

**An International Network of Field Sites with Continuous Demographic  
Evaluation of Populations and Their Health in Developing Countries**

# **INDEPTH NETWORK**

## **Strategic Plan**

**2005-2009**

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Two years following incorporation, Arnon Mishkin (Mishkin Associates, New York) conducted an evaluation of the progress that the Network has made, based on interviews with Board members, a survey of the member sites, and interviews with key donors and external stakeholders. This evaluation is the basis for this revised document – the INDEPTH Strategic Plan 2005-2009. INDEPTH would therefore like to acknowledge the invaluable contribution made by Arnon Mishkin to the successful completion of its new 5-year Strategic Plan.

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## **I. Executive Summary**

### **Introduction and Background**

Each year millions of people around the world die from preventable acute and chronic diseases. A contributing factor to this high burden of treatable disease is the lack of a reliable information base to support the identification, assessment and cost-effective prevention and treatment of disease and associated social issues in resource constrained countries.

INDEPTH – and its member independent Demographic Surveillance Sites – provide a unique window for developing that reliable information base.

INDEPTH was incorporated in 2002, emerging from a loose confederation of independent Demographic Surveillance Sites. The organization seeks to help all the sites join together to develop unique studies and impact, only available from leveraging the core longitudinal health and demographic data of DSS.

Demographic Surveillance Sites have existed for over forty years, providing the only real window into health and mortality patterns in parts of Africa, Asia, Latin America and Oceania, where effective national programs of vital statistics often do not exist. DSS sites continuously monitor all individuals in a given area – births and deaths, in- and out-migrations, diseases and health interventions, as well as parameters of economic conditions. Because of the ongoing and complete monitoring of an area, DSS enables scientists to understand both current conditions and, uniquely, longitudinal trends. Moreover, a DSS site with its built-in monitoring mechanism provides a unique setting in which to introduce and assess the impact of various types of health interventions.

Among the scientific and policy findings that have been developed, tested and demonstrated by DSS sites are:

- The effectiveness of Insecticide Treated Nets (ITNs) in reducing the incidence of malaria mortality.
- The impact of expanding the health care workers on health outcomes in a community.
- The first real model life tables for sub-Saharan Africa, which had previously relied on estimates over one hundred years old.
- Family planning strategies tested at Matlab have been adopted nationwide and led to Bangladesh's recognition at the 1994 United Nations Conference on Population and Development in Cairo as a family planning success story.
- DSS sites in Tanzania have shown how district health strengthening and health impacts can accrue through the use of an extra \$1 per person per year plus systematic use of annual sentinel health intervention profiles from the DSS.

While DSS sites had operated independently, the INDEPTH Network has provided them the ability to pool findings, and develop cross-site evaluations and studies. By linking sites together, the network has shown it can improve the technical strength and scientific value of studies from any one site, as well as streamline processes for launching multi-site studies. This, for the first time, enables effective cross-site data aggregation and analysis thereby increasing the power and applicability of population-based data for health and well being.

INDEPTH is a network of community-based demographic surveillance sites that combats this dearth of health and social data by harnessing the latent potential that exists in individual surveillance sites positioned around the developing world. INDEPTH utilizes its resources to provide an empirical understanding of health and social issues in resource-constrained countries, and to apply this understanding to alleviate the most severe health and social challenges.

INDEPTH also seeks to improve the efficiency and effectiveness of research initiatives by playing a key coordination function for research sponsors, institutions and international organizations. INDEPTH provides donor organizations with a single point of contact to launch and conduct multi-site initiatives. Through the relationships and infrastructure within the network, INDEPTH can significantly reduce the time and effort required to identify and select the most appropriate sites for studies and coordinate ongoing multi-site initiatives. In addition, the network can utilize its global reach and scientific credibility to maximize the impact of research on policy and practice. INDEPTH further enhances the effectiveness of funding efforts by providing donors with quantitative feedback mechanisms regarding the impact of the programs being sponsored.

The INDEPTH network currently consists of 33 demographic surveillance system (DSS) field sites in 19 countries that collectively monitor 2,200,000 people at a household-level. INDEPTH exists as an independent entity and will contract with individual demographic surveillance system (DSS) sites to execute cross-site studies, multi-site research and other network-level activities. In addition, INDEPTH is strongly committed to strengthening the scientific and technical capacity at the site-level.

INDEPTH member sites are currently located in Africa, Asia, Latin America and Oceania, with the majority of sites located in sub-Saharan Africa (SSA). Each site operates in geographically defined populations and conducts longitudinal, demographic monitoring, with timely production of data on all births, deaths, causes of death and migration. This monitoring system provides a platform for the design and evaluation of a wide range of innovations in health care as well as social, economic, behavioral and health interventions and research studies.

### **INDEPTH Economic Overview**

INDEPTH's network budget is used to support the Secretariat and maintain a high level of collaboration within the network. The INDEPTH budget is approximately \$1.86M per year with 56.4% allocation for facilitating cross-site scientific opportunities, 16.1% for facilitating Network capacity building initiatives, and 27.5% allocation for supporting the Secretariat running cost, its staff, and the Board,

Funding for the creation of INDEPTH has been provided by the Andrew W. Mellon Foundation, Navrongo Health Research Centre, the Population Council, and the Rockefeller Foundation. Since its inception, the Network has also received critical support from member DSS sites and their respective donors and institutions including the World Bank, the Rockefeller Foundation, the Wellcome Trust, and Sida/SAREC. Ongoing funding of core activities will be provided through a variety of donors, investors and partnerships named in the Strategic Plan. Additional funding for activities will be recovered from individual network studies in accordance with the funding guidelines of each investor organization.

### **INDEPTH Progress and Accomplishments: 2002-2004**

Two years following incorporation, an independent evaluation of the network – based on interviews with board members, a survey of the member sites, and interviews with key donors and external stakeholders – found substantial support for the work of the network and a belief that INDEPTH has made substantial progress in reaching its major goals. A belief supported by tangible evidence of scientifically valuable output.

- INDEPTH is regarded as a key source of multi-centre demographic studies in the international health community. It is seen by many donors as a “go-to” facilitator of attaining essential demographic data;
- INDEPTH has completed the following three publications: 1) *Population and Health in Developing Countries, Volume 1: Population, Health and Survival at INDEPTH Sites*; 2) *INDEPTH Model Life Tables for Sub-Saharan Africa*; and 3) *Measuring Health Equity in Small Areas – Findings from Demographic Surveillance Sites*;
- INDEPTH has launched an important set of capacity building initiatives to help member sites. It is highly regarded by member sites as a way for them to help build capacity and train their staff. Measurable success is the increase in developing-country scientists in INDEPTH sites;
- INDEPTH is developing a strong platform to use in conducting clinical trials, both as the best place to obtain core baseline epidemiological data, as well as a scientific/medical infrastructure that can be leveraged to execute trials of clinical and other interventions. This is in direct response to the need identified by public and private sectors;
- INDEPTH has increased the visibility of member sites which operate mostly in remote communities in resource-constrained countries in the developing world; and
- INDEPTH developed and published online and as a book a starter kit for new DSS sites.

The evaluation found substantial support for the scientific and capacity building initiatives that the network is now embarking on. At the same time, it found evidence for the need to continue focus on several internal process imperatives. These imperatives are provided in a separate section.

### **Scientific and Capacity Building Priorities: 2005-2009**

INDEPTH has already started work on a set of seven priority scientific initiatives for the next five years. These initiatives have been selected based on the needs of the studied populations as well as the major concerns of public health authorities, NGOs and major donor organizations. The priority areas are:

1. Create the capability to design and test new effective and affordable interventions and delivery mechanisms by building an Integrated INDEPTH Health Intervention Trials Platform
2. Malaria transmission and intensity and burden, and design, test and help roll out interventions and delivery mechanisms to control the disease
3. Work to better measure the impact and burden of HIV/AIDS and design and test interventions to limit its spread and contain the disease
4. Continue to pursue efforts at measuring the cost of health inequities and health impact of economic inequity
5. Assess the impact of key demographic factors including migration and urbanization on health
6. Assess the impact of chronic illness and lifestyles on households and their

productivity

7. Disseminate scientific findings through peer-reviewed publications and continue work on “Cause of Death at INDEPTH Sites”
8. Leverage the scientific findings from INDEPTH sites and studies into health policy/practice recommendations and changes

INDEPTH is organizing capacity building initiatives across the lifecycle of both institutional DSS site development and individual professional training. These initiatives will help the global public health sector get better information and scientific work from the efforts of the sites, and increase the scientific and operational strength of “Southern-based” institutions.

INDEPTH is building institutional DSS capacity by:

1. Helping sites develop regional groups and teams to focus on the specific issues facing their regions
2. Developing and deploying new tools to help sites simplify the core DSS process
3. Helping sites showcase their research and results for better policy influence
4. Speeding the creation of new DSS sites/INDEPTH members
5. Helping sites improve general management, financial and IT operations
6. Improving support and coordinating capacity at the Secretariat for more efficiency and effectiveness

INDEPTH is building professional capacity at DSS sites by:

1. Improving the skills of the current leadership of DSS sites, through the ongoing activities of the working groups and interest groups, direct training of managers and active participation in the Annual General and Scientific Meeting (AGM) and other scientific meetings.
2. Developing the next generation of DSS and other public health professionals through the creation of a joint Masters Program with the University of the Witwatersrand in epidemiology, biostatistics and social sciences.

### **Project Timeline**

The project opportunities identified will leverage existing INDEPTH and member site capabilities and resources. While INDEPTH plans to obtain some additional network resources, the implementation of future studies must be planned in a coordinated and staged manner that avoids overloading network or site resources at any given time. The start dates of INDEPTH studies will be staggered over the next five years.

### **Partnerships**

Maintaining and establishing partnerships – both with funders and donors as well as with parallel groups – is essential to realizing INDEPTH’s vision and mission. INDEPTH has developed a parallel partner with its work with the African Census Analysis Project (ACAP). It is also looking at specific opportunities including the European Malaria Vaccine Initiative (EMVI), the European and Developing Countries Clinical Trials Platform (EDCTP) and International Clinical Epidemiology Network (INCLEN). In addition, it looks to work closely with donors, product development groups (including the orphan disease public/private partnerships), parallel groups (such as INCLEN and research NGOs), local governments, policy makers (including national ministries of health and census bureaus), service delivery

NGOs and local community-based groups. Each of these partnerships will provide resource support and expertise that will be needed for the new opportunities identified for demographic surveillance in developing countries.

## **II. INDEPTH's Vision, Mission and Objectives**

The INDEPTH network continues to pursue its underlying Vision and Mission, as articulated in 2002:

### **INDEPTH's Vision**

INDEPTH will be an international platform of sentinel demographic sites that provides health and demographic data and research to enable developing countries to set health priorities and policies based on longitudinal evidence. INDEPTH's data and research will guide the cost effective use of tools, interventions and systems to ensure and monitor progress towards national goals.

### **INDEPTH's Mission**

To harness the collective potential of the world's community-based longitudinal demographic surveillance initiatives in resource constrained countries to provide a better, empirical understanding of health and social issues, and to apply this understanding to alleviate the most severe health and social challenges.

### **INDEPTH's Objectives**

1. To initiate and facilitate cross-site, longitudinal health and social studies and impact assessments in severely resource constrained populations.
2. To disseminate study findings with all external stakeholders to maximize impact on policy and practice.
3. To support capacity building and cross-site collaborations among INDEPTH member sites.
4. To facilitate the process for donors to fund multi-site health and social research projects in the developing world and especially Africa and Asia.

### **INDEPTH's Core Activities**

At incorporation, it agreed on five core activities:

1. Cultivate cross-site activity through:
  - Execution of comparative studies and exchange of experiences on critical common problems.
  - Creation and sharing of regional health status assessments relevant to global priority setting.
  - Coordinated multi-center research collaborations that evaluate interventions in diverse socio-culture and geographic environments.
  - Recruitment and/or creation of additional sites; particularly sites that provide INDEPTH with presence in current geographic gaps.
2. Generate longitudinal data and analysis that can be used to impact ongoing health and social reforms, inform health and social policy and practice and contribute to governmental, NGO, private and community health efforts.
3. Broaden the scope of health research by confronting the emerging agenda of

non-communicable disease and aging, violence and injury, migration and urbanization and the problems associated with vulnerable population segments.

4. Continually improve the methods and technologies used by member sites to ensure all participating groups have access to the most valid and appropriate methodologies available.
5. Generate visibility and recognition for INDEPTH and member sites among critical constituencies, including academic, government and international agencies and donors.
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### III. Situation Assessment

**Significant opportunity exists to positively impact the health of populations at greatest risk by harnessing the capabilities of individual Demographic Surveillance System (DSS) sites to better assess, investigate and monitor health and social status and interventions.**

Despite the existence of affordable and effective interventions, high mortality societies contain a growing population whose health profile reflects surprisingly high rates of treatable acute and chronic diseases. A factor contributing to this high burden of treatable disease is the lack of a reliable information base to support health development. Without the guidance of valid population-based health data, health policies and interventions of greatest impact are rarely identified and implemented to improve the health of those at greatest risk. Lack of adequate data also severely limits the capacity to assess the ultimate health benefit of interventions that have been implemented, and ensure resources are being allocated in an optimal manner.

Despite the overall lack of reliable information, a growing number of field stations based on DSS have a proven track record in providing high quality population-based information in their defined geography. These local DSSs generate data that positively impact the health of the research community by informing health priority setting, policy and practice, and the allocation of resources. These sites are also a critical resource to support highly focused, intervention-oriented, research efforts.

DSS sites constitute a critical yet weakly harnessed alternative to the dearth of valid, population-based information in much of the developing world. DSS sites have had a positive impact at both the local level and internationally, but broader research and information generation efforts in data-poor countries are constrained by limited coordination, communication and standardization. The tremendous potential that exists through the coordination and collaboration between multiple DSS sites in multiple countries is now realized through the establishment of the INDEPTH Network.

**Donor funding and interest in health issues in the developing world is increasing.**

The past decade has seen an overall increase in funding for health issues. Between 1995 and 2004 foundations significantly increased overall health funding. In addition, a number of global funds focused on developing country health issues were established. These include funds established by the Global Funds for AIDS, Global Alliance for Tuberculosis (GATB), Medicines for Malaria Venture (MMV) and Global Alliance for Vaccines and Immunizations (GAVI).

**Global opinion has begun to shift toward an increased concern for the reduction of health inequities.**

Efforts to improve health in developing countries are often limited by the inequity in access to health and related services among various population groups. Equal access depends upon the availability of services and the presence of organizations with the financial and resource capacity to help those in need. Unfortunately, as previously mentioned, these resources are often not available to those in most need.

There is currently a lack of data focusing on the distribution of health conditions and health service utilization among different population sub-groups. In addition, few studies have

sought to address the question of how inequalities are initially created and what factors cause these inequalities to persist and even expand over time.

Many organizations have created programs to focus on issues of health equity. For example, The World Bank Group is sponsoring multi-country study programs on equity, poverty and health. These studies seek to understand how health inequalities vary across countries and what factors account for intra-country inequities. In addition, the studies seek to identify poor/non-poor differences in access to health care, utilization of different types of services relative to medical need, and the benefits received from public health care subsidies.

**Malaria continues to be a leading cause of death in many countries despite the existence of cost-effective interventions.**

Significant interest remains focused on reducing the burden of malaria within Africa. Government and external donors continue to direct significant resources towards this effort.

In the 2000 Abuja Declaration, the WHO and Roll Back Malaria Initiative (RBM) established the goal to reduce malaria in Africa by 50% by 2005. This is an aggressive goal that will require substantial local support in the deployment of interventions and the measurement of their impact. Government and donor organizations will likely leverage interventions that have already been proven effective in combating malaria at a local level. Efforts are increasing to utilize DSS sites to scale-up these successful local interventions within and across countries. An example of a successful intervention is the Insecticide Treated Net (ITN) project conducted within specific areas of Tanzania in which mosquito nets are distributed to households and their utilization is supported by a social marketing campaign. The Tanzanian Ministry of Health is looking to replicate the ITN project in other parts of Tanzania and there is significant potential to expand the ITN project to additional countries.

Scaling up interventions within countries and across countries will require the coordination of activities across multiple DSS sites and health facilities. Governments and external donors will be looking for coordination experience, research capability, a strong track record and resources to support the process of broadening the reach of proven interventions.

**HIV / AIDS epidemic continues to grow in Africa and Southeast Asia.**

The HIV/AIDS epidemic continues to ravage the developing world, particularly in sub-Saharan Africa and Southeast Asia. Seroprevalence rates are reaching as high as 30-40% among some populations and HIV/AIDS is now the leading cause of death in sub-Saharan Africa. HIV/AIDS has a tremendous impact on the livelihoods of people in sub-Saharan Africa and Southeast Asia. The availability of labor for agriculture and a great number of activities for sustaining well-being are negatively affected by the disease. Households, communities, enterprises, and both governmental and non-governmental organizations must grapple with the burden of prolonged illness, death and bereavement caused by HIV/AIDS. Indisputably, the HIV/AIDS epidemic has worsened poverty levels in already impoverished nations. Beyond even the appalling toll in individual human misery, the epidemic in these areas has now reached levels at which the economic development of entire communities is threatened, with further devastating consequences.

The lack of representative AIDS data about Africa and Asia severely limits the ability of the national governments and district authorities to assess the impact of AIDS and implement appropriate initiatives to combat the disease. INDEPTH is providing the representative population based data that is currently lacking in many parts of Africa.

NGOs and other external donors have shown a strong willingness to support initiatives within Africa that are geared towards reducing the burden of HIV/AIDS in the continent. Up until this point, however, much more emphasis has been placed on the execution of the various interventions and little attention or resources have been placed on the evaluation of the effectiveness of these interventions. Additional education on the evaluation capabilities of the DSS and the utility of evaluation information will be required to stimulate donor interest in this area.

The following are two main research areas to be covered:

1. Population-based determinants of success and socioeconomic impact of ART
2. Impact of HIV on socio-demographic measures (mortality, fertility, household structures and family dynamics)

**Demand for clinical and community trial sites is increasing.**

There is growing demand among pharmaceutical companies, public-private partnerships and non-profits for clinical trial sites for their emerging drugs, technologies and products. Many of these new products target diseases that have significantly contributed to the burden of disease in Africa and Asia (e.g. HIV/AIDS) and an increasing number of these trials are being situated in the developing world. This shift is reflected in the percentage of non-U.S. investigators, which increased from 13% to 28% between 1995 and 2000. While a majority of these trials are conducted in more developed nations, considerable money is spent on clinical trials in developing nations.

Important selection criteria for clinical trial sites include the site's diagnostic capability, ability to administer interventions and monitor treatment results, clinical research experience, community and health service acceptance and familiarity with and ability to implement ethical review standards. Based on these criteria, a subset of DSS sites is providing an ideal platform for clinical trials.

**Significant potential exists in understanding complex migration issues at member sites.**

As a consequence of evolving health conditions, the burden of chronic disease among people in the developing world is becoming clearer, including the debilitating economic consequences of these conditions. Population migration and urbanization are critical dimensions of ongoing societal transition but our understanding of these forces are insufficient.

Currently, migration studies are primarily conducted at the national-level and provide only crude international migration statistics. In addition, some individual DSS sites are conducting independent local migration studies that look at migration within a defined geography and seek to explain the cause and effect of these migrations with regard to health and socioeconomic factors. These studies have been valuable in understanding the relationship between migration and health and the information generated by these studies has had impact on policy and health initiatives within the study area.

While valuable at the local level, the specific focus of DSS migration studies and the data definitions used in these studies are not currently standardized. This lack of standardization makes it infeasible to utilize this rich migration data at a broader level. Significant potential exists in coordinating and standardizing individual studies so that the data can be aggregated and used to impact policies and interventions at a multi-country level.

### **INDEPTH Scientific Development and Leadership Program**

One of INDEPTH's key missions is to strengthen the capacity of developing-country scientific research. In February 2005, INDEPTH launched a Masters in Population-based Field Research program in partnership with the University of the Witwatersrand in Johannesburg, South Africa, which operates the Agincourt demographic surveillance system through its School of Public Health.

The eighteen-month course combines face-to-face teaching with at least six months of fieldwork at INDEPTH sites in Navrongo (Ghana), Umkhanyakude (South Africa) and Ifakara (Tanzania). This will enable students to benefit from the wealth of data available at DSS sites, as well as drawing on the experience of multidisciplinary teams of epidemiologists, biostatisticians, demographers and social scientists. During the fieldwork period, teaching will be conducted through a distance-learning module that will be developed with the London School of Hygiene and Tropical Medicine and other partners.

The course will focus on five areas:

- Epidemiology
- Biostatistics and data management
- Demography and other social sciences
- Information technologies for demographic and health surveillance
- Leadership

The course aims to develop scientists who can identify and find solutions to key biomedical and public health problems that may be addressed by epidemiological or demographic studies. It will teach students how to plan, execute and analyze field-based scientific research, and give them the communication and leadership skills to explain and promote the research with different audiences, including policy-makers, donors and academics. It is hoped that after three years, the University of the Witwatersrand will continue to develop the program.

## IV. Overview of Existing Organization

### INDEPTH General Overview

INDEPTH is an international network currently consisting of 36 demographic surveillance system (DSS) field sites in 19 countries that collectively monitor 2,000,000 people at a household-level. The sites are currently located in Africa, Asia, Latin America and Oceania with the majority of sites located in sub-Saharan Africa. Each site operates in geographically defined populations, and conducts continuous, longitudinal, demographic monitoring, with timely production of data on all births, deaths, causes of death, and migration. This monitoring system provides a platform for the design and evaluation of a wide range of health care innovations as well as social, economic, behavioral and health interventions and research studies.

The INDEPTH network was established in 1998 through a series of meetings of DSS site leaders who were seeking to network and coordinate their disparate efforts. INDEPTH was subsequently registered as a not-for-profit, international, non-governmental organization and launched activities in 1999 with modest support from a variety of donors. INDEPTH is currently served by an active Secretariat in Accra, Ghana, obtained registration as an international NGO in the USA and Ghana.

INDEPTH's major product is its monograph series entitled *Population and Health in Developing Countries*, a comparative study of recent trends in mortality in Africa and Asia. Titled *Population, Health, and Survival at INDEPTH Sites*, Volume 1 presents age-specific mortality data for INDEPTH field sites and contributes new knowledge on African and Asian mortality patterns in an era of HIV/AIDS. Within the monograph, each participating DSS site has contributed a chapter in which it describes itself and the data it is contributing. In addition to the site profile chapters, the monograph includes chapters that describe the basic methodology employed by all of the field sites and two chapters that compare and summarize the mortality data across all sites, using an empirically derived INDEPTH standard population.

The second volume entitled *INDEPTH Model Life Tables for Sub-Saharan Africa* was published in 2004 by Ashgate Publishing UK. Model life tables provide ways of deriving accurate mortality schedules or predicting future trends from scanty data. In settings where accurate data are unavailable, these are invaluable methods for assessing mortality rates. This book presents model life tables for Africa using accurate empirical data from 19 demographic surveillance system sites throughout sub-Saharan Africa. A Brass logic system is used to produce mortality models that are unique in that they incorporate for the first time empirical and accurate data representing prevailing mortality patterns in developing countries, which take into account the effect of the HIV/AIDS epidemic.

INDEPTH currently has in press a third volume entitled *Measuring Health Equity in Small Areas: Findings from Demographic Surveillance Sites*. Over the past decade, several initiatives have been launched to address the major health problems affecting the world's poorest countries, including global efforts to combat HIV/AIDS, TB and malaria. More recently, a millennial challenge has been laid down to root out and confront the links between poverty and health. While there has been a spate of studies and reports devoted to this subject, it has been noted that policies meant to address the needs of the global poor are based on indirect estimates and data from urban centers and health facilities that do not

accurately reflect their experience. Using demographic surveillance systems, the INDEPTH researchers aim to contribute both to the empirical knowledge about health equity in developing countries and to report on the application of and innovation in tools and methods. Illustrated with case studies from sub-Saharan Africa and Asia, this book puts forward a comprehensive view of the INDEPTH methodologies and findings. It develops and measures concepts and constructs of ‘poverty’ and ‘equity’ and relates these to each health status. While tools and concepts for measuring health status are more developed, this volume contributes by grappling with new concepts and tools to measure changes in deprivation and disadvantage, adding to this intense theoretical and methodological debate.

INDEPTH has supported member sites through annual general and scientific meetings, multiple workshops and training courses, and ongoing technical support and troubleshooting in DSS computing and data management. INDEPTH has also established several Working Groups including: Technical Support to Field Sites; Analytical Methods and Capacity Strengthening; Malaria; Reproductive Health; Health Equity; Adult Health and Aging; Cause Specific Mortality; and Applications of Research to Policy and Practice.

## **Organizational Structure and Governance**

### ***Organization***

INDEPTH exists as an independent entity, with dedicated resources supported by the Secretariat staff. INDEPTH contracts on an arm’s length basis with individual sites to execute multi-site research other network-level activities. INDEPTH funds its activities via direct support from donor organizations. Figure 1 illustrates INDEPTH’s organizational structure and governance.

### ***The Secretariat***

INDEPTH is led by a permanent executive body (“the Secretariat”), which is headed by a full-time Executive Director appointed by and accountable to the Board of Trustees. Additional network support capabilities are to be provided by the Secretariat through a Communications and External Relations Manager, IT Manager, Finance Manager and Administrative Assistant(s). The Communications and External Relations Manager is responsible for identifying knowledge marketing objectives and implementing strategies to meet those objectives, acting as INDEPTH’s senior public relations representative and raising awareness and enhancing the positive image of the INDEPTH network. The IT Manager is responsible for supporting the Secretariat and INDEPTH sites in maintaining an effective flow of information within the network and specific research teams. The Finance Manager is responsible for finalizing and enforcing consistent usage of a transparent, standardized chart of accounts for sites participating in INDEPTH projects. All members of the Secretariat are employees of INDEPTH and receive their full compensation from INDEPTH.

The principal overall responsibilities of the Secretariat are to:

- Identify key health and social issues and questions that need to be investigated
- Maintain donor relations and generate funding for network-level studies and evaluations
- Efficiently coordinate and support the conduct of network studies and evaluations
- Publish and disseminate results to impact health and social policy and practice
- Promote DSS and its capabilities
- Position INDEPTH among regional and international institutions

In identifying key issues and raising funds for network studies, the Secretariat maintains ongoing dialogues with sites and with key donors and other stakeholders. In developing specific proposals the Secretariat will work closely with interested sites to build a Working Group and nominate the Principal Investigator.

### ***The Board of Trustees***

A Board of Trustees provides oversight for the activities of the Secretariat. A Chair, elected from among the 6 site members, leads the Board of Trustees. The Board consists of 9 total members: 6 Elected Members representing the sites and selected by them; 2 Appointed Members selected by the Elected Members to reflect donor perspectives, and 1 unaffiliated member, also selected by the Elected Members. The Board of Trustees is scheduled to meet on a semi-annual basis.

The Board of Trustees' primary role is to provide oversight and accountability for the activities of the Secretariat and network as a whole. In addition, the Board of Trustees is responsible for appointing the Executive Director.

### ***The Scientific Advisory Committee***

A permanent Scientific Advisory Committee (SAC) assists in maintaining the focus of INDEPTH on health, population and social issues and areas of greatest potential impact; encourages linkages between INDEPTH and related agencies, research bodies and networks; and helps maintain the highest scientific standard for INDEPTH studies. In addition, the SAC facilitates ongoing communication between INDEPTH and donors and key scientific stakeholders. The SAC consists of 15 members selected on their personal merits and representing diverse constituencies including NGOs, academic institutions pharmaceutical and clinical research organizations, etc. Members of the SAC will receive a limited honorarium from INDEPTH.

The SAC is scheduled to meet twice per year. The main activities of these meetings include:

- A review of the current portfolio of INDEPTH network-level studies and impact assessments for scientific rigor and policy impact.
- Suggestions for additional avenues for research or other network activity.
- Identification of new sources of funding opportunities to support these additional avenues.
- Consideration of ethical issues related to the scientific program and making recommendations to the INDEPTH Ethical Committee;
- Evaluation of the opportunities, strengths and weaknesses of the scientific activities of the Network;
- Support INDEPTH Working Groups through technical input or review of their scientific programs; and
- Review procedure developed by INDEPTH on sharing of data

Members of the SAC may be compensated for additional tasks performed in accordance with local regulations and donor guidelines.

### ***Working Groups***

INDEPTH actively utilizes Working Groups dedicated to key issues of interest to INDEPTH. Current Working Groups include Health Equity, Cause Specific Mortality, and ACAP-INDEPTH Collaboration. The Working Groups act as generators and incubators for multi-site research and development projects. Working Group members may include scientists

from INDEPTH sites, Secretariat staff, and members of the Board of Trustees and/or Scientific Advisory Committee. Site participants are not compensated by INDEPTH for their contributions to a Working Group. The Working Groups ultimately report to the Executive Director of INDEPTH. Each Working Group is led by a leader who is responsible for reporting on Working Group progress and is also accountable to Working Group participants and participating sites. The Secretariat will consider ways and means of making working groups work effectively.

### ***Interest Groups***

Interest Groups are mostly 'virtual' with members rarely, if ever, meet face-to-face, unless perhaps at Annual General and Scientific meetings. The Secretariat will accord an interest group the full status of a *Working Group* if it has a defined research question with a draft proposal that will lead to a cross-site collaborative project within the INDEPTH research portfolio.

### ***The Principal Investigator***

Each network study will be led by a Principal Investigator (PI) who is selected from among the researchers participating in the study. The participating researchers and relevant donors will nominate the PI, who must then be approved by the Executive Director and ratified by the Board. The PI is responsible for the execution of the study including design, data collection, analysis and reporting. The PI reports to the Executive Director and the Communications and External Relations Manager. The PI is compensated by INDEPTH for work done in support of funded network studies. A similar approach may be used with regard to capacity building efforts.

### ***The INDEPTH Annual General and Scientific Meeting (AGM)***

INDEPTH actively utilizes its Annual General and Scientific Meetings (AGMs) as forums for discussing organizational matters of the Network, election of officials, reviewing reports by the Board and the Executive Director, and reviewing progress of the Secretariat. The AGM is the General Assembly of the Network that takes final decisions on issues tabled by the Board and/or the Executive Director. It generates the scientific agenda through its Working Groups and reviews progress of joint work undertaken. In addition, INDEPTH utilizes its Annual General Meetings as Scientific Forums for members to share their experiences in demographic surveillance in the form of presentations of scientific papers. Posters are also presented at the AGM especially by young scientists who are sponsored by the Network.

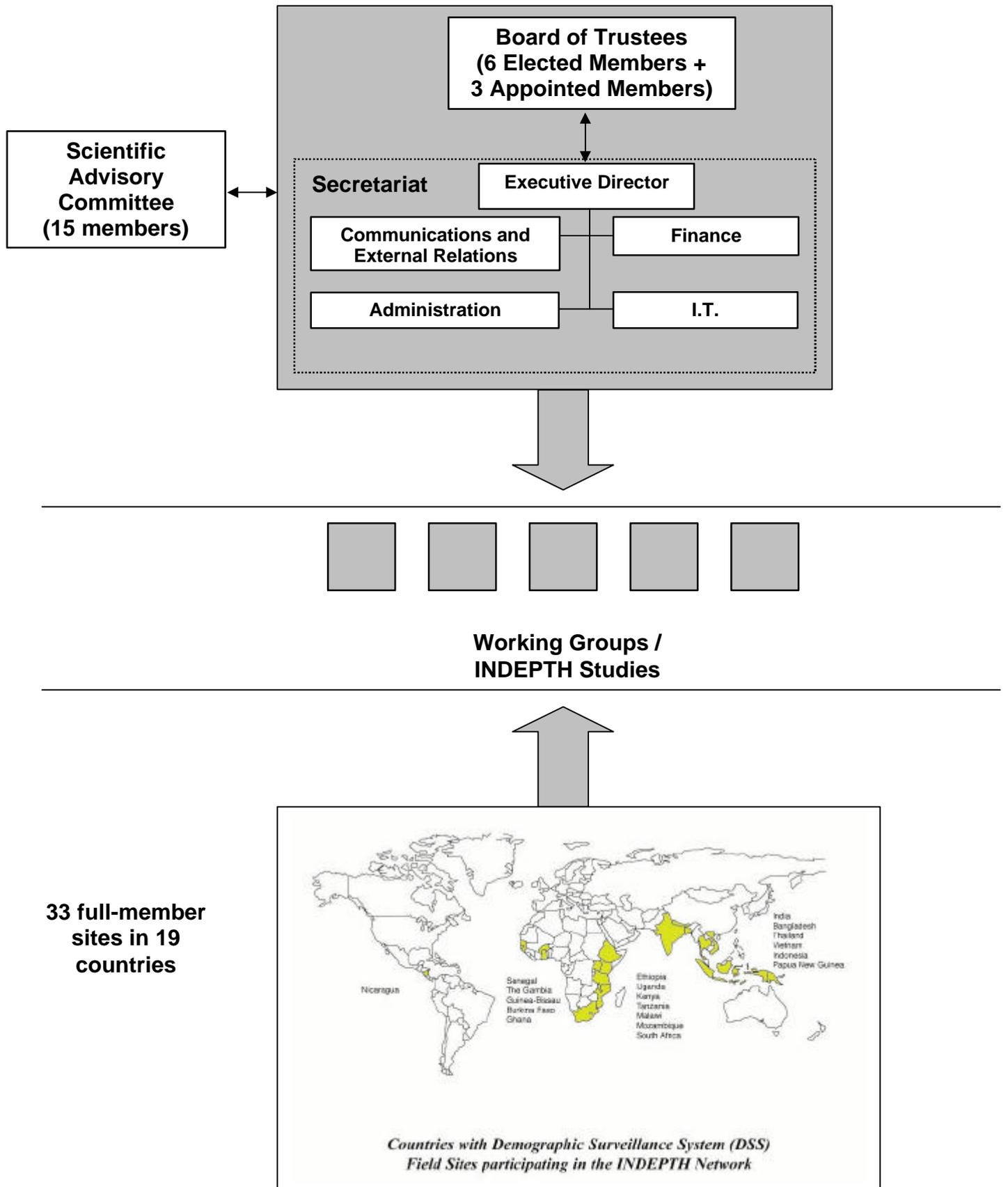


Figure 1: INDEPTH Organization

## **V. INDEPTH Value Proposition**

INDEPTH is committed to harnessing the potential of the world's demographic surveillance initiatives through their global network of sites. This network generates significant value for both the member sites and external stakeholders who both stand to benefit from the knowledge and resources of the network. By coordinating the activities of individual demographic surveillance initiatives and facilitating ongoing collaboration within the network, INDEPTH can generate new knowledge and insights for critical health and social challenges. Through the existing network relationships and infrastructure, INDEPTH can greatly enhance the efficiency and effectiveness of multi-site research initiatives. The combined influence and credibility of INDEPTH and member sites enable the network to have significant influence on key decision and policy makers. INDEPTH will use this influence to ensure knowledge is disseminated and is translated into improved policy and practice.

### **Leverage the Unique Insights Available only through DSS information**

INDEPTH sites are unique in providing complete, household-level, longitudinal information about health conditions, treatment and outcomes, demographic information (including all births & deaths and all in- and out-migrations), as well as household economic indicators. This information provides the only baseline to enable tracking of changes in outcomes and enable the monitoring of the impact of various interventions.

### **Enhance Site Capabilities and Local Knowledge Dissemination**

INDEPTH will provide value to member sites through increased access to multi-site research opportunities, network collaboration and best-practices. INDEPTH is committed to helping sites expand their intellectual capital, scope of research and research infrastructure through network studies and ongoing network activities. Improved site capabilities can be used to generate more robust data and knowledge on the key health and social issue of the DSS coverage area. This information can better inform policy and planning by local and national governments, which can in turn benefit the communities and households the DSS sites are seeking to aid.

### **New Knowledge and Insights from Multi-Site Studies**

INDEPTH studies have the advantage of incorporating longitudinal data from multiple sites that are located across different countries, regions and continents. INDEPTH has the unique ability to undertake studies across a broad geography while maintaining the rich longitudinal data that exist at an individual site level. This capability enables new insights to be drawn from studies that have traditionally been limited to a targeted geographic region. This capability also enables a new category of multi-site studies to be designed and executed that can generate new knowledge and insights that have previously been unavailable or infeasible. The INDEPTH publications provide examples of the new knowledge that can be generated by the network of INDEPTH sites. Current and future INDEPTH projects will provide new insights in their own findings and will stimulate new studies and insights from other researcher organizations who have access to the output from INDEPTH.

### **Improved Effectiveness and Efficiency of Research Efforts**

In addition to offering new insights through longitudinal, multi-site studies, INDEPTH also improves the efficiency of these studies by coordinating site activities through the relationships and infrastructure that exist within the network. By creating an integrated

network of sites, INDEPTH offers project sponsors with a single, “one-stop” solution for studies that require the identification, selection and coordination of multiple sites. Traditionally, the study sponsor has been required to identify, evaluate, select and coordinate site activities in support of individual studies. This process consumes both time and resources that would be better allocated to executing the actual study. INDEPTH is now able to facilitate the launch and ongoing coordination of multi-site projects using the INDEPTH network infrastructure. This capability enables site selection and coordination to be completed in a much shorter timeframe and with significantly less expense to the sponsor. The INDEPTH infrastructure also increases the effectiveness of this process and ensures that participating sites meet study requirements and will yield optimal results.

### **Impact on Multi-National Policy and Practice**

By utilizing its broad membership base, geographic reach and credibility with the scientific community and governmental bodies, INDEPTH can effectively translate research findings into improved policy and practice. By sharing information across sites and using the combined influence of INDEPTH and its members, INDEPTH can have significant influence within individual governments and among international organizations. This influence will be used to ensure that knowledge generated within the network is disseminated and ultimately used to impact policy and practice for health and social issues.

### **A Southern-Led Partnership**

The network is headquartered in Accra, Ghana and consists entirely of sites in the South – Africa, Asia, Latin America and Oceania. While it leverages the skills and support of scientists from the North, it seeks to develop Southern capacity both in the conduct of actual studies as well as in leading scientific and research organizations.

## VI. INDEPTH Economic Overview

### INDEPTH Network Core Costs

**NOTE: The “Network Core Costs” do not include project-specific funding allocation.** Funding for projects is raised through specific grant proposals written by Working Groups.

INDEPTH Network core costs refer to the costs required to support the ongoing maintenance and expansion of the INDEPTH Network and the costs required to facilitate the cross-site scientific opportunities (see section VII A) and capacity building initiatives (see section VII B) of the Network.

The costs have been estimated for 2005 based on the existing strategic plan. A more detailed budget information is available on request.

The annual Network budget is estimated to be \$1.86M. This budget estimate includes:

#### Facilitating Cross-Site Scientific Opportunities (56.4%)

- *Facilitating key scientific activities* – Funds will be used to facilitate activities involving the INDEPTH Health Intervention Trials Platform, Health Equity Study, Adult Health Study and Migration and Urbanization.
- *Annual General and Scientific Meeting* – This meeting is a key activity of the Network.
- *INDEPTH Working Groups* – Working groups are convened to proactively identify new INDEPTH research opportunities. The budget includes 5 working group meetings per year.
- *Production of INDEPTH Publications* – This is a key Network activity. Requires the formation of editorial groups from several sites, as well as hiring consultants to support the production of INDEPTH publications.
- *Scientific Advisory Group* – This group provides scientific guidance to the Network. Funds are used to support its meetings – face-to-face and telephone meetings.
- *Technical Exchange and site visits* – INDEPTH support technical exchanges and site visits.
- *Secretariat Staff time* – The Executive Director, the Communications and External Relations Manager and the IT Manager spend their time on forging Network’s scientific activities. It is expected that these staff will use 30% of their total time.

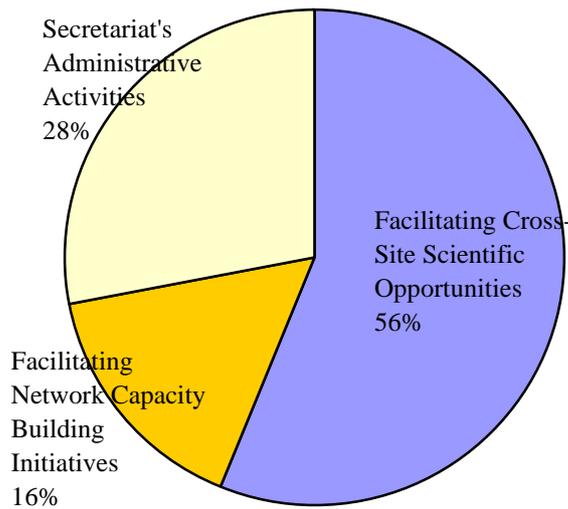
#### Facilitating Network Capacity Building Initiatives (16.07%)

- *Helping sites develop regional groups and teams to focus on the specific issues facing their regions.*
- *Developing and deploying new tools to help sites simplify the core DSS process.*
- *Helping sites showcase their research and results for better policy influence.*
- *Speeding the creation of new DSS sites/INDEPTH members.*
- *Helping sites improve general management, financial and IT operations.*

#### Secretariat – Administrative Activities (27.5%)

- *Secretariat Personnel Costs* – The budget includes 7 FTEs including an Executive Director, Communications and External Relations Manager, IT Manager, Finance Manager, and 3 administrative support personnel.

- *Secretariat Travel Expense* –This includes travel by the Executive Director and Communications and External Relations Manager for internal and external meetings.
- *Secretariat’s Running Cost* – Secretariat office and equipment expense.
- *Board of Trustees* – Funds will be used to support meetings of the Board of Trustees and the Board Chair.



**Breakdown of INDEPTH Network Core Costs**

**Network Funding**

INDEPTH’s initial start-up activities and cross-site research initiatives to date have been directly funded by the Andrew Mellon Foundation, Navrongo Health Research Centre, The Population Council, The Rockefeller Foundation, The Wellcome Trust and World Health Organization. INDEPTH was able to extend its funding base to include the World Bank, Sida/SAREC and the Gates Foundation. INDEPTH also relies on the individuals, DSS sites and associated universities and institutes who have contributed their time, expertise and resources to building the network.

Ongoing funding of INDEPTH will be provided through a donor consortium in which individual contributions will be combined to support efforts to maintain and expand the INDEPTH network and support collaboration and new research initiatives among INDEPTH sites.

**Project-Specific Funding**

Funding for specific studies that utilize the INDEPTH network will be negotiated on a case-by-case basis. Project funding will be allocated to participating DSS sites consistent with protocols and INDEPTH funding allocation guidelines. Project-specific funding will include cost recovery for core network costs and/or core site costs when appropriate and in accordance with the funding guidelines of each donor organization. Additional allowances for investment in site infrastructure and development of long-term expertise in key areas of work may also be made when appropriate and in accordance with funding guidelines.

### **Network Financial Reporting**

INDEPTH is implementing a standard chart of accounts to provide consistent and transparent financial external reporting for all INDEPTH projects. This chart of account has been reviewed and approved by a 3<sup>rd</sup> party accountant to ensure alignment with legal and reporting requirements. Included in the chart of accounts are all assets, liabilities, revenue and expenses of the network.

All sites participating in an INDEPTH study will be required to use the standardized chart of accounts for financial reporting for site work done in support of network studies. Site participation in the chart of accounts enables consistent and transparent financial reporting at the site-level for INDEPTH projects.

## **VII. INDEPTH Opportunity Assessment**

### **A. INDEPTH Study Opportunities**

INDEPTH has already started work on a set of seven priority scientific initiatives for the next five years. These initiatives have been selected based on the needs of the studied populations as well as the major concerns of public health authorities, NGOs and major donor organizations. The priorities will enable INDEPTH to grow into a major Southern-based institution, with the capabilities to design and test new interventions, monitor the ongoing burden of high-prevalence diseases, and assess the impact of socio-economic demographic factors, including economic inequity, migration and urbanization.

The priority areas are:

1. Create the capability to design and test new effective and affordable interventions and delivery mechanisms by building an Integrated INDEPTH Health Intervention Trials Platform
2. Measure the risk factors and burden of Malaria and design, test and help roll out interventions and delivery mechanisms to control the disease
3. Work to better measure the impact and burden of HIV/AIDS and design and test interventions to limit its spread and contain the disease
4. Continue to pursue efforts at measuring the cost of health inequities and health impact of economic inequity
5. Assess the impact of key demographic factors including migration and urbanization on health
6. Increase knowledge of adult health in developing countries
7. Disseminate scientific findings and complete the monograph on “Cause of Death at INDEPTH Sites” and continue the “Population and Health” monograph series
8. Leverage the scientific findings from INDEPTH sites and studies into health policy/practice recommendations and changes
9. Integrate DSS data with census data to better understand the population dynamics in Africa.

#### **1. Build an Integrated INDEPTH Health Intervention Trials Platform**

DSS sites provide health information that more accurately reflects the prevailing disease burden of their communities in the developing world. The DSS assists in monitoring and tracking new health threats, such as emerging and re-emerging infectious diseases and drug resistance, and can help the health community develop a response.

Because of the unique combination of accurate baseline epidemiological information and the existing medical and scientific infrastructure, INDEPTH sites can serve as a platform for action-oriented research to test and evaluate health interventions, including new vaccines, drugs, health-education messages, and other initiatives.

Because of the complete local and longitudinal coverage of the DSS sites, INDEPTH is uniquely positioned to test both specific interventions and delivery mechanisms.

INDEPTH has launched an effort to further develop infrastructure and human resource capacities at member sites to conduct health intervention trials with a focus on the following poverty-related diseases: malaria, HIV/AIDS, TB and rotavirus.

In order to develop a useable interventions platform, it is working in particular to:

- Collect epidemiological data and other information for current and other diseases researched at the sites;
- Identify suitable cohorts for the conduct of clinical trials;
- Strengthen infrastructure and human capacity at sites with the basic infrastructure for intervention trials, and build it at interested member sites without the basic capacity
- Train site leaders to negotiate with various international sponsors of intervention trails in developing countries
- Establish quality-control, regulatory and ethical procedures, including helping participating sites get GCP and GLP accreditation
- Create a monitoring unit including a site assessment manual; and
- Establish INDEPTH data management, biostatistical and epidemiological procedures for trials.

INDEPTH will work to promote its effectiveness as a platform for both the baseline epidemiological data and the execution of actual health intervention and clinical trials with funding organizations, particularly the EDCTP. Its leadership has been a major part of the EDCTP effort and INDEPTH is well positioned to ensure that the EDCTP vision becomes real.

## **2. Continue INDEPTH's efforts to measure the burden of Malaria and design, test and help roll out interventions to control the disease**

Malaria continues to be a leading cause of death in many countries despite the existence of cost-effective interventions. As a result, public health authorities will continue to seek to reduce the burden of malaria within Africa and government and external donors will direct significant resources towards these efforts and their level of support is expected to grow over the next 5 years.

In the 2000 Abuja Declaration, the WHO and Roll Back Malaria Initiative (RBM) established the goal to reduce malaria in Africa by 50% by 2005. This aggressive goal will require substantial local support to deploy interventions and measure their impact.

DSS sites are uniquely positioned to help local authorities design and assess the impact of new interventions, because of their longitudinal tracking of impact and their built in "baselines." For example, DSS sites in Tanzania launched and designed an effective social marketing campaign to distribute and ensure the utilization of Insecticide Treated Net (ITN). The Tanzanian Ministry of Health is now leveraging the lessons from the DSS site to replicate the ITN project in other parts of Tanzania. There is significant potential to expand the ITN project to additional countries.

Designing and setting up processes to scale up Malaria interventions within and across countries will require the coordination of activities across multiple DSS sites and health facilities. INDEPTH will work with its sites to design similar programs, coordinate experience and research capability and appeal to governments and external donors to support the process of broadening the reach of proven interventions.

### **3. Work to better measure the burden of HIV/AIDS and design and test interventions and delivery approaches to limit its spread and control it**

The HIV/AIDS epidemic continues to ravage the developing world, particularly in sub-Saharan Africa and Southeast Asia. Seroprevalence rates reach as high as 30-40% among some populations and HIV/AIDS now appears to be the leading cause of death in sub-Saharan Africa. Moreover, HIV/AIDS has had a tremendous impact on the livelihoods of people in sub-Saharan Africa and Southeast Asia, reducing the availability of labor for agriculture and industry and worsening poverty levels in already impoverished regions. Households, communities, enterprises, and both governmental and non-governmental organizations must grapple with the burden of prolonged illness, death and bereavement caused by HIV/AIDS. Beyond even the appalling toll in individual human misery, the epidemic in these areas has now reached levels which threaten the economic development of entire communities, with further devastating consequences.

The lack of truly representative data about AIDS in Africa and Asia severely limits the ability of the national governments and district authorities to assess its impact and implement appropriate initiatives to combat the disease. INDEPTH sites have the potential to provide the representative population based data that is currently lacking.

Moreover, because of the complete local and longitudinal tracking of DSS sites, INDEPTH can provide ideal testing grounds for all forms of interventions and delivery mechanisms that either seek to limit the spread of the virus or provide treatment to control it.

NGOs and other external donors have shown a strong willingness to support initiatives within Africa focused on reducing the burden of HIV/AIDS in the continent. Until now, however, they have placed primary emphasis on the execution of the various interventions and little or no resources on the evaluation of the effectiveness of these interventions.

INDEPTH will launch an effort to design programs to monitor the ongoing burden of AIDS in our site locations and to design and test the potential of new interventions. We will work to demonstrate the importance both of launching new programs, but – even more important – of testing the impact of these interventions to determine the optimal ways to utilize treatments and approaches to fighting the epidemic in Africa and Asia.

### **4. Continue to pursue efforts at measuring the cost of health inequities**

Efforts to improve health in developing countries are often limited by the inequity in access to health and related services among various population groups. Equal access depends upon the availability of services and the presence of organizations with the

financial and resource capacity to help those in need. Unfortunately, these resources are often not available to those in most need. There is currently a need for better analysis of the distribution of health conditions and health service utilization among different population sub-groups. In addition, there is a need for studies to address the question of how inequalities are initially created and what factors cause these inequalities to persist and even expand over time.

Because many DSS track both health outcomes and economic conditions and because of the longitudinal nature of the analysis, INDEPTH is uniquely positioned to measure and monitor the impact of health equity in the small areas its sites are located. The INDEPTH Health Equity I study – currently being published – showed that significant disparities exist in health outcomes among different socio-economic subgroups, even within small areas.. The Network is now embarking on Health Equity II and developing intervention studies to understand how to improve health outcomes at the lower equity levels and to better inform policy.

#### **5. INDEPTH will study the impact of Migration and Urbanization on our study populations**

Across Africa and Asia, there are large – and substantial unmeasured – population movements from rural areas and substantial expansion of the population of urban centers. INDEPTH’s migration & urbanization interest group will conduct a study of population migration streams and trends across multiple countries and continents, with special emphasis on internal migration and local mobility, and look at mortality outcomes. The aim will be a monograph on “Migration, Mobility and Mortality”. Because the study will measure health outcomes including mortality, it will offer a unique insight into health conditions and the impacts of movement, urbanization and change. Each site in the study will supplement its work by conducting independent local migration studies examining migration within a defined geography and seeking to assess the cause of these migrations and the impact on health and socio-economic factors. The INDEPTH initiative will set out to co-ordinate and standardize existing site-level data to enable the comparison of data and findings across multiple sites, countries and continents.

#### **6. INDEPTH will continue to assess the impact of chronic illness and lifestyles on households and their productivity**

There is a gap in our knowledge about adult health in developing countries. Statistics on adult morbidity or mortality are practically unavailable in most settings. Even where such data are available, they are either of limited value or the quality is seriously suspect. Using indirect techniques, demographers have tried to provide some insights on levels of adult mortality, but many question the accuracy of these estimates. The situation has been complicated further with the rise of the HIV/AIDS epidemic because the indirect methods for estimating adult mortality are even more seriously questioned because of opportunistic and intra-family infections that result from HIV/AIDS infections. Because of the in-depth and longitudinal nature of DSS analysis, INDEPTH sites have a unique ability to track and assess the impact and causes of adult morbidity.

**7. INDEPTH will continue its work to create a platform of sentinel sites to measure the burden of disease and monitor progress and trends regarding the main causes of death in Africa and Asia**

The Network is working to produce a monograph on the key causes of death at its member sites in Africa and Asia. These efforts started in 2002 to complement a partner program funded by WHO/TDR/RBM – Malaria Transmission Intensity and Mortality Burden Across Africa (MTIMBA) – to generate new understanding of the relationship between malaria transmission intensity, mortality and the effect of malaria control.

Because most of the DSS sites conduct verbal autopsies with the study populations, INDEPTH's ongoing work tracks the specific causes of death at the sites, in addition to malaria. The efforts of MTIMBA and that of INDEPTH's broad-based work on causes of death will create a platform of sentinel sites to measure the burden of disease and monitor progress and trends regarding the main causes of death in Africa and Asia. INDEPTH sites have contributed chapters on cause-specific mortality. This monograph will provide the first cause-specific mortality using empirical data in many developing countries, especially those in Africa where such data hardly exist. It will be a major contribution to the disease control efforts in the developing world.

**8. Leverage the scientific findings from INDEPTH sites and studies into health policy/practice recommendations and changes**

DSS sites have a unique ability in the developing world to provide real monitor-able settings to measure the impact of various health practice or policy interventions. The sites in Tanzania and Ghana have received particular attention for their ability to identify and demonstrate the value of new/modified practices/interventions, which have been used by the Ministry of Health and successfully implemented outside of the DSS location and across the country or outside the country.

INDEPTH will expand its effort to identify the practical implications of scientific findings at each site and across sites.

It is now working to launch a develop a set of case studies showing the scientific findings from DSS, the practice implications and the process and impact of expanding that change not just outside of the immediate DSS, but also nationally and internationally. Its goal is to develop a regular publication illustrating the practical implications of DSS findings and the impact it has had on policy, practice and health.

It will also work to identify processes to help individual sites and the overall network use their findings to influence the decisions of health policy makers and affect policy and practice.

**9. Integrate DSS data with Census data to better understand the population dynamics in Africa**

Recognizing that both African censuses archived by the African Census Analysis Project (ACAP) and the Demographic Surveillance Systems (DSS) coordinated by the INDEPTH Network produce vast and complementary kinds of demographic data for Africa that offers an exciting potential to examine African population and health, a

collaboration between the two institutions was consolidated. The main objective of this collaboration is to pool the resources and expertise of ACAP and INDEPTH to undertake high-quality joint research projects in order to inform demographic and health policy in Africa.

With initial funding from the Rockefeller Foundation the collaboration began in 2002. This initial funding led to the production of a research proposal to secure further funding to address specific scientific questions, and eventually to broaden the participation of countries/sites for the long-term realization of the set objectives. Over the period of the grant considerable accomplishments were made. The Bellagio workshop on *Demography and Health in Africa* was convened where the strategy for the collaboration was outlined and a joint research agenda was adopted. A grant proposal was submitted to the National Institutes of Health (NIH) and several researchers and students have been integrated into the program.

A large amount of data has been acquired from both ACAP country-collaborators and the INDEPTH DSS sites identified for the initial phase. The datasets have been created for use in the program and some preliminary analyses have been conducted using these data. Initial interest focused on comparable data analysis of geography or administrative regions by locating the exact census area covered by each DSS. For most of the sites a lower administrative district that houses the DSA was located and mortality indicators both from the DSS data and the census data compared. Another area of interest has been the relationship between poverty and health in Africa. Poverty, as we know, exacerbates ill health and often tends to negatively affect the health status of individuals. In the absence of reliable income data in Africa, one of the markers of poverty or socioeconomic status is ownership of durable assets and housing/household conditions. Data on these variables have been used to generate an index of poverty or socioeconomic status.

## **B. INDEPTH Network Capacity Building**

INDEPTH is organizing capacity building initiatives across the lifecycle of both institutional DSS site development and individual professional training. These initiatives will help the global public health sector get better information and scientific work from the efforts of the sites, and increase the scientific and operational strength of “Southern-based” institutions.

### **INDEPTH is building institutional DSS capacity by:**

1. Helping sites develop regional groups and teams to focus on the specific issues facing their regions
2. Developing and deploying new tools to help sites simplify the core DSS process
3. Helping sites showcase their research and results by helping create websites for each
4. Speeding the creation of new DSS sites/INDEPTH members
5. Helping sites improve general management, financial and IT operations
6. Improving support and coordinating capacity at the Secretariat for more efficiency and effectiveness

### **INDEPTH is building professional capacity at DSS sites by:**

7. Improving the skills of the current leadership of DSS sites, through the ongoing activities of the working groups and interest groups, direct training of managers and active participation in the Annual General and Scientific Meeting (AGM) and other scientific meetings.
8. Developing the next generation of DSS and other public health professionals through the creation of a joint Masters Program with the University of Witwatersrand in epidemiology, biostatistics and social sciences.

#### **1. Helping sites develop regional groups or teams to focus on the specific issues facing their regions**

While the majority of INDEPTH sites are in Africa, and there have been many intra-African collaborations among those sites, the Secretariat is working to help sites in other regions, particularly Asia/Southeast Asia, develop regional groups and ensure intra-regional collaboration. While regional meetings have often occurred at the AGM, the first meeting of the Asia/Oceania sites will take place in August in Indonesia. It will focus on identifying ways to improve partnerships among Asian/Oceania sites, as well as to plan specific efforts in Adult Health, Health Systems Research, Mortality Differentials and Reproductive Health.

In addition, as more sites from Latin America get started and join the network, the

network will work to help establish Latin American regional collaboration, to complement efforts in Africa and Asia/Oceania.

## **2. Developing and deploying new tools to help sites simplify the core DSS process**

The data management workshop (see 2c above) will develop a common architecture for Longitudinal Database Systems. In addition, the Secretariat is planning two initiatives to increase site and network capacity in data collection and data sharing. First, it plans to help the University of Ghana to launch a new Health Informatics program to develop new capabilities in the use of computer-based tools for health care delivery, and to support 2-3 students from INDEPTH sites to enroll in the program. Second, it will work to leverage the Collexis® technology to enable greater access by INDEPTH to global population and health data and greater access to INDEPTH data across the research world

### *a. Help Launch the University of Ghana Health Informatics Program*

INDEPTH will provide technical support to the University of Ghana to develop a new program in Health Informatics, which will research the use of computer-based tools and information management in health care delivery: data storage, information retrieval, data analysis, and data communication.

The program will be cross-disciplinary with the School of Public Health and the Computer Science Department, and will award an MPH in Health Informatics. It will focus on capacity building, combining knowledge of current applications with a broad appreciation of the issues involved in the management and use of Health Information Systems. The emphasis will be on the scientific methods required to build systems that process health information systems effectively. INDEPTH will support the time of Professor Bruce Macleod (University of South Maine, USA) in developing the program. Prof. Macleod has worked extensively with INDEPTH sites in supporting the Household Registration System (HRS).

The network will also support 2-3 students from INDEPTH sites to participate in this programme. We will seek to create local capacity to take over from Prof. Macleod in the development and support of the HRS software used by many INDEPTH Sites.

### *b. Help Leverage Collexis® technology across the network*

INDEPTH will help increase network access to global medical information and help ensure global access to network findings and data by leveraging Collexis® technology. Collexis® “fingerprints” valuable collections in the private sector, such as Elsevier Science, all free medical and agricultural journals, E-BioSci, all HINARI publishers, GeneBio/SwissProt etc. Through an arrangement with I2A, a not-for-profit organization, it makes the data available for non-commercial use, in exchange for all valuable content made and published by any I2A customer, such as INDEPTH.

INDEPTH will initially offer all practical work of INDEPTH members and ensure member access to the major health information resources obtainable through I2A.

In the long-term, we will seek to connect INDEPTH to the global initiatives set up to connect all available genetic, proteomic and epidemiological data, like E-BioSci, link all experts of INDEPTH, and stimulate the participation of health and population research institutions in its member profiles. In addition, the project will prepare INDEPTH to be one of the first networks to implement the meta-analysis software currently developed at the University of Rotterdam as soon as it becomes a Collexis product and consequently becomes freely available under the I2A license

### **3. Helping sites showcase their research and results for better policy influence**

In order to help improve the visibility of INDEPTH sites, we are working to help them develop their own websites. In many cases, sites either do not have their own websites, or the websites are buried in a “small corner” of the parent organization’s website. This situation does not give DSS sites the prominence and visibility that they need. So far INDEPTH has registered domains and created websites for 4 DSS sites, in addition to the network-wide, Secretariat website. To ensure regular updating of sites, the Secretariat has started the INDEPTH Prize for the best website, i.e. the site has most content and is updated frequently.

### **4. Speeding Creation of New DSS Sites/INDEPTH Members**

The network believes strongly that DSS sites can help every developing country test and design important new health interventions. Ideally, each country should have at least two such sites, one rural and one urban, which together with reliable census data could help each country’s public health sector assess and improve health conditions and treatment. The secretariat is working to create tools to help speed the set up of DSS sites. It has developed a new handbook for new site creation, including making the required IT tools and applications available. And, for new sites, it organizes teams from existing and successful sites to provide required services. These new tools have already helped several sites improve operations, including the new site in Uganda.

### **5. Helping Sites Improve General Management, Financial and IT Operations**

The INDEPTH secretariat is planning training programs to help sites improve their general management, financial and IT operations, and ensure first rate leadership over the coming years

#### **a. General Management Training**

The Secretariat is already organizing a workshop on leadership and management to train/develop current and future leaders of DSS sites and provide the opportunity to interact and share their experiences in leading high-quality and complex research institutions in mostly rural areas in Africa and Asia. The training will be provided both by experienced site leaders as well as by professionals from other networks. All current INDEPTH site leaders and potential future research administrators nominated by site leaders will be invited to attend.

The training will help participants learn more about their own individual

leadership styles and how they can become more effective leaders. It will also provide tools and frameworks for:

- The process of the INDEPTH network, including the roles of site leaders and the Secretariat
- Overall management of their institution and their personnel
- Financial management
- Setting and funding the research agenda
- Evaluating ethical considerations in research
- Improving collaboration with research and other partners
- Increasing dissemination of results, including publications and other communications

The training will help improve general operations at all participating sites. The Secretariat also plans to develop further training on a case-by-case basis, including exchange visits. Over the next five years, the network will monitor operations across sites and ensure ongoing improvement.

#### *b. Improving Financial Management*

The Secretariat is planning a financial workshop to help sites work together to develop standard INDEPTH financial management and financial reporting procedures. The Workshop will provide a forum to standardize needed internal controls at DSS sites, budgeting, budget controls, financial management and financial reporting. It will enable sites to obtain timely and accurate financial reports as well as provide better reporting to donors and other stakeholders.

The training will be led by an experienced financial professional from a DSS Site describing the needs of health institutions and two others focused on financial management and financial reporting.

The workshop will help develop a standard chart of accounts which will be able to be used by all DSS sites, and will help them to better manage their costs and the financial requirements for ongoing operations. Even though each INDEPTH site is financially independent, a standard chart of accounts will help sites develop cross site projects and initiatives. Over the next five years, the network will implement and monitor the operations of the standard chart of accounts.

#### *c. Improving Data Management and Data Sharing*

In its first two years of operation, INDEPTH Secretariat has faced many difficulties in getting data from DSS sites for network level activities. Even though DSS sites generate and store large volumes of data, it is often technically very difficult to obtain data to enable cross network analyses. Data Managers have to grapple with difficulties caused by a multiplicity of factors:

- Technological Constraints
- Human Resource Constraints

- Absence of effective support network for database systems used in DSS sites

These sentiments have been raised in various INDEPTH sessions, including the 2003 annual general meeting and the recent SQL meeting held in South Africa. At the same time, it is clear that the network has the skills and expertise to harness for the benefit of all member sites.

The Secretariat is planning a workshop to facilitate sharing of experiences, solutions, and other related issues to ensure that the data is readily provided for network-level activities.

The workshop will seek to:

- Identify common problems encountered by Data Managers in INDEPTH DSS sites.
- Identify common required capacity development initiatives for INDEPTH sites.
- Outline a strategy for the Secretariat to provide effective assistance through the INDEPTH Data Systems Group and other sources of expertise. This would include the formation of “Expert Groups” within the Network to address problems in specific areas.
- Develop a framework to enable sites to pool data when embarking on join site analyses and meta-analyses
- Agree on a common architecture for Longitudinal Database Systems used in INDEPTH sites, as a target for sites

The workshop will provide a long-range plan for upgrading and continuously improving IT operations at each site.

## **6. Improving Support and Coordinating Capacity at the Secretariat**

INDEPTH is working to build capacity by ensuring ongoing capabilities within its Accra, Ghana-based Secretariat, as well as within each of its member sites. The secretariat employs two full-time scientists, including the executive director, as well as an IT professional. It also has access to consulting services provided by financial accountants, IT organizations as well as scientists.

The Secretariat is the nucleus of an emerging Southern-based and Southern-managed institution. Its principal responsibilities are to:

- Identify key health and social issues and questions that need to be investigated
- Maintain donor relations and generate funding for network-level studies and evaluations
- Efficiently coordinate and support the conduct of network studies and evaluations
- Publish and disseminate results to impact health and social policy and practice
- Promote DSS and its capabilities
- Position INDEPTH among regional and international institutions

In addition, the Secretariat will provides diverse support services to INDEPTH sites, including supporting efforts to build site capacity, organizing scientific and capacity-building workshops as well as the Annual General and Scientific Meeting (AGM)

Over the next five years, the Secretariat intends to have leading research and management capabilities for a Southern-based institution.

### **7. Improving the Skills of DSS Site Leadership: INDEPTH Workshops and Scientific Meetings**

As noted above, the network is launching a series of capacity-building workshops in general, financial and IT management, which will both build site capabilities and help train individual leaders. In addition, the network organizes workshops for its Working Groups and Interest Groups, which enable both the ongoing scientific work of the network as well as the improvement of individual's scientific capabilities

### **8. Developing the next generation of DSS/other public health professionals: The INDEPTH Scientific Development and Leadership Program**

In order to grow the next generation of DSS/public health professionals, the INDEPTH Scientific Development and Leadership Program aims to develop – in a first phase – African scientists from INDEPTH sites and elsewhere through practical on-the-job training. It is setting up a unique Masters program that combines epidemiology, biostatistics, demography and other social sciences with a focus on demographic and health surveillance in developing countries. Such scientists would have the capacity to engage external collaborators, compete effectively for international resources, and take leadership roles at their workplaces.

The network is working in partnership with The University of Witwatersrand (WITS) to launch the one-year Masters Degree program in field-based epidemiology and admit the first group of students by February 2005. In addition the network and the University will develop new distance learning modules on leadership training to be taken either as standalone modules or as part of the Masters curriculum.

With the host university identified, it is now looking to identify a northern-based university partner to help develop the distance learning modules, and seeking additional funding for the program.

## VIII. INDEPTH Process Priorities to Continue to Achieve Scientific and Capacity Building Goals

Our interviews with board members, external stakeholders and survey of site leaders underscored the need for a set of process initiatives to improve operations at the network and further help it achieve its overarching goal of ensuring impact on health in the developing world:

- 1. Increase publications and publication rate,** both the monographs as well as the ongoing peer review studies that leverage data from multiple sites. These reports are both the core work of the network as well the best tool for demonstrating the ongoing importance of the network
- 2. Ensure impact on policy/practice:** Ensuring impact on policy and practice has always been a core goal of the network. We found that the network can do more, both to show the impact its findings have already had on policy and practice and to use its findings. This could help strengthen INDEPTH's position as a core part of international health care development. We also found that by focusing more on policy and practice, the network could additional funds for studies, as well as identify new sources of support for core site operations.
- 3. Strengthen appreciation of the value of DSS:** Although the longitudinal DSS methodology has been around for over thirty years, we found continued skepticism about the unique value of DSS, and more feeling than we had expected that it was not worth the high cost of developing the data. Therefore, we found a need to continue to develop ways to demonstrate and "sell" the value of DSS, both to funders as well as to policy makers.
- 4. Enable greater donor support for site core DSS operations:** Many of the sites are looking to the network to help them sustain core funding for their DSS efforts. While this has not been a core goal of the network, the network will need to consider its business model so that it can best ensure that the cost of network level studies helps defray the cost of the core DSS operation. In addition, it will work to help sites build capacity and to help them raise money for core operations.
- 5. Enable greater support for Secretariat/central functions.** As the work of the network expands, demands on Secretariat operations do as well, potentially requiring the expansion of its scientific/professional staff. Moreover, once the initial Rockefeller core operations grant ends in 2005, the network will need to identify replacement funding to pay for growing Secretariat operations.
- 6. Data Sharing and Analysis.** There is need for the Network to help sites with the complex issues of data sharing and analysis. There is a growing demand to make data freely available. However, given different data ownership structures at sites, the Secretariat will need to organize workshops on data access and sharing to help member sites share their data more effectively.

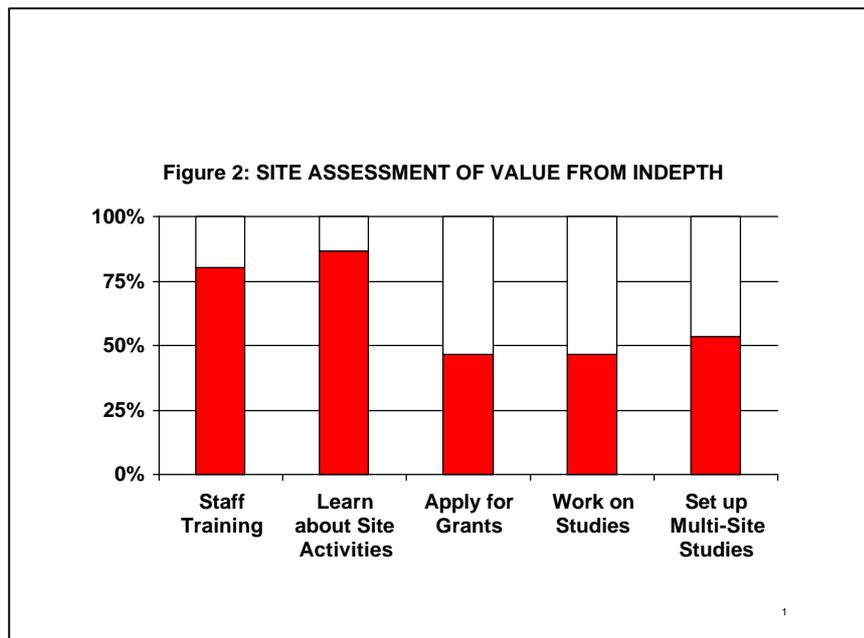
## IX. Sites and External Stakeholders Assess Progress of INDEPTH and Strategic Imperatives

The need for five 2004-05 Strategic Imperatives was underscored in the survey of sites, interviews with external stakeholders and ongoing discussions with the board and secretariat principals.

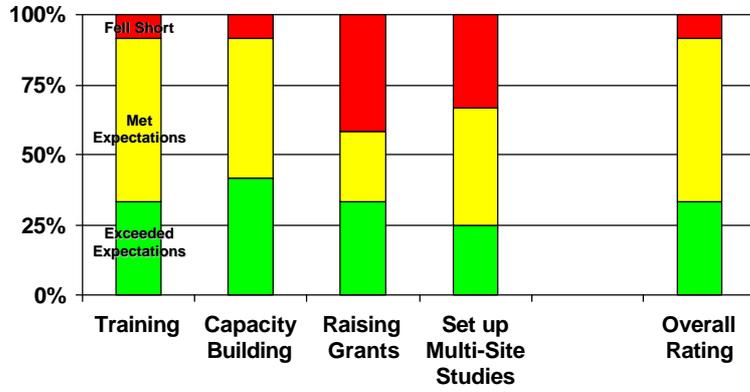
### 1. Increase number and frequency of publications

Both the survey of sites and interviews with external stakeholders understood the challenges, but felt the need to increase the rate and number of INDEPTH publications.

Amid the very high marks that sites gave INDEPTH in the survey, less than 50% said that INDEPTH had helped them to set up multi-site studies and only 25% said that INDEPTH had exceeded expectations in setting up multi-site studies. Over 50% of sites felt that INDEPTH should increase its attention on setting up multi-site studies. (See figures 2, 3 and 4.) In comments, one site leader wrote, “INDEPTH’s strength lies in how well sites engage in multi-site studies and their capacity to contribute to them,” while another commented that the organization “should work to play more facilitative role in getting sites to work on issues that contribute to overall value of data coming from individual sites.”

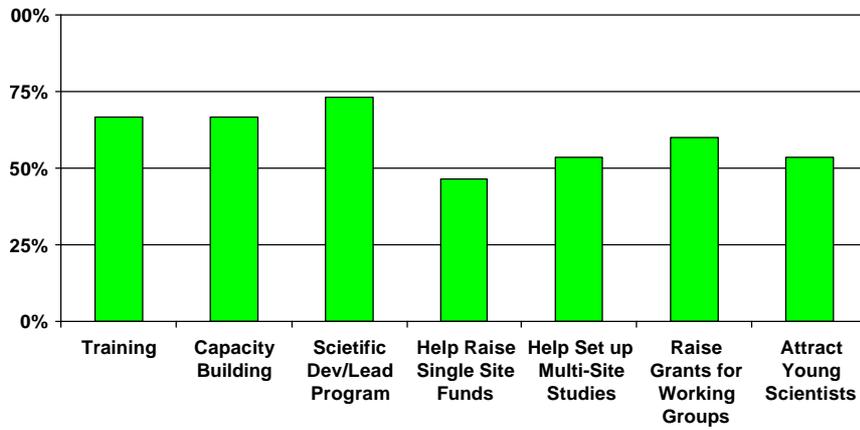


**Figure 3: SITE RATINGS OF INDEPTH EFFORTS**



2

**Figure 4: WHERE INDEPTH SHOULD INCREASE EFFORTS**



3

The interviews with external stakeholders also underscored the need for additional studies and publications, with one asking for more frequent monographs and another suggesting the need for increased peer review publications.

But both the sites and the external stakeholders recognized the challenge to publication speed and setting up additional studies: the challenges to working group operations, the need to simplify the process of data sharing across sites, and the need to improve the process of work between and among the secretariat and the sites.

**Working Group Operations:** the survey indicated a wide disparity of site participation in working groups and discussions with the Secretariat and the participants at the AGM showed a wide variation in performance and output of the working groups. The interviews suggested the need for INDEPTH to examine what makes for an effective working group and to develop a set of standards and processes to help make all the working groups as effective as possible. Among the specific ideas that we heard were:

- Ensuring that each working group target at least one publication or scientific report annually
- Getting the working groups to identify funding sources to enable at least one member of the working group to function as the “principal investigator” and to be paid for his or her time in working on the multi-site activities of the working group
- Developing a set of training for working group leaders

**Data Sharing:** Only 35% of site leaders thought that the sites did a good job of sharing data in multi-site studies, and, based on the interviews, that number appears to be generous. The site leaders agree that substantial progress needs to be made in ensuring better sharing of data. Site leaders suggested the need for a formalized policy or “memo of understanding” about data sharing, including assurances of confidentiality, coverage of the cost of data sharing, and agreements on authorship of studies using shared data. Over time, there would also need to be more standardized data collection to simplify the process. Making the challenge more complex, many external stakeholders do not see the internal challenges within INDEPTH to data sharing, which sometimes makes it more challenging to work with the external stakeholders in setting up studies involving data sharing.

**Priority Setting:** Interviews with the sites and with the secretariat indicated some need to improve the process for setting specific INDEPTH-wide priorities. Often times, the Secretariat will identify donor interest in particular studies, but has trouble identifying specific sites willing to participate or take the lead in the study. Similarly, sites may identify a potential multi-site study, but have trouble getting other sites to agree to participate.

When INDEPTH was first incorporated, it had a very clear goal of streamlining the process of setting up multi-site studies and research. Thus, in order to increase publication frequency, we would recommend launching specific efforts to:

- Set formal agreed process for obtaining, sharing and paying for data
- Develop training on improving working groups
- Improve the process of secretariat-site effectiveness

## 2. Grow to be an Essential Part of the Public Health Policy/Practice Development

Interviews with external stakeholders suggested that INDEPTH has developed a respected platform for scientific studies of health care and demographic trends, indeed what could be regarded as the “gold standard” at this stage. In order to get to the next level, these observers felt that INDEPTH should seek to become more of a crucial component of public health policy development.

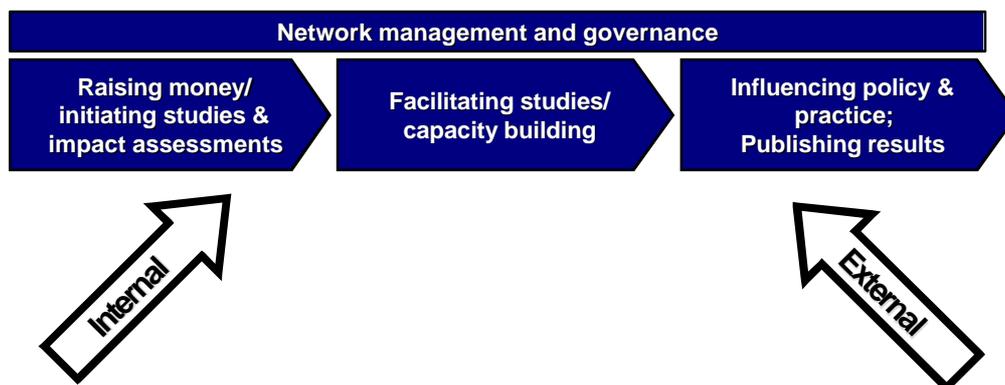
A number of funders – but not all – have pointed out that they prefer grant applications from organizations that can clearly demonstrate impact or potential impact on health care policy and practice.

And, site leaders have said that they have developed more receptivity at the ministries of health – and potentially financial support – when they clearly can demonstrate that they can positively affect practice.

From the start, INDEPTH has had a mission to affect policy and practice at the local, national and international level (See figure 5 on overall process of INDEPTH.) It feels that its prime ability to track current trends and to test interventions and policy makes it the best platform for improving health care policy and practice.

Many sites, notably Navrongo in Ghana and the Tanzania sites have already become part of their national health care policy development processes. Navrongo has a regular publication, “What Works...What Doesn't” which is used by public health officials in assessing potential policies. The Tanzania sites have shown ways to get their localities, and by extension their countries, to the Millennium Development Goals much faster than had been anticipated in 2000.

**Figure 5: OVERALL INDEPTH PROCESSES**



The network, as a network, can move further to make itself a part of international public health policy making, as well as to help build capacity at each of the sites to become part of their local/national health care policies.

Still, a number in the network leadership point out that affecting policy and practice requires a number of capabilities, and a commitment of time and resources that the network does not have today.

Thus, INDEPTH will need to set an overall approach for how it should ensure that it

affects policy and practice. INDEPTH should potentially identify specific funding for this initiative that would seek to study and plan how best to affect policy and practice. The effort would begin by identifying DSS Sites' historical impact on policy and practice, talk with policy makers on how they can best use results, develop regular publications targeted at policy makers/not scientists, and develop a team or working group of representatives from INDEPTH sites as well as policy making institutions and governments/ministries of health to continuously seek to leverage the findings and recommendations from INDEPTH site studies.

### **3. Strengthen support for value of DSS**

The interviews with external stakeholders suggested more skepticism about value of DSS than would have been expected. Many, who were either specifically involved in funding, or worked in organizations that could fund INDEPTH, either had specific questions of their own or felt their colleagues questioned whether DSS was truly “value for the high cost of operations” and whether other methodologies could offer almost as good data at a fraction of the investment.

The sites also felt that there was a lack of appreciation of the full extent of the potential value of DSS research on demography and health care. Several pointed to the success that Tanzania is having in reaching its Millennium Development Goals, by leveraging the results of the work of DSS sites. Still others talked about the sheer number of important scientific findings that resulted from DSS research and could not have been identified without it.

As a result, it appears that INDEPTH and the sites should work to underscore the ongoing utility of DSS, not just to donors but also to other scientists and to policy makers.

There appears to be a large number of ways to achieve this strategic imperative, some that were specifically mentioned include:

- Developing an ongoing, retrospective bibliography of studies that have leveraged DSS data
- Seeking, prospectively, to get all scientists writing papers using DSS data to clearly label the results as using that data
- Developing a set of materials summarizing the power, cost and value of getting and using DSS data.

### **4. Enable greater donor support for site core DSS operations**

While the network does not have a specific goal of helping sites get core support for their DSS operations, many sites are looking to the network for strategies and ideas on getting support. Moreover almost all sites say that when they participate in multi-site studies, or do a single site analytic review, the donors are unwilling to pay a portion of the underlying cost of initially collecting the data.

In the site survey, almost 50% of respondents said that they wanted INDEPTH to help them raise funds for local activities. While that number was smaller than most others, it underscores the need for INDEPTH to at least help sites identify optimal strategies for raising funds for core DSS. In addition, INDEPTH should help sites do a better

job of tracking the underlying fixed cost of collecting core DSS data, together with the variable cost of using that data to develop interesting research. By helping sites develop these important tracking measures, they can help sites do a better job of setting the real cost of conducting a study leveraging existing data.

Achieving several of the current strategic imperatives will also help sites raise additional funding for core DSS activities, INDEPTH should work to continue to develop awareness and support for the value of DSS, as well as help it to have a greater impact on policy and practice, which can help generate more support for core DSS activities.

To help sites with their financial tracking, INDEPTH will need to work with sites to improve their financial controls as well as set network-standards for how sites can best apply the fixed cost of the core DSS activities to the variable cost of each study.

INDEPTH can do the following to help enable greater support for site core DSS operations.

- First, it can launch an effort to improve financial tracking so that sites can better assess the cost of each study, and the shared cost of the core DSS operations, both for their own assessments, as well as in working with donors. This financial tracking effort will help both the individual sites as well as help the secretariat figure out the use and cost of their time.
- Second, it can continue efforts to help core funders and policy makers understand the core value of DSS and particularly its potential impact on policy. Discussions at the AGM underscored that the more INDEPTH is an important tool in policy making/practice development, the easier it will be for sites to ensure ongoing support for their DSS tracking. In addition, getting INDEPTH to play more of a role in policy development in a particular country can potentially get Ministry of Health support – at even a low level – which can further get the attention of Bilateral organizations.

## **5. Enable greater support for Secretariat/central functions**

With funding running out in 2005 and the growing demands on the secretariat, including the potential need for personnel focused on policy/practice impact as well as the potential need for additional scientific personnel, INDEPTH will need to identify new and continues sources of funding.

According to the site survey, the network can consider charging sites for some of the activities of the network, including potentially the AGM or attendance at some workshops. But, it is clear that while there was some willingness to pay for some services, they will not likely have sufficient funding in the near future to cover the underlying cost of the Secretariat.

There are four specific steps to helping to raise additional funding for core support for the network secretariat:

- Segment donors and potential donors based on their level of interest in the activities and potential activities of INDEPTH. This will enable the network to target applications and specific efforts based on the real interest of different funders.

- a. Traditional demographic studies/monographs, that INDEPTH has been known for
  - b. Clinical trials in the developing world, as INDEPTH is working on
  - c. Affecting policy and practice of countries and internationally
  - d. Health care capacity building in the developing world
- Develop a “best-accurate” assessment of the actual costs involved in the Secretariat helping to launch and manage multi-site studies, activities, working groups, etc. This will require improved financial tracking – to understand and track better the level of effort in each activity. This will enable INDEPTH grant applications to reflect and retain the actual cost of its activities.
  - Continued efforts to expand the network, underscore the value of DSS and make INDEPTH/DSS more of a crucial part of the process of improving health and health care in the developing world.
  - Target another “Donor’s conference” in the next 6-12 months to review recent activities and current plans of the network.

## **X. Operating Plan**

The general process for executing INDEPTH network level studies includes several main activities (See figure 6):

- Area of opportunity identified
- Solicit site inputs for network study
- Generate network proposal and secure funding
- Determine participating sites
- Define data requirements and develop data model
- Collect and aggregate data
- Analyze data and create network report and other project deliverables

This process provides a general framework for the completion of network studies. A more specific and customized operating plan will be developed for each INDEPTH study based on its specific requirements. More detail is provided at the end of this section for two INDEPTH projects currently in-process: health equity and the INDEPTH monograph series.

### **Area of opportunity identified**

The study opportunity will first be identified by any one of a variety of parties that have a relationship with INDEPTH. The Secretariat, INDEPTH working groups, site leaders and donors all play an active role in identifying opportunities. An actionable opportunity requires sufficient body of interest (generally 3 or more sites wanting to participate). The Secretariat is responsible for the final prioritization of INDEPTH network studies. This is presented to the Board for approval.

### **Solicit site proposals for network study**

Prior to developing the INDEPTH proposal, a call for proposals will be sent by the acting Principal Investigator and/or Executive Director to all INDEPTH sites to obtain recommendations on interest areas and information on site capabilities.

### **Determine participating sites, generate network proposal and secure funding**

A call for proposals will be issued to all sites. The ongoing Principal Investigator for the study will be selected at this stage. Sites participating in the study will be selected by the Principal Investigator and Secretariat based on their proposal submissions and the requirements and budget constraints of the network study.

Funding will be secured using a combination of donor meetings, proactive proposals and RFP responses. Existing relationships within the INDEPTH network and other external partners will be used to identify potential funding sources and facilitate the proposal process. No additional work will begin on this study until sufficient funding has been committed.

### **Define data requirements and develop data model**

Once the key research questions have been finalized, the Principal Investigator will work with participating site leaders/scientists to finalize the research approach, study design, individual data fields etc., required for this study. The Principal Investigator will work with internal INDEPTH resources to develop the data model that will be used in the network study.

**Collect and Aggregate Data**

Sites will collect the data required for network studies using their existing DSS frameworks when appropriate. Modifications to this framework will be made to assure consistency of data across sites.

Required data from each site will be transferred from the site to the Principal Investigator on a scheduled basis. An electronic transfer will be performed whenever possible. If an electronic transfer is not possible, data will be sent via conventional mail.

Aggregation of study data will be performed by an individual designated by the Principal Investigator. This individual is responsible for ensuring the timely and accurate collection and aggregation of data across participating sites. Individual site data will then be aggregated to enable network-level analysis.

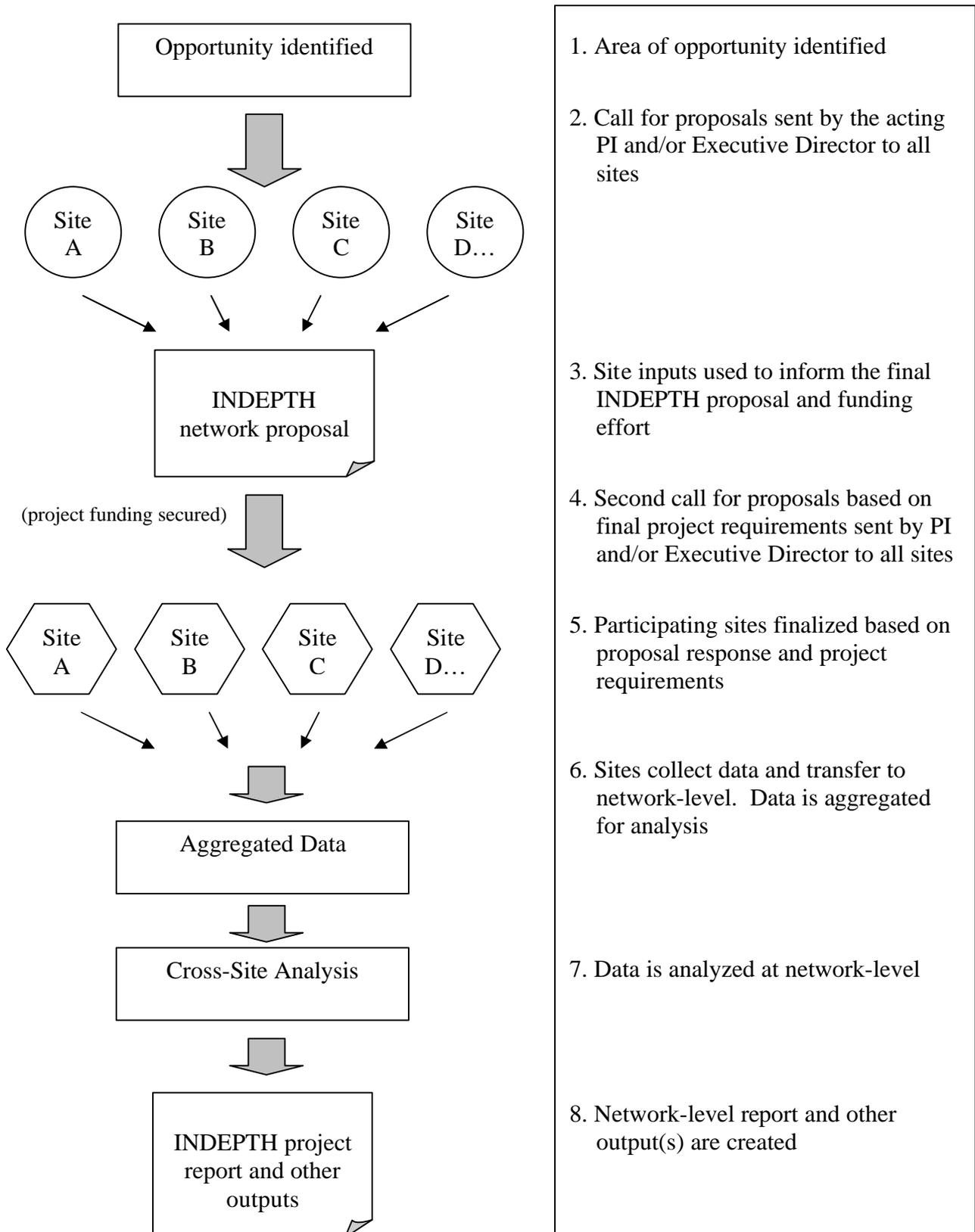
**Analyze site data and create network report**

The network-level data will be analyzed by a project researcher. In addition, each site will analyze and report on site-level data. The output from site-level analysis and reports will be shared with the network researcher. The final report will be created using the site-level and network-level analysis.

**The role of workshops**

A series of workshops will be necessary for the various activities discussed above in the operating plan.

**Figure 6: INDEPTH Operating Framework**



## **XI. Opportunity Timeline**

The opportunities identified will utilize existing INDEPTH and member site capabilities and resources. While INDEPTH plans to obtain some additional network resources, the implementation of future projects must be planned in a coordinated and staged manner that avoids overloading network or site resources at any given time.

## **XII. Alternative Information Sources**

INDEPTH has the unique capability to design and execute studies using multi-country, population-based, longitudinal data. The breadth and depth of the INDEPTH network, combined with the strong capabilities of individual member sites, enable INDEPTH to generate knowledge and insights into critical health and social challenges that was previously unavailable. To secure funding and continued support from donors, governments, research institutions and other external stakeholders, INDEPTH is differentiating itself from alternative information sources. Examples of these information sources include independent DSS sites, cross sectional population studies and other multi-country research projects.

### **Independent DSS Sites**

Independent DSS sites provide a strong platform from which to execute studies that do not require broad geographic coverage or large population sample sizes. Examples of these studies include intra-country burden of disease assessments, intervention assessments and clinical trials. Donor organizations have traditionally used independent DSS sites to support their research needs and these relationships will continue.

INDEPTH will appeal to organizations that require broader coverage than can be obtained from an individual DSS site. INDEPTH currently monitors approximately 2 million individuals across 19 countries. INDEPTH provides a one-stop solution that combines the strength of individual community-based DSS initiatives with the broad geographic reach made possible through the coordination and infrastructure within the INDEPTH network. By establishing a network of sites, INDEPTH provides a pre-existing multi-site framework to organizations that would otherwise have to individually select and coordinate the efforts of multiple independent DSS sites. Such project-specific coordination is both time and resource consuming and often results in sub-optimal results.

Due to their narrow geographic coverage, individual DSS sites also typically influence policy and practice at a local or national level. Through its broad coverage and deep expertise, INDEPTH will concentrate on impacting policy and practice at the multi-country level. This ability to impact policy at the macro-level will appeal to organizations seeking to have a broad impact on health and social issues.

### **Cross Sectional Population Studies (e.g., Demographic and Household Survey (DHS), National Bureaus of Statistics, Central Statistics Offices)**

Many population studies rely on population-level, cross-sectional studies for data generation and analysis. Examples of cross-sectional studies include the Demographic and Household Survey (DHS) and studies conducted by national bureau of statistics, central statistics office or corresponding organizations. These studies provide policy makers with information on the health and social status trends of the population within their country. The perceived advantages of these programs is that they utilize sampling of the entire population of the country and can generate data at a relatively low cost by sampling the population on an annual or semi-annual basis.

While cross-sectional studies provide a low-cost approach to population health and social data generation, the application of the data has some significant limitations. First, cross-sectional data is suitable only to the identification of health and social trends. This data is not preferred for monitoring specific outcomes (e.g. current child mortality) or the evaluation of current health and social needs at the individual level. Due to these limitations, cross-sectional

studies are primarily retrospective in nature and a significant period of time must pass (e.g. 5 years) before substantive conclusions can be made about the current health and social landscape.

INDEPTH is focused on executing population-based studies that rely on longitudinal-based, household level data that is only provided by DSS initiatives. Unlike cross-sectional studies, DSS data can be used to monitor health outcomes and current health and social needs at the individual level. Due to the longitudinal nature of the data, INDEPTH is able to provide immediate insight into the critical health and social issues. The studies that INDEPTH will pursue rely on the information that is available from only DSS sites.

**Individual Multi-Country Research Projects and Multi-Country Organizations (e.g., TDR, WHO Insecticide Treated Net (ITN) trials, UNICEF)**

Several multi-country groups undertake population studies using research networks specifically created to support an individual study. While this has been the traditional approach to multi-site studies, the process of creating one-off networks is often resource intensive as the project sponsor is responsible for identifying potential sites, evaluating sites, training site staff and coordinating the activities across independent sites. This process also often results in sub-optimal site participation, as the sponsor must often initially rely on existing relationships with a limited set of sites. These sites may not provide the optimal health and social environment for a given study, but may be the only feasible options for executing the study.

INDEPTH offers an attractive alternative to one-off network creation by providing a one-stop-shop research platform that organizations can access to execute multi-site studies. By creating an integrated network of sites, INDEPTH offers project sponsors with a single, integrated solution for studies that require the identification, selection and coordination of multiple sites. INDEPTH is able to facilitate the launch and ongoing coordination of multi-site projects using the INDEPTH network infrastructure. This capability enables site selection and coordination to be completed in a much shorter timeframe and with significantly less expense to the sponsor (see Section V. INDEPTH Value Proposition). The INDEPTH infrastructure also increases the effectiveness of this process and ensures that participating sites meet study requirements and will yield optimal results.

## **XIII. Partnerships**

### **Existing Partnerships**

#### **1. African Census Analysis Project (ACAP)**

The African Census Analysis Project (ACAP) is a collaborative initiative between the University of Pennsylvania and African institutions specializing in demographic research and training. This initiative was started as an effort to try and maximize the use of African census micro-data for academic and policy oriented research that will be beneficial both to African governments and individuals interested in African research.

ACAP pursues three specific aims: archiving of African census data, research collaboration with African researchers, and demographic capacity strengthening in Africa. To date, ACAP has obtained and archived 38 censuses from 16 African nations thus preventing some of them from further destruction. The fifteen countries from which we currently have data spread across all regions of Africa.

ACAP and INDEPTH maintain research databases that complement one another. ACAP census data covers whole national populations at consecutive ten-year intervals whereas INDEPTH data is collected around small populations and is acquired continuously. Each data set provides a different perspective on the African population and great benefit can be realized through the integration of the two. Access to INDEPTH data will provide ACAP with better African based model life tables and provide a validity check for ACAP data. Access to ACAP data will provide a broader national context for INDEPTH data. The integration of data will not only lead to policy oriented studies, but will also produce new analytical methods for demographic analysis in the developing world and correction factors for national census.

### **Potential Partnerships**

Developing partnerships will be critical to the success of INDEPTH. A host of organizations have resources that would substantially enhance the INDEPTH's ability to successfully execute current and future projects. A brief description of potential partner organizations is presented below:

#### **1. The European Malaria Vaccine Initiative / African Malaria Vaccine Testing Network**

The European Malaria Vaccine Initiative (EMVI) was established in 1998 by the European Commission and interested European Union Member States, in order to address identified structural deficiencies in public funded malaria vaccine development.

The aim of EMVI is to provide a mechanism through which the development of experimental malaria vaccines can be accelerated within Europe and in developing countries.

EMVI aims to facilitate and contribute to the post validation phase of nationally and internationally funded malaria vaccine research and development, and seeks to provide a mechanism to see candidate molecules through to limited GMP production and clinical trials in close collaboration with the African Malaria Vaccine Testing Network, AMVTN. EMVI also provides a forum for scientists and policy makers engaged in malaria vaccine research and development

The African Malaria Vaccine Testing Network (AMVTN) is a non-profit network established in 1995 in Arusha, Tanzania. Its overall objective is to provide a forum for scientists and policy makers involved in the planning, coordination, and execution of malaria vaccination trials in Africa.

## **2. INCLEN**

INCLEN provides a forum for researchers to discuss critical health issues through educational programs, global meetings, and an international communications network. INCLEN supports young researchers and provides network members opportunities to participate in collaborative clinical studies.

INCLEN comprises health specialists concerned with the availability, effectiveness and efficiency of health care in their home countries. The organization was created in 1980 as a project of The Rockefeller Foundation and its membership now includes over 56 medical institutions in 24 countries throughout the world. The multi-disciplinary faculty includes clinical epidemiologists, health social scientists, biostatisticians, and clinical economists.

## **3. EDCTP**

The EDCTP goals are to increase the effectiveness of Europe's investment in clinical trials for interventions against HIV/AIDS, TB and Malaria and to attract more resources into developing interventions. The EDCTP will be distinguished from many other international initiatives to fight these poverty-related diseases by its long-term relationship with the DCs, and the proposal to form the EDCTP as a North-South partnership.

The aims of the EDCTP are:

- Increase the effectiveness of Europe's investment in clinical trials for interventions against PRDs;
- Attract more resources into developing these interventions;
- Accelerate candidate products and other interventions through the developmental pipeline (translational research); and
- Accelerate the development of capacity and capability in DCs to test the efficacy and effectiveness of interventions against PRDs.

## **XIV. Key and Potential Threats**

### **Lack of sufficient funding to maintain network**

The sustainability of INDEPTH relies on the ability of the network to generate sufficient funding to support the core network-level activities. Without sufficient funding allocated to recovering network overhead costs, INDEPTH will be unable to provide the coordination function and site support required for cross-site studies.

To mitigate this overhead funding risk, INDEPTH is pursuing multiple strategies. First, the Secretariat filed 501 (c) (3) forms that provide INDEPTH with status as a charitable organization and enable tax exemption for funds donated to INDEPTH. This status enables INDEPTH to recover a percentage of its overhead costs from study funding originating in the United States. In addition, INDEPTH continues to proactively seek funding to directly support the maintenance of the INDEPTH network and development of network capabilities

A second funding risk relates to the quantity of additional funding individual sites gain access to as a result of INDEPTH's activities. If INDEPTH is unable to increase the flow of funds to individual sites, these sites may be less able to contribute the time and resources required to maximize the value of the network. INDEPTH must therefore generate sufficient funding for all participating sites to demonstrate the value and importance of the network to member sites. To manage this risk, INDEPTH will generally focus on pursuing studies that require contributions from several sites rather than studies that may only require participation of one or two sites. In addition, INDEPTH will seek to allocate a portion of funds to support sites who are most resource and funding constrained to ensure these sites have the ability and incentive to participate in network activities.

### **Balancing interests between sites and network**

While the INDEPTH network provides a unique platform for multi-country studies, there may be instances when individual sites have the opportunity to participate in a specific study as a stand-alone site or as part of the INDEPTH network. In such a scenario, the funding potential for the site may be greater if it secures the study independently rather than as part of the INDEPTH network. For some sites, this tension may provide a disincentive to be part of the network for particular studies. It will also limit INDEPTH's ability to secure these studies, and has the potential to create dissonance within the network.

To minimize the potential for this conflict, INDEPTH will maintain a transparent process with sites regarding the focus areas of the network and specific proposals it is pursuing. Individual sites will equally be requested to maintain transparency to ensure clear communication between sites and network.

### **Ensuring Sufficient Scientific Leadership**

The Secretariat needs to provide scientific leadership of the sites, in addition to leading the effort to secure funding for important cross-site studies. The Secretariat will need to ensure that it is tapping into the best scientific leaders from both within and outside the network, so that its judgment continues to be valued by donors, funders and sites.

### **Insufficient coordination of network activities**

Effective coordination of the activities of the 36 INDEPTH field sites is critical to the success of network projects. Each site contributes an individual piece to the network study and it is critical that all of the pieces fit well together. This will require clear and appropriate division

of responsibility, ongoing communication between the network and sites, consistency in methods and output, and accountability for quality deliverables. If any part of this coordination falters, the quality of the output and credibility of the network will be threatened.

To ensure effective ongoing coordination, INDEPTH is using multiple strategies and tools. To ensure appropriate division of responsibility, each study will have a Principal Investigator who will be responsible for managing an individual network study, assigning roles and responsibilities for this study and managing the ongoing work. To maintain ongoing communication between sites and the network, each Principal Investigator will host conference calls and meetings with study contributors to monitor progress and ensure each participant has a clear understanding of their responsibilities and the responsibilities of others. In addition, the Secretariat will facilitate communication within the network through regular INDEPTH newsletters, email announcements and periodic network meetings involving the key staff from each site.

Consistency in methods will be achieved through a combination of processes and tools. For example, each site will be required to submit standardized financial reports to the Secretariat for the purpose of budget creation and cost tracking. Each site will be provided with the tools and training required to create these standardized reports. In addition, standardized research methods, data definitions and data entry formats will be defined at the outset of each study to ensure the collection and entry of data that can support network-level analysis. When comparable site outputs are required, templates and instructions regarding these outputs may be provided to participating sites prior to beginning the study. This will usually be preceded by a research planning process that will ensure the necessary internal agreements and compatibilities.

Individual sites will also be held accountable for quality and timely outputs. Prior to each study, individual sites will need to sign a participation agreement that clearly defines what is required for the study. Any sites not meeting these requirements will not receive study funding and will be removed from the study without exception.

## **XV. INDEPTH Board of Trustees**

### **Stephan M. Tollman – Chair of the Board of Trustees, BSc, MBBCh, Mmed, MPH, MA Agincourt Health and Population Unit, Johannesburg, South Africa**

Stephan Tollman is an Associate Professor at the School of Public Health, University of Witwatersrand where he is Head of the Division of Health, Development and Non-communicable Disease. Professor Tollman also serves as the Director of the Agincourt Health and Population Research Unit where he has worked since 1998.

Professor Tollman played a leading role in the foundation of the INDEPTH network. From 1998 until his appointment as the Chair of the Board of Trustees Prof Tollman served as the Deputy Chairman of the Coordinating Committee. He has been actively involved in the INDEPTH working group on Adult Health and Productivity.

Professor Tollman is also actively involved in issues of public health in South Africa working with the Department of Health, the Medical Research Council and the Health Systems Trust in South Africa.

Professor Tollman received his undergraduate degree (BSc) in Anatomy and Physiology in 1979 from the University of Witwatersrand; a Rhodes scholarship to Oxford in 1980; a degree in Medicine (MBBCh) from the University of Witwatersrand in 1984; a masters in Health Services Administration (MPH) from the Harvard School of Public Health in 1988 and most recently in 1999 a Masters in Public Health Medicine (Mmed) from the University of Witwatersrand.

### **Alex Chika Ezeh, Ph.D, MA, MS, BSc**

#### **African Population and Health Research Centre, Nairobi, Kenya**

Dr Ezeh is currently the Executive Director of the African Population and Health Research Center in Nairobi, Kenya where he has worked since 1998. He is also currently a member of the Regional Advisory Panel for African and the Eastern Mediterranean, Department of Reproductive Health and Research for the World Health Organization.

Dr Ezeh received his undergraduate degree (BSc) in 1985 from Imo State University, Nigeria; a master's degree (MS) in 1988 from the University of Ibadan, Nigeria; a master's degree (MA.) in 1990 and a doctoral degree (Ph. D.) in 1993 from the University of Pennsylvania, USA. During his academic studies Dr Ezeh received fellowships from the Rockefeller Foundation (1992-1993, 1989-1991), the Population Council (1991-1992), and USAID (1991-1992).

### **Bocar Kouyate, MD, MPH**

#### **Centre de Recherche en Santé de Nouna, Nouna, Burkina Faso**

Dr Kouyate is currently the Director of Centre de Recherche en Santé de Nouna (CRSN), Nouna, Burkina Faso and has held the position since October 1999. He is also a member of the Steering Committee of the "Centre Nationale de Recherche Scientifique et Technologique, Ouagadougou, Burkina Faso. Dr Kouyate was a member of the INDEPTH Coordinating Committee prior to his election to the Board of Trustees.

Dr Kouyate received his undergraduate degree (MD) in 1983 from the University of Bénén, Lomé Togo, a masters degree (MPH) in 1994 Cotonou, Bénén. During his academic studies, Dr Kouyate received fellowships from WHO (1987-1988) and University of Heideberg-Germany (1998-1999).

**Anita Sandström**

**Swedish HIV/AIDS Program for Africa, Embassy of Sweden, Lusaka, Zambia**

Anita Sandström is an associate Professor in epidemiology and public health from the University of Umeå, Sweden. Anita has been working with two of the INDEPTH sites - Butajira in Ethiopia and Bandim in Guinea Bissau. Anita is now working with the Swedish International Cooperation Agency (Sida), and is heading the Regional HIV/AIDS Team for Africa based in Lusaka, Zambia.

**Peter Kim Streatfield, B.Sc., M.Sc., M.Sc., Ph.D. Health & Demographic Surveillance Program (Matlab), Public Health Sciences Division, ICDDR, Dhaka, Bangladesh.**

Kim Streatfield is head of the HDSP and is currently involved in expanding the Matlab HDSS to collect more detailed information on chronic (adult) diseases, on equity issues, on health systems research, in addition to modernizing the data systems.

For three decades he has been involved in health and population research and training, particularly child survival and reproductive health. Half of this time has been spent working in Asia.

His undergraduate training (B.Sc.) was in Physiology and Biochemistry from University of Sydney in 1971, then M.Sc. (Physiology) from University of Melbourne in 1976; M.Sc (Medical Demography) from London University (LSHTM) in 1977 and Ph.D. (Demography) from Australian National University in 1982.

**Chuc Nguyen Thi Kim**

**Institute of Health Strategy and Policy, Hanoi, Vietnam**

Dr Chuc Nguyen Thi Kim is currently the Vice Head of Health Economic Department, Health Strategy and Policy Institute (HSPI) and senior lecturer on Health Economics at the Hanoi Medical University, Vietnam. She is presently Coordinator of Health System Research Project in Vietnam, supported by Sida/SAREC, Sweden.

Dr Chuc NTK received her undergraduate degree (Pharmacy) in 1976 from the School of Pharmacy in Hanoi, Vietnam; a Master's degree (MSc in Health Economics) in 1994 from Chulalongkor University, Bangkok, Thailand and a doctoral degree (Ph. D.) in 1996 from Army Medical University, Vietnam.

**Donald H. de Savigny, PhD, MSc, BSc**

**International Development Research Centre, Canada**

Tanzania Essential Health Interventions Program, Ministry of Health, Dar es Salaam, Tanzania

Dr. Don de Savigny is Principal Health Specialist for the International Development Research Centre, Canada since 1988 and is presently the Research Manager for the IDRC/MOH Tanzania Essential Health Interventions Program based in Dar es Salaam at the National Institute for Medical Research since 1996.

Dr. de Savigny played a leading role in the conceptualization and foundation of INDEPTH and served on its first Coordinating Committee facilitating a number of startup initiatives. He also managed the installation and development of the Rufiji DSS site in Tanzania, and was formerly Director of the Swiss Tropical Institute, Ifakara Health Research Centre in Tanzania. Dr. de Savigny has been actively involved in public health research and research facilitation internationally, and particularly in Africa since 1980 with emphasis on epidemiology, health systems research and health information systems.

Dr. de Savigny received his undergraduate degree (BSc) in Medical Microbiology in 1970 from the University of Guelph, Canada; a masters degree (MSc) in Parasite Immunology in 1975 from the Ontario Veterinary College, University of Guelph, Canada, and a doctoral degree (PhD) in Epidemiology in 1980 from London University, London School of Hygiene and Tropical Medicine, UK, all with fellowships from the Ontario Ministry of Health.

**N. Regina Rabinovich, M.D., M.P.H**  
**Director, Infectious Diseases**  
**Bill & Melinda Gates Foundation**

Dr. Regina Rabinovich directs the Infectious Diseases program of the Bill & Melinda Gates Foundation's Global Health program. Previously, Dr. Rabinovich served as director of the Malaria Vaccine Initiative where she advanced efforts to develop promising malaria vaccine candidates and ensure their availability and accessibility in developing world settings.

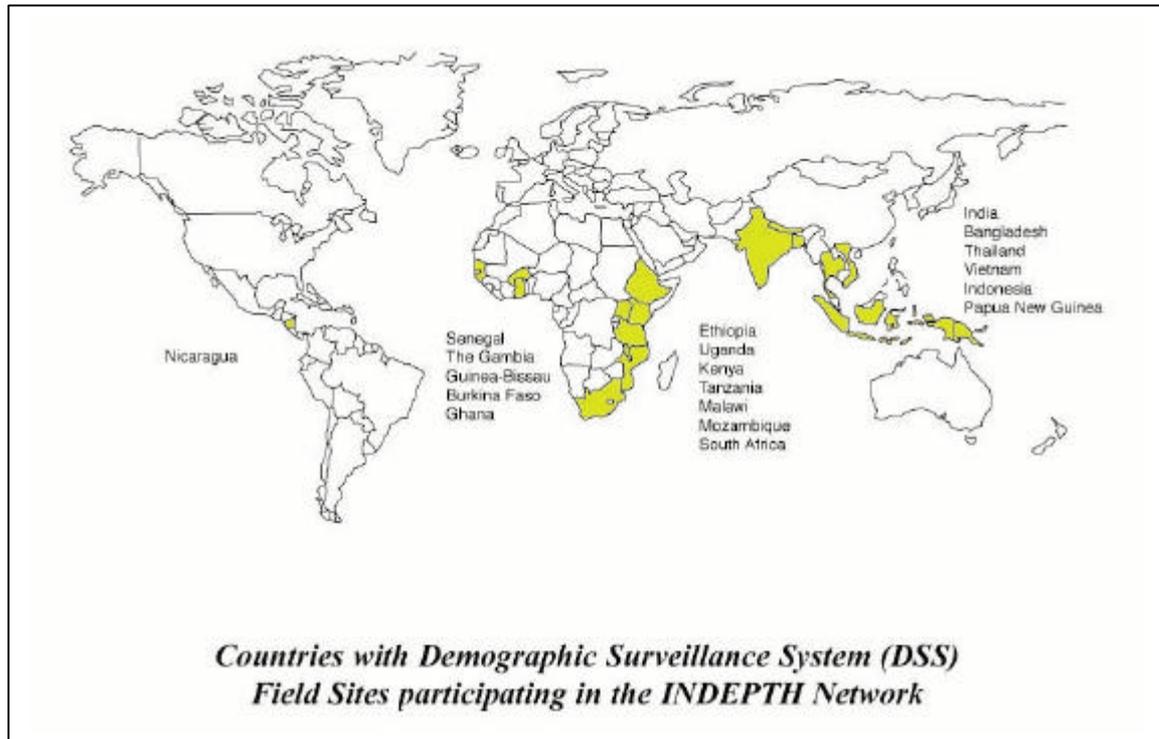
Rabinovich spent 11 years at the National Institute of Allergy and Infectious Diseases (NIAID) where she most recently served as chief of the Clinical and Regulatory Affairs Branch of the Division of Microbiology and Infectious Diseases, which oversees the regulatory affairs for the division. At NIAID, Dr. Rabinovich managed a network of U.S. vaccine and treatment evaluation units and pilot production projects. During her tenure as branch chief, the units completed large multi-center trials of pertussis and influenza vaccines, as well as a number of phase I trials of platform technologies such as edible vaccines.

Rabinovich has served on a variety of national and international committees for the Institute of Medicine, Centers for Disease Control and Prevention, the National Vaccine Program Office, the American Academy of Pediatrics, and the World Health Organization. Rabinovich received the National Institutes for Health (NIH) Merit Award in 1993 for her contribution to NIH's vaccine research program. In 1995, she was given the NIH Director's Award for successful advocacy for vaccine research. Rabinovich has received training in pediatrics, epidemiology, maternal and child health and preventive medicine.

Rabinovich received her B.A. from the University of Iowa, her M.D. from Southern Illinois University, and M.P.H. from the University of North Carolina, Chapel Hill.

## XVI. Appendix Materials

### INDEPTH Member Site Location Map



#### **Current DSS Site Membership**

##### **West Africa**

Nouna, Oubritenga (Burkina Faso), Farafenni (Gambia), Kintampo, Navrongo (Ghana), Bandim (Guinea Bissau), Mlomp and Bandafassi, Niakhar (Senegal)

##### **East Africa**

Butajira (Ethiopia), Nairobi, Kisumu (Kenya), Ifakara, Rufiji, Magu (Tanzania), Rakai (Uganda)

##### **Southern Africa**

Manhica (Mozambique), Agincourt, Digkale, Africa Centre DIS (South Africa), Karonga (Malawi)

##### **Asia**

Watch, Matlab, HSID (Bangladesh), Purwojero (Indonesia), Filabavi (Vietnam), Kanchanaburi (Thailand), Vadu, Ballabgarh (India)

##### **Oceania**

Wosera (Papua New Guinea)

##### **Central America**

Leon (Nicaragua)