



EVERY WOMAN
EVERY CHILD

EVERY NEWBORN ACTION PLAN
PARTNERING WITH ENDING PREVENTABLE MATERNAL MORTALITY

ENAP & INDEPTH RESEARCH PROTOCOL DESIGN WORKSHOP



15TH-17TH JUNE 2016
HOTEL AFRICANA, KAMPALA, UGANDA
WORKSHOP REPORT



INDEPTH Network
Better Health Information for Better Health Policy



Save the Children



**CHILDREN'S
INVESTMENT FUND
FOUNDATION**

MARCH
centre for
MATERNAL
ADOLESCENT
REPRODUCTIVE &
CHILD
HEALTH

EVERY NEWBORN AN ACTION PLAN TO END
PREVENTABLE DEATHS

EVERY NEWBORN ACTION PLAN METRICS
ENAP & INDEPTH Research Protocol Design Workshop

15th-17th June 2016

Hotel Africana, Kampala, Uganda

CONTENTS

ACKNOWLEDGEMENTS.....	3
ACRONYMS.....	4
EXECUTIVE SUMMARY	5
BACKGROUND TO THE INDEPTH NETWORK ENAP METRICS WORK.....	7
Aim of the 2016 ENAP Metrics Design Kampala Workshop.....	7
Expected Outputs	7
OPENING SESSION	8
ENAP MEASUREMENT IMPROVEMENT ROADMAP: INDEPTH LEADERSHIP ROLE.....	9
Where are we now	9
DRAFT PROTOCOL FOR INDEPTH AND ENAP METRICS WORK.....	13
SITE PRESENTATIONS ON THEIR TRACKING AND OUTCOME MEASURES.....	16
IMPROVE HOUSEHOLD SURVEY CAPTURE OF STILLBIRTHS AND NEONATAL DEATHS	23
Survey design questions and issues	23
Survey questionnaire content to capture pregnancy losses	24
Data collection processes/modalities	24
Key emerging issues from discussions on objective 1.....	25
IMPROVING HOUSEHOLD SURVEY CAPTURE OF BIRTH WEIGHT AND GESTATIONAL AGE	26
Working group 2: discussions on objective 2	28
OPTIMIZING HDSS CAPTURE OF PREGNANCY OUTCOMES	32
Sample size calculations	34
Site-specific feedback and strategies	35
DATA SHARING.....	44
NEXT STEPS	45
ADMINISTRATIVE NEXT STEPS	46
CLOSURE OF THE WORKSHOP.....	47
ANNEX 1: Agenda.....	50
ANNEX 2: Summary of available data regarding use of modules for pregnancy history versus birth history	54
ANNEX 3: ENAP Participants profile.....	55

ACKNOWLEDGMENTS

The London School of Hygiene & Tropical Medicine, Save The Children and The INDEPTH Network Maternal and Newborn Working Group Secretariat at Makerere University School of Public Health Department of Health Policy Planning and Management co-lead the INDEPTH work of the Every Newborn Action Plan. The INDEPTH and ENAP Metrics Working Group includes Joy Lawn, Angela Baschieri, Peter Waiswa, Kate Kerber, Hannah Blencowe, Joseph Akuze, Vladimir Gordeev, Georgia Gore-Langton, Dorothy Boggs, Doris Kwesiga, Ronald Muhumuza and Michael Ediau. The contributions of all members of the INDEPTH ENAP metrics working group and all the meeting participants to the preparation of this workshop are gratefully acknowledged. A special thanks to Samuelina Arthur for logistical support.

The main funding for the workshop was provided by the Children's Investment Fund Foundation.

Joseph Akuze and Doris Kwesiga for the INDEPTH Secretariat drafted the initial outline of the report, collated inputs from the workshop participants and coordinated the final report.

With thanks to all the participants for their input and contributions to this report and with particular appreciation to the country teams from the five INDEPTH member Health Demographic Surveillance Sites in Bangladesh, Ethiopia, Ghana, Guinea Bissau and Uganda.

ACRONYMS

ANC	Antenatal Care
BW	Birth Weight
CIFF	Children's Investment Fund Foundation
CKIs	Community Key Informants
CRVS	Civil Registration and Vital Statistics
DHS	Demographic and Health Survey
EDD	Expected Date of Delivery
ENAP	Every Newborn Action Plan
EPMM	Ending Preventable Maternal Mortality
FP	Family Planning
FSB	Fresh Stillbirth
GA	Gestational Age
HC	Health Centre
HDSS	Health and Demographic Surveillance System
HF	Health Facility
HMIS	Health Management Information System
ID	Identification
INDEPTH	International Network for the Demographic Evaluation of Populations and Their Health
LBW	Low Birth Weight
LMICs	Low and Middle Income Countries
LMP	Last Menstrual Period
LSHTM	London School of Hygiene & Tropical Medicine
MakSPH	Makerere University School of Public Health
MCH	Maternal and Child Health
MDGs	Millennium Development Goals
MICS	Multiple Indicator Cluster Surveys
MNWG	Maternal and Newborn Working Group
MOU	Memorandum of Understanding
MUAC	Mid-Upper Arm Circumference
MSB	Macerated Stillbirth
NMR	Neonatal Mortality Rate
PH	Pregnancy History
SBR	Stillbirth Rate
SDGs	Sustainable Development Goals
USS	Ultra Sound Scan
VA	Verbal Autopsy
VHT	Village Health Team
WHO	World Health Organization
WRA	Women of Reproductive Age

EXECUTIVE SUMMARY

The Maternal Newborn Working Group (MNWG) of the INDEPTH Network, together with London School of Hygiene & Tropical Medicine (LSHTM), were awarded a grant from the Children's Investment Fund Foundation (CIFF). The research focuses on three objectives:

1. Improving household survey capture of stillbirths and neonatal deaths;
2. Improving household survey capture of birth weight (BW) and gestational age (GA);
3. Optimizing the data capture of pregnancy outcomes in Health and Demographic Surveillance Sites (HDSS).

This work will be done through five HDSS that are members of the INDEPTH Network MNWG and won grants to conduct this work around the Every Newborn Action Plan (ENAP). These are Bandim HDSS centre in Guinea-Bissau; Dabat HDSS in Ethiopia; Iganga-Mayuge HDSS in Uganda; Kintampo HDSS in Ghana; and Matlab HDSS in Bangladesh.

The 2016 ENAP metrics workshop took place in Kampala, from 15th – 17th June 2016. The aim was to work with these site teams to review the objectives of the ENAP work and refine a generic protocol and relevant tools. The group was able to successfully work through a wide range of topics. There were a number of presentations, with the first by Prof. Joy Lawn from LSHTM contextualizing the current newborn health situation globally, and the role of the INDEPTH Network MNWG in this work and the ENAP metrics work. Prof. Lawn explained that a global voice is needed for stillbirths and newborn deaths which have been neglected in the global development agenda. Mr. Joseph Akuze, the technical coordinator in the INDEPTH Network MNWG technical secretariat at Makerere University, then guided the participants through the draft generic protocol that had been written to guide the sites in the work that will be undertaken. He explained the study research questions, objectives and methods in detail. He elaborated that the current ENAP metrics study has been designed to collect HDSS data from the five INDEPTH sites, and specifically how the study will assess the two alternative survey modules to measure the pregnancy outcomes and stillbirths.

Dr Angela Baschieri gave a detailed description of the methods and processes of objective one, to compare the two questionnaires: DHS-7 (a major improvement

from the previous version, with a full birth history plus information on pregnancy outcomes for the last five years using a reverse truncated - calendar) and the pregnancy history (which asks about all pregnancies together with the information on pregnancy outcomes for the last five years using a reverse truncated calendar). She took the participants through the relevant sections of the DHS-7 and the pregnancy histories modules and explained the differences between them. She reiterated that previous studies have found some evidence that birth history data with additional questions on pregnancy losses collected in standard surveys such as demographic health survey (DHS) /multiple indicator cluster surveys (MICS) underestimate stillbirths and early neonatal deaths, and gave evidence to support these findings.

The session on the second objective of the study was led by Dr. Hannah Blencowe, who began by providing the standard definitions for the relevant variables relating to birthweight and gestational age. She also elaborated on the various methods of measurement of these parameters, sources of data and challenges with available data. Following this, the current approaches to capture birth weight and gestational age in surveys were outlined.

Ms. Kate Kerber made a presentation on the third objective and how to optimize measurement of events around pregnancy and the time of birth. She emphasized that there are a few markers of outcome capture that can be examined as measures of quality, such as approximately similar number of stillbirths and neonatal deaths. She further explained a variety of scenarios in which the HDSS sites can miss pregnancy and outcome registration during a round of surveillance. Assoc. Prof. Peter Waiswa, principal investigator and the team lead of the INDEPTH Network Technical Secretariat in Makerere, led the participants through a discussion on data sharing. He explained that the data to be shared was strictly the ENAP metrics project data. He acknowledged that sites have their other HDSS work and data with restrictions on sharing as per funding and that sites also have their own sensitive data. However, for analysis of ENAP metrics work we need to cross-link sites. Ms. Samuelina Arthur from the INDEPTH Network took the participants through the administrative steps of the ENAP metrics work.

Between these presentations, the site representatives joined together in working groups to deliberate about the study objectives, methods, and the protocol. Discussions were held on survey design questions and issues (sample size calculations, randomization); survey questionnaire content to capture pregnancy losses (questions to add e.g. gestational age in weeks); data collection processes/modalities (enumerators, process of data entry, data linkage and country specific sensitivity of issues around abortions); refining current survey birth weight questions; barriers and enablers to birth weight measurement and recording; and feasibility of using data from the pregnancy card if retained (last menstrual period and date of delivery).

The sites' representatives also made presentations on their individual pregnancy surveillance and outcome tracking methods, for instance, who carries out the routine visits and how often; who the primary respondents are in the households; notification and follow-up of vital events; data linking; measuring of birth weight and GA; their specific thoughts/questions on enhancing surveillance, among others. Throughout the workshop, the sites' representatives were able to learn from each other and identify good practices that could be replicated in their own sites, for instance, the in-migration form used in Kintampo that tracks pregnancies; provision of maternal and child health services in Matlab; placing somebody at a health facility to collect data in Bandim; incentives given to local guides in Dabat; and the use of the village health team in Ilanga-Mayuge.

There were a number of key emerging issues from the workshop, for instance:

- Randomization in the survey will be done at the level of the individual woman, rather than through the use of clusters or villages to minimize the sample size required for the study.
- The enumerator should not be somebody who knows the family well and should be someone different from the routine HDSS team that collected data from that particular woman to allow the comparisons of the mortality data with the routine HDSS data collection.
- The use of electronic data collection supported by tablets to randomly distribute the tools was welcomed as an important suggestion to facilitate the randomization process and the data quality.

- Inclusion of minors varies across sites: asking questions to children below 18 years depends on whether they are married and have a baby and the country laws and cultural taboos. It was decided to aim for standardization of 15 years and above for the respondents (like the DHS), but using married women only in some sites where it is culturally unacceptable to have a child outside wedlock and so you would not be able to ask unmarried females about pregnancy, for instance, in Matlab HDSS.
- It is necessary to find a way to inquire about abortion indirectly, in order to get correct and reliable information without scaring respondents or getting them into trouble where such practice is illegal.
- Suggestions were also made on how to improve birth weight measurement in surveys and HDSS, for instance through sensitizing the community; processing of birth certificates as an incentive to parents; use of Mid-Upper Arm Circumference (MUAC) or foot size in the community as a proxy to birth weight and GA; etc.
- To improve GA measurement, ideas ranged from the use of menstrual calendars and beads to scans and urine tests.

The workshop concluded with some strategies for going forward, including:

- Completion of the generic protocol by the core team. Each HDSS will then adapt the generic protocol and develop a protocol to suit their site-specific needs before submitting for ethical review and approval in January 2017, after which data collection can start.
- Analysis of data will be done jointly through sharing specific data, rather than pooled datasets.
- A data sharing agreement will be drafted, led by INDEPTH Network.
- The participants identified two further multi-site grants that they are going to collaborate on to get further funding for this and future work.
- The next face-to-face meeting will be held in April 2017, to discuss progress and other issues such as verbal autopsy.

BACKGROUND TO THE INDEPTH NETWORK ENAP METRICS WORK

The Maternal Newborn Working Group (MNWG) of the INDEPTH Network, together with London School of Hygiene & Tropical Medicine (LSHTM), were awarded a grant from the Children's Investment Fund Foundation (CIFF) to conduct research to improve metrics around the time of pregnancy and birth, a key priority for the sustainable development goals (SDGs). Specifically, the research will focus on three objectives:

1. Improve household survey capture of stillbirths and neonatal deaths in terms of assessing pregnancy history compared to live birth history modules;
2. Improve household survey capture of birth weight (BW) and gestational age (GA) by assessing various methods for measuring these outcomes in surveys;
3. Optimize the Health and Demographic Surveillance Sites (HDSS) data capture of pregnancy outcomes (stillbirths, neonatal deaths, birth weight and gestational age) to link and compare with survey data to examine who is missing and why.

The request for applications (RFA) was sent out across the 53 HDSS sites by the INDEPTH Network Secretariat, and fourteen proposals were received. The received proposals underwent an expert review through an internal review process spearheaded by LSHTM, Makerere University School of Public Health (MakSPH) and INDEPTH Network Secretariat. Five applications were selected for funding to conduct collaborative work towards the ENAP Measurement Improvement Roadmap based on the following: HDSS total population more than 30,000, annual stillbirth rate (SBR) and neonatal mortality rate (NMR) greater than 15 per 1,000 live births, high quality surveillance for birth outcomes including neonatal deaths and stillbirths, present expertise related to maternal, newborn health and stillbirths of the team members from the applying HDSS and evidence of co-funding in the estimated budgets submitted by the HDSS.

The following HDSS sites were selected:

- Bandim HDSS in Guinea-Bissau,
- Dabat HDSS in Ethiopia,
- Iganga-Mayuge HDSS in Uganda,

- Kintampo HDSS in Ghana,
- Matlab HDSS in Bangladesh.

Aim of the 2016 ENAP Metrics Design Kampala Workshop

The main focus of this workshop was to work with site teams to review the objectives of the Every Newborn Action Plan (ENAP) work and refine a generic protocol and relevant tools in order to meet these objectives. The timetable is included at the end of the report as Annex 1.

Expected Outputs

The following outputs were expected from the workshop:

- Advance the collaborative planning for this research, including:
 - » A generic protocol refined together to later be adjusted by each site to fit their unique requirements and methods and submitted to institutional review boards for ethical approval,
 - » Draft survey tools, with action points for finalising these,
 - » Draft consent forms.
- A site specific enhancement plan for pregnancy surveillance and for measuring birthweight and gestational age as appropriate.
- A draft analysis plan.
- Data and authorship sharing plan.
- Updated INDEPTH ENAP Gantt chart for this work stream, including communication and site support mechanisms.
- Workshop report.

OPENING SESSION

Day one began with colorful introductions from the participants of the workshop and speeches from Assoc. Prof. Peter Waiswa, Dr. Dan Kajungu, Ms. Suzanne Fournier and Assoc. Prof. Ssengooba Freddie.

Assoc. Prof. Peter Waiswa, the chair of the session and the chair of the MNWG within the INDEPTH Network, welcomed the participants to Uganda. He revealed that people want to work with the MNWG, but they always first ask what the quality of the data is and where the people are whom they can work with. He emphasized the need for the health and demographic surveillance sites to position themselves, network and make use of these opportunities to share their work. Assoc. Prof. Waiswa reiterated the need for the participants to be the best at measurement of indicators around pregnancies and their outcomes. He thanked the MakSPH team (Doris, Joseph and Michael) for all the input they have made so far towards the ENAP work, Prof. Joy Lawn for supporting and working tirelessly on the ENAP metrics work, and also CIFF for its support and investment towards newborn and stillbirths research.

Dr. Dan Kajungu, the centre leader of the Iganga-Mayuge Health and Demographic Surveillance Site expressed his excitement about the ENAP metrics work, and encouraged the site representatives present to ensure that they put in maximum effort in order to have better metrics from the sites. He expressed his appreciation for the research adopted by the project and the effort in improving the quality of the data. He thanked the hosts and organizers and concluded by cautioning sites that people should stop saying that the quality of HDSS data is poor after this project.

Ms. Suzanne Fournier from CIFF explained that the organization is a philanthropic institution which has grown to be one of the largest charities in the United Kingdom. It was founded in 2004 by a couple who wanted to improve the lives of children living in poverty. CIFF's endowment has its roots in investment banking and as such, the organization takes business-like approach to funding. Ms. Fournier emphasized the fact that CIFF focuses on using data and evidence to guide its investments and to measure results. "We make grants but we call these investments, because a good investment gives you manifold returns. Therefore, investment in research is not solely about

producing good quality evidence, but the long term view of how the evidence contributes to changes in practice." Ms. Fournier explained that one of the missing links in maternal and newborn health has been better accountability, especially for stillbirths. She concluded by emphasizing that the ENAP metrics program is extremely compelling to CIFF's principles on using data and evidence to drive accountability for newborn health.

Assoc. Prof. Freddie Ssengoba, the Chair of the Department of Health Policy, Planning and Management at Makerere University School of Public Health officially opened the two and a half day workshop. He expressed his pleasure in seeing the group that intends to generate common protocols and data around maternal and newborn health, while also aligning the work around the global agenda. He highlighted the fact that universal health coverage still has many unclear terms, and those working in the area have been struggling to get indicators for things like catastrophic health expenditure, because the current ones are so hard to measure or track, and policy makers won't understand them. This leads to using many assumptions that will generate unrealistic information. He emphasized that data is important and we should all build robustness in how to track progress. He further clarified that his daily work is on the policy side, which "navigates hard science and tries to make it soft". He described the difficulty in taking things up to a policy level, including the fact that people ask what the process was for getting these outcomes, and yet in many cases, like the maternal and newborn health work, the inputs and processes are not defined.

Assoc. Prof. Ssengoba emphasized that advocacy needs us to be mindful of how to take data to policy makers and back again to implementation. He recognized the uniqueness of the INDEPTH network, and cautioned that although many good things come because of having data, many times the HDSS sites also become islands. He therefore advised the site representatives at the workshop to think about how the data generated can be used for scale up, especially in areas with low resources and weak capacity. He also thanked Assoc. Prof. Waiswa for the leadership that he has provided in this work locally and at a global level.

ENAP MEASUREMENT IMPROVEMENT ROADMAP: INDEPTH LEADERSHIP ROLE

Presented by Prof. Joy Lawn

In order to place the workshop in the appropriate context, Prof. Lawn reminded the participants about where the world currently is in terms of maternal and newborn health and data, as we transition from the Millennium Development Goals (MDGs) to the Sustainable Development Goals (SDGs).

Where we are now

There have been shifts in births across eras, influenced by differences in urbanization and other factors, and by the end of the SDGs, there will have been even more changes. For instance, 1 in 5 births are now in Africa, but by the end of the SDGs these will be at 40%. Additionally, although there are increased births in facilities, there continue to be many hidden births at home.

Figure 1. The four worlds into which 135 million newborns are born each year¹



¹ Republished with permission from Howson CP, Kinney M, Lawn JE (Eds.). Born Too Soon: The Global Action Report on Preterm Birth. March of Dimes, PMNCH, Save the Children, WHO. Geneva: Switzerland, 2012

Despite the reduction in the rates of child and maternal mortality, there has been slower progress for newborn mortality and stillbirths globally. By the end of the MDGs, there were 2.7 million newborn deaths and 2.6 million stillbirths annually. These statistics are often much worse in low income countries, particularly in sub Saharan Africa and parts of Asia. As Prof Lawn stated, “Although we

all come into the world the same, we are not equal- it depends on who our mother is, her health, her access to healthcare before and during pregnancy and during birth”. There is also still very weak accountability, mention and attention of newborn health, especially for stillbirths. The absence of stillbirths from most global agendas remains a problem. For instance, regardless of the definition

used for stillbirths, they were not included in MDG tracking or in the denominator.

She acknowledged that there has been an improvement in data over the last five years. Annual estimates are now available due to accountability through the MDGs. However, there are still many challenges, including poor quality of the data available and a lot of missing information, even with health facility data. The differences in births between high, middle and low income countries, in terms of where they are occurring, and who is attending them, are also evident in the data. For instance, middle income countries are in transition: five years ago they only relied on household surveys, but now they are also using health facility data that is linked to Civil Registration and Vital Statistics (CRVS), as do the high income countries. This is different from the low income countries that predominantly still rely on nationally representative surveys carried out once every five years. In many countries people want to use demographic surveillance data, but concerns remain about the representativeness of these data.

Professor Lawn noted that we are making good progress through combined Ending Preventable Maternal Mortality (EPMM) and ENAP meetings,

and that this joint approach of considering the mother and baby together is essential. This will be increasingly important under the SDGs, where increased attention is being given to economic development and education, rather than maternal and newborn health.

Professor Lawn noted that the Global Strategy for Women, Children and Adolescents (2016-2030) is the greatest policy we have at the moment, and that data must be framed to fit into the political agenda. To change the trajectory, data at national and sub-national level needs to be changed. Strategies presented for moving forward to improve the quality of data around newborn health included the following:

- Focusing on using surveillance and health facility data in addition to surveys (for low and middle income countries where surveys are the predominant data source).
- Working with other partners to improve the coverage and quality of CRVS data, and the quality of perinatal outcome data from surveys.
- Using HDSS as a resource to improve understanding of factors affecting data quality and missingness.

Figure 2. Global Strategy for Women, Children and Adolescents



- Learn from how coverage data has been improved in other health sectors, for example HIV 3 by 5².
- Continuation of the joint collaboration of ENAP and EPMM activities.

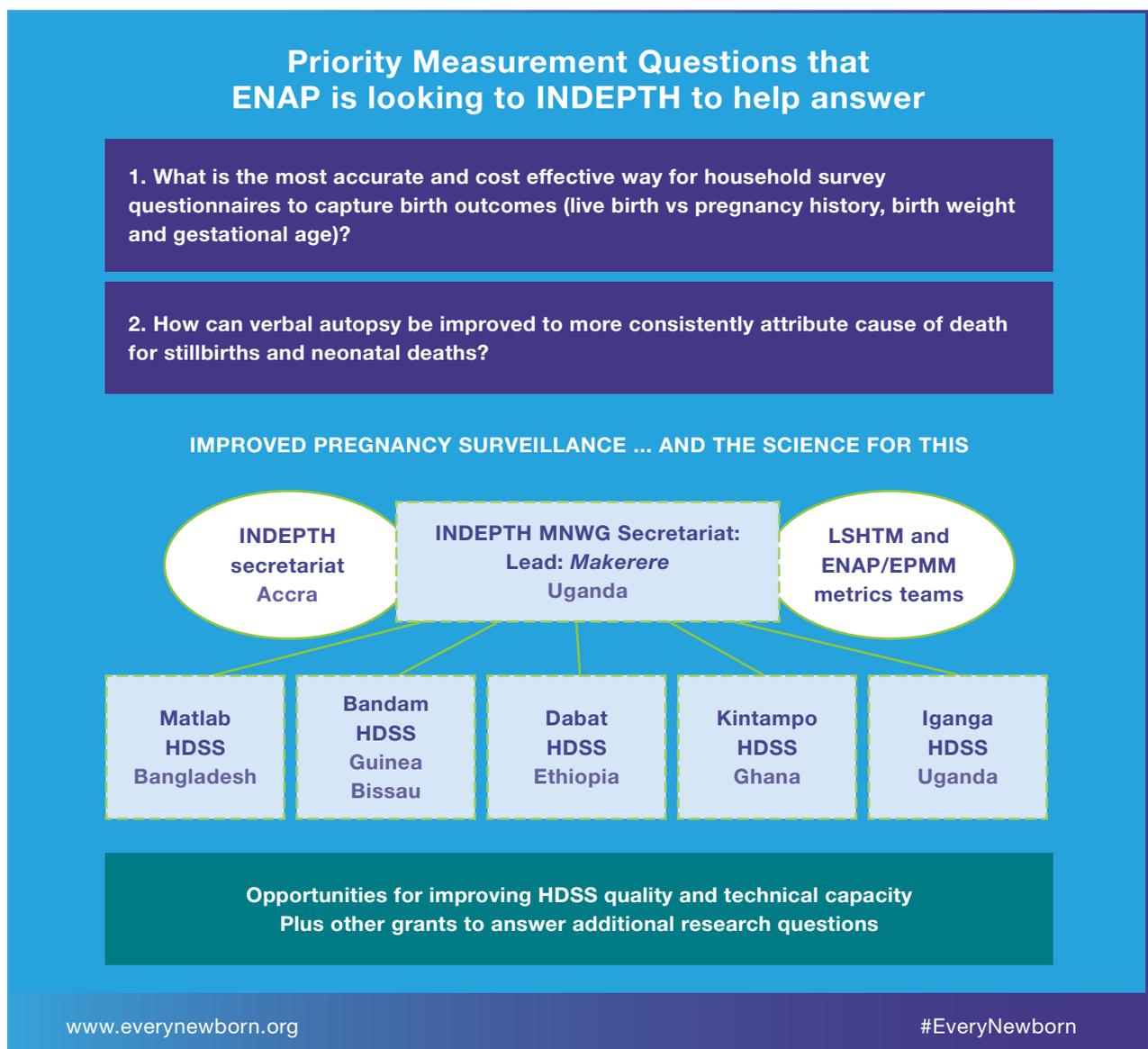
This ENAP metrics work by the INDEPTH network should take leadership in improving data on impact level outcomes, improving surveillance, and more.

2 World Health Organization, Treating 3 million by 2005: making it happen: the WHO strategy: the WHO and UNAIDS global initiative to provide antiretroviral therapy to 3 million people with HIV/AIDS in developing countries by the end of 2005 / Treat 3 Million by 2005. 2003; Available from: <http://www.who.int/3by5/en/>

In order for ENAP to be successful, we need better data by 2020 so that we have 10 years to use data to drive change. We need to start where we are and build upwards.

For the first priority question, the INDEPTH MNWG member sites that won grants are working together with the ENAP metrics core team to develop a joint protocol, with joint authorship. Part of the work is the focus of the 2016 Kampala workshop. The verbal autopsy (VA) question will be discussed in detail at the next workshop in 2017.

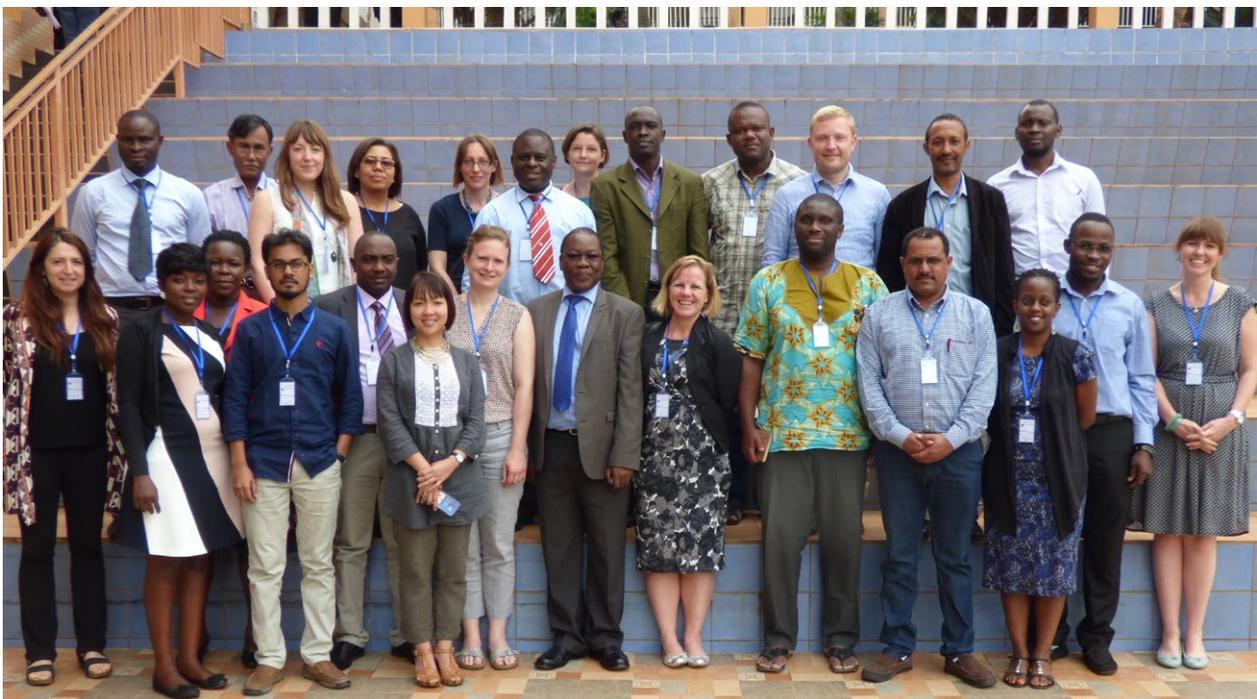
Figure 3. Priority Measurement Questions that ENAP is looking to INDEPTH to help answer



Prof. Lawn concluded her presentation by reminding the participants about the many opportunities available to members of the INDEPTH network MNWG. “One of the major unique things is the chance to improve pregnancy surveillance, which is the cornerstone of the HDSS. The HDSS cannot be of good quality if it

is missing births and deaths. Having a network of data with which you are comfortable is vital. You can take leadership in data analysis, write joint proposals, improve the sites and answer relevant global questions together. To change things, we need technical leadership and capacity in each of the sites,” she emphasized.

Figure 4. Group photo of participants at the 2016 ENAP metrics workshop in Kampala



DRAFT PROTOCOL FOR INDEPTH AND ENAP METRICS WORK

Presented by Joseph Akuze

Mr. Akuze gave an overview of the draft generic protocol, including the background and rationale for the ENAP metrics work. He explained that population based surveys are an important source of population level data on stillbirth and neonatal mortality rates in settings with weak CRVS systems, or none at all. Currently there are two methodologies used to estimate stillbirth rates from survey data:

- A birth history questionnaire and a reproductive calendar (see Box 1).
- A pregnancy history questionnaire and a reproductive calendar (see Box 1).

Box 1. Terminology of survey modules used to collect pregnancy outcomes including stillbirth and neonatal death

Survey Questions	Components
DHS-7 Birth History (BH)	<ul style="list-style-type: none"> • Full history of all live births • Additional questions on pregnancies in the last 5 years resulting in a non-livebirth (including miscarriage, termination of pregnancy and stillbirth) • Details of all pregnancies and outcomes in the last 5 years entered in the reproductive calendar (calendar history) <p><i>As used in reproduction module in DHS-7 model questionnaire</i></p>
Full Pregnancy History (PH)	<ul style="list-style-type: none"> • Full history of all pregnancies and their outcomes (including livebirth, miscarriage, termination of pregnancy and stillbirth) • Details of all pregnancies and outcomes in the last 5 years entered in the reproductive calendar (calendar history) <p><i>Used in the reproduction module in some nationally adapted DHS questionnaires</i></p>

Box 1 shows the terminology of survey modules used to collect pregnancy outcomes including stillbirth and neonatal death. However, no direct comparison has been made between these two approaches, each of which has advantages and disadvantages as shown below:

1. Full live birth histories with pregnancy loss questions (calendar histories, last 5 years)
 - » MICS collect information on live birth histories only (no information on stillbirths).
 - » Standard DHS collect information on live births with additional pregnancy loss calendar histories for last 5 years.
2. Full Pregnancy history (all live births and pregnancy losses)
 - » Previous standard DHS questionnaires underestimated stillbirths. Changes have been made in DHS-7.
 - » Used in some DHS surveys (for example Nepal, Philippines, Vietnam).
 - » Is likely to take longer to collect.
 - » More evidence is needed to show benefit over the standard DHS approach.

He further explained that while birthweight and gestational age are important indicators to measure neonatal health, survey data on birthweight and gestational age are

known to be of poor quality (missing data, poor recall, etc). More studies are needed to assess how best to improve survey capture of these metrics, and the HDSS provide an optimal platform to test how to improve data collection of these indicators. Mr. Akuze explained that the DHS has just slightly adjusted what they do, and some countries are already doing a full pregnancy history, for example Nepal, Philippines and Vietnam. This is said to better capture stillbirths and pregnancy loss, including abortions. “People have hypothesized for 30 years but nobody has done a full study on this,” he reiterated.

two questionnaires in each study site, with the intention of finding out the best way to measure the pregnancy outcomes and if these will help to identify more stillbirths. “The data from the HDSS surveillance/survey modules will be handled and managed at the site by the HDSS statisticians and data managers. At the end of each round of surveillance the data on the ENAP measurement roadmap will be extracted and submitted to the technical coordinator to be appended to the common database for all the five sites. A meta-database will be developed for the available data,” he explained.

Mr. Akuze elaborated that the current ENAP metrics study has been designed to collect HDSS data from the five INDEPTH sites. There will be randomization of the

A summary of other aspects of the draft protocol is outlined in table 1.

Table 1. Summary of the study objectives, research questions and methods

Objectives	Research questions	Data and methods
Improve household survey capture of stillbirths and neonatal deaths	<ol style="list-style-type: none"> 1. Is the “pregnancy history” approach better at capturing stillbirths and neonatal deaths in the last 5 years than the “DHS-7 birth history” approach? 2. How long does it take to collect data using the pregnancy history questionnaire? Does the length of data collection considerably vary by context and/or fertility level? 	<ul style="list-style-type: none"> • Randomization at individual level (woman) of two survey questionnaires in the five INDEPTH sites • Pool dataset of survey data on pregnancy/birth history to estimate stillbirths and neonatal death rates • Assess if the standard DHS-7 birth history module underestimates by more than 15% stillbirths/neonatal death rates • Comparison of rates • Assessment of the length of time it takes to collect the two survey modules
Improve household survey capture of birth weight and gestational age	<ol style="list-style-type: none"> 1. What is the quality of recall data on birthweight in survey data? Does the quality of recall vary with time since birth? 2. What are the community members and health care worker’s knowledge and attitudes on the importance of birth weight measurement? 3. How can survey response of birthweight be improved in survey data? 4. How can gestational age data be captured in survey data? 	<ol style="list-style-type: none"> A. Assessment of quality of recall of the information on birth weight (survey data versus HDSS) <ul style="list-style-type: none"> • Data on birth weight in survey (question on perceived birth size, health cards) • HDSS data on birth weight (collects similar data, health facility data: specialized equipment) B. Assessment of data on gestational age in survey data – comparing with HDSS <ul style="list-style-type: none"> • Data on gestational age - survey question on the last menstrual period or survey data on gestational age • HDSS links with health facility - clinicians make a clinical assessment of gestational age and record their assessment in hospital registers, in other circumstances ultrasound is used • Selected HDSS sites are collecting birth weight data at the community level

<p>Optimize the HDSS data capture of stillbirths and neonatal deaths</p>	<ol style="list-style-type: none"> 1. How can demographic surveillance be optimized for measurement of events around pregnancy and time of birth? 2. What are the socioeconomic and cultural characteristics and determinants of missing pregnancies and pregnancy outcomes? 	<ol style="list-style-type: none"> A. Review alternative modalities of linking health data with community surveillance <ul style="list-style-type: none"> • Different HDSS sites have alternative systems for collecting pregnancy outcomes • Different intervals • Different types of village informant • Linking health facility data with community surveillance B. Assessment of the level of misclassification between miscarriages, stillbirths and neonatal deaths <ul style="list-style-type: none"> • Quantitative analysis of HDSS/Survey - individual level comparison
---	--	--

There was a discussion on how the (suggested) sample size was calculated. It was suggested to randomize the survey at the level of individual women rather than cluster or village level. This is mainly to maximize the statistical power and reduce the total sample size required across all sites (randomizing at cluster or household level will require a much larger number of births to enable the study to have enough statistical power to detect the difference between the two methodological approaches). The discussion on the sample size and method of randomization was resumed on day two of the workshop, and is outlined later in this report.

Each HDSS site will seek for ethical approval from an Institutional and Scientific Review Board within their own country. In addition, ethical approval will be sought from the INDEPTH Network Research and Ethics Committee as well as the ethics committee at LSHTM. To conclude his presentation, Mr. Akuze emphasized that the development and writing of the protocol is collaborative work that is intended for joint publication with all sites, the core team and advisors, and he guided the team through the timelines for the work.



SITE PRESENTATIONS ON THEIR TRACKING AND OUTCOME MEASURES

Each site gave an overview of their HDSS, including how pregnancy surveillance is done, their data linking system and how they measure birth weight and gestational age. A summary of each sites' systems and indicators is shown in Table 2.

Table 2. Overview of the HDSS systems and surveillance

	SITE				
	Bandim (Guinea Bissau)	Dabat (Ethiopia)	Iganga-Ma-yuge (Uganda)	Kintampo (Ghana)	Matlab (Bangladesh)
Population	Urban: ~90,000; Rural: ~27,000 WRA and ~21,000 children <5yrs	69,468	84,466	152,519	230,185
Pregnancy surveillance					
Who carries out routine surveillance visits?	Field assistants	Data collected by trained and full-time field workers who have completed high school and are living in the district Supervisors present	Uses field assistants, Community "Scouts" & recently Village Health Team (VHT)	Field workers / supervisors	Female Community Health Research Workers
Who is allowed to be the primary respondent during visits?	The individuals, parents, neighbours	Mothers	Must be adult usual resident (18yrs +yrs)	Household heads or any responsible adults i.e. > 15 years (including pregnant women) within the household visited	Adult female members (usually wife of household head)



	SITE				
	Bandim (Guinea Bissau)	Dabat (Ethiopia)	Iganga-Ma-yuge (Uganda)	Kintampo (Ghana)	Matlab (Bangladesh)
How often are routine surveillance visits made?	Urban: monthly Rural: Every six months (in 3 northern regions- 2 months)	Update routine surveillance every six months for pregnancy observation and outcomes, migration, death, and marital status	2 rounds per year to record births and deaths	From March 2016, once a year	Bi-monthly
How are vital events notified and followed up?	Through the routine visits (in three regions – +community key informants)	Vital events for births and deaths are notified within 24/48 hours		Routine HDSS surveillance Community Key Informants (CKIs) record pregnancies and births in their communities. This information is extracted by HDSS supervisors who visit every 2 weeks to check for new events	Household visit



	SITE				
	Bandim (Guinea Bissau)	Dabat (Ethiopia)	Iganga-Ma-yuge (Uganda)	Kintampo (Ghana)	Matlab (Bangladesh)
What happens when a birth is captured when the pregnancy was not previously recorded?	For all children registered– a birth form is filled out	Pregnancy observation history form will be filled retrospectively and pregnancy outcome will also be registered		The pregnancy is retrospectively registered, after which a pregnancy termination form will be completed together with a birth form if the woman is a resident of the HDSS	Birth is recorded (rare event)
Data Linking System					
How can pregnancy, surveillance and outcome (births/vital events) data be linked?	Through Individual ID	Individual ID from residency table and mother ID from pregnancy outcomes	Using location ID and individual unique ID	Linked by identifiers such as individual ID, compound ID and household ID and date of event in related data tables	By mother's ID
What percentage of births is in a facility?	Urban: 65% Rural: 39%		64%	61.1%	69% [MCH-FP service area: 87%, Comparison area: 50%]
Is facility birth data linked to HDSS?	National maternity ward and Bandim health center in Bissau (women are identified)	Facility birth data were not linked to HDSS previously but now in the pilot stage	No	No, but this can be done if required	Only Matlab hospital data

	SITE				
	Bandim (Guinea Bissau)	Dabat (Ethiopia)	Iganga-Ma-yuge (Uganda)	Kintampo (Ghana)	Matlab (Bangladesh)
Measuring Birth weight					
Any data on birth weight?	Collected in urban area if available for those born at a health facility	Currently have started maternal and child health surveillance	Yes	Yes, from January 2015	Yes if available
Is the data from facility records only or is weight taken at home by HDSS staff?	Collected by HDSS staff from vaccination card/ ANC card/other document	It is planned to record weight data both from facility and at home by HDSS staff	Done at facility. Since 2013 we rely on health card	Field workers record weight information from children's weighing cards	Facility records only. In a few cases it is from the mother's report
Is it captured in routine surveillance visits?	Yes (birth form or specific studies)	Plan to capture in routine surveillance		Yes	Yes
Are women asked about perceived size of baby at birth?	No	Starting from 2014 women are asked	Yes, once during pregnancy history survey	Yes	No
Is the data available as a subset of the routine surveillance or sub studies?	Routine data	Data available as subset of the routine surveillance		Yes, part of routine surveillance	Not applicable

	SITE				
	Bandim (Guinea Bissau)	Dabat (Ethiopia)	Iganga-Ma-yuge (Uganda)	Kintampo (Ghana)	Matlab (Bangladesh)
Measuring Gestational Age					
Is there data on gestational age at delivery?	Yes, but of questionable reliability	In recent years pregnancy outcome tool addressed gestational age of mothers at delivery	No	No variable for this, but can be estimated by other variables (date of delivery and LMP)	Yes
If so, what data exist?	Response provided by the mother/ parents on month of pregnancy termination (urban)	Gestational age of mothers at delivery		Date of delivery and last menstrual period (LMP)	LMP date and the date of delivery
Is it captured in routine surveillance visits or linked to facility data?	Captured in routine visits (urban)	Captured in routine surveillance and linked to facility data	No (a pilot using 1 or 2 facilities is being discussed)	Routine surveillance	Routine surveillance visits
Are the data available as a subset of the routine surveillance or sub studies?	Both (sub studies in Bissau)	Data available as subset of the routine surveillance	Part of surveillance	Yes, part of routine surveillance	Routine surveillance visits

	SITE				
	Bandim (Guinea Bissau)	Dabat (Ethiopia)	Iganga-Ma- yuge (Uganda)	Kintampo (Ghana)	Matlab (Bangladesh)
Specific thoughts/questions on enhancing surveillance and making sure we capture all outcomes?	<ul style="list-style-type: none"> Urban area: improve field workers' performance in terms of pregnancy registration; linking to HF data (gestational age) Rural: Calculation of gestational age based on data at registration of pregnancy and outcome 	<ul style="list-style-type: none"> Definitions and consistency of data especially stillbirths Measurement tools be used to measure GA Gaps in coverage definitions, validation & feasibility testing for HMIS use Improve how to capture birth outcomes without pregnancy observation 	<ul style="list-style-type: none"> Provision of services to pregnant women e.g. health education, counselling and checking blood pressure at home 	<ul style="list-style-type: none"> Early pregnancy [first trimester ultrasonography for dating of pregnancy] to augment LMP – is that practised in any of the other sites? If yes, how do they go about it? Early capture of pregnancies could enhance capture of stillbirths, as we could trace each woman who has a record of pregnancy for its outcome Overcoming socio-cultural resistance to stillbirth registration 	
Challenges expected in harmonisation of data across sites	Misclassification of stillbirth or neonatal death based on recall (dates, born alive or not, etc.)	Using the same kind of study tools to measure parameters	Data missing	Different metadata structures across sites. There may be need to provide standardised data descriptions across HDSS sites	<ul style="list-style-type: none"> Information not available for core ENAP indicators Information not available for additional indicator (the challenges are for all sites, not of specific Matlab site)

	SITE				
	Bandim (Guinea Bissau)	Dabat (Ethiopia)	Iganga-Ma- yuge (Uganda)	Kintampo (Ghana)	Matlab (Bangladesh)
Other thoughts or ideas				<ul style="list-style-type: none"> • Need to link up health facility data with HDSS to improve data quality especially for stillbirth registration • Can we provide standardized data forms at health facilities for nurses to fill out stillbirths, live births, deaths, etc., and field supervisors regularly visit these facilities to collect, follow-up using compound number, place of residence, and complete these forms by relying on and entering these into the databases? 	

Although each HDSS site is unique and there were a number of variations, we saw some similarities. For instance, retrospective registration of missed pregnancies was similar across four sites, except for the Matlab site which said it is rare (only 2% of all pregnancies were missed by the HDSS system, however Matlab only collects data on pregnancies amongst married women, due to the cultural issues

surrounding pregnancies among unmarried women). Additionally, the issue of registration of births where pregnancy was not previously registered was continuously raised across the five INDEPTH sites. It is possible that this may be one of the theories on low stillbirth rates, since you can't register what is not there.

IMPROVE HOUSEHOLD SURVEY CAPTURE OF STILLBIRTHS AND NEONATAL DEATHS

Presented by Dr Angela Baschieri

The first objective of the ENAP metrics study is to improve household survey capture of stillbirths and neonatal deaths by comparing birth history and pregnancy history approaches.

Dr Angela Baschieri explained that there are mainly two methodologies to estimate stillbirth rates from survey data: the standard DHS approach “birth history” and an alternative approach “pregnancy history” (see Box 1). Dr Baschieri gave a detailed description of the methods and processes of objective one as well as the tools and modules (DHS-7 and the full pregnancy history questionnaires).

Dr Baschieri explained that DHS have over the past 30 years advanced global understanding of health and population trends in developing countries. UNICEF initiated the MICS to complement the DHS, and the DHS/MICS provide international comparable estimates of key maternal and child health indicators, fostering and reinforcing host country ownership of data. Survey data are an important source of information of child health, and measurement of neonatal and stillbirth deaths needs to be improved.

Previous studies have found some evidence that birth history data with additional questions on pregnancy losses collected in standard surveys such as DHS/MICS underestimate stillbirths and early neonatal deaths, and gave evidence to support these findings. Please see Annex 2 for further details. Dr Baschieri also took the participants through the relevant sections of the DHS-7 and the pregnancy histories modules and explained the differences between them. She explained that there have been improvements in the DHS-7 in the way the reproductive calendar data are linked with the birth history data compared to DHS-6 and DHS-5. However, it is still not clear whether the data on pregnancy losses collected with the pregnancy history approach provides better measurement of stillbirth and neonatal health than the birth history approach.

The first objective of this work is to compare the two questionnaires: DHS-7 (a major improvement from the previous version, with a full birth history plus information

on pregnancy outcomes for the last five years using a reverse truncated calendar) and the pregnancy history (which asks about all pregnancies together with the information on pregnancy outcomes for the last five years using a reverse truncated calendar). She highlighted that the main difference between these two approaches is that the pregnancy history collects data on all pregnancies in a woman’s lifetime, as opposed to all live births only. All pregnancy outcomes in the five years preceding the survey should be captured by the reproductive calendar history used in both approaches.

This presentation set the course for the afternoon’s group discussions on objective 1, which was further elaborated on by Ms. Doris Kwesiga. Both groups had three main areas to deliberate on: the survey design questions; the survey questionnaire content to capture pregnancy losses; and the data collection questions. Highlights from this session are given below.

Survey design questions and issues (sample size calculations, randomization)

Dr Baschieri illustrated the assumptions made for the sample size calculations. Some of the assumptions were discussed and agreed. The participants agreed that the final sample size and composition of births across the five INDEPTH sites should be looked at in more details. This new set of estimates will have specific cost implications and should be further reviewed and assessed. Following the sample size calculations, it was suggested that each site should further discuss the feasibility of reaching the required number of births from their site.

Everybody was in agreement with the randomization of individual women into either survey. They pointed out some limitations and methodological issues, including:

- How to handle temporary absence of a woman e.g. go back at least twice; acceptance of failure to capture some respondents (analyze characteristics of some of those we fail to get); and sampling by replacement. It was recommended that we accept a 10% chance of missed responses.

- Addressing maternal deaths by updating the list of women of child bearing age to include recent deaths so that interviewers do not go to a household where a woman has recently died and start asking about her.
- Inclusion of minors varies across sites: asking questions to children below 18 years depends on whether they are married and have a baby and the country laws and cultural taboos. It was decided to aim for standardization of 15 years and above as the respondents (as in the DHS), but using married women only in some sites where it is culturally unacceptable to have a child outside wedlock and so you would not be able to ask unmarried females about pregnancy, for instance in Matlab HDSS.

The use of electronic data collection supported by tablets to randomly distribute the tools was welcomed as an important suggestion. Some sites like Guinea Bissau and Bangladesh have already used them in surveys. However, all sites are eager to use the tablets for the ENAP metrics work, pending assessment of:

- Costs,
- Operational issues (batteries, coverage, backup system, etc.),
- Experience,
- Whether the DHS questionnaire is already in a tablet- software format.

Survey questionnaire content to capture pregnancy losses (questions to add e.g. gestational age in weeks)

The pros and cons of measuring GA in weeks were discussed, and it was realized that while most health workers actually inform the mothers about GA in weeks, the mothers tend to count these in months. The debate was mostly around what to do for mothers who do not go to the health facility for antenatal care, and therefore do not get this information from health workers. Completion of this issue was deferred to the group work on objective 2 and to the site-specific next steps which took place on day two.

Translation of the tools to local languages was noted as very critical, especially for questions about “loss” and duration of pregnancy. Additionally, possible qualitative

questions arose around exploring the experiences of interviewers in asking respondents about loss of life.

Data collection processes/ modalities (enumerators, process of data entry, data linkage and issues around abortions)

The participants discussed the pros and cons of using enumerators who usually collect data in the area. The participants at the workshop were in agreement that the enumerator should not be someone who usually collects data in the area. Therefore, it was suggested to avoid having enumerators that have already collected the information as part of the HDSS data collection. However, using enumerators from the HDSS site has its benefit. That they know how to approach the people, understand the community dynamics and can easily administer the survey versus the new, inexperienced ones who require more training but are probably more open minded was a focal point of the data collection modalities discussion. Viable options suggested were to have an enumerator from another area to conduct the survey, or to have a new enumerator conduct the survey alongside the HDSS team.

Participants also discussed the feasibility of this survey in relation to the routine HDSS surveys, for instance deliberations on how long it will take to conduct so that it does not destabilize the existing surveillance rounds. It was noted that this depends on the sample size and will differ for each site. It is also contingent on how long each interview will take and how many interviews each enumerator can do per day. This was reliant a lot on the practicality of meeting the ample sample size within the original budget discussed, and was to be debated further within the site-specific working groups.

The participants discussed site specific issues on abortions. In some sites like Dabat communities attach a stigma to women who perform abortion, and abortions are not openly recorded due to negative cultural perceptions of abortions. On the other hand, in Ghana there are less cultural sensitivities around abortions and in their questionnaire they ask about abortion through indirect questions.

In addition, participants discussed alternative ways to link survey and HDSS data. For women’s records it was suggested to use a woman’s ID from HDSS for the

survey, whereas for babies data could be linked through a comparison of date of birth of the child between HDSS and survey databases. Each site will further explore how best to secure this data linkage between the survey and the HDSS.

Key emerging issues from discussions on objective 1

- The total sample size calculation as well as the distribution of the sample across sites needed to be redone, bearing in mind each site's catchment population, total fertility rate, stillbirth rates, high levels of migration, issues of tracking pregnancy, and loss to follow up of residents.
- More information on the feasibility of measuring gestational age in weeks is needed.
- The issue of registration of pregnancy outcomes in case of maternal deaths requires more discussion.
- More attention should be paid to data quality in the case of linking women and baby IDs.
- It was agreed that a question related to abortions was needed. However, everybody was in agreement that three pages of questions about who conducted the procedure, which method was used and why may be sensitive where abortion is illegal, as well as too long. This needs to be reviewed and shortened.
- There are numerous opportunities for sites to learn from each other and share good practices. Different sites have variations in their pregnancy tracking ability and each has good practices that they are using; for instance, in Ghana there is an in-migration form that asks about pregnancies, which other sites could adopt.
- The dynamics of tracking a pregnant woman throughout the nine months need to be considered. For example, the woman may join someone else outside or within the site, so how can the outcome of her pregnancy be captured?
- The timing of when to begin the survey modules needed to be discussed further. There was a possibility that some sites may be able to start on this earlier if they are not making major adjustments. Sites were advised to think of their own customized timelines and their update rounds, in order to detail what could work and note the issues or changes needed to fit within the resources available.

IMPROVING HOUSEHOLD SURVEY CAPTURE OF BIRTH WEIGHT AND GESTATIONAL AGE

Presented by Dr. Hannah Blencowe

The second objective of the ENAP metrics study is to improve household survey capture of birth weight and gestational age by assessing various methods for measuring these outcomes in surveys. The objective has the following research questions.

1. What is the quality of recall data on birth weight in survey data? Does the quality of recall vary with time since birth?
2. How can we improve the quality of birth weight capture in survey data?
3. How can we better capture gestational age in survey data?

Dr. Hannah Blencowe began her presentation by providing the standard definitions for the relevant gestational age and birthweight variables, which are often misunderstood or incorrectly interpreted and therefore measured differently, leading to unreliable data.

Box 2. Low birth weight and preterm birth definitions

- **Low birth weight:** Arbitrary dichotomous cut off at 2,500 gm (challenges for both numerator and denominator)
- **Preterm birth:** Any live birth before 37 completed weeks of gestation, or fewer than 259 days since first day of last menstrual period. Can be extremely preterm (<28 weeks), very preterm (28- <32 weeks), moderate or late preterm (32-<37 weeks)

Dr. Blencowe noted that extremely pre-term births, with the highest mortality risk, are often not counted or misclassified as stillbirths. All fetal

deaths (stillbirths) should have gestational age at delivery recorded. All fetal deaths from 22 weeks of gestational age should be counted as stillbirths. Losses prior to 22 weeks should be recorded as spontaneous miscarriages or induced abortions. In many settings the capture of stillbirths at 22 – 28 weeks is low, and therefore World Health Organization also recommended reporting late fetal deaths at ≥ 28 weeks for international comparison. INDEPTH sites should seek to follow this guidance and collect data on stillbirths so that it can be presented as early fetal deaths ≥ 22 weeks and late fetal deaths ≥ 28 weeks.

In addition to explaining the policy importance of monitoring low birth weight and preterm birth trends, Dr. Blencowe gave further information on birthweight and GA measurement and data, excerpts of which are shown in Table 3.

Table 3. Birthweight and gestational age assessment and measurement

	Birth weight	Gestational age
Measurement: overview of data sources	<p>National routine data from:</p> <ul style="list-style-type: none"> • Civil Registration and Vital Statistics (CRVS) • Facility based birth registries including HMIS <p>Nationally representative household survey data (currently for LBW only):</p> <ul style="list-style-type: none"> • Multiple Indicator Cluster Surveys • Demographic and Health Surveys • Nutrition Surveys <p>Other sub-national population based data:</p> <ul style="list-style-type: none"> • Sub-national household surveys • Population based studies 	
Challenges with data	<ul style="list-style-type: none"> • Most LMICs have low rates for weighing of newborns at birth especially for non-facility births • Across all DHS 0% to 100% of infants were not weighed at birth • Heaping of weights, especially on 100g and 500g 	<p>Low coverage of early USS dating of pregnancies:</p> <ul style="list-style-type: none"> • Absence of early antenatal care visits; lack of equipment; training and costs <p>Barriers to higher quality LMP data:</p> <ul style="list-style-type: none"> • Relatively high prevalence of lactational amenorrhoea prior to conception • Low use of urine pregnancy testing after missed periods • Late or missed pregnancy registration prior to birth
Current approach in surveys	<p>Current survey question in DHS asked for last and next to last live birth (+ sometimes second to last birth):</p> <ul style="list-style-type: none"> • When (NAME) was born, was (NAME) very large, larger than average, average, smaller than average, or very small? • Was (NAME) weighed at birth? • How much did (NAME) weigh? <p>Record weight in kilograms from health card, if available.</p>	<p>Data that could be used to estimate GA currently collected in surveys is not analysed:</p> <ul style="list-style-type: none"> • Concerns raised over data quality • All data currently collected in completed months and not completed weeks <p>For each birth/ pregnancy in last five years enter data in calendar:</p> <ul style="list-style-type: none"> • Current standard DHS surveys (NB - data not analysed): • Most DHS surveys with pregnancy histories (eg Pakistan 2013/14, Nepal 2011, Tajikistan 2012, Kyrgyz Republic) • Ask about length of pregnancy in questionnaire for pregnancy outcomes (eg Philippines 2013) <p>For live births add additional question(s) to postnatal questions alongside birth weight:</p> <ul style="list-style-type: none"> • Not currently done in any identified surveys • Potentially useful for live births only

Current status of recording in the five HDSS	<ul style="list-style-type: none"> • Birth weight captured in all sites except Dabat where mothers are asked about perceived size since 2014 • Data captured from health cards / ANC cards / vaccination card / facility data / recall • In most sites, percentage of babies with birth weight recorded is low or unknown, except Iganga-Mayuge 	<ul style="list-style-type: none"> • Captured in routine surveillance except in Iganga and Kintampo • Data collected from LMP (linked to facility data in Bandim), date of delivery and pregnancy outcome tool
Possible options for strengthening gestational age assessment, e.g. routine urine pregnancy tests in women missing two periods as used in Bangladesh, were highlighted in the presentation		

Barriers and facilitators to birth weight measurement in HDSS, linking to ENAP facility-based testing work

The following barriers and facilitators to birthweight measurement in HDSS, linking to ENAP facility-based testing work, were highlighted during the session:

Enabling environment

- Suitable weighing device available, functional and calibrated.
- Trained staff who have a culture of weighing all babies.

Practice (assessment of quality)

- Baby weighed.

Immediate communication of the results

- Mother informed of birth weight and the weight is recorded in medical notes and in the register.

Availability of information at a later stage

- Mother is able to accurately record birth weight; handheld medical notes that the mother is able to record; and register data is linked to a data collection system or platform.

Working group 2: discussions on objective 2

This working group focused on discussion of the second objective of the study. Participants were divided into two groups to deliberate on the following themes:

1. Improving gestational age data in surveys
2. Improving birth weight data in surveys
3. Capturing of gestational age in the HDSS
4. Capturing of birth weight in the HDSS

The groups discussed both short and long term activities that can be undertaken, divided into three broad phases.

- *Phase I* of the long term agenda is to add questions relating to birth weight and gestational age to the survey planned for 2017 to compare “standard DHS-7 birth history” approach and “pregnancy history” approach. Some information is already available in present surveillance and the sites will be able to compare the survey information with surveillance information.
- *Phase II* will involve writing a grant application for submission in the first instance to the MRC methods call, deadline 16th November 2016. The focus of the grant will be to improve birth weight capture through innovative approaches.
- *Phase III* includes developing a grant application during the first half of 2017 to improve GA capture through innovative approaches.

Some of the highlights from both groups are shown in Tables 4a and 4b.

Table 4a. Highlights of group one's discussion on improving birth weight data in both surveys and HDSS

Improving birth weight data in surveys	
Current survey birth weight questions – any suggestions for refinement	<ul style="list-style-type: none"> • Collect data from ANC card, vaccination card, piece of paper not dependent on women's recall • Mother's perception of weight of child i.e. small, very small, etc. • Use BW in card or use mother's perception • Can compare mother's perception with that from card and check just like DHS to see any associations
Feasibility of linking survey data with health facility data	<ul style="list-style-type: none"> • Some use unique variables-not only name, but other variables like place of residence, age, etc. to link information in community to that of facility • Others have used biometric identifiers while some sites are going to pilot them
Other discussion points	<ul style="list-style-type: none"> • Use of community health workers to go to those who deliver at home for BW measurement within 72 hours • Sensitization issues, education of the community, etc. that will enhance their response and acceptance • Processing of birth certificates, etc. as an incentive to parents • Use of MUAC or foot size in the community as a proxy to birth weight and GA
Capturing of birth weight in HDSS	
Current status	<ul style="list-style-type: none"> • In rural Bandim setting: BCG trial (weighing babies at home with digital scales before age of 3)
Barriers and enablers to birth weight measurement and recording	<ul style="list-style-type: none"> • Institutions not taking BW because there are no scales, etc. • In Dabat HDSS, most births are at home. Weighing in the community is challenging (cultural taboo to put the baby on scales alone) • Challenges with weighing in health facilities • Need to understand local health workers' attitudes and practices of BW measurement and resource issues • Need to study community attitudes to birth weight and whether women perceive birth weight as important • Should come up with innovative ideas to measure birth weight within the community
Possible activities in the next year	<ul style="list-style-type: none"> • Algorithm is needed to impute the weight in Bandim • Give maternal passports/ antenatal cards early in pregnancy to seek to improve LMP accuracy

Table 4b. Highlights of group two's discussion on improving birth weight data in both surveys and HDSS

Improving gestational age data in surveys	
Methods currently in use – any other suggestions	<ul style="list-style-type: none"> • LMP used in current surveys. In Bandim (urban) it is collected at delivery and linked to facility data but in the rural site it is collected during registration of pregnancy • Women who attend at least one ANC will have a card; portion of LMP on ANC card but cards can be lost • Also collected in pregnancy observation tool and birth outcome form • Information when recorded is stated as “mother’s recall” or “from ANC card” • Woman’s recollection of month in which she became pregnant
Feasibility of asking women to report pregnancy length in weeks	<ul style="list-style-type: none"> • LMP is not well remembered by mothers. Women are told GA in weeks and they convert it into months so it is feasible to report in weeks. The ANC card is a feasible way of reporting pregnancy length, although in Asia ANC attendances are lower than in Africa • In Dabat, LMP from women recall (in weeks) can be done. The number of women can be calculated
Feasibility of using data from pregnancy card if retained (LMP and date of delivery)	<ul style="list-style-type: none"> • It is feasible if sensitization of health care providers and the community on the use of the card is done. However, in Ethiopia the cards are retained at the health facility
Other discussion points	<ul style="list-style-type: none"> • Research question – what influences women to retain their ANC cards? • Qualitative study to explore what information is captured and how in the different sites
Capturing of gestational age in HDSS	
What is feasible to add to LMP in routine HDSS (versus research setting)	<ul style="list-style-type: none"> • Menstrual calendars & beads, future research like scans, urine tests, etc. in this area • In urban Bandim: a subset has clinically estimated GA – see if it is possible to cross-link • Improve form to collect Expected Date of Delivery (EDD) for the sites that do not have this
Training / other tools to reduce error in calculating gestational age from LMP	<ul style="list-style-type: none"> • Use of the gestational wheel • Other options are the use of a mobile phone application or computer
Other discussion points	<ul style="list-style-type: none"> • Carry out a systematic review • Qualitative study to see issues related to having cards, willingness to use, etc. • Matlab can report on GA in the next annual report

During the plenary, the two groups presented their discussions noting the differences and similarities. As part of the next steps, participants agreed on the following:

- To apply for the UK MRC methods grant approach together as a group, with specific focus on improving birth weight. A joint proposal from the five sites will be written, led by the LSHTM and the INDEPTH Network MNWG secretariat. This is to be submitted by 16th November 2016.
- Improving GA measurement will require sites with a good link between the HDSS and health facilities with capacity for early dating ultrasound scanning. Availability of good laboratory services may also be beneficial. GA is therefore more complex and the grant writing will be opened up to other member sites of the MNWG beyond the five sites doing the ENAP metrics grant. It was also suggested that it can be submitted to the Gates Foundation that is interested in GA.

As Assoc. Prof. Waiswa remarked while closing this session, “This is how you develop a research area and it continues growing, by one thing leading to another. We need people who will help to ask and answer questions, especially when they potentially have a career that they can build. We need to include young people who have the capacity to develop and lead and we support them.”

Prof Joy Lawn concluded by saying, “It is like building a health system. You won’t have universal health coverage of everything by the end of 2017. We need to phase this work, with each site starting from a different point.”

OPTIMIZING HDSS CAPTURE OF PREGNANCY OUTCOMES

Presented by Ms. Kate Kerber

The final presentation on the second day of the workshop was by Ms. Kate Kerber, who walked the participants through the third objective of the ENAP metrics work, on optimizing HDSS capture of pregnancy outcomes. It is underpinned by two research questions:

1. How can demographic surveillance systems be optimized for measurement of events around

pregnancy and time of birth?

2. What are the socioeconomic and cultural characteristics and determinants of missing pregnancies and pregnancy outcomes?

Ms. Kerber emphasized that as one measure of outcome capture, sites can look at the ratio of stillbirths to early neonatal deaths, which should be roughly 1:1 (see table 5).

Table 5. HDSS Site data: 3-5 year averages

	Iganga-Mayuge	Bandim	Matlab (2014)	Kintampo	Dabat
Population	83,000	180,000	230,185	152,519	69,468
Households	16,000	22,000	53,226	32,000	16,016
Live births	2,264	5,790	4,863	4,710	1,320
Stillbirths	45	297	92	86	34
Stillbirth Rate (SBR)	19	49	19	18	25
Neonatal deaths	118	204	104	95	53
Neonatal Mortality Rate (NMR)	52	35	21	20	40
Total Fertility Rate	4.3		2.6	4.1	3.8

*The information in table 5 is based on data (raw numbers) submitted with the proposal.

*The stillbirth rate is calculated on live births plus stillbirths, not recorded pregnancies.

Ms. Kerber then gave a systems overview of the different sites. This summarized the presentations from each site, by highlighting the key system issues, similarities and differences in table 6.

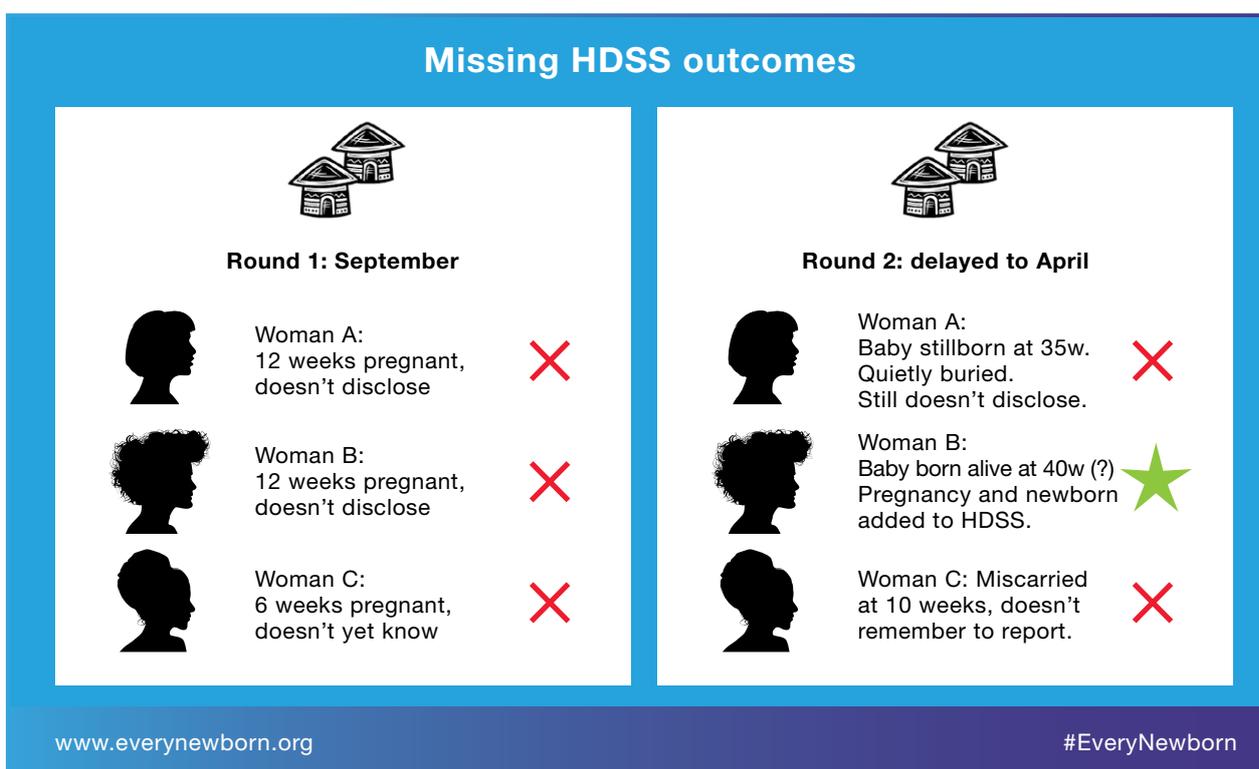
Table 6. HDSS systems overview

	Dabat	Kintampo	Matlab	Bandim	Iganga-Mayuge
Frequency of rounds	2 per year	1 per year	6 per year	Urban: Monthly Rural: 2 per year	2 per year
Informants/scouts	Local guides report within 48 hours	Community key informants		Recently started using community key informants	64 Community based "scouts" and VHTs

Incentives for reporting	83% female enumerators	Each woman is asked about pregnancy status	Urine test and free ORS supply in entire area; free maternal and child health services in half of the DSS area	Each woman is asked about pregnancy status	
Age of informants	15+ if married	10+ in some surveys	15+ if married	15+	15+
Frequency of re-censusing the area	Every 7 years	Last census 2003	8 years or more	Every 2 years	Each update round
Facility births	17%	61%	69% (Intervention area: 87%; Comparison area: 50%)	Urban: 65% Rural: 39%	64%
Links to facility	Pilot study ongoing	Not currently	Matlab hospital only (17% of births)	In national hospital, not in rural	Not currently
Data entry	Piloting tablet	Paper-based	Galaxy tablets	Tablet planned in rural area in 2017	Paper-based

Following the systems overview she explained a variety of scenarios in which the HDSS sites can miss pregnancy and outcomes registration during a round of surveillance, as presented in the figure below.

Figure 5. Missing HDSS outcomes



Sample size calculations

Presented by Dr Angela Baschieri

Dr Baschieri illustrated the main assumptions used to determine the sample size calculations for the study. As already discussed, this study aims to assess whether the stillbirth rates estimated with the pregnancy history approach are at least 15% higher than the stillbirths and neonatal death rates estimated with the DHS-7 birth history approach. If this study is able to prove this level of difference it would provide a strong argument to support a change in the standard DHS questionnaire.

Four main assumptions were made:

1. *Stillbirth Rate (SBR) across the five sites:*

Alternative assumptions on the average SBRs across sites were made. The preferred assumption was to consider the weighted average of the stillbirth rates in the past five years across the five sites using annual information on live births and stillbirths in the past five years.

2. *Difference in SBR captured by the two alternative methodologies (see box 1):*

The minimum level of difference that we would need in order to be able to assess the level of SBR captured by the two alternative approaches was also discussed. It was agreed that in order to make a compelling case to the global community and other international stakeholders it would be necessary to capture at least a 15% difference between the two methodological approaches.

3. *Design Effect:*

We assumed a design effect of 1.1.

4. *Non-response/missing/not found/migrated out:*

We assumed that across the five INDEPTH sites on average there was a likelihood that 10% to 15% of the observations would be lost due to either non-response, loss to follow up or the respondent (pregnant woman) migrating out.

5. *We used a two-sample proportions test (Pearson's chi-squared test) to have 80% and at the 5% significance level ($\alpha=0.05$)*

As discussed, the unit of randomization will be individual women. This will minimize the design effect and will help to reduce the total sample size required. The weighting means SBR across all five INDEPTH sites for the years 2010 – 2015 recorded in the HDSS is 24.7 stillbirths per 1,000 total births. Assuming that the DHS-7 birth history will capture as many stillbirths as the HDSS over

the past 5 years, to detect a difference of 15%, we would require the pregnancy history approach to record a SBR of at least 28.4 per 1,000 total births.

The estimated sample size required based on a two-sample proportions test (Pearson's chi-squared test) to have 80% power to detect a difference of 15% or more between the proportion of total births that are stillbirths in the pregnancy history compared to DHS-7 birth history, at the 5% significance level ($\alpha=0.05$) is between 71,717 to 74,977 total births over the preceding five years, including a 10% to 15% non-response rate. We have made a small adjustment for design effect ($DEFF=1.1$) as births to an individual woman may be reported more similarly than births between women.

There were approximately 90,000 recorded total births across the five INDEPTH sites over the preceding five years. In order to reach the required sample size to allow for capture of the above mentioned difference in SBR with the two questionnaires, we would need to sample at least 74,000 births.

Proposed survey / sample size feasibility for each site

After the group discussions and presentation by Dr Baschieri on the optimum sample size for the survey, the following preliminary issues were raised by each site:

Bandim

Would be able to cover approximately 80% of women if data were collected over a year, so that they fall into 2 routine visits. They need to estimate how much time is needed to interview and get consent, and could put it on top of routine work but need time frames.

Dabat

Could be possible to reach every woman of reproductive age in their HDSS because the population is small.

Iganga-Mayuge

Can reach all women of reproductive age in the HDSS if resources allow.

Kintampo

Has around 36,000-38,000 women of reproductive age so it may be difficult to interview the entire population. Would go for a sample of the women.

Matlab

Can interview maybe 10,000-15,000 women comfortably (half or less of the women of reproductive

age) using the existing workers by cancelling one routine round. Otherwise they also need more resources.

However, after the workshop each site will be contacted individually to finalise the sample size that is feasible with the existing, or a slightly enhanced, budget.

Site-specific feedback and strategies

The morning of day three was dedicated to presentations from the site representatives on the questions they were asked from the excel templates that were sent to them before the meeting.

BANDIM HDSS (GUINEA BISSAU)

QUESTIONS TO HDSS SITE	RESPONSE
Registered and unregistered pregnancies	
Do you think your HDSS is missing pregnancies? If so, which ones?	Yes, an ID number is assigned already to the pregnancy and the follow up of the child therefore starts before birth. However, with 6-monthly visits not all pregnancies are disclosed. We therefore miss early miscarriages. We would also miss more premature births and stillbirths than live births who are only registered after date of birth. However, the rate of stillbirths, neonatal deaths and later miscarriages among registered pregnancies is correct.
Are outcome definitions clear enough in your tools?	
How are induced vs spontaneous abortions defined?	Induced abortions not captured – stigma?
How are stillbirths defined? Any difference between macerated stillbirth (MSB) and fresh stillbirth (FSB)?	Maternal report, can be supplemented with reported GA, but not routinely done. Verbal autopsy (VA) supplements the classification.
Are there probes about whether a baby that died moved/cried/ breathed at all (not just in VA)?	No, only in VA (VA mainly for neonatal deaths and stillbirths).
What are the specific local barriers around reporting pregnancy loss, if any, that may impede reporting to surveyors/enumerators?	Losses not spontaneously reported <ul style="list-style-type: none"> • Prospective recorded: 94%LB, 4% SB, 2% AB • Retrospectively: 92% LB, 2.5% SB, 5% AB
Improving HDSS capture	
Barriers for pregnancy	<ul style="list-style-type: none"> • Interval • Travelling woman (ask family about the pregnancy)
Barriers for pregnancy outcome missingness	Very rare if pregnancy registered (ID to pregnancy)
Barriers for misclassification	<ul style="list-style-type: none"> • GA – Miscarriage/stillbirth • Early NN death / stillbirth – linkage to National Hospital for 45% of urban births (but stillbirths over reported at national hospital)

What are possible enhancements to the pregnancy surveillance system and reporting?		
Currently	Proposed	
Month of pregnancy captured at registration of pregnancy	<ul style="list-style-type: none"> Piloting questions on LMP/weeks of pregnancy with female nurse working in the rural areas Piloting questions on LMP/weeks of pregnancy with Midwife at Bandim HC in the urban area 	
Varying performance by assistants - Performance indicator	Continued follow-up of every assistant closely including targeted field supervision.	
Prenatal card given to women in urban area at registration of pregnancy (with CNO)	Maybe test in rural? <ul style="list-style-type: none"> Pregnancy cards rarely filled out with LMP and EDD Selling card also income for nurses at health centre 	
Rural: Pilot testing community key informants	Mobile pay? (CKIs report takes a while, hence incentive)	
Urban: census of whole population: Every 2-4 years depending on funding	Census update on women of fertile age more often (yearly)	
Urban: We ask for pregnancies in the household	Try to ask for each registered woman's pregnancy status	
Operationalizing the household survey birth history vs pregnancy history comparison		
Does your site reach all women of childbearing age with each surveillance round? If not, how often?		
If not, would you do a stand-alone survey? If so, how and when?	Urban <ul style="list-style-type: none"> Stand-alone survey Depending on number of interviewers: <ul style="list-style-type: none"> » Up to 90% July 2017 – Nov 2017 	Rural <ul style="list-style-type: none"> Survey at time of routine visit (1 day / village every 6 months) Present at visit: 2/3 -> 2 visits: 80% June 2017 – May 2018
	Cost implications of trying to cover 80% of all – 85 months of data collection in each of the 2 systems (approx. 16 persons for 1 year)	
What needs to be changed to link the HDSS information to the survey data, particularly for babies?	Nothing to link to HDSS – but will need some manual linking and searching due to imprecisions (date of birth, name) in survey.	

DABAT HDSS (ETHIOPIA)

QUESTIONS TO HDSS SITE	RESPONSE
Improving HDSS capture	
What are the barriers in your site for pregnancy, pregnancy outcome missingness and misclassification?	<ul style="list-style-type: none"> Pregnancies are thought to be well reported but the fact that stillbirth rate is lower than neonatal mortality rate suggests otherwise Analysing the data for the current inconsistencies

What are possible enhancements to the pregnancy surveillance system and reporting?	
Low cost	Higher cost
<ul style="list-style-type: none"> • Use quality flags in the data analysis (e.g. expected stillbirths vs neonatal deaths) • Check pregnancies reported by male and female guides and enumerators • ~90% local guides are male: we are recruiting more female key informants • More training of both enumerators and local guides; additional follow-up on early pregnancy capture 	<ul style="list-style-type: none"> • Introduce ANC cards as soon as pregnancy registered (for those without) • More and better quality digital weighing scales • Link urine pregnancy testing being offered by health extension workers to HDSS so they are informed whenever a pregnancy test is positive
Operationalizing the household survey birth history vs pregnancy history comparison	
Does your site reach all women of childbearing age with each surveillance round? If not, how often?	Yes, reaches all
If not, would you do a stand-alone survey? If so, how and when?	N/A
Assuming you will use the list of women of childbearing age <ul style="list-style-type: none"> • What is the percentage of out-migration? Is there birth-related migration out of the HDSS? • Can we administer the survey to a woman not on the list but in the household? 	<ul style="list-style-type: none"> • Out migration higher among women than men in age group 22-24 years but still very low • If a woman is in the HH but not on the list can still administer survey, tablet could be programmed to automatically randomize- needs to be discussed further if feasible
What needs to be changed to link the HDSS information to the survey data, particularly for babies?	This shouldn't be a problem- all babies have same ID as mother. Individual births can be linked.
Expected timeline	
When is the next HDSS round?	<ul style="list-style-type: none"> • Mid-July special nutrition, maternal and child survey happening • Next HDSS around August / September, depending on rain
When would you need the tablets by in order to translate, train and test?	October / November
When do you expect to be able to: <ul style="list-style-type: none"> • Pilot the survey? • Start the survey? 	<ul style="list-style-type: none"> • Pilot: January / February 2017 • Start: March 2017
General HDSS issues	
Are there data sharing implications?	No
Are there other questions you will face when you go back that we can discuss now?	We may have cost issues

IGANGA-MAYUGE HDSS (UGANDA)

QUESTIONS TO HDSS SITE	RESPONSE
Registered and unregistered pregnancies	
Do you think your HDSS is missing pregnancies? If so, which ones?	<p>Yes</p> <ul style="list-style-type: none"> • Pregnancies are missed because of cultural issues (disclosure effect) • Long interval between rounds at & effect of population mobility (within, in and out migration) • The tool is not detailed enough to capture earlier pregnancies • We rely on the mother to distinguish the type of birth • Verbal autopsy is done on neonatal deaths but not stillbirths • Pregnancies which are lost between survey rounds may be missed out • Sometimes the Research Assistants (RAs) may miss asking a question about pregnancy – this might require capacity building • Design of Household Records Book (HRB), no written questions • A quality assurance system is however in place – supervisors checking completeness of forms
Are outcome definitions clear enough in your tools?	
How are induced vs spontaneous abortions defined?	We talk about miscarriage and abortion only. The answer options available on the tool are; “Live birth, miscarriage, stillbirth and abortion”
How are stillbirths defined? Any difference between MSB/FSB?	Defined as pregnancy loss after pregnancy age of seven months. No distinction between MSB/FSB
Are there probes about whether a baby that died moved/cried/ breathed at all (not just in VA)?	No
What are the specific local barriers around reporting pregnancy loss, if any, that may impede reporting to surveyors/enumerators	<ul style="list-style-type: none"> • Cultural barriers (reporting miscarriages, or pregnancy losses is often related to superstition, and stigma) • Under-aged pregnant mothers may decline to disclose due to stigma, if pregnancy is socially unacceptable, e.g. by a married or polygamous man • Rate of in- and out-migration as well as internal mobility • If information is by proxy, e.g. interviewing parent about her daughter • Possible solutions • Community sensitization and advocacy to minimize stigma and superstitious beliefs • Must talk to each woman

What are possible enhancements to the pregnancy surveillance system and reporting?	
Low cost	Higher cost
<ul style="list-style-type: none"> VHTs: no need to focus on females. Women can open to male VHTs as well. Therefore, the current VHTs can still be used Explore possibility of giving urine testing kits to VHTs to conduct pregnancy testing (explore cost of kit) Mobile phone app/ calendar to calculate gestational age – not many phones in the community can do this. Consider using a calendar and a wheel, moon beads NB. More questions mean increased workload for RAs and respondents. This has a cost and moral implication <ul style="list-style-type: none"> » Is it possible to ensure the tool is not “heavy”, i.e. short? » Is it plausible/practical for site to compensate respondents for their time 	<p>Enhancing the work of VHTs to capture more events:</p> <ul style="list-style-type: none"> Training of VHTs; rewards such as provision of certificates may be reward for exemplary performance at end of year; Facilitate supervision mechanism of VHTs through district system; improve VHT registers to avoid several photocopying needs; introduce other services to be provided by VHTs Consider introducing an electronic system for pregnancy tracking Introduction of Phone SMS platform to give feedback to households e.g. immunization reminder messages, FP, ANC, delivery in HC, etc. Provide weighing scales in health facilities (with maternity services) & / or to selected VHTs
Operationalizing the household survey birth history vs pregnancy history comparison	
<p>Does your site reach all women of childbearing age with each surveillance round? If not, how often?</p> <ul style="list-style-type: none"> What is the feasibility of linking the surveillance round to the timing of the survey? 	<p>Need to separate the two as this survey may prolong the routine update round. Furthermore, in routine HDSS they ask the adult in the house, but in this case they have to ask the woman, so may need to separate from routine round, or use separate teams</p>
<p>If not, would you do a stand-alone survey? If so, how and when?</p>	<p>Yes</p>
<p>Assuming you will use the list of women of childbearing age</p> <ul style="list-style-type: none"> What is the percentage of out-migration? Is there birth-related migration out of the HDSS? Can we administer the survey to a woman not on the list but in the household? 	<p>This may affect follow-up</p>
<p>What needs to be changed to link the HDSS information to the survey data, particularly for babies?</p>	
Expected timeline	
<p>When is the next HDSS round?</p>	<p>September 2016</p>
<p>When would you need the tablets by in order to translate, train and test?</p>	<p>November 2016</p>
<p>When do you expect to be able to:</p> <ul style="list-style-type: none"> Pilot the survey? Start the survey? 	<ul style="list-style-type: none"> Pilot: January 2017 Start: May 2017

General HDSS issues	
Are there data sharing implications?	<ul style="list-style-type: none"> • What data exactly is to be shared? • Publication/dissemination plan for the project • Ethical issues to be considered • After how long will the data be shared?
Are there other questions you will face when you go back that we can discuss now?	<ul style="list-style-type: none"> • Impact of this project on routine HDSS activities? – more staff and logistics? • Feedback to community

KINTAMPO HDSS (GHANA)

QUESTIONS TO HDSS SITE	RESPONSE
Registered and unregistered pregnancies	
Do you think your HDSS is missing pregnancies? If so, which ones?	Yes: through migration, unwanted pregnancies, early pregnancy loss and adolescents not disclosing
Are outcome definitions clear enough in your tools?	No
How are induced vs spontaneous abortions defined?	<ul style="list-style-type: none"> • Pregnancy loss is at 24 weeks [not by WHO standard of 28 weeks] • No breakdown into spontaneous and induced abortions (just captures it as pregnancy lost before 6 months) • Some terms not conforming to WHO definitions
How are stillbirths defined? Any difference between MSB/FSB?	<ul style="list-style-type: none"> • A birth that showed no sign of life • Not differentiated into MSB / FSB • Birth outcomes have been monitored –need to check for tools from LSHTM, etc.
Are there probes about whether a baby that died moved/cried/ breathed at all (not just in VA)?	Yes
What are the specific local barriers around reporting pregnancy loss, if any, that may impede reporting to surveyors/enumerators?	<ul style="list-style-type: none"> • Induced and spontaneous abortions • Issues of stigma • Miscarriage considered as bleeding • Not reporting early stillbirths as foetal deaths • When newborn is less than seven days [kept within family] • Need more research on contextual issues

What are possible enhancements to the pregnancy surveillance system and reporting?	
Low cost	Higher cost
<ul style="list-style-type: none"> • Improve training for key informants • Have informants report pregnancy as a vital event • Advocacy around early disclosure / reporting of pregnancies • Enumerators ask individual women about pregnancy status • Use quality flags in the data analysis (e.g. expected stillbirths, distribution of preterm and low birth weight) <ul style="list-style-type: none"> » Compare to regional and national indicators; other ratios like neonatal/infant or under five mortality, etc. 	<ul style="list-style-type: none"> • Early pregnancy identification <ul style="list-style-type: none"> » Training of CKIs and higher tokens for early pregnancy identification » Educating mothers/community on medical relevance/benefits of early reporting » Care provider education/sensitization [they should encourage first trimester reporting] » Improving availability of testing services [pregnancy test, ultrasound sonography test (USG)] for early pregnancy [consider resource implications] » Pilot urine tests to assess feasibility • Pregnancy wheel is used for calculation of GA. An app might come with some resource demands as not all enumerators will have smart phones • Calibrating/standardizing/new scales will come with cost implications
Operationalizing the household survey birth history vs pregnancy history comparison	
<p>Does your site reach all women of childbearing age with each surveillance round? If not, how often?</p> <p>What is the feasibility of linking the surveillance round to the timing of the survey?</p>	<p>All women are reached.</p> <p>Doing both the surveillance and survey simultaneously will be chaotic</p>
<p>If not, would you do a stand-alone survey? If so, how and when?</p>	<ul style="list-style-type: none"> • Women in fertility age ~ 35,000- that will require additional personnel • Probably from September – December 2017
<p>Assuming you will use the list of women of childbearing age</p> <ul style="list-style-type: none"> • What is the percentage of out-migration? Is there birth-related migration out of the HDSS? • Can we administer the survey to a woman not on the list but in the household? 	<ul style="list-style-type: none"> • About 12% of Women in fertility age moved out in 2014
<p>What needs to be changed to link the HDSS information to the survey data, particularly for babies?</p>	
Expected timeline	
<p>When is the next HDSS round?</p>	<ul style="list-style-type: none"> • January 2017
<p>When would you need the tablets by in order to translate, train and test?</p>	<ul style="list-style-type: none"> • Minimum of 6 months to start of study (preferably November 2016)

When do you expect to be able to:	
<ul style="list-style-type: none"> • Pilot the survey? • Start the survey? 	<ul style="list-style-type: none"> • Pilot: early 2017 • Start: September 2017
General HDSS issues	
Are there data sharing implications?	We will need to get clear and acceptable guidelines from the start of the study.
Are there other questions you will face when you go back that we can discuss now?	VA issues to be discussed later on

MATLAB HDSS (BANGLADESH)

QUESTIONS TO HDSS SITE	RESPONSE
Registered and unregistered pregnancies	
Do you think your HDSS is missing pregnancies? If so, which ones?	<p>No, except very few exceptions. This is because when we miss one or two cases, we are reminded by other groups in the HDSS</p> <p>Pre-marital pregnancies are not socially and culturally accepted in Bangladesh, so all information is on marital pregnancies. DHS also doesn't ask about other pregnancies</p>
Are outcome definitions clear enough in your tools?	
How are induced vs spontaneous abortions defined?	<ul style="list-style-type: none"> • Induced: Terminated by intention • Spontaneous: Spontaneously terminated
How are stillbirths defined? Any difference between MSB/FSB?	<ul style="list-style-type: none"> • Pregnancy termination on or after 28 weeks • Yes, difference between MSB/FSB in VA
Are there probes about whether a baby that died moved/cried/ breathed at all (not just in VA)?	Yes (both in VA and birth registration form)
What are the specific local barriers around reporting pregnancy loss, if any, that may impede reporting to surveyors/enumerators	<ul style="list-style-type: none"> • There may be some underreporting due to stigma, superstition, abuse • Probably not due to divorce
Improving HDSS capture	
Barriers for pregnancy outcome missingness	No pregnancy outcome missing
Barriers for misclassification	In some cases, stillbirths may be misclassified as neonatal deaths and vice-versa
What are possible enhancements to the pregnancy surveillance system and reporting?	
Matlab has done pregnancy surveillance for many years, including urine tests	No enhancements needed
Operationalizing the household survey birth history vs pregnancy history comparison	
Does your site reach all women of childbearing age with each surveillance round? If not, how often?	Yes

What is the feasibility of linking the surveillance round to the timing of the survey?	Feasible. Some additional information in survey question may be needed.
If not, would you do a stand-alone survey? If so, how and when?	
Assuming you will use the list of women of childbearing age <ul style="list-style-type: none"> • What is the percentage of out-migration? • Is there birth-related migration out of the HDSS? • Can we administer the survey to a woman not on the list but in the household? 	<ul style="list-style-type: none"> • Around 5%. Lower for women • Yes • Possible but can't be linked with the DSS (rare). Can ask women outside the list just to increase sample size for this study
What needs to be changed to link the HDSS information to the survey data, particularly for babies?	<ul style="list-style-type: none"> • No change is needed if DSS ID is used • Maybe an additional question is to include the ID of the child
Cost implication in conducting the survey	Change in sample size will increase survey cost <ul style="list-style-type: none"> • Human resource: field workers, programmer, tablets • Training • Survey questionnaire customization - translation • Monitoring and supervision
Expected timeline	
When is the next HDSS round?	Every household is visited every two months
When would you need the tablets by in order to translate, train and test?	Two months prior to the survey
When do you expect to be able to: <ul style="list-style-type: none"> • Pilot the survey? • Start the survey? 	<ul style="list-style-type: none"> • Pilot: January 2017 • Start: February 2017
General HDSS issues	
Are there data sharing implications?	There is the ICDDR,B data policy that we have to consider
Are there other questions you will face when you go back that we can discuss now?	Yes. Survey implementation and management may need discussion with manager and head of HDSS

Emerging issues from site-specific presentations

- Most of the sites are ready to pilot test the study in January and February 2017. Two sites were ready to start the survey in February and March 2017 (Matlab and Dabat respectively), while Iganga-Mayuge proposed May 2017, Bandim proposed June 2017 for the rural area and July 2017 for the urban area, and Kintampo suggested September 2017. A middle ground for the start of data collection needs to be agreed on. A stand-alone survey was the preferred mode of conducting the work, pending sorting out of enumerators and other costs.
- The ability of sites to reach all women of reproductive age during the survey depends on the size of the site and topographical and resource challenges. Most sites believed that they could access the required sample size if cost issues were met.

- None of the sites were in agreement with the idea of uploading data in the clouds, where it would be centralized, without having physical data at the sites. This is how the tools work, but a solution needs to be found because for instance the institutional review board in Uganda won't pass a protocol that has cloud data storage only. Sites also emphasized that it is not good for them not to have the data on their servers.
- The sites that are routinely doing verbal autopsy on stillbirths are Matlab, Dabat, and simple verbal autopsy in Bandim.
- It was suggested that sites collect the survey data and conduct randomization using tablets, all sites were in agreement on this. Tablets need to be received by sites in October/November 2016 in order to facilitate the start of data collection. However, tablets were not included in the original budgets, so ways have to be explored of obtaining them for the sites. Prof. Lawn and Assoc. Prof. Waiswa suggested that some of the people present volunteer to form a group that will look at this issue.

DATA SHARING

The development and later publication of the joint protocol is setting the stage for sharing data within this CIFF work. Assoc. Prof. Waiswa explained to the participants that the data to be shared was strictly the ENAP metrics project data. He acknowledged that sites have their other HDSS work and data with restrictions on sharing as per funding, and that sites also have their own sensitive data. However, for analysis of ENAP metrics work we need to cross-link sites and the sites would know best how this can be done. He emphasized that all data belongs to the sites, but there is also joint sharing of data. Assoc. Prof. Waiswa further explained how the INDEPTH member sites have been sharing data: "If we need a question that requires sharing data, then we approach sites, and these are usually happy to share, depending on the agreement e.g. if there is joint authorship. We would like to have authors from the south leading. We want to be transparent and responsive to the world. As we do this work, look for the questions you want to answer and we share them."

Ms. Kate Kerber further clarified that this study may highlight some HDSS challenges and therefore might be controversial findings to publish. Clear data sharing and publication guidelines must be in place. For the few sites that were still unclear about what exactly the data sharing process would entail, Prof. Lawn explained that sites would be asked to provide specific and relevant parameters from their work on a shell table, for instance an excel sheet to report on, and not pooling of datasets. One of the advantages of this is identifying process

improvement data, because you can see the changes in sites' data and there is real south-south learning from each other. To quote Assoc. Prof. Waiswa, "We also need to have standardized definitions and data. At a recent INDEPTH Network meeting, the funders asked where the joint projects are. What is the additional value in having INDEPTH? As the Maternal and Newborn Working Group, we would like to achieve standard definitions and quality data as an end point."

The following was agreed upon with regard to data sharing and publication.

- A data sharing and publication agreement is going to be drafted, led by INDEPTH Network, which will then be shared with the five sites and the core team from LSHTM.
- Sites with data sharing and publication agreements should submit them to the core team, so that they are considered in the development of the agreement.
- Sites whose representatives were not sure about the agreement will talk to their HDSS leaders and provide feedback.
- The MNWG has a technical secretariat at Makerere School of Public Health which is trying to create metadata. This involves putting together the tools for all the sites so that we have a database that is cross-cutting, but this requires permission from each site.

NEXT STEPS

The following next steps for the study were agreed at the workshop.

Protocol and data collection

- The core team from LSHTM and INDEPTH Network MNWG is going to complete the generic protocol, including the suggestions given during the workshop.
- Each HDSS will then adapt this and develop a protocol to suit their site-specific needs and submit it for ethical review and approval in January 2017, after which data collection can start.
- The LSHTM team has to check if they can get a pre-review from LSHTM which can be given to sites to back up their ethical review submission, as some sites may be asked whether LSHTM has already received ethical approval, and yet LSHTM only gives this when the sites have approval. Sites also need to ask about the requirements of the institutional review boards in relation to this scenario.
- A data sharing agreement must be signed before IRB submission.
- Analysis of data will be done jointly through sharing specific data, rather than pooled datasets.
- A team was put together to finalize the sample size calculation.
- The protocol is to be submitted for publication as a group later this year, with all those who have participated listed as authors.

Tools (for ENAP metrics work)

- The consent forms and tools need to be translated into the local languages. These have to be finalized, so the sites will get them by late October or November 2016 so that they can translate them and program the tablets accordingly.

Grant writing

The participants identified two other multi-site grants that they are going to collaborate on to get further funding for ENAP metrics and future work.

- For the birth weight application, Hannah will be the leader, supported by one person from each site to represent the site team.
- A grant will be written for funding that will enable the tablets to be bought for sites to be used in data collection for this study. The INDEPTH

secretariat usually has small grants for sites that have agreed to work together, so this could be one of the venues to get tablets.

Site tools

- The sites whose tools INDEPTH MNWG does not already have are to share their tools so that each site can see how others are differentiating between stillbirths and neonatal deaths, and what they are using.
- Ms. Kate Kerber and Mr. Ronald Kananura are going to work together to put VA tools together, pregnancy tools, etc. We shall then be able to matrix key things on the tools, and then ask for permission to share, so that by April 2017 we could matrix what some of the sites are doing.

Meetings

- The next face-to-face meeting will be held in April 2017, to discuss progress and other issues like verbal autopsy.
- Skype calls for the whole group will be held every two months.
- Email communication to the group will continue, for example conversations on workload.
- There will be separate communication with individual sites as needed.

Extra research ideas

- Focus Group Discussions with the people who administer the survey because they are a good source of information on the women's perceptions.
- Using the social economic data / equity.
- INDEPTH can also focus on meeting the SDG agenda.

Verbal autopsy

- Verbal autopsy is also part of the ClIFF grant. The intention is to go back to the group of 18 sites that attended the Kampala workshop in 2015, and include also Matlab and Bandim that were not there. Together, the sites can think about stillbirths and neonatal deaths and how we use our algorithms. We can have individually linked data or people send the existing data in table format. Before April 2017 we need to have more thoughts on VA and think about how people would like to do this work and also to compare the different methods across sites.

Capacity building

- Identify people who are interested in working on VA and also doing PhDs in that area.

Additional data required from the sites

- More data on birth weight, including what percentage of babies have it measured, and the source of that data.

- Examples of site consent forms.
- Site tools.
- Data sharing agreements.
- Site institutional review board forms.
- Sites to indicate whether they need LSHTM approval before IRB submission.
- Any specific comments one may have on the protocol.

ADMINISTRATIVE NEXT STEPS

Samuelina Arthur

Item	Update
Contracts /funds	<ul style="list-style-type: none"> • INDEPTH/LSHTM contract signed • 60% of year 1 money received from LSHTM • MOU signed and money transferred to technical office at MakSPH • MOU sent to all the five HDSSs • Sites to return signed MOU to the Secretariat
Disbursement of funds-2016	<ul style="list-style-type: none"> • 60% of year 1 money to be transferred to all the five sites • Second tranche of money to be received from LSHTM after submission of interim report • INDEPTH to disburse 40% of year 2 money to Makerere University and sites • Submission of end of year report to INDEPTH/LSHTM
2017-2018	<ul style="list-style-type: none"> • 60% of year 2 money (first quarter of the year) • 40% of year 2 money • 60% of year 3 money (first quarter of the year)
Data sharing/data submission	<ul style="list-style-type: none"> • 40% of year 3 money

CLOSURE OF THE WORKSHOP

The workshop ended on a high note after two and a half intensive days. Mr Joseph Akuze expressed his happiness with its success and completion of the checklist: “If we did not fly over the radar, we excelled,” he said. He conveyed his hope that all participants had had a pleasant time in Kampala, and thanked LSHTM, ClIFF, and everybody for making the workshop possible. He concluded by stating that he was looking forward to the future collaborations and work ahead of the team.

Ms Suzanne Fournier emphasized that while it is known that the burden of preventable child deaths is shifting, there is still a huge challenge for neonatal deaths and in the coming years more focus is needed on this. “Today, this is the start of a revolution for birth outcomes, especially stillbirths. We are making an investment that should include both facility data and household surveillance of events and outcomes, including birth weight and gestational age. This is exciting research, and will make an addition to the DHS mix and the huge work that USAID and WHO are doing on stillbirths,” she remarked. She emphasized that she had taken away three major things from the workshop: “I found it interesting because I got to learn about the different HDSS, how they track pregnancies, and the cultural differences in tracking stillbirths and abortions. It was also academically gruelling, because even though I am an epidemiologist, there is so much expertise in this room. Finally, I find it inspirational that this is the first multi-country study in the MNWG

of the INDEPTH Network and that ClIFF is a part of this.” She concluded by thanking the team for the opportunity to participate, as well as the Ugandan team for organising, the facilitators, and everybody present.

The workshop was officially closed by Assoc. Prof. Peter Waiswa, who said, “I see ourselves as touching the sky. It is an opportunity for us in the south to make a major contribution to the maternal and newborn health space. If we operationalize this work and its outputs across our sites, it will be impossible for the world to ignore us and our maternal and newborn health work. We are building standards across sites, and we shall take these to the other sites. This will be catalytic and we have a platform to do so. Investment returns come as early as tomorrow. We want to write papers, policy briefs, and do capacity building. The data we have leads to accountability.” He concluded with a vote of thanks to Prof. Joy Lawn for making the time for this work and for always being a mother to us. He revealed that she had once said, “When I see many people working, then my work is done,” and hoped that she felt that what she planted was coming to maturity. He also thanked the ENAP metrics core group and the facilitators for the endless work, emails and calls. Assoc. Prof. Waiswa thanked ClIFF and the participants for sharing their systems and being open and learning from each other. He reiterated the need for them to take part in the MNWG, lead the writing of grants and papers, and make this joint work.

Workshop in Pictures





ANNEX 1. Agenda

SESSION	TIME	ACTIVITY	PRESENTER/PERSON RESPONSIBLE/ FACILITATOR
14TH JUNE 2016			
	17:00 – 20:00 pm	Preparatory meeting / dinner for all facilitators at Hotel Africana	Doris / Josephine
DAY ONE: 15TH JUNE 2016			
Session Chair: Dr. Peter Waiswa			
PLENARY 1	8:00 - 8:15 am	Arrival of participants and registration	Samuelina Arthur / Josephine Adikini
	8:15 - 8:30 am	Introduction of participants	All
	8:30 - 8:45 am	Opening remarks and discussion of expected workshop outputs	Dr. Peter Waiswa
	8:45 - 8:50 am	Remarks from the site leader of Iganga-Mayuge HDSS	Dr. Dan Kajungu
	8:50 – 9:00 am	Official opening of the workshop	Prof Tumwine, Board Chair of Makerere University Center for Health and Population Research (MUCHAP)
	9:00 - 9:10 am	Address from Assoc. Prof. Ssengooba	Head of Department of Health Policy, Planning & Management, MakSPH
	9:10 – 9:20 am	Children's Investment Fund Foundation's (CIFF) Perspective	Suzanne Fournier, Manager, Saving Lives, CIFF
	9:20 - 9:40 am	INDEPTH Network & ENAP metrics work relevant to INDEPTH (15 minutes for presentation & 15 minutes for discussion)	Prof. Joy Lawn with LSHTM team
	9.40 - 10:20 am	Draft protocol for INDEPTH & ENAP metrics work (20 minutes for presentation and 20 minutes for discussion)	Mr. Joseph Akuze and core team

	10.20 - 10.40 am	Proposed survey modules (10 minutes for presentation and 10 minutes for discussion)	Dr Angela Baschieri and Dr Hannah Blencowe
	10:40 - 11:00 am	Tea Break	
Session Chair: Ms. Kate Kerber			
PLENARY 2	11:00 am – 12:40 pm	Updates from sites on their HDSS tracking and outcome measures for maternal and newborn health indicators (10 for presentation based on a standard power point template & 10 for discussion)	Site representatives (Bandim, Dabat, Iganga-Mayuge, Kintampo, Matlab)
	12:40 – 13:00 pm	Prep talk for WG 1 session- recap of Objective 1 and WG tasks	Doris and Joseph
	13:00 – 14:00 pm	Lunch	
WORKING GROUP 1	14:00 – 16:15 pm	Small group discussions on aspects of objective 1 (comparing survey modules to capture SBR and NMR, linked to HDSS data) <ul style="list-style-type: none"> • 3 groups (with a rep from each site in each group) • Discussion on objective 1, sample size, survey tools, HDSS data linkage 	All, facilitated by Peter, Joy, Angela, Kate, Hannah, Joseph, Vladimir, Doris, Michael
		Working tea during Working Group 1	
Session Chair: Dr. Angela Baschieri			
PLENARY 3	16:30 - 17:45 pm	Feedback from small groups 1 (10 minutes per group) Discussion	Rapporteurs from the 3 small groups for Working Group 1
	18:00 pm till late	Social evening	
END OF DAY ONE			

DAY TWO: 16TH JUNE 2016

PLENARY 4	8:00 – 8:30 am	Arrival of participants, registration and house keeping	Samuelina Arthur / Josephine Adikini
	8:30 - 8:45 am	Recap of day 1	Mr. Joseph Akuze and Ms. Doris Kwesiga With ENAP/MNWG team
Session Chair: Dr. Ane B. Fisker			
	8:45 – 9:45 am	<ul style="list-style-type: none"> • LBW and Gestational age assessment in survey and HDSS • Expectations of Group Work 2 • Discussion 	Dr Hannah Blencowe with Dr Angela Baschieri
WORKING GROUP 2	9:45 – 11:45 am	<p>Small group discussions on objective 2 (comparing survey methods to capture BWT and GA, linked to HDSS data).</p> <ul style="list-style-type: none"> • 3 groups • Discussion on objective 2 	Site representatives, facilitated by Peter, Angela, Joy, Kate, Hannah, Joseph, Vladimir, Doris, Michael
		Working tea during Working Group 2	
PLENARY 5	11.45 am - 13.00 pm	<p>Feedback from small groups 2</p> <p>(10 minutes per group)</p>	Rapporteurs from the 3 small groups for Working Group 2
	13:00 - 14:00 pm	Lunch	
Session Chair: Dr. Gashaw Andargie Biks			
WORKING GROUP 3	14.00 - 15.00 pm	Prep talk for Working Group 3 discussion	Ms. Kate Kerber and Mr. Joeseeph Akuze
	15:00 – 17:00 pm	<p>Small group discussions on aspects of objective 3</p> <ul style="list-style-type: none"> • Designing the HDSS site specific enhancements of pregnancy surveillance, data linkage, etc • 5 groups (divided by site) 	Site representatives, facilitated by Peter, Angela, Joy, Kate, Hannah, Joseph, Vladimir, Doris, Michael

		Working tea during Working Group 3	
	17:00 - 18.00 pm	Working group meeting <ul style="list-style-type: none"> • Review of the workshop to date • ENAP grants operational issues • Work plan review and discussion of activities for the second half of 2016 	
END OF DAY TWO			
DAY Three: 17TH JUNE 2016			
Session Chair: Prof. Joy Lawn			
Plenary 6	8.30 - 10.30 am	Feedback from small groups 3 (20 minutes for each group: 10 for presentation and 10 for discussion)	Site representatives (Matlab, Kintampo, Bandim, Dabat, Iganga-Mayuge)
	10.30 – 11.00 am	Tea Break	
Plenary 7	11.00 – 11:45 am	Final discussion on protocol and tools	Mr Joseph Akuze supported by ENAP/ INDEPTH team
	11:45 am - 12.00 pm	Discussion of data sharing and authorship plan <ul style="list-style-type: none"> • Action points and how to proceed 	Dr. Peter Waiswa
	12.00 – 12:20 pm	<ul style="list-style-type: none"> • Conclusion and next steps • Plans for workshop in 2017 • Workshop evaluation 	Prof. Joy Lawn and Dr. Peter Waiswa
	12.20 – 12.30 pm	Administrative Next Steps	Samuelina Arthur
	12:30 pm	Closing of workshop	Prof. William Bazeyo, Dean, School of Public Health, Makerere University
	12:30 - 13:30 pm	Lunch	
END OF DAY THREE			

ANNEX 2. Summary of available data regarding use of modules for pregnancy history versus birth history

Source	Reference	Study site	Dates of Study	Comparator 1	Comparator 2	Number of observations	Rates in comparator 1	Rates in comparator 2	Differences
Stanton C.	PhD JHU	Philippines, National INDEPTH Network & ENAP metrics work relevant to INDEPTH (15 minutes for presentation & 15 minutes for discussion)	1993 DHS and SMS surveys	Standard DHS with full pregnancy history replacing birth history	Safe Motherhood Survey (SMS)– duplicate pregnancy history plus sex of stillbirth, additional probe if pregnancy interval ≥ 4 years	In SMS 6329 births in 3 years prior to survey			# stillbirths 34% higher in SMS # early losses 26% higher in SMS
Espeut D., Becker S.	Journal of Health, Population and Nutrition	Bangladesh, Matlab HDSS	1994 Matlab Demographic survey	50% questionnaire forward full birth history (as per Bangladesh DHS)	50% questionnaire forward full pregnancy history	MDHS – 3225 households sampled, 3009 household interviews, 3480 women reproductive age, 3039 women interviews	ENND – 46/58 (79%) (HDSS baseline) captured in survey Late NND – 22/26 captured	ENND – 63/77 (82%) (HDSS baseline) captured in survey	Did not report on stillbirths For ENNDs – 2 – 3% higher capture in pregnancy history
DHS program		Ghana (national)	2008 DHS (birth history) and 2007 Maternal Health Survey (full pregnancy history)	Standard DHS with full birth history	Maternal Health Survey (MHS) with full pregnancy history	DHS – 2,949 MHS – 6,960	Stillbirths 40/2949 13.6 per 1,000	Stillbirths 146/6960 21.0 per 1,000	Rates were 35% lower in birth history compared to pregnancy history RR=0.65 (0.46 – 0.93) There was no difference in ENND between the two surveys RR=1.08 (0.82 – 1.42)
DHS program			107 surveys using birth history 13 surveys using pregnancy history						

ANNEX 3. ENAP Participants profile

Participants from the five HDSSs



Name: Md. Moinuddin Haider

Organisation: Matlab HDSS, Bangladesh, Initiative for Climate Change and Health, Health System and Population Studies Division, ICDDR,B

Position: Research Investigator

Contact: moin@icddr.org

Md Moinuddin Haider has been working in ICDDR,B since 2010. He joined Matlab HDSS as a Research Investigator in 2014. He also works for a number of impact evaluation projects of MEASURE Evaluation, University of North Carolina at Chapel Hill, USA. His major career interests include health and demographic surveillance system, monitoring and evaluation of population, health and nutrition programs, health system strengthening, social determinants of health and application of statistical methods in social and health research. He completed his BSc in Applied Statistics from University of Dhaka, Bangladesh, in 2006 and MSc in Applied Statistics in 2007 from the same institute. He acquired his MPH from Independent University, Bangladesh, in 2013.



Name: Dr. Ernest Nettey

Organisation: Kintampo HDSS, Ghana

Position: Demograher

Contact: ernest.nettey@kintampo-hrc.org

Mr. Nettey has worked as a demographer at the Kintampo Health Research Centre (KHRC) since February 2010. From February 2009, he was INDEPTH Network Fellow attached to the Kintampo Health and Demographic Surveillance System for demographic analyses. His research interests are: Urbanization, Health and Mortality in low and middle-income countries (LMICs), Demographic and Epidemiological transitions; Fertility and Reproductive Health; Population, socio-economic development interrelationships and inequalities in LMICs. He has also worked in other research undertaken by the KHRC, mainly in the area of social and demographic research. He has an M.Phil in Population Studies from University of Ghana.



Name: Dr. Gashaw Andargie Biks

Organisation: Dabat HDSS, Ethiopia

Position: Site Leader

Contact: gashawab@gmail.com

Dr. Biks is a researcher, site leader for Dabat HDSS and a field Program Manager for a randomized control trial on integrated community case management pneumonia treatment in Ethiopia (2013 to 2018). He also works at the University of Gondar where he has assumed numerous responsibilities in different capacities over a 20 year period. Some of his duties include teaching and supervising postgraduate taught and research students, developing teaching modules and publishing widely in peer-reviewed international journals. Dr. Biks completed his undergraduate degree at Jimma University in Environmental Health Sciences in 1999. In 2006, he completed his MSc. in Public Health at Addis Ababa University and in 2013 he acquired his PhD in Child Health and Public Health from the University of Gondar. His main research interests include neonatal mortality, child and maternal health issues.



Name: Dr. Solomon Mekonnen
Organisation: Dabat HDSS, Ethiopia
Position: Technical team member
Contact: solomekonnen@yahoo.com

Dr. Mekonnen currently works at the Institute of Public Health at the University of Gondar. He worked as a project coordinator for a field research entitled “Evaluation of a multi-sectorial community based approach in Amhara, Ethiopia”. He is also the technical team member for the DHS of Dabat, the principal investigator and Co-investigator in two large projects: “Disability among Populations of Dabat Demographic Health Surveillance Site: Linking Community with Rehabilitation Facilities; an Integrated Approach; and “Assessing the prevalence and awareness of risk factors for cardiovascular disease in adolescent and adult population of Gondar city, 2015 “. He is the director of Non-communicable Disease and Post-graduate program coordinator at University of Gondar. He completed his MSc in Exercise Physiology from Punjabi University India in 2006 and completed his PhD in Public Health in 2014. Dr. Mekonnen has published research articles on clinical epidemiologist. He has many years of service as dean, dean of students, department headship and university registrar at the University of Gondar.



Name: Dr. Simon Kasasa
Organisation: Iganga-Mayuge HDSS, Uganda
Position: Biostatistician
Contact: skasasa@musph.ac.ug

Dr. Kasasa is a Senior Lecturer in the Department of Epidemiology & Biostatistics at Makerere University School of Public Health. He holds a PhD from the Swiss Tropical and Public Health Institute, a Master’s of Science from Case Western Reserve University (CWRU) , USA and a Bachelors in Statistics from Makerere University. His PhD focused on Bayesian modeling and mapping mortality of malaria transmission intensity using HDSS data. He is involved in teaching and research activities at the School of Public Health. Research areas include: HIV/AIDS, Malaria, Pneumonia, TB and health systems. He is an Epidemiologist on the on-going national TB prevalence survey and mapping HIV high risk places in Uganda and Supporting Policy Engagement for Evidence-Based Decisions (SPEED) . Dr. Kasasa is a Field Coordinator for the Masters of Public Health (Distance Education) program. He is a member of the Higher Degrees, Research and Ethics committee and a board member of the Makerere University Lung Institute.



Name: Dr. Nurul Alam
Organisation: Matlab HDSS, Bangladesh
Position: Scientist (Initiative for Climate Change and Health)
Contact: nalam@icddr.org

Dr. Alam has served at ICDDR,B in different capacities in the last three decades and is currently a Scientist of its Initiative for Climate Change and Health. He is actively involved in the planning and management of the Matlab health and demographic surveillance system (HDSS) with research focuses on epidemiologic transitions, epidemiology of perinatal and neonatal mortality, verbal autopsy, migration and urbanisation, chronic diseases and healthcare-seeking behavior, poverty and food security. He has a long collaboration with INDEPTH research, focusing on cross-country comparisons of health issues. He serves as a member of the technical committee of Bangladesh Bureau of Statistics, the Ethical Review Committee of ICDDR,B, and Bangladesh Breastfeeding Foundation. He is involved in the Gavi Full Country Evaluation, and has been involved in many health and nutrition surveys and evaluation of intervention projects as an Epidemiologist-Statistician. He has published more than 75 research papers as principal author or co-author in peer-review journals and several papers in conference proceedings, book chapters, working papers, and monographs and participated in many scientific conferences and workshops at home and abroad for sharing findings.



Name: Dr. Yeetey Enuameh

Organisation: Kintampo HDSS, Ghana

Position: Clinical Research Fellow

Contact: yeetey@gmail.com

Dr. Enuameh is a Clinical Research Fellow at the Kintampo Health Research Centre in Ghana. Prior to assuming that role in 2007, he had worked in several other roles with the Ghana Health Service. Yeetey is also a Research Scientist with the Drexel University, Philadelphia and a Clinical Lecturer with the University of Adelaide, and a Lecturer at the Kwame Nkrumah University of Science and Technology, Kumasi, Ghana. His research are mainly in the areas of Adolescent Health, Maternal, Child and Newborn Health, Infectious/Tropical Diseases and Evidence-based Health Care. Dr. Enuameh had his Medical Degree from the Pirogov's Vinnitsya State Medical University, Vinnitsya, Ukraine. He completed his Masters in Health Service Planning and Management at the Kwame Nkrumah University of Science and Technology, Kumasi, Ghana.



Name: Dr. Ane B. Fisker

Organisation: Bandim HDSS, Guinea Bissau

Position: Researcher

Contact: a.fisker@bandim.org

Dr. Fisker conducts research on the real life effects of preventive child health interventions. She coordinates Bandim Health Projects rural data collection, and examines the implementation of vitamin A and vaccination programmes with a focus on illuminating the gap between policy and the real life implementation of policy. Dr. Fisker holds a PhD in Medicine from the University of Aarhus, Denmark (2011). She has been working with the Bandim Health Project since a pre-graduate researcher in 2004. Since obtaining her MD degree (2007), she has managed three large randomized trials testing improvements to the current vitamin A and vaccination programme.



Name: Dr. Amabelia Rodrigues

Organisation: Bandim HDSS, Guinea Bissau

Position: Research director

Contact: a.rodrigues@bandim.org

Dr. Rodrigues is currently director of research at the Bandim Health Project. Prior to this she was General Director of the National Institute of Public Health in Guinea-Bissau. She was trained in public health and epidemiology in the Soviet Union (1991), obtained her PhD at the University of Copenhagen in 2002 and from 2001 to 2004 she hold a post doc fellowship from the Gates Malaria Partnership at the LSHTM. She has an interest on the evaluation of the impact of health interventions, policy prioritisation and is currently focused in the training and mentoring of Guinean researchers. The specific topics of her interest are malaria, cholera, rotavirus, apart from child and women mortality. She has experience in running HDSS, and both hospital and community based studies.



Name: Mr. Edward Galiwango

Organisation: Iganga-Mayuge HDSS, Uganda

Position: Site Operations Coordinator

Contact: egaliwango@musph.ac.ug

Edward Galiwango is the Site Operations Coordinator at the Iganga-Mayuge Health & Demographic Surveillance Site, Uganda, operated by the Makerere University Center for Health & Population Research (MUCHAP) since its inception in 2004. Prior to this, he served as Data Manager on a Ministry of Health Implemented Multi-Country project until 2004; Research Supervisor on a Monitoring & Evaluation Project of the national Nutritional & Early Childhood Development Program that was implemented by the Ministry of Health in Uganda among others. He has experience in research and program implementation, monitoring & evaluation. He has coordinated several research projects funded by as the World Bank, WHO & USAID, Sida and EDCTP. He trained at Makerere University and has an M.A and a Post-Graduate Diploma in Demography.



Name: Dr. Dan Kajungu

Organization: Iganga-Mayuge HDSS

Position: Centre Leader

Contact: dan.kajungu@gmail.com

Dr. Dan Kajungu is a biostatistician with over 10 years extensive experience in public health research, statistical practice, consultancy, and teaching in Africa. His professional direction is aimed at using statistics to improve health and socio-economic status among communities affected by poverty related diseases, and other social inequalities. His research interests in public health cover infectious diseases, neglected tropical diseases, and noncommunicable diseases. In addition to public health metrics, his other passion is improving pharmacovigilance, pharmacoepidemiology and drug utilisation research in Africa. Dan holds a PhD in public health from Universite catholique de Louvain (UCL), Belgium, a masters in Biostatistics (Epidemiology) and Msc Applied Statistics (Data mining) both from the University of Hasselt in Belgium. He is the President of International Biometric Society (IBS) Uganda, Region Chair of IBS travel awards committee, and a member IBS representatives Council. He has published in and reviewed for high impact peer reviewed journals.

Profile of Partners



Name: Professor Joy Lawn

Organisation: London School of Hygiene and Tropical Medicine, United Kingdom

Position: Director of the MARCH

Contact: Joy.Lawn@lshtm.ac.uk

Prof. Lawn is the director of the MARCH Centre at the London School of Hygiene and Tropical Medicine and a Senior Health Advisor to Save the Children. She is an African-born paediatrician and perinatal epidemiologist. She has over 20 years' experience in newborn health with a specific focus on Africa, including four years as a lecturer and neonatologist in Ghana. She shifted to public health and global estimation whilst at the WHO Collaborating Center, CDC Atlanta, USA (1998-2001), and then at the Institute of Child Health, London, UK (2001-2004), completing a Masters of Public Health at Emory University, Atlanta and PhD at University College London. In March 2013, she was appointed Professor of Maternal, Reproductive and Child Health and Director of MARCH Centre at the London School of Hygiene and Tropical Medicine. For over ten years she worked for Save the Children's Saving Newborn Lives program, funded by the Bill & Melinda Gates Foundation. Most recently she was their Director of Global Evidence and Policy, and worked with governments and partners to integrate, scale up and evaluate newborn care. In 2011 she was appointed as the UK AID (DfID)'s Senior Research Fellow for newborn health (part-time). Since 2004, Joy has coordinated the United Nation's Child Health Epidemiology Reference Group's (CHERG) Neonatal Team and developed the first cause-of-death estimates for 4 million neonatal deaths each year, published in 2005 in The Lancet Neonatal series and WHO's World Health Report. She also co-led The Lancet Stillbirth series in 2011 including developing WHO's first national estimates of stillbirth rates, highlighting 2.6 million stillbirths worldwide.



Name: Dr. Hannah Blencowe

Organisation: London School of Hygiene and Tropical Medicine, United Kingdom

Position: Lecturer

Contact: Hannah.Blencowe@lshtm.ac.uk

Dr. Blencowe is a lecturer at the London School of Hygiene and Tropical Medicine, coming from a clinical background with experience in paediatrics, general practice and obstetrics and gynaecology. Her main interests are in maternal, prenatal and newborn health, with a particular focus on stillbirth. Recently, her work has focussed on global estimates of perinatal conditions (including preterm birth, low birth weight, small-for-gestational-age, stillbirths, congenital abnormalities and neonatal morbidity and associated long term consequences) and improving the measurement of pregnancy outcomes and perinatal conditions as part of the measurement improvement agenda for the Every Newborn Action plan to end preventable maternal and neonatal mortality and stillbirths which was launched in June 2014.



Name: Ms. Kate Kerber

Organisation: Save the Children, United Kingdom

Position: Senior Specialist

Contact: kkerber@savechildren.org

Kate Kerber is a Senior Specialist with Save the Children's Saving Newborn Lives Programme, providing technical and programmatic support to improve maternal and newborn health and survival, particularly around generating and translating data and evidence for decision making at country level. She is a founding member of the INDEPTH maternal and newborn working group and is a member of the steering committee. She now resides in Canada after living in South Africa for ten years with extensive work in Ghana, Nigeria, Tanzania and Uganda. Kate holds an MPH from the University of Cape Town and is currently working on her PhD looking at the causes of neonatal and child deaths in South Africa, with a focus on understanding the rapidly changing contribution of AIDS-related mortality.



Name: Assoc. Prof. Angela Baschieri

Organisation: London School of Hygiene and Tropical Medicine, United Kingdom

Position: Associate Professor/Deputy Manager of Every Newborn Action Plan

Contact: angela.baschieri@lshtm.ac.uk

Dr. Baschieri is an Associate Professor and Deputy Manager of the ENAP Metrics Team at the London School of Hygiene and Tropical Medicine. She is an economic demographer, international development specialist and statistician with experience in data collection and analysis of complex datasets. She recently rejoined the LSHTM after two years working as a Research and Evaluation Specialist for UNICEF Ethiopia and 3 years working as a Health and Population Advisor for the Department of International Development of the UK Government (DFID) where she provided technical and programmatic advice to population and reproductive health policies and programmes. Prior to these appointments, she was a Lecturer at the Centre for Population Studies, London School of Hygiene and Tropical Medicine. She holds a PhD in Demography from the University of Southampton and an MSc in Economics from the University of Pisa, Italy.



Name: Dr. Vladimir S. Gordeev

Organisation: London School of Hygiene and Tropical Medicine, United Kingdom

Position: Research Fellow

Contact: vladimir.gordeev@lshtm.ac.uk

Dr. Gordeev joined the ENAP Metrics team at the London School of Hygiene & Tropical Medicine as a data analyst and lecturer in July 2016. He has been working at the London School of Hygiene & Tropical Medicine since 2013, first as a research fellow in health economics at the European Centre on Health of Societies in Transition and then as a research fellow in local policy evaluation at the National Institute for Health Research School for Public Health Research. He is a steering committee and board member of Emerging Voices for Global Health, one of the Health Systems Global thematic working groups. He has a background in internal medicine, public health and economics.



Name: Ms. Georgia Gore-Langton

Organisation: London School of Hygiene and Tropical Medicine, United Kingdom

Position: ENAP Metrics Technical Coordinator

Contact: georgia.gore-langton@lshtm.ac.uk

Georgia Gore-Langton became the ENAP Metrics Technical Coordinator in April 2016. Before that she was a Research Officer at Malaria Consortium, managing a malaria in pregnancy operational research study in West Nile, Uganda. And before that she was Operational Research Programme Coordinator at the MENTOR Initiative. Georgia's publications appear in Malaria Journal and American Journal of Tropical Medicine and Hygiene. Georgia has an MSc in Control of Infectious Diseases and a BSc in Biological Sciences.



Name: Ms. Suzanne Fournier

Organisation: Children investment Foundation Fund (CIFF), United Kingdom

Position: Manager, Saving Lives

Contact: SFournier@ciff.org;

Suzanne Fournier is a manager in the Saving Lives team at CIFF. She leads CIFF's perinatal survival strategy and manages a portfolio of investments in perinatal health in Sub-Saharan Africa and India. Prior to joining CIFF, Suzanne was a Senior Development Officer at the Department of Foreign Affairs, Trade and Development Canada where her work included community based child survival programming, the Global Fund to Fight AIDS Tuberculosis and Malaria, and pandemic influenza. Suzanne studied Molecular Biology at McMaster University in Canada, and received her MHS in Community Health and Epidemiology from the University of Toronto.



Name: Ms. Ly Nguyen

Organisation: Children Investment Fund Foundation, United Kingdom

Position: Manager, Evidence, Measurement and Evaluation

Contact: lnguyen@ciff.org

Ly Nguyen is a manager in the Evidence, Measurement and Evaluation team at CIFF London. In this role, she is responsible to ensure that CIFF grant making process is informed by latest evidence. She also commissions and manages independent evaluations of CIFF grants in health, climate change and modern slavery. Prior to CIFF, Ly Nguyen held monitoring and evaluation positions at the United Nations Children's Fund (in New York HQ and Zambia), Elizabeth Glaser Paediatric AIDS Foundation and MEASURE Evaluation. Her work covered measurements and evaluation of HIV/AIDS, MNCH and social cash transfer programmes. Ly Nguyen has a Master's degree in health policy and management from the University of North Carolina at Chapel Hill. She co-authored papers on Sample Vital Registration with Verbal Autopsy (SAVVY).

INDEPTH Network Maternal and Newborn Technical Secretariat in Kampala



Name: Assoc. Prof. Peter Waiswa

Organisation: Makerere University, Uganda

Position: Principal Investigator, ENAP project

Contact: pwaiswa@musph.ac.ug

Dr. Waiswa is an Associate Professor at Makerere University, medical doctor and health systems researcher with particular focus on newborn health and development and maternal-newborn-child health services. He leads the INDEPTH Network working group on Maternal Newborn health and is a frequent advisor to international organisations on perinatal-newborn health. With a background in district health service provision in rural Uganda he holds a joint PhD degree from Karolinska Institutet and Makerere University, and is on the faculty at Makerere University School of Public Health, Uganda, as well as at Karolinska Institutet, Sweden.



Name: Mr. Joseph Akuze

Organization: Makerere University, Uganda

Position: Technical Coordinator, ENAP project

Contact: jakuze@musph.ac.ug

Mr. Akuze is a Research fellow at the Makerere University School of Public Health (MakSPH) in the Department of Health Policy Planning and Management (HPPM). He is also the assistant coordinator of the Center of Excellence for Maternal and Newborn Health. He has an MSc in Public Health from the Hebrew University of Jerusalem, Israel, and a BSc in Statistics (Honours). Joseph is technical coordinator of the ENAP project of the INDEPTH Network Maternal Newborn Working Group.



Name: Ms. Doris Kwesiga

Organisation: Makerere University, Uganda

Position: Research Fellow

Contact: dknnkwesiga@gmail.com

Ms. Doris Kwesiga holds a Master's degree in Health Services Research and a Bachelor's degree in Social Work and Social Administration, both from Makerere University, Uganda. She is a research fellow in the INDEPTH Network Maternal and Newborn Working Group. She is also the principal investigator for a study "assessing uptake, adherence and acceptability of Kangaroo Mother Care in Eastern Uganda". Doris has previously worked as acting manager and research consultant at GlobalHealth Economics Ltd, Uganda. Prior to that, she was an assistant lecturer at the School of Public Health, Makerere University, where she was also a researcher in the REBUILD program as well as the deputy team leader for reviewing the Masters in Health Services Research Program. Doris has also been employed as a researcher at Child Health and Development Centre, Makerere, on a study promoting parent-child communication on sexual and reproductive health, and was previously a program officer at Kigezi Healthcare Foundation, Uganda. Additionally, she has been a consultant for various short term projects.



Name: Mr. Michael Ediau

Organisation: Makerere University, Uganda

Position: Resident Mentor - MPH Program (Research Fellow)

Contact: ediaumichael@gmail.com

Michael Ediau is a Resident Mentor for the MPH Program at Makerere University School of Public Health (MakSPH) (January 2015 to date). He also provides support to the INDEPTH Network Maternal and Newborn Health Working Group. Before that, he worked as a Public Health Specialist for the Implementation Science at US Centers for Disease Control & Prevention (2013 - October 2014). He also worked with ChildFund International as a MNCH and HIV&AIDS Projects Coordinator (2010-2013). In addition, he was a Health Programmes Manager with Vision TERUDO (2006-2008). His main career interests include: research and strengthening of health systems to improve MNCH and HIV&AIDS response. He completed the MakSPH-CDC Fellowship Program (2010-2012): <http://www.musphcdc.ac.ug/>. He holds MPH (2010) and Bachelor of Environmental Health Science (2004) degrees both from Makerere University. He has successfully designed and managed a number of MNCH and HIV&AIDS Projects.

INDEPTH Network Secretariat in Ghana



Name: Ms. Samuelina Siipara Arthur

Organisation: INDEPTH Network, Ghana

Position: Research Fellow

Contact: samuelina.arthur@indepth-network.org

Ms. Arthur is a Research Fellow at INDEPTH. She has an MSc in Population Studies (2010) and a Bachelor of Arts in Political Science and Sociology (2007) from the University of Ghana. Prior to joining INDEPTH, she held a position as Assistant Population Officer at the National Population Council attached to the Reproductive Health Department. Ms. Arthur also worked with the Internal Revenue Service as a national service personnel. Her research interests include: adolescent reproductive health, maternal health and cause specific mortality determination. She is currently a PhD candidate at Wits with the Population Studies and Demography Department.



Design and layout: Miracle Interactive

Report date: September 2016

Photo credits: Front cover photo: © Kiselev Andrey Valerevich/shutterstock.com; pp12 and 48-49 © Ayub Kakaire Kirunda/Center of Excellence for Maternal and Newborn Health Research; p15 © Hannah Maule-finch/Save the Children; p16 Left: © Suzanna Klaucke/Save the Children; Right: © Isabel Pinto/PMNCH; p17 © Susan Warner/Save the Children

