ANALYSIS, WRITING, AND DISSEMINATION OF HDSS DATA

Report from the Cross-site Analysis Workshop

28th – 31st May 2018

Hosted by Makerere University School of Public Health and African Population and Health Research Center, Nairobi

Venue: Nairobi, Kenya

African Population and Health Research Center

INDEPTH Network

Better Health Information for Better Health Policy

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New Venture Fund

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Contents

Acronyms

APHRC	African Population and Health Research Center
CARTA	Consortium for Advanced Research Training in Africa
DSA	Data Sharing Agreement
HDSS	Health and Demographic Surveillance System
INDEPTH	International Network for the Demographic Evaluation of Populations and Their Health
MakSPH	Makerere University School of Public Health
MDGs	Millennium Development Goals
MNCH	Maternal, Newborn and Child Health
NUHDSS	Nairobi Urban Health and Demographic Surveillance System
NVF	New Venture Fund
SDGs	Sustainable Development Goals
UHC	Universal Health Coverage

1.0 Background

Global estimates show that 2.9 million babies die in the first month of their lives, 2.6 million babies are stillborn (die in the last 3 months of pregnancy or during childbirth), and an estimated 289,000 women die each year due to pregnancy and childbirth related complications such as maternal deaths. Although considerable progress has been made globally in reducing maternal, newborn and child deaths over the past two decades, there was a significant unfinished agenda for Maternal, Newborn and Child Health (MNCH) in the Millennium Development Goals (MDGs), with many countries failing to achieve MDGs four and five.

The MDGs were replaced by the Sustainable Development Goals (SDGs), with goal three focusing on health. Among the targets to be achieved is a reduction in the global maternal mortality ratio, to less than 70 per 100,000 live births by 2030; and ending preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births by 2030.

Most of the deaths among newborns and mothers, as well as stillbirths, occur in Sub-Saharan Africa and South Asia. However, Africa is the region with the least data. Availability of high quality data is critical for precision public health in terms of guiding programming and policies for achieving the SDGs in Africa. Data available within the INDEPTH Network is yet to be harnessed as a powerful advocacy tool to inform SDG implementation in Africa. The INDEPTH network is the largest cohort of population level data in the world, with nearly 4 million people under surveillance from 54 sites in more than 20 countries, most of them in Sub Saharan Africa. The network has prospective data for over 20 countries. This data can be used to show the burden of maternal, newborn and child health and how this is changing, including data on equity, gender and other disparities.

The current study that is the focus of this workshop is using multi-country data from Health and Demographic Surveillance System (HDSS) sites for newborn and maternal advocacy in Africa. It is coordinated by the technical secretariat of the INDEPTH Network Maternal, Newborn, and Child Health working group, based at Makerere University School of Public Health, Uganda.

1.1 Overall objectives of the study

To use data to advocate for newborn and maternal policy and funding for Africa's mothers, newborns and stillbirths in order to facilitate SDG achievement. We believe that when we use locally available high quality data and an innovative advocacy process, policy and program managers are more likely to be responsive.

Specific objectives

1. To support sites to analyze this data in collaboration with local and national governments
2. To use this data to show country and regional trends
3. To develop an advocacy toolkit to inform SDG implementation in Africa
4. To build HDSS capacity to regularly produce and disseminate such high quality data and to increase on the number of African newborn and maternal health experts

Expected outcomes

1. An African report on the status of maternal, newborn health and stillbirths
2. An advocacy package on Africa's maternal and newborn deaths and stillbirths
3. A scientific publication on Africa's maternal and newborn deaths and stillbirths
4. Capacity for at least 10 African HDSS sites built to produce and disseminate high quality data on Africa's newborn and maternal deaths and stillbirths

1.2 Methods

For the analysis and publication component of the study, the MNCH working group technical secretariat designed draft templates for collecting data on pregnancy outcomes in HDSS sites between 2012 and 2016. It then individually and through the INDEPTH Network approached HDSS sites that are members of the MNCH working group, to explain the study and let sites express their interest in it, depending on whether they had the required data available, and other considerations. This was followed by planning for an analysis and writing workshop that would bring the HDSS sites together to agree on certain aspects of the work and how to collaborate going forward.

At the same time, APHRC was also hosting an HDSS analysis and writing workshop as a follow up to another that had previously taken place. It was agreed that MakSPH and APHRC co-host the workshop and include more HDSS sites.

1.3 Objectives of the workshop

As part of the study, participating HDSS sites are undertaking analysis of their data collected on key MNCH indicators over a number of years. They will also participate in the writing of an African, cross-site publication, in addition to individual site reports and manuscripts.

It was therefore necessary to hold a workshop for the different participating sites, in order to achieve the following objectives.

1. To present draft findings from the analyses done so far
2. To agree on the key indicators that data is being collected on
3. To harmonize definitions of the key indicators under analysis
4. To complete the analysis plan for the study
5. To discuss the reports and manuscripts that will be an output of this study
6. To draft outlines for the manuscripts and agree on who will lead the different writing
7. To agree on data sharing and authorship modalities
8. To identify opportunities for collaboration

Each site nominated one or two people to attend.

The workshop took part in two phases:

1. The technical meeting held at Jacaranda Hotel, Nairobi, from 28th-30th May 2018. This included the HDSS site representatives, APHRC staff, as well as staff from MakSPH (This is the focus of this report).

2. The strategic meeting, held at the APHRC offices in Nairobi on 31st May 2018. Participants were APHRC and MakSPH staff.

2.0 Technical Meeting

2.1 Overview

The technical meeting of the HDSS analysis workshop took place over two and a half days. It was a vibrant gathering of multiple nationalities and diverse expertise, all with the aim of working together to analyze data from the HDSS sites, and planning for future collaborations.

Participants were from 11 HDSS sites in Kenya, Ethiopia, Uganda and Tanzania, in addition to staff from APHRC and MakSPH. These sites are members of the Maternal, Newborn and Child Health (MNCH) working group of the INDEPTH Network. The sites represented in the meeting were:

- Nairobi Urban HDSS from Kenya
- Kersa, Dabat, Butajira, Arba Minch and Gilgel Gibe HDSS sites from Ethiopia
- Magu and Ifakara/Rufiji from Tanzania
- Rakai, Iganga-Mayuge and MRC Kyamulibwa HDSS from Uganda

Expertise was varied, in the areas of statistics, econometrics, data management, medicine, nutrition, social sciences, health systems research, maternal, newborn and child health and more. This report provides a summary of the key issues that were discussed, gaps noted and the way forward.

2.2 The value of HDSS data

During the opening session of the workshop, the following key speakers made remarks on the purpose of workshop and the value of HDSS data.

- Ms. Elizabeth Kimani, head of Maternal and Child Wellbeing at APHRC
- Ms. Marylene Wamukoya, lead data analyst at NUHDSS
- Assoc. Prof. Peter Waiswa from MakSPH and leader of the MNCH working group technical secretariat
- Dr. Ravi Ram, Head of Data, Measurement and Evaluation at APHRC
- Dr. Claudious Chikozho, Director of Research at APHRC

It was emphasized that through this workshop, participants would benefit from learning about each other's research interests, identify those with whom their interests overlap, and who they can collaborate with in the future. Although the current challenges and transition in the INDEPTH Network management were acknowledged, all participants appreciated the fact that the workshop was proceeding either way, regardless of these trials.

Furthermore, the benefit of HDSS data was reiterated, including the fact that it is prospective and so events can be tracked and measured in real time, unlike other surveys that are done after the event has already taken place. However, it was acknowledged that it is critical to keep data quality good, so that it can be informative, relevant and trusted. Additionally, HDSS sites need to collaborate with each other, because when one HDSS writes a publication alone, although people will read their output, they may not be greatly impacted by it. It is much better when sites work and write together because then it is more powerful data that can be appreciated by a global audience. Indeed, one of the challenges realized with individual site work is that it often cannot get into journals because editors prefer work that is for a global audience, not just one country's output.

Among the advantages of HDSS sites is that their outputs are based on real data, not on modelling like other groups do. However, a lot of the work done in the sites is not getting to the global audience. For instance, in HDSS sites they say sepsis is the leading cause of neonatal deaths, yet global statistics show that it is prematurity, but sites are not reporting what they have. Indeed, it was noted that in some places, after holding so many rounds of HDSS data collection, management are not convinced that they have been getting value for money – that is, the number of outputs from the rounds. More so, few people present in the room had published from the HDSS data, which is very worrying.

Therefore, it was acknowledged that the workshop is important for value addition, which we can demonstrate through having more outputs. This should attract increased funding and change the mindsets of the boards members and management in different sites who think that the HDSS should be suspended until further notice.

Key things to consider for HDSS sites:

- How do we work in the region? How do we work in the world?
- How can the sites present do what the world is interested in, and do some creative analysis that is of global, regional or national importance?
- Why are sites not reporting what they have? For instance, HDSS sites collect data on socio-economic status and migration but who ever looks at that data?
- What use do we make of the data? We cannot inform policy and practice if we don't translate the data into specific outputs.

Visibility, Value, and Business

If your work is Visible and people see the Value of it, then you can get Business.
What is the value of this network of HDSS sites, and where is the cross-site research?

3.0 Profiles of The HDSS Sites

Each HDSS represented at the workshop made a presentation profiling their site, with a specific focus on maternal, newborn and child health.

Site name	Location Background Total size of HDSS	Key population indicators	Key indicators on which data is collected	Pregnancy surveillance
Kersa, Ethiopia	Kersa (Rural) • Established 2015: • 23,542 Houses (2015) • Population: 130,099 Harar (Urban) • Established 2012 • 15,148 Houses • Population: 57,937 (2016)	Kersa • Total fertility rate (2016): 5.3-3.9 • Women (15-49 years): 22.8% Harar • Total fertility rate (2016): 1.95-3.49 • Women (15-49 years): 31.0%	• Individual socio demographic information • Household related variables • Maternal mortality • ANC • Family planning prevalence • Mortality rates (stillbirth, neonatal, infant, child, under five) • Morbidity • Fertility rates • Immunization • Data collected every 6 months • Use tablets • Census: done once at establishment	• Respondent-woman • Surveillance-every 3 months • Started after 2011 • Vital events notification: Not notified, rather during periodic surveillance they are picked at home
Butajira, Ethiopia	• Initiated as PhD work in 1987 • Households: 19,613 • Population: 74,204 (2017)	• Total Fertility Rate: 1.8 • Women (15-49 years): 20,241 (2017)	• Birth • Death • Migration • Household • Pregnancy follow-up (paper based) • Rounds per year: Monthly until 1999, quarterly since • Census: 1987, 1995 and 1999	• Respondent –woman • Quarterly surveillance • Vital events notification: Birth and death is reported weekly
Magu, Tanzania	• Established in 1994 • Population: 35,228 (end of 2015) • Households: 6219	• Total fertility rate: 4.7 in 2015 • Women (15-49 years): 8159	• Pregnancy • Residence • Death • In-migration • Out-migration • Birth • Marital status • Education • Rounds per year: 2	• Respondent: Head of household / spouse/ well informed member of household • Surveillance twice a year • Death: when notified a household visit is made,

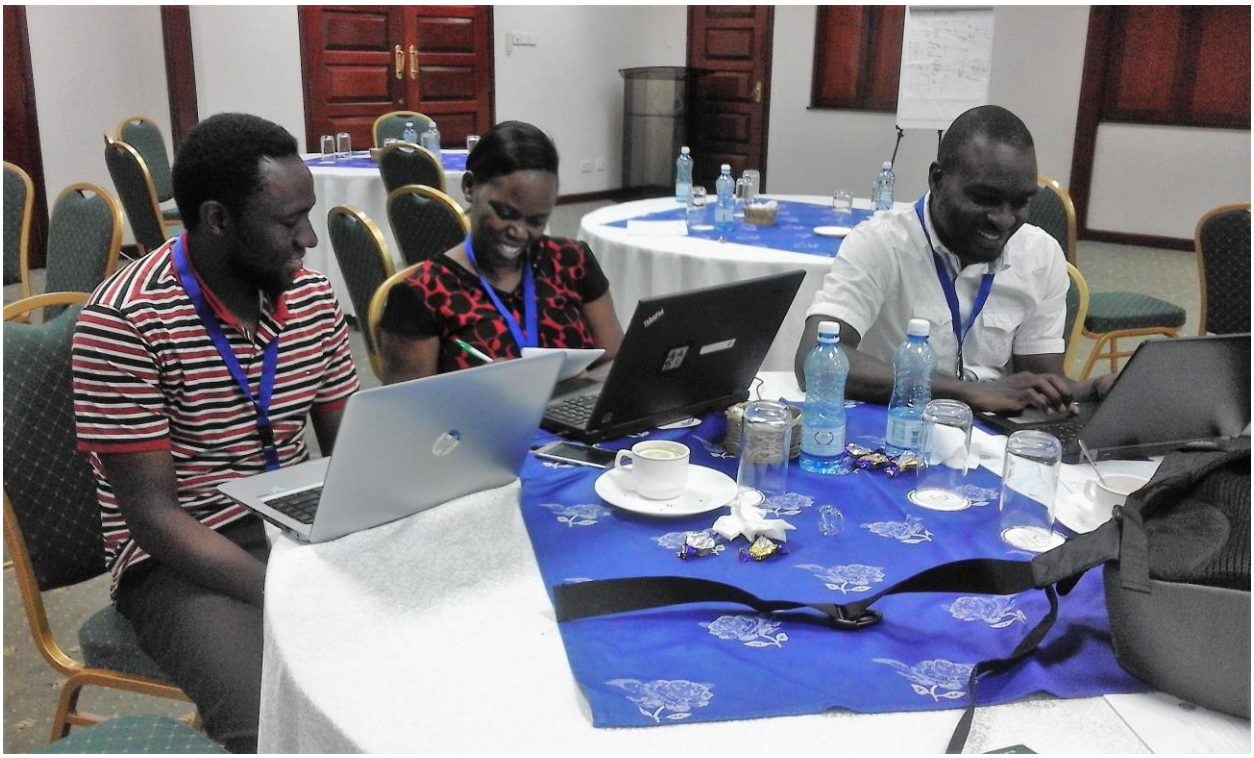
				followed by VA interview
Gilgel Gibe, Ethiopia	• Established in 2005 • Households: 13,577 • Population: 66,251 (2016)	• Total fertility rate: 5.0 (2016) • Women (15-49 years): 15,808 (2016)	• Birth • Death • Migration • Pregnancy Observation • Marital Change • Causes of Death Using Verbal Autopsy • Rounds per year: 2 • Census: Done once after baseline in 2010	• Respondent: Woman • Surveillance: every 6 months (from 2010) • Vital events notification: house to house visit and resident guides to report deaths for verbal autopsy
MRC Kyamulibwa, Uganda	• Established in 1989 • Households: 3800 • Population: 22,000	• Total fertility rate: 5.8 • Women (15-49 years): 6,914 (2016)	• Mapping data • Census data • Medical survey including verbal autopsy • Census: 1 round per calendar year • Survey: 1 round over 2 calendar years	• Respondent: Head of household or next of kin belonging to that household or the village local council leader • Surveillance: On a monthly basis • Vital events notification: through village informants monthly, census team annually (including VAs)
Arba Minch, Ethiopia	• Established in 2009 • Households: 18,700 • Population: 133,468	• Total fertility rate: 4.4(2015) • Women (15-49 years): 16,708 (2015)	• Birth • Death • Migration • Pregnancy observation • Pregnancy outcome • Marital status change • 2 rounds per year • Census: done at baseline	• Respondent: Adult • Surveillance: Done by field data collector recruited from each kebele • Vital events notification: Key informants from each kebele inform the data collector who follows up

4.0 Trends of pregnancy outcomes and their determinants in African HDSS sites

At the start of this study, the MNCH working group technical secretariat outlined some ideas for cross-site analysis, with the possibility of writing individual HDSS site papers, as well as country papers. Before the workshop, the following were suggested:

- Trends of pregnancy outcomes and their determinants in African HDSS sites from 2010-2016, with possible sub-themes depending on availability of data; possibility for cross-country collaboration, etcetera
    - Trends of abortions and their determinants
    - Trends of maternal deaths and their determinants
    - Trends of neonatal deaths and their determinants
    - Trends of stillbirths and their determinants

For the workshop, it was decided that more progress would be made if focus was on the major paper, looking at pregnancy outcomes across the HDSS sites. Therefore, a lot of time was spent discussing the indicators in the template, agreeing on definitions, highlighting if and how the different sites collect these data, agreeing on what is feasible, and revising the template to the satisfaction of each site present. Although not all sites collect all the indicators shown in the template, this session achieved harmonization in understanding the definitions of the variables by those present.



The standard variable descriptions are shown in the table below.

Pregnancy outcomes analysis from 2012-2016

Variable	Description and comments
Size of HDSS population Total population Urban Rural	Considers person-years for each of the indicators. Also, calculate the total population in terms of absolute number for 31-December
Number of women of childbearing age	Female 15-49 person-years Also, calculate the total population in terms of absolute number from January-December during that period (whether died or left)
Number of pregnancies identified	Number of identified pregnancies in terms of absolute number from January-December during that period **Gilgel Gibe and Iganga do not capture the event dates
Birth type Singleton Multiple Don't know Missing	This should be live birth
Sex of baby Male Female Don't know	
Mother's age at birth <15 years 15-17 18-19 20-24 25-34 35-49 Don't know	
Mothers education (highest level attended) None Incomplete Primary Complete primary Incomplete Secondary Complete Secondary Tertiary	There are differences in education level across the countries. This is education at the date of delivery
Household wealth quintiles index Lowest Second Third Highest Unknown	Wealth index at the time of delivery
Marital status Currently married	Marital status at the time of delivery. However, in some site countries like Iganga, this is not collected regularly.

Living with a man Widowed Divorced Separated Never married or lived with a man	
Parity 1 2 3 4+	28 weeks of gestation age irrespective of outcome
Gravida 1 2 3 4+	
Residence Urban Rural	
ANC attendance Attended at least one Attended at least 4 times	
Health facility delivery Delivered at the health facility Delivered in community, home or TBA	
Live births	
Neonatal deaths 0-28 days Early neonatal deaths (0-7 days) Late neonatal deaths (8-28 days)	
Stillbirths	Baby born at 28 weeks of gestation age with no sign of life
Abortions Spontaneous abortions (miscarriage) Induced abortions	A pregnancy terminated before 28 weeks
Maternal deaths 15-19 20-24 25-34 35-49 Don't know	
Prematurity	Total number of premature babies registered.
Prematurity deaths	

5.0 Thematic areas for developing research papers using cross-site HDSS data

The teams present at the workshop had multiple discussions on the different papers that they could collaborate on using HDSS data, both within and beyond MNCH.

The table below shows a summary of the papers suggested, the HDSS sites keen to participate as per the data they have available, and their areas of interest. While some were originally suggested by one or two sites, other sites agreed to join them or will do so once the objectives of the paper are more clear. During the discussions, the teams working on the proposed papers got positive and useful feedback. As a result, many are going back to the drawing board and indeed, some of the papers listed may undergo a change of objectives and / or methodology, but are still shown in the table because they were part of the discussions.

Proposed title / Thematic Area	**Description / objectives / research questions**	**HDSS site(s) involved**	**Team lead**
Trends of pregnancy outcomes and their determinants across HDSS sites in Africa *Likely to be merged with the one below, that NUHDSS was working on*	1. To determine the rates of pregnancy outcomes in African HDSS sites from 2010-2016 2. To assess the determinants of pregnancy outcomes across African HDSS sites from 2010-2016	All HDSS sites at the workshop	Makerere; Gershim; Damazo Kadengye
Pregnancy outcomes – Ethiopian specific country paper	Country specific objectives	Butajira, Dabat, Gilgel Gibe, Kersa and Arba Minch (Kilite Awlaeolo may be included as well)	Fassil
Access and equity in utilization of MCH services	Examine pattern of health care overtime If there are deductions in equity in health care utilization over time using equity measures	NUHDSS	Estelle Sidze
Moving in and out of food insecurity	Establish trends in food security Factors associated with changing food security status	NUHDSS Gilgel Gibe does food security Dabat does nutritional surveillance	Triza Njoki
CVD risk profile and mortality over a 10-year period in the NUHDSS	Trends of deaths from CVD (and other deaths) in urban slums from 2008	NUHDSS	Fred Wekesah
Under-5 death experience and changes in fertility levels (2003-2016)	A paper on contraception / realization of preferences among sexually active young people A Paper could cover trends in and determinants of the uptake of SRH services, e.g. by focusing on adolescent females	NUHDSS Kersa	Tizta Melkamu
Gender analysis of all cause morbidity and mortality for people aged above 15 years	Is there a difference between gender in mortality; factors associated with mortality and morbidity for different genders	NUHDSS	Anne Khisa
Patterns of Under 5 mortality based on housing types in Nairobi slums	To investigate patterns and causes of under 5 mortality by housing type	NUHDSS	Esther Kinuthia; Damazo

		Iganga Mayuge	
Relationship between non-traditional measurements of access to health care and under 5 mortality in Nairobi Slums: Evidence from NUHDSS	To assess access to health care using non-traditional variables, and determine the relationship between these and under 5 mortality	NUHDSS	Esther Kinuthia
Impact of homebased counselling on post-birth maternal deaths: Maternal mortality trend during the counselling period 2012-2015	What impact does homebased counselling by CHVs have on post birth maternal mortality?	NUHDSS	Caroline Wainaina
Trends in water and sanitation and the drivers	Piped water, unsafe drinking water, sanitation and garbage disposal Trends since HDSS started-what are the key drivers if change is positive?	NUHDSS	Claudious Chikozho
Socio-demographic and education differential on pregnancy outcome: Analysis from rural Demographic Surveillance system in Tanzania, 1999-2014	Objective: To assess socio-demographic inequalities on pregnancy outcomes (HH-SES, Mother highest level of education, Marital status, resident,) Research Question: Is there a difference in pregnancy outcomes by socio-demographic factors (HH-SES, Mother highest level of education, Marital status, resident)	Rufiji DSS + Ifakara Rural DSS combined	
Deaths among women of child bearing age		Rakai, MRC, Iganga NUHDSS/APHRC Ifakara Magu	Dorean Nabukalu
Maternal mortality over 5-year trend (2012-2017) and COD post-delivery up to 6 weeks	Trends and key factors that exacerbate risks for post-delivery maternal mortality Determine impact of counseling information on maternal health outcomes to explain the trends of post-delivery maternal mortality.	NUHDSS *Can combine with other sites plus another paper (Ziraba)	Caroline Wainaina
Birth weight	HDSS data, linked to verbal autopsy		Rornald
Review of Verbal and Social Autopsy data	The narratives that come out of verbal autopsy-what VASA data is available, and what comes out of this	NUHDSS Iganga interested Rornald to link PhD work	Caroline Wainaina
Education			Edward and NUHDSS

6.0 Strengths, gaps, opportunities and threats facing HDSS sites

STRENGTHS	GAPS / AREAS THAT NEED STRENGTHENING	OPPORTUNITIES	THREATS
• Prospective data collection • Many rounds and years of data already collected • Sites can potentially collaborate and do joint analysis • Populations are clearly known, with some HDSS sites using GPS, so people can be tracked • Good platform for testing and implementing interventions • Good reputation and trusted in the community, especially where they have offered services to the community • INDEPTH Network tried to ensure that sites use the same tool and capture data in the same way • Expertise available in the HDSS sites	**Variable definitions and terminology** • Lack of standard definitions of variables • No standard definition of what qualifies to be an urban area • Abortion – most sites do not differentiate between induced and spontaneous abortion, except for a few like NUHDSS which separate miscarriage from abortion • Differences in standardization of age during pregnancy surveillance, with different lower and upper limits. For instance some sites have an upper limit of 54 years of age (Iganga starts at 12 years; Magu is 15-49 years; MRC does 13-54 years; NUHDSS is 12-49 years) **Data collection process** • The type of respondent may affect the data collected. For instance, during pregnancy registration, some HDSS sites ask the household head or man present if the adolescent in the house is pregnant, which he might not know • Electronic versus paper data collection. While a number of sites are collecting data electronically, others are still using paper. The paper data collection results in a time lag as long as three months as data entry is done, thus delays in producing outputs • Sites sometimes miss registering pregnancies and / or their outcomes	• Modify the pregnancy history form, e.g. try to link it to the "owner" of the pregnancy • Strategize on how to be more useful to the countries • Ability to provide baseline data for different studies • New emerging global health issues that need a platform for testing indicators e.g. drug and vaccine industry • Tracking the Sustainable Development Goals • PhD and Master's students can use the HDSS data or conduct studies within the HDSS • Opportunities for data strengthening and learning from each other: INDEPTH Network and Working Groups can collaborate and move together as a team	• Running an HDSS site is an expensive venture. Those that are the most stable are the ones supported by their national Governments or which have big amounts of donor sponsorship. Many others are facing financial challenges, and are resorting to doing fewer rounds a year. • A number of HDSS sites have closed, including Ifakara which first had to reduce the rounds, but then eventually closed in 2016 • Not publicizing HDSS work and data and linking to national and global agendas keeps the sites hidden and not well known • Respondent fatigue in HDSS communities, due to regular interviews with no direct rewards or incentives • Current challenges with INDEPTH Network Management

	• No clear standardized way on how data collectors collect the social autopsy information		
	Migration • This is a constant thing that sites have to handle, i.e. in and out migration, which may affect their analysis and results		
	Data quality and reporting challenges • Under reporting of abortions		
	Data analysis challenges • How to deal with the outcome that is registered retrospectively, for instance a baby or death whose pregnancy was not registered in the first place		
	Database challenges • INDEPTH Network introduced the open HDSS platform and encouraged sites to migrate to it. However, some sites experienced problems with it after migration, e.g. Ifakara. Other sites like NUHDSS are not using it, thus differences in the kind of database systems used		
	Policy and dissemination • Often, HDSS sites do not share their data and it is not used to contribute evidence to improve national planning. There is often weak engagement with policy makers, and a lack of awareness on the policy makers side about the importance of the HDSS work and the potential usefulness of their data		

7.0 Next steps

Throughout the workshop, a number of suggestions were made to take forward not only the MNCH work, but also the collaboration of the HDSS sites that participated, and indeed the whole MNCH working group. The last day included a session specifically focused on planning these next steps. The ideas that emerged during the workshop are summarized in this section.

General collaboration

- Develop a clear mechanism for the working group to collaborate better together
- Communication has been difficult e.g. through INDEPTH. HDSS sites agreed to also communicate with each other directly and with the MNCH working group technical secretariat, so as to know what is going on in each site, share information and cooperate on various issues that arise
- Establish a small sub-committee to generate the groups' ideas into a concept for what we want to do, and to reach out to other sites as well. It will have representatives from Makerere; APHRC; INDEPTH when leadership is clear; and country representatives for HDSS sites (e.g. Ethiopian sites already have a network with a leader)
- Further collaboration between APHRC and Makerere

Collaboration on paper writing

- Write up joint papers: this will show that there is a Network that can work together and generate products. These should be high impact papers that matter. We should not just be descriptive but probe into the deeper issues.
    - As a group, we shall start with the multi-site pregnancy outcomes paper.
- Plan for a special journal supplement to be released at the end of the year, from the different papers suggested during the workshop, especially the cross site papers. We could invite some international figures as editors, who will help with promotion.
    - Suggested potential journals were International Journal of Public Health; Global Health Action; African Health Sciences Journal; AFENET journal and others.
- Development of a group data sharing agreement. This must first be shared with the site leader in each participating HDSS.
- Authorship for scientific publications is well defined. All sites are expected to be among the authors, with two or three key names for the paper.
- For the papers you initiate you are the first author, and everybody was encouraged to do so.
- Papers are richer when the primary data is available. In future, sites can outline key papers and variables, then ask other interested sites to share primary data. This would be guided by a data sharing agreement for each paper.
- An important paper that was not discussed is the one on data gaps and quality. The plan is to work on a data strengthening paper, to improve the quality of HDSS data. The MNCH working group technical secretariat has a draft to revise, which suggests the core things an HDSS must do. We can have this data strengthening guide and turn it into a paper. Sites can also propose ways to improve data management.

Data strengthening

- Through this workshop and the subsequent analysis, we shall identify the major gaps in HDSS data and work on improving its quality and completeness. This may necessitate a data quality assessment across sites.
- Creation of a platform to standardize and strengthen data across HDSS sites, including and beyond those that were a part of the workshop.
- Creation of a standard structure for how we want the data to be. Although each site collects data for different purposes, we should make a big effort to streamline the structure. Data managers are tagged to multiple grants or funding, so they get busy and take longer to do things but with a standard structure, they can work faster.

Capacity Building

- Write a project to help sites generate their data almost instantly like Nairobi Urban HDSS does.
- It is generally hard to get money for capacity building. Suggestions to build capacity were:
    - Using the process of doing this cross-site research to build capacity for Masters and PhD students to use site data.
    - Discussing with the CARTA secretariat so that in the next call for fellowships there is a possibility that INDEPTH / HDSS data can be used to answer priority questions or issues. There would be a specific thematic area in the call for the use of this data.

Generation and dissemination of data

- Taking advantage of the many opportunities available, especially around the SDGs. The HDSS sites have the potential to generate evidence to inform national, regional and global issues.
- This requires good data. Nairobi Urban HDSS has such an excellent system for producing data, and other HDSS sites could learn from them.

Country relevance

- HDSS sites need to also reach out to the policy makers, researchers and other key groups in their country to show their data and value. They should link to the available country programs.
- HDSS sites in the same country can work together to generate and share their data. Ethiopian HDSS sites are a good example, since they are already networked.
- Use the available opportunities to inform the country agendas.

Global relevance

- Find a niche to work in and generate products and new knowledge.
- Be the answer to SDGs, UNICEF and universal health coverage by providing data and reports, even at a country level, for instance on the state of MNCH and beyond, annually. We can also identify particular SDGs we can look at and if we have the data, we answer the question in a similar manner among sites.

- Take advantage of regional and global conferences to market ourselves as a network. For instance, we can share resources and do a special session to show our work in one of the bigger conferences so we need to identify which one.
- The above should be one of the means to attracting further funding for the HDSS sites and the MNCH working group.
- Exhibit our work on our websites.

Attracting funding

- In addition to writing proposals, APHRC can have discussions with Wellcome Trust and SIDA with regard to funding for data strengthening.

Collaboration on projects and research

- Write proposals for collaboration on projects and research. The project lead / the one who developed the idea can be in charge, working with cross-site teams where possible, and in line with committees.
- Identify thematic areas within the global agenda, and work on 2-4 page concepts that our leaders can market to people e.g. in GAVI.

The following ideas were suggested for potential project collaboration:

- Maternal Immunization
- Equity, e.g. tracking equity using HDSS data
- Tracking of SDGs regularly, annually or every 3 years. We can also compare with other surveys like DHS
- Address the priorities of the “Every woman Every Child” document
- Assessment of early childhood development, in line with SDGs talk of thriving yet there is no data on this.
- There is currently a lot of interest in the age group 5-19 years but little known is known about them. HDSS sites should work on this - what do we know now and can we track them better?
- Monitoring impact of programs
- Agriculture and food security. There is a call by Horizon 2020 that is not yet open but we can have a concept by October 2018, and then proposal next year. APHRC is going to work on this and Iganga-Mayuge HDSS expressed interest in partnering with them

8.0 Achievements from the workshop and the study so far

For the HDSS Sites

- Opportunity to utilize and analyze existing data and identify strengths and limitations
- Identifying opportunities for data strengthening
- Identifying papers that can be written from HDSS data
- Networking with other HDSS sites and establishing collaborations

For individuals

- Capacity building through learning from and with others
- Capacity building in data analysis
- Building their professional networks
- Identifying individual ideas for analysis, paper writing and research

For the MNCH working group, Makerere, and APHRC

- Successfully coordinating HDSS sites and bringing them together to do work of global relevance
- Capacity building in data analysis
- Increasing the visibility of the working group and APHRC
- Building future collaborations
- Identifying ideas for analysis, paper writing and research

ANNEX 1: Program

Day	Time	Topic	Facilitator
DAY 1 **Monday, 28th May 2018**	**08:30-09:00**	Arrival	
	09:00-09:30	Welcome remarks, introductions, objectives, expectations, paper topics	Damazo, APHRC Marylene, APHRC
	09:30-10:00	The value of DSS data	Ravi, APHRC
		Presentation from INDEPTH MNCH Working Group on the current work	Peter/Rornald/Dan, Makerere U.
	10:00-11:00	Presentations from other sites *(Profile of each site as per templates given)*	Sites representatives
	11:00-11:30	**Tea break**	
	11:30-13:00	Analysis approaches for DSS data Longitudinal data structure Event history analysis Exploring the NUHDSS microdata portal	Marylene, APHRC Site representatives
	13:00-14:00	**Lunch**	
	14:00-15:45	Thematic areas for developing research papers using cross-sites DSS data ***Note:*** *These are paper ideas participants have. Each will quickly present the idea in 10 minutes. In-depth discussions on ongoing papers will happen in day 2* ** Ongoing papers are those where authors have already done some work on analyses*	ALL
	15:45-16:00	**Tea Break**	
		Parallel session 1 (NUHDSS)	
	16:00-17:00	Consultations on the NUHDSS data	Marylene, APHRC
		Parallel session 2 (MNCH)	
	16:00-17:30	Discussion of site data submitted in the templates Discussion of key paper on pregnancy outcomes	ALL, led by Dan, Rornald. Each site should be ready with template
DAY 2 **Tuesday, 29th May 2018**	**07:30-08:00**	Arrival	Peter, Makerere U. APHRC
	08:00-08:45	Recap of day 1	Marylene, APHRC Peter, Rornald, Dan
	08:45-9:45	Discussion on potential collaborative work beyond papers	Peter, Makerere U.
		Parallel session 1 (NUHDSS)	

	9:45-10:30	In-depth presentations of papers ***Note:*** *each paper lead will have 10 minutes to present the paper objective, methodology, variables, results (if any) and timelines. We highly encourage each paper lead to prepare a structured PowerPoint presentation*	Damazo, APHRC
	10:30-11:00	**Tea Break**	
	11:00-13:00	In-depth presentations of ongoing papers	Damazo, APHRC
	13:00-14:00	**Lunch**	
	14:00-15:30	In-depth presentations of ongoing papers	Damazo, APHRC
	15:30-15:45	**Tea Break**	
		Parallel session 2 (MNCH)	
	9:45-10:30	Further analyses of site data submitted in the templates	ALL, led by Dan, Rornald
	10:30-11:00	**Tea Break**	
	11:00-12:00	Further analyses of site data submitted in the templates	ALL, led by Dan, Rornald
	12:00-13:00	Discussion of manuscripts • Drafting paper outlines; Agreeing on team leaders; Authorship and data sharing	ALL, led by Rornald, Peter
	13:00-14:00	**Lunch**	
	14:00-15:30	Discussion of manuscripts • Drafting paper outlines; Agreeing on team leaders; Authorship and data sharing	ALL, led by Rornald, Peter
	15:30-15:45	**Tea Break**	
	15:45-17:00	Summary from both parallel sessions Discussion on joint publication outputs (e.g. supplement in journals)	Estelle, APHRC Rornald, Makerere U.

Day	Time	Topic	Facilitator
DAY 3 **Wednesday, 30th May 2018**	**07:30-08:00**	Arrival	
	08:00-09:00	Further discussion on potential collaborative work beyond papers	Ravi, APHRC
	09:00-10:30	Protected time to further work on papers ***Note:*** *We will split in small groups working on papers to continue with analyses. The expectation is that at the end of the day each paper will have significantly progress and that all co-authors will go back home with their assigned tasks to finalize the paper for submission for publication.*	ALL
	10:30-11:00	**Tea Break**	
	11:00-13:00	Further work on papers in small groups of co-authors	
	13:00-14:00	**Lunch**	
	14:00-15:30	Further work on papers in small groups of co-authors	ALL
	15:30-15:45	**Tea Break**	
	15:45-16:15	Next steps for continued analysis and writing	Damazo, APHRC
	16:15-16:30	Feedback on the workshop	ALL
DAY 4 (APHRC/MCH group only) **Thursday 31st May, 2018**	**9:00-10:30**	Strategies on joint research concepts: 1) Breastfeeding including the Baby Friendly Community Initiative (BFCI), workplace support for breastfeeding and human milk banking 2) Maternal mental health 3) mHealth Others as suggested	Peter, Makerere U. Elizabeth, APHRC Estelle, APHRC Pauline, APHRC
	10:30-11:00	**Tea break**	
	11:00-13:00	Strategies on joint research concepts (continued) + way forward	ALL
	13:00-14:00	**Lunch and departure at own leisure**	