



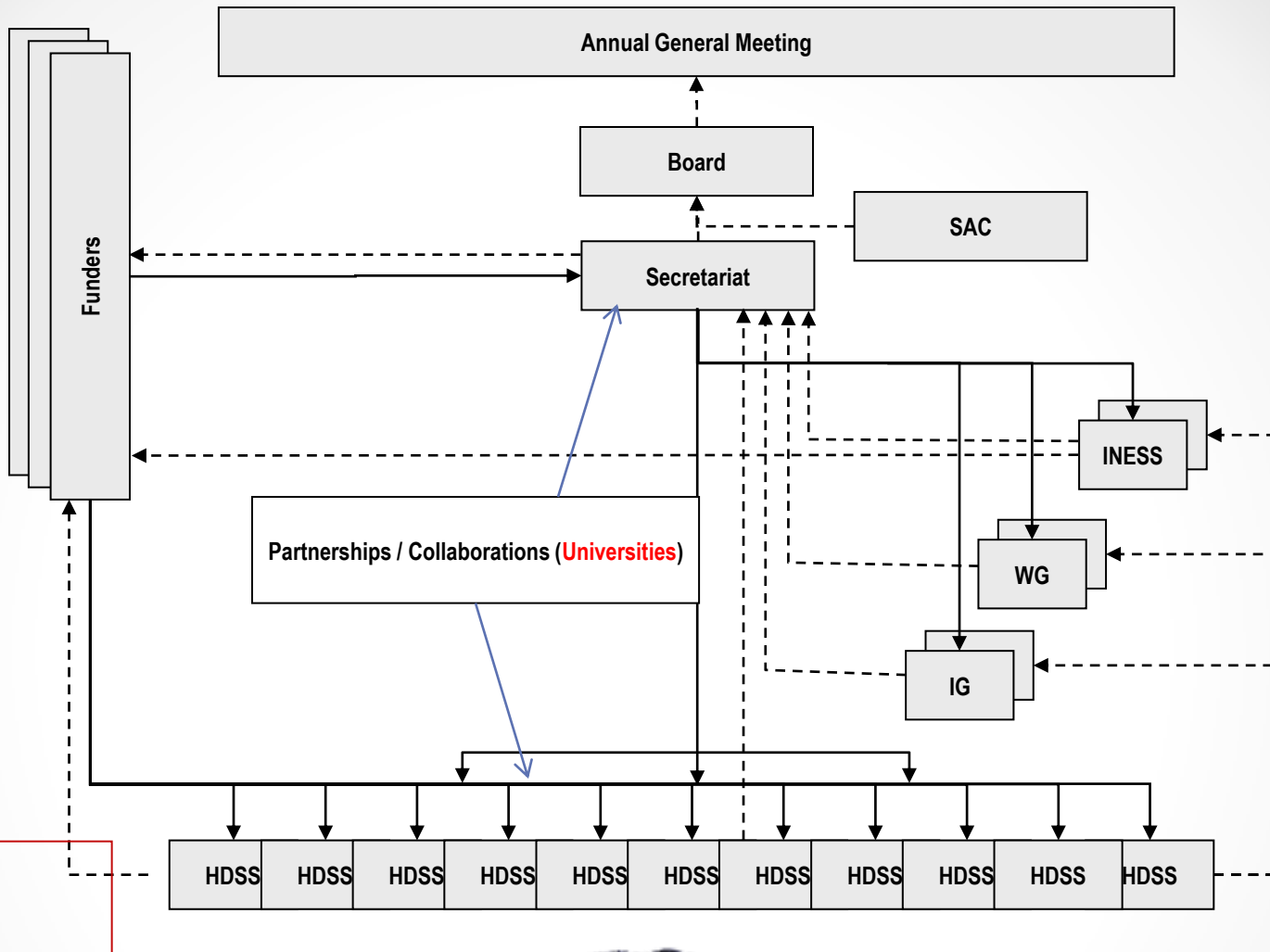
Legal capacity and needs of institutions within the INDEPTH Network

Where there is no lawyer: Meeting on fair research contracting
Bellagio Centre
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Jeannette Quarcoopome

Communications & External Relations Manager





Membership Criteria



—→ Funding line
 - - - -> Reporting line

Why INDEPTH?

- Lack of reliable population-based data on health across many LMICs in Africa, Asia and Oceania.
- Coupled with the lack of adequate human capacity to make use of the data, even if they existed.
- Still a dream - universal individual registration of populations in LMICs.
- Health policy making often lacks its essential evidence base => Failing to use scarce resources effectively in some of the world's poorest countries.

INDEPTH tackles these needs

- Replication or multi-site studies/trials
- Pooling of data facilitates extrapolation
- Networking and sharing information/results, building knowledge partnerships - previously HDSS sites working in isolation; incredible capacity when connected
- Strengthening capacity for data management and analysis - essential to build successive generation of African and Asian scientists
- creates visibility for centres located mostly in rural areas

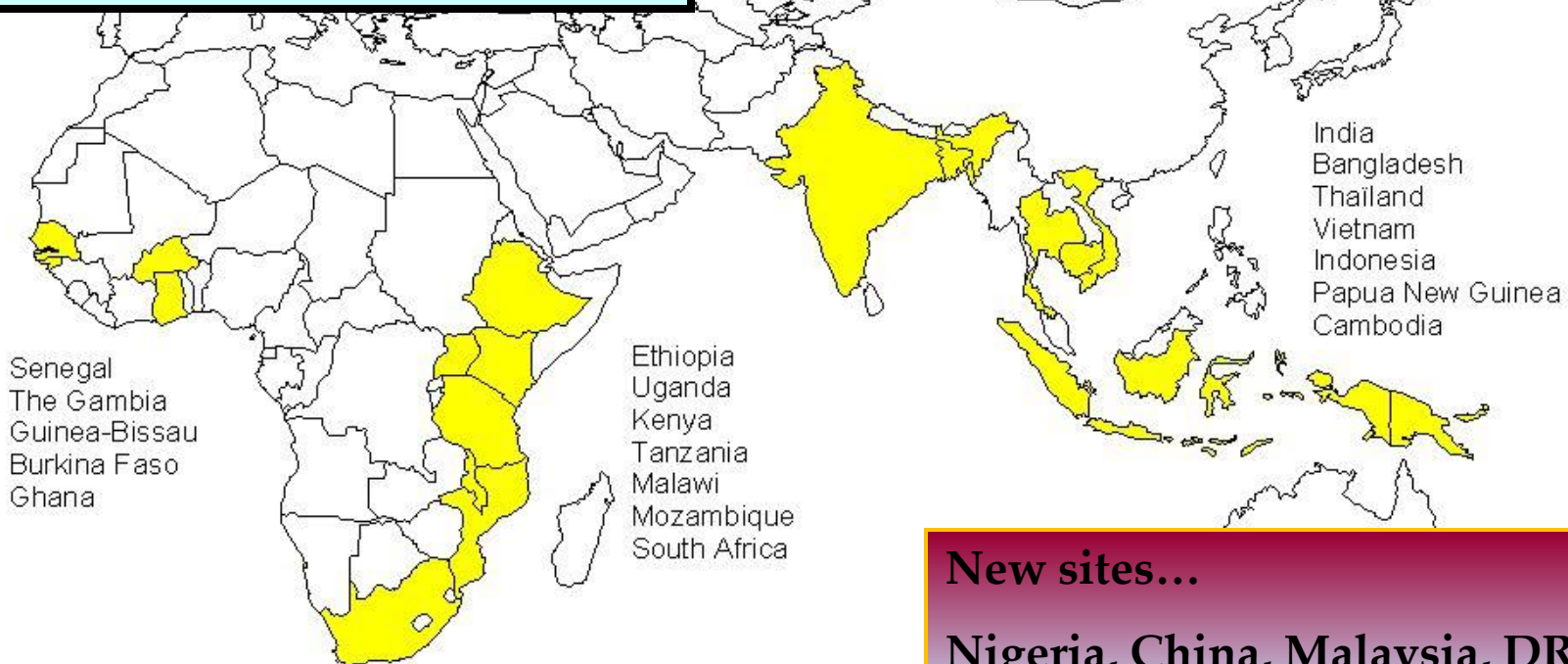
HDSS – A viable medium-term solution

- Health and Demographic Surveillance System (HDSS) - provides a fuller picture
- HDSS collects data from a whole community over time, and hence:
 - *Monitors new health threats;*
 - *Tracks population changes;*
 - *Can monitor health interventions; and*
 - *Can assess policy interventions.*

 Insights into **causality**

Low- and Middle-Income Countries with INDEPTH member centres Running Health and Demographic Surveillance Systems (HDSSs)

Currently 44 HDSSs in 20 countries
32 HDSSs in Africa
11 HDSSs in Asia
1 HDSS in Oceania



Over 3,200,000 people under
surveillance

New sites...

Nigeria, China, Malaysia, DRC,
Zambia, Angola, Madagascar,
Gabon, Mali, Sierra Leone,
Rwanda.

INDEPTH cross-centre, cross-national, cross-continental research

- Vaccination & Child Survival
- **Mortality levels, patterns, and trends**
- Causes of death in developing countries
- **Malaria transmission and mortality**
- HIV/AIDS
- **Health equity studies**
- Migration and urbanization
- **Sexual and Reproductive Health**
- Indicators for measuring MDG progress
- **NCD Risk Factor Surveillance in Asia**
- Adult Health and Aging
- **Climate Change, Migration and Health**
- Effectiveness and Safety Studies of Antimalarials
- **Indoor Air Pollution**
- Social Autopsy

Capacity strengthening activities

- MSc programme at Wits
- Support short courses in relevant areas of our work
- Scientific writing and data analysis workshops
- Posting INDEPTH fellows at member centres
- Technical assistances to members
- Improving data quality
- Standardising methods and tools

Data Sharing

Categories

- **Centre-Specific Data** are all data generated by and specific to a particular member centre.
- **Network Core Data** are data contributed by a member centre as a condition of Network membership.
- **Network Project Data** are data resulting from Network activities

Levels of Access

- **Open Access:** Except for attribution of origin, no conditions and prior registration are applicable to the use of the data.
- **Licensed Access:** A registration by a prospective data user is required on the INDEPTH data repository
- **Restricted Licensed Access:** In addition to the requirements above the prospective data user will require endorsement from the institution s/he is affiliated with.
- **Closed Access:** This applies to highly sensitive or individually identifiable data and will happen at Centre level.

Legal Capacity & Needs

Introduction

Contracts at **INDEPTH as a Network** are usually entered into for various project activities:

- Scientific programmes/research
- Capacity development/educational trainings
- Fellowships
- Intervention studies
- Clinical trials
- Workshops etc

What pertains at INDEPTH

- There is a Grants Manager
- There is a legal advisor who drafts and/or reads every contract and advises the ED before signature on behalf of INDEPTH. These include:
 - Contracts with Funders on grants to INDEPTH
 - Contracts on sub-grants from INDEPTH to member centres
 - MOUs and Contracts with external Collaborators/Partners
 - Contracts with Service Providers (especially international)
 - Travel award letters to scientists/students

Legal Capacity & Needs at HDSS Centres

Contracts at the HDSSs are usually entered into for similar project activities:

- Scientific programmes/research
- Capacity development/educational trainings
- Fellowships
- Intervention studies
- Clinical trials
- Workshops etc

The Status Quo

Many HDSSs have not considered fair research contracting as a legal issue

Use of conventions and contract templates

Some have managed by using contract templates that have been developed and applied over time. Example:

Vadu HDSS (India): Has used several different contract templates for the past 45 years of its existence and these have worked for them.

Use of conventions and contract templates

Butajira HDSS (Ethiopia): By convention has developed a negotiating procedure through which they request the following:

- A Co-PI should be appointed from the site
- 10% of the project cost to support site strengthening
- Some other forms of assistant to the base
- Ethical clearance from a local institute

Use of conventions and templates

Agincourt HDSS (South Africa): Use of the Director of Finance and a team at the Finance office - They admit that this procedure has its challenges and sometimes the need for negotiation among different parties does arise indicating that some capacity is required to get things right.

Access to legal capacity

At some HDSSs legal capacity is available and legal advice is sought and obtained from a legal advisor as and when necessary.

Examples

Vadu HDSS: in addition to the use of templates they have developed they also have access to a legal advisor based in Pune

Examples contd.

Africa Centre for Health and Population Studies(South Africa) has a clearly laid out process which uses a two-step approach to scrutinising contracts:

1. Head of Research Administration in consultation with the Principal Investigators (PIs) scrutinises all contracts and looks out for:
 - Whether or not the contract encompasses what was set out to achieve
 - Legal names and addresses are correct
 - Intellectual Property, acknowledgements and details on how any future publications will be handled.

Contd.

2. The documents then go to the lawyer at the University of KZN for the final scrutiny and authorisation. The Africa Centre is legally embedded in the University of KZN and as such, authority to process and sign contracts lies with the university.

Examples Contd.

Bandafassi & Mlomp HDSS (Senegal) are under the Institute de Recherche de Developpment (IRD): There is an entire juridical service that scrutinises all contracts and ensures their fairness.

Another example

Manhica HDSS (Mozambique): Also has adequate legal support for scrutinising their contracts

No capacity but need identified

No capacity but the need is there:

- **Most other HDSSs do** not have any official legal capacity to negotiate fair research contracting or evaluate contracts. They are of the view that upon reflection such expertise is critical

In Conclusion....

Contracting for research at INDEPTH and our membercentres can be assessed as Very Strong, Strong and Weak

- Very Strong
 - INDEPTH
 - Member centres - Well established centres like ICDDR,B, KEMRI-CDC, KEMRI-WELLCOME TRUST, MANHICA, etc...

Contd.

- **Strong**

- Those affiliated to Universities:

University of KwaZulu-Natal, South Africa

School of Public Health, Addis Ababa University, Ethiopia

University of the Witwatersrand, Johannesburg, South Africa

University of Limpopo, South Africa

Nagasaki University, Japan

- **Weak**

Those that have an independent or semi-independent status - The 3 HDSSs in Ghana etc.



Thank you