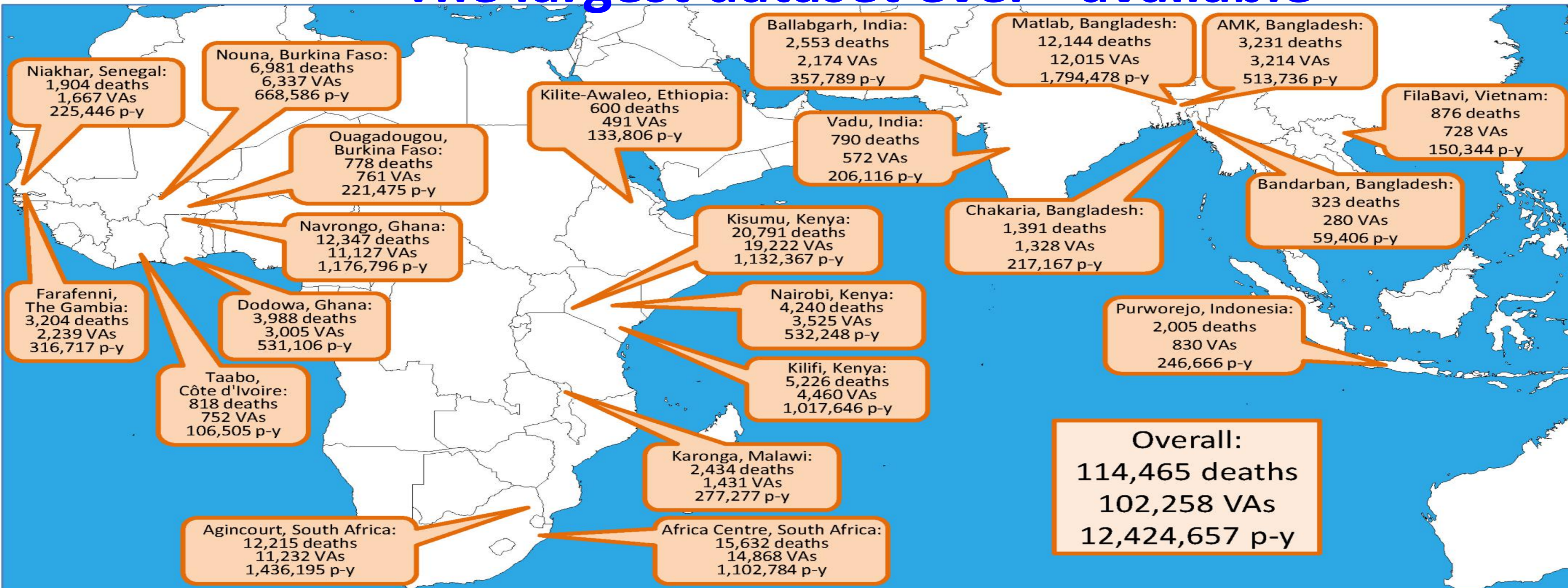
Intervention-research: including community-based trials, and systems and policy evaluations

Health and social policy and programmes: Apply findings to health and development with support to scaling-up

Methodological innovation: verbal autopsy, the linking of population-based and health service data, etc.

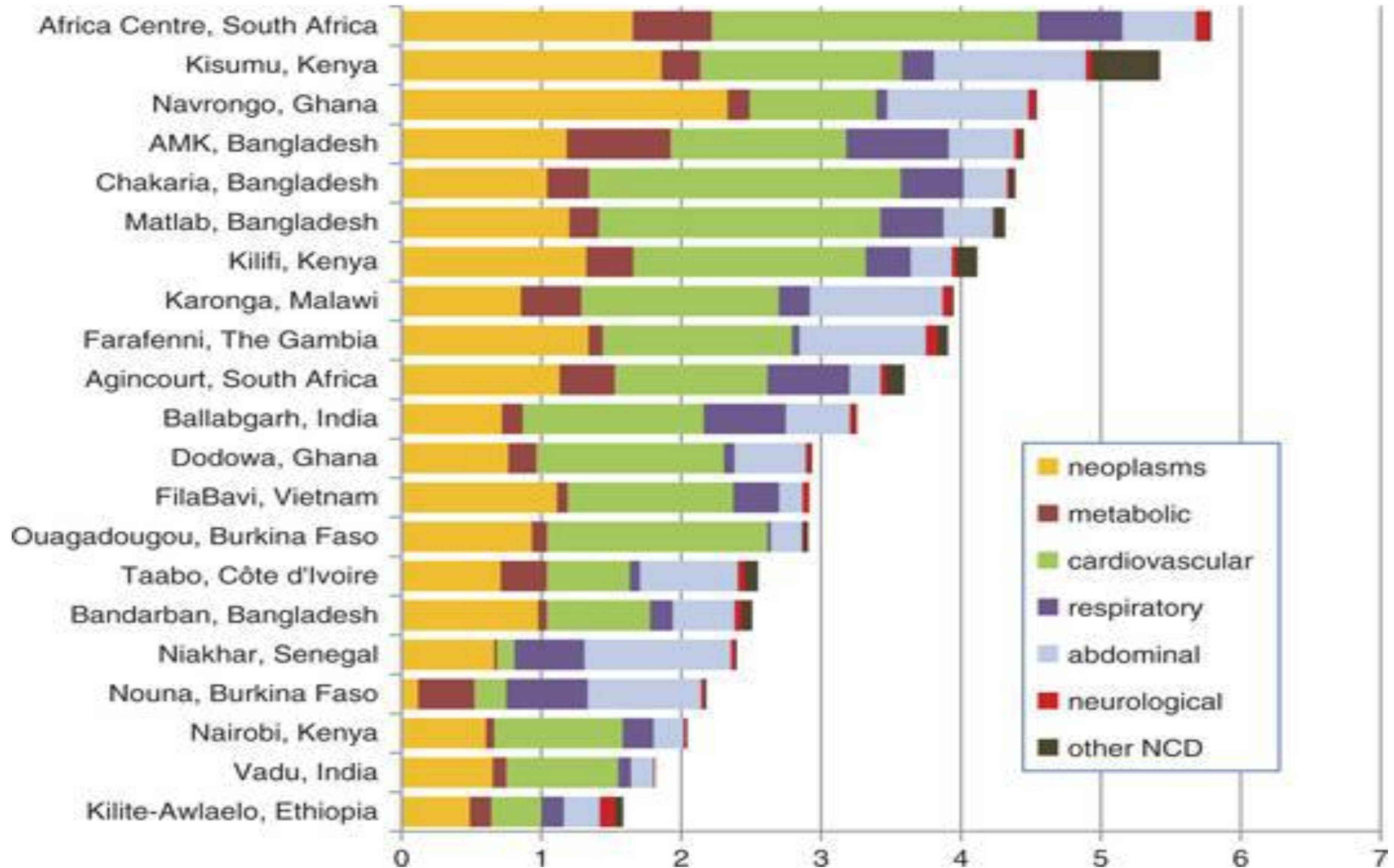
INDEPTH Cause of Death Data (2014)

The largest dataset ever - available



INDEPTH Data Repository: www.indepth-ishare.org

Age–sex–time standardised mortality rates per 1,000 person-years among adults (15 years and over) in 21 INDEPTH HDSS sites in Africa and Asia, by sub-category of non-communicable diseases causing



Capacity Strengthening and training

Help **individual centres** to publicise their research and results for greater policy influence.

At a **multi-centre level**, our workshops train data managers and analysts and help develop the next generation of HDSS professionals.

And at a **broader network level**, we assist centres in developing regional groups and teams.

We support Masters/PhD Training...

- **Masters Training**

- School of Public Health, University of the Witwatersrand, Johannesburg, South Africa (**44 graduates**)
- JP Grant SPH at BRAC University, Bangladesh (**2 graduates**)
- Health Economics and Health Care Management at Chulanlongkorn University in Bangkok, Thailand (**2 graduates**)



PhD training support (**direct or nested in Working Groups**)

INDIA



Policy Engagement

GHANA



INDEPTH in-country policy engagement meetings (India, Ghana, Tanzania)



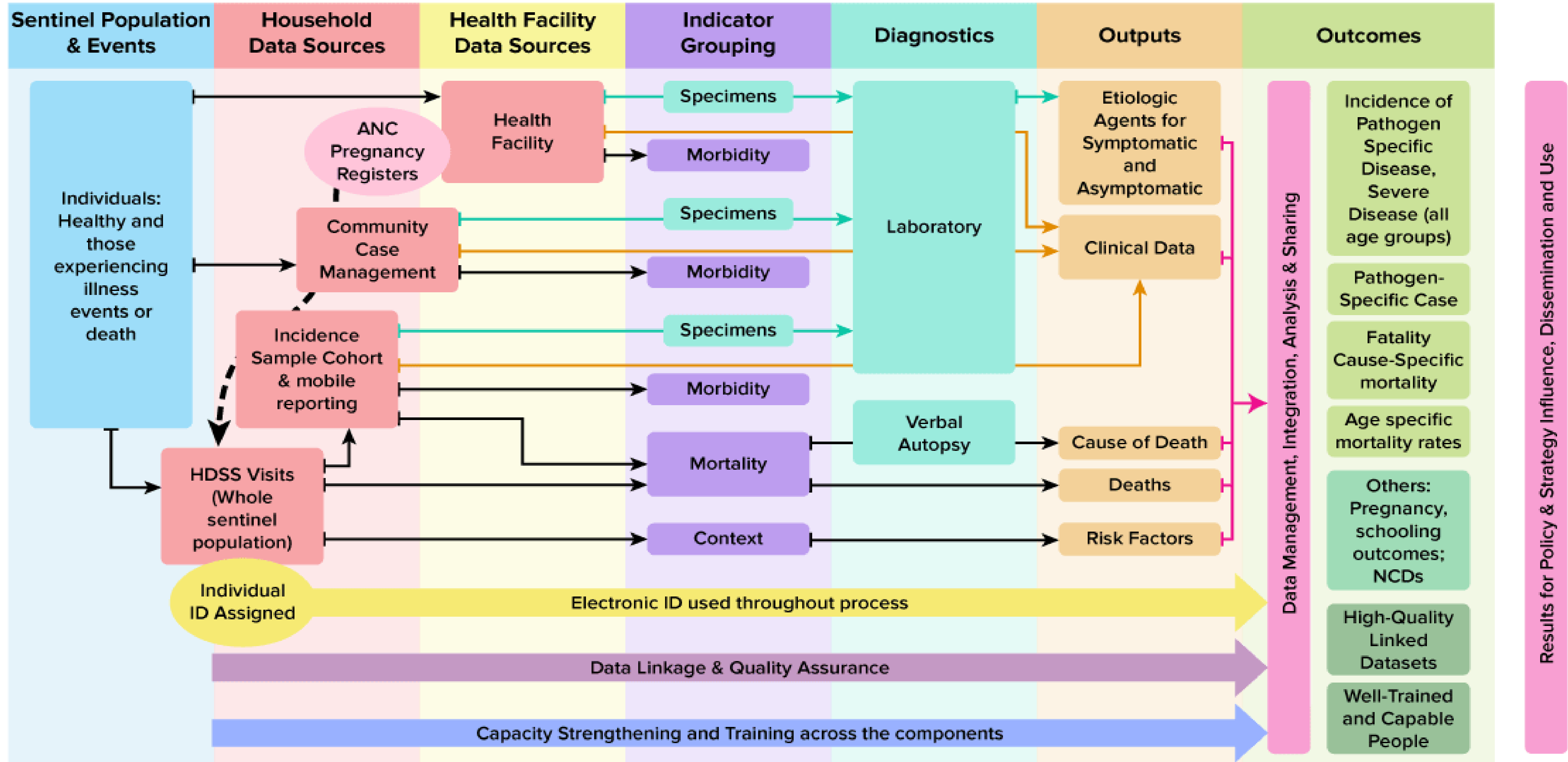
TANZANIA

Innovation: CHESS

- Integration across **population** and **health facility** data systems:
 - ✓ linking demographic, mortality, **morbidity, clinical, laboratory**, household and other contextual data
 - ✓ unique electronic individual identification system

INDEPTH in the near future

Comprehensive Health and Epidemiological Surveillance System (CHESS)



HDSS

Health and Demographic Surveillance System

(Sankoh & Byass, 2012, Int. Journal of Epidemiology)



CHES

Comprehensive Health and Epidemiological Surveillance System

(Sankoh et al, 2015, The Lancet Global Health)



INDEPTH Data Repository

Home

What is this?

How to use it?

History

Data

Citations

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INDEPTHStats

Acknowledgements

Feedback



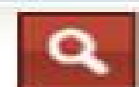
iSHARE2 4th Training Workshop

iSHARE2 4th Training workshop was conducted successfully in Dubai, UAE from 18th Nov - 25th Nov 2014. Seven centres participated in the workshop and were given a detailed knowledge for installing, configuring, maintaining and working with the different components of CiB so that they would be able manage the entire life-cycle of research data management at their respective centre's HDSS data.

Central Data Catalog

The Central Data Catalog is a portal for all surveys and datasets held in catalogs maintained by the INDEPTH Network and a number of contributing external catalogs.

Search the Central Microdata Catalog



[View all Surveys »](#)

INDEPTHStats

Displays yearly health and demographic indicators calculated from INDEPTH Data Repository; for researchers, government officials and policymakers. [Read More...](#)

As of September 08, 2015 the Library contains

41 surveys

3,181 citations

1,016 variables

FAQ'S

- ▶ How can I contribute to improving the catalog?
- ▶ Can you help with analyzing the data?
- ▶ Can I get help in implementing a survey catalog in my agency?

[Click here for more...](#)

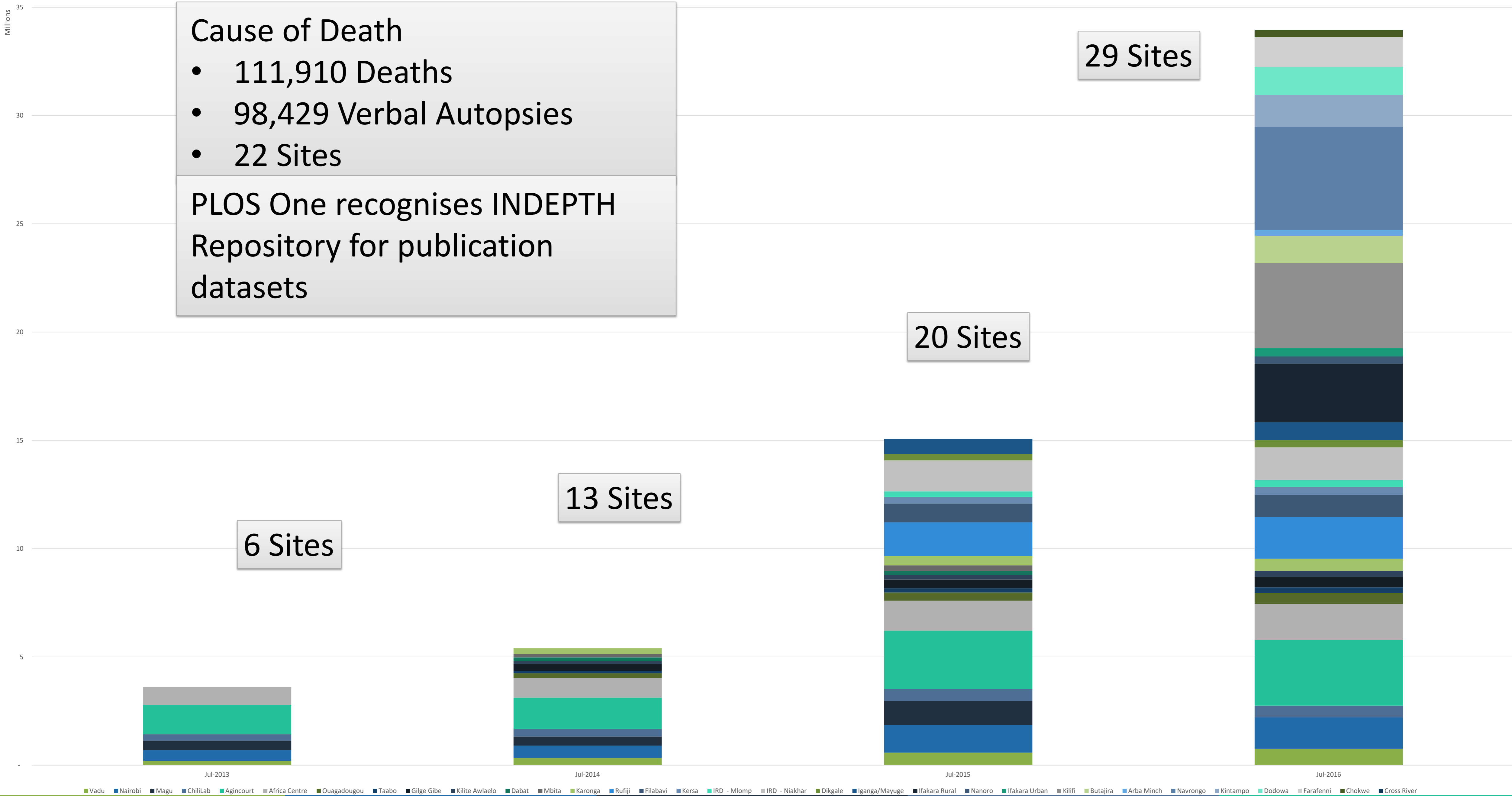
NEWS

INDEPTH Repository : Shared Individual Level Data

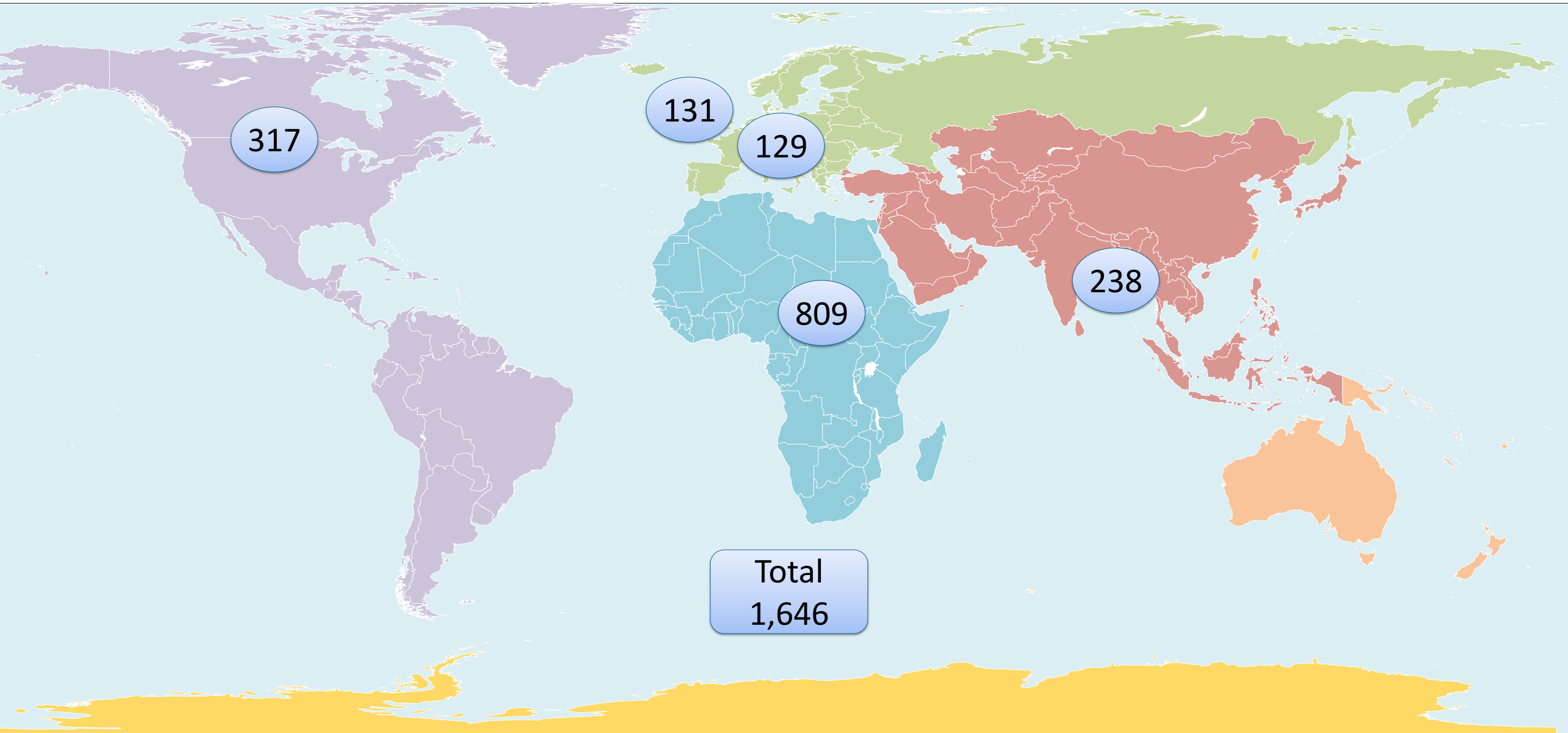
Cause of Death

- 111,910 Deaths
- 98,429 Verbal Autopsies
- 22 Sites

PLOS One recognises INDEPTH Repository for publication datasets



Who is downloading?





Some Challenges

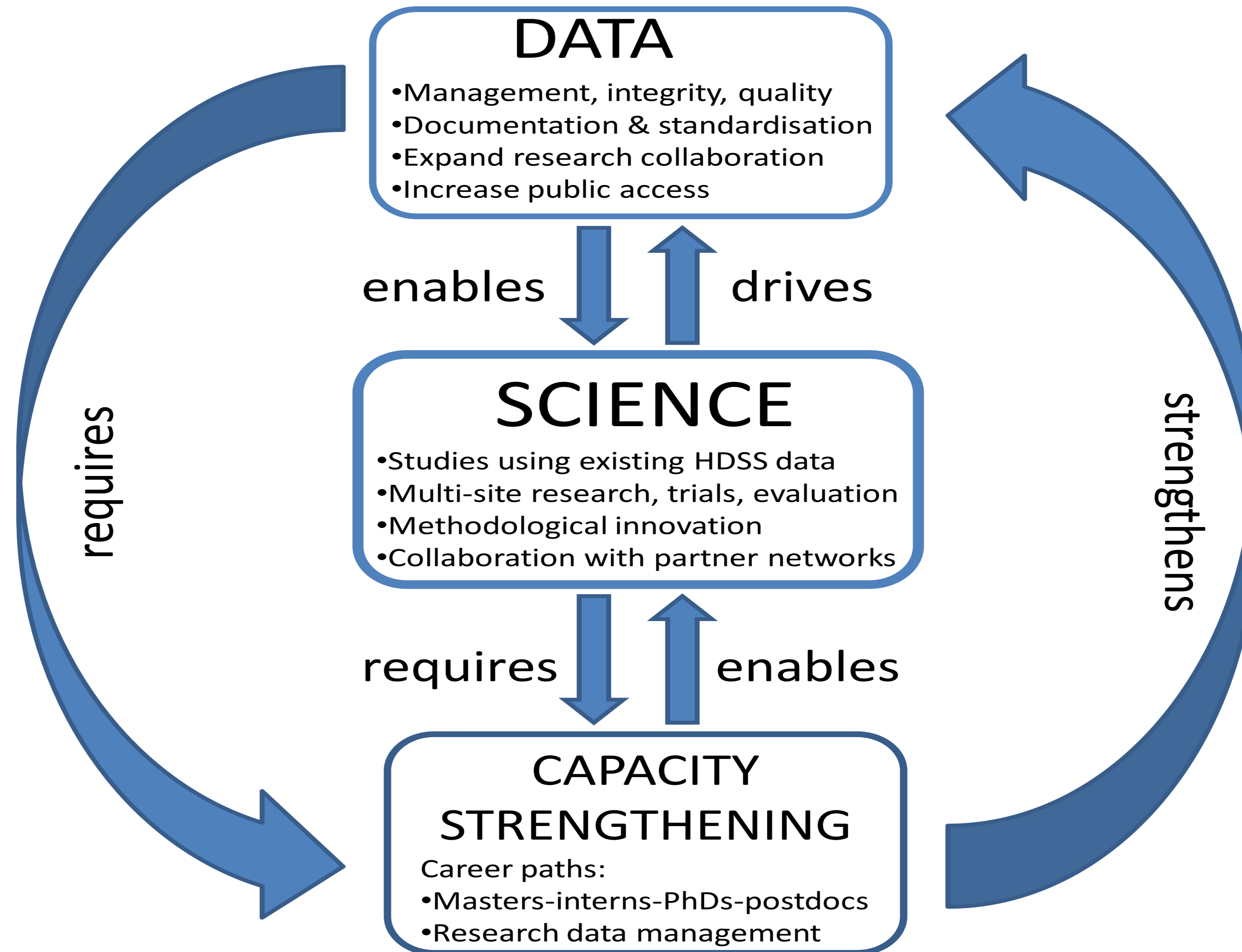
- Different levels of information technology
- Different data structures and database technology

- Limited research data management skills
- Difficulty in retaining those skills
- Data quality and harmonisation issues
- Identity disclosure risk

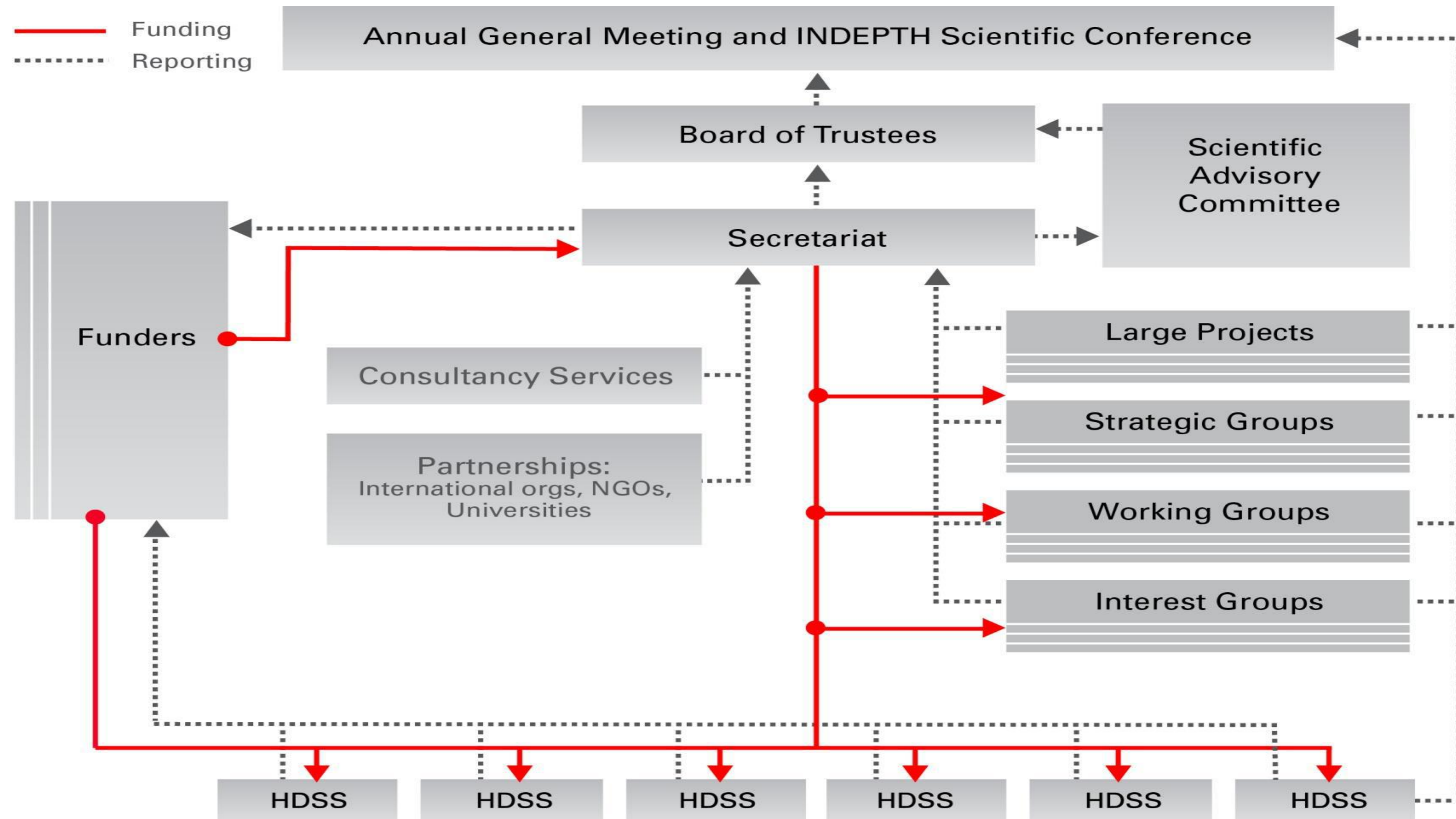


INDEPTH Cooperative's Core Business

We are open
to
partnerships
with
Universities



INDEPTH Governance Structure





National Institutes of Health



Swiss TPH



**We thank the community leaders and share the information
with them**

