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

- Full registration: Complete coverage of the population
- Sample registration: Representative of the population (e.g., sample vital registration system, sample vital registration with verbal autopsy)
- Sentinel registration: Not representative of the population (e.g., urban/rural demographic surveillance sites)

Increasing coverage of civil registration over time
HDSS – A viable solution

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

Initial Census
(Unique ID given)
(Rural/Urban/Peri-Urban)

Enter
Follow up of pregnancies and their outcomes

Dynamic Cohort

In-migrate after 6 months

Out-migrate after 6 months

Exit

Verbal Autopsy on all deaths

Ideal cycles of enumeration 2-4/year

HDSS Core Equation
Examples of Observed Exposed Intervals

Follow-up of an individual (Person Years)

1. Birth (in DSA)
2. Move in
3. Move out
4. Move in
5. Move out
6. Death (not in DSA)
7. Birth (in DSA)
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12. Death (in DSA)

Observed Exposed Interval

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Population Data Structure – HDSS Participants

- Unique ID given
- Individual
  - Measurements
  - Date of Birth
  - Place of Birth
  - Sex
  - Parents
  - Source of income

- Household
  - Measurements
  - Headship
  - Members
  - Income

- Dwelling
  - Measurements
  - Type
  - GPS location
  - Owner
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

INDEPTH Network
Outputs from an HDSS

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

INDEPTH Member HDSS Sentinel Surveillance Countries

Senegal
The Gambia
Guinea-Bissau
Burkina Faso
Ghana
Nigeria

Ethiopia
Uganda
Kenya
Tanzania
Malawi
Mozambique
South Africa

India
Bangladesh
Thailand
Vietnam
Indonesia
PNG

Through INDEPTH to diverse countries and continents

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

RESEARCH AREAS

1: Epi-demographic transitions
   - producing comparable indicators on levels, trends and transition dynamics

2: Social and economic determinants of health inequalities
   - investigating relationships between poverty, social determinants and health inequality

3: Health and welfare systems
   - investigating implications of epi-demographic change for health and social systems

4: Health across the life course
   - examining social/physical/genetic factors and health, change over the life course, pathways to risk or resilience, intergenerational effects

Influences across the life course
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)

WE WANT TO BE ABLE TO SUPPORT MORE...
INDEPTH in-country policy engagement meetings (India, Ghana, 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)

<table>
<thead>
<tr>
<th>Sentinel Population &amp; Events</th>
<th>Household Data Sources</th>
<th>Health Facility Data Sources</th>
<th>Indicator Grouping</th>
<th>Diagnostics</th>
<th>Outputs</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Individuals: Healthy and those experiencing illness events or death</td>
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<td>ANC Pregnancy Registers</td>
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<td>Community Case Management</td>
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<td>Incidence Sample Cohort &amp; mobile reporting</td>
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<td>HDSS Visits (Whole sentinel population)</td>
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<tr>
<td>Individual ID Assigned</td>
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Electronic ID used throughout process

Data Linkage & Quality Assurance

Capacity Strengthening and Training across the components

Results for Policy & Strategy, Influence, Dissemination and Use

- Incidence of Pathogen Specific Disease, Severe Disease (all age groups)
- Pathogen-Specific Case
- Fatality Cause-Specific mortality
- Age specific mortality rates
- Others: Pregnancy, schooling outcomes; NCDs
- High-Quality Linked Datasets
- Well-Trained and Capable People
HDSS

Health and Demographic Surveillance System

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

CHESS

Comprehensive Health and Epidemiological Surveillance System

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

INDEPTH Cooperative is focused on enhancing scientific research, data management, and capacity strengthening. Our approach involves:

**SCIENCE**
- Studies using existing HDSS data
- Multi-site research, trials, evaluation
- Methodological innovation
- Collaboration with partner networks

**DATA**
- Management, integrity, quality
- Documentation & standardisation
- Expand research collaboration
- Increase public access

**CAPACITY STRENGTHENING**
- Career paths: Masters-interns-PhDs-postdocs
- Research data management

We are open to partnerships with Universities.
We thank the community leaders and share the information with them