Summary Report:
Newborn Research Meeting in the INDEPTH Sites
Getting newborns counted and to count in Sub-Saharan Africa and Asia
Mensvic Hotel, Accra
1st October 2010

Organised by: Peter Waiswa, Iganga HDSS
Hosted by: Iganga HDSS, INDEPTH Secretariat, Saving Newborn Lives / Save the Children

Number of participants: 16
HDSS sites represented: 10

PROCEEDINGS

The meeting took the form of a series of presentations, question/answer sessions and plenary discussions.

Opening, Background and Objectives – Peter Waiswa
The meeting was opened by Peter Waiswa with Greetings, thanks for attendance and introduction of participants (see Annex 1. List of Participants).

Peter provided an overview giving the background and expected outcomes of the meeting.

Background: Evidence suggests that most of the Sub-Saharan African countries will not achieve the fourth Millennium Development Goal (MDG- Reduce child mortality) unless there are substantial reductions on neonatal mortality. Despite improvements in child survival, the burden of mortality in the first month of life has remained virtually unchanged. Most of these deaths are caused by three preventable causes - complications of preterm birth, infections, and birth asphyxia. Although many of these deaths maybe avoidable, newborn health is now just getting on the policy agenda of many African and Asian countries and assessment of progress to achieving MDG 4 in response to different interventions in various countries is and will be hampered by a dearth of data on newborn epidemiology especially in SSA coupled with a lack of a complete civil registration systems and information on causes of newborn deaths in many SSA and Asian countries.

The INDEPTH-Network can help to contribute in bridging this gap:
• HDSS centers are relevant for monitoring epidemiological trends and generating evidence relevant for MDGs as they collect longitudinal data.
• INDEPTH Network has already identified newborn issues as a key research gap
• Multi-HDSS centre research is encouraged by INDEPTH Network

Objectives:
- Share experiences on newborn research in HDSS centres
- Develop a forum for HDSS centres conducting newborn research
- Develop and implement a newborn research agenda within the INDEPTH Network
- Identify common research questions
- Develop a pathway to forming a newborn working group in the INDETH Network

Expected outcomes;
- Agree on a common research agenda and coordination mechanism
- Identify potential partners and funders
- Develop a pathway for formation of a newborn working group in the INDEPTH Network

Overview of newborn health research priorities – Kate Kerber

Kate Kerber from Saving Newborn Lives, a project of Save the Children funded by the Bill & Melinda Gates Foundation gave a general overview presentation on newborn health with an emphasis on the situation in Africa and highlighted opportunities for improving Newborn health epidemiology and linking to evidence based research.

She brought to the meeting's attention, the **burden** of newborn death, the **gaps** in newborn 'health research funding and focus, and the major research **priorities** in newborn health. She highlighted convincing evidence from Asia of how **delivery** of integrated MNCH packages can be used to reduce neonatal deaths and the need to assess integrated, scalable packages, especially in Africa. She concluded with the potential **role** an INDEPTH interest group can play especially in description and delivery research.

The burden and evidence base
The epidemiological evidence is there to guide a global newborn research agenda shows that there are 3.6 million neonatal deaths annually and in ALL regions, deaths in the neonatal period are a major contributor to mortality; up to 27% to 54% of under-five deaths. The 3 main killers are prematurity, infection and intrapartum deaths and account for 81% of all neonatal deaths. Up to 50% of neonatal deaths occur in the first 24 hours and 75% of neonatal deaths occur in the first week.

The gap in global research priorities
The global research priorities needs to be evidence based; currently there is a mismatch of burden and research in terms of amounts and focus. Newborn health research funding is low relative to the burden. There is no systematic tracking of Newborn research funding.

Also the burden is among the rural and urban poor, marginalized groups and in emergency and post conflict situations but the focus is on high income families mainly in urban setting. The burden is at home where about 60 million births occur, at basic health centres and on the way to care (>2 million neonatal deaths take place on the way) but the focus is in hospitals.

The standard research pipeline – Description – Discovery – Development – Delivery provides a helpful framework to determine priorities for research. INDEPTH focus is most likely around Description and Delivery research rather than front-end Discovery and Development.

Priorities for newborn health
- Three main causes of newborn death are preventable but existing "delivery" questions remain
- Stillbirths are also missing on the global agenda. There is both a data collection gap (most stillbirths are uncounted, up to half are at home; globally 75% of child death data comes from Demographic Health Survey (DHS) data – which is currently not reliable for stillbirth rates), as well as a data consistency gap (Definition confusion for "stillbirth"; multiple cause of death classification systems; lack of consistency in attributing cause of death)
- Key area of research - delivery of integrated MNCH packages to reduce neonatal deaths. Priorities for DELIVERY research for health system packages include:
    - Routine postnatal care for mother and baby
    - Treating neonatal infections (and maternal postnatal complications) especially where referral is not possible
    - Extra care of preterm babies in the community, and linking to improved facility care, KMC
    - Integrated service delivery in practice, e.g. in settings with high HIV/AIDS prevalence through PMTCT and early feeding support
    - Improved facility-based care, especially improved neonatal care at district hospital level

Role of a Newborn interest group within INDEPTH in filling the gaps
Description
- Research agenda: Improving estimates, understanding relationships, determinants; improving data, tools, collection systems, local use of data
- Pregnancy surveillance
    - Gestational age
    - IUGR and preterm birth and overlap
    - Stillbirth and neonatal death misclassification
    - Stillbirth to Early NND ratios
- Standard verbal and social autopsy tools and hierarchies
- Coverage of care

Delivery – already some HDSS are helping answer delivery questions. Examples are:
- Newhints (Kintampo)
- UNEST (Iganga)
- INSIST (Mtwara/IHI)
- Home visit package
- mHealth – use of cell phones, PDAs for monitoring health outcomes and coverage

Ghana Newhints trial overview – Charlotte Tawiah
The Newborn Home Intervention Trial (NEWHINTS) study was presented by Charlotte Tawiah on behalf of the NEWHINTS Team at Kintampo Health Research Centre in Ghana. This cluster-randomised trial is designed to evaluate the impact of routine home visits to women and their

families in pregnancy and in the 1st week of life of the baby on neonatal mortality. The team worked with local DHMT and community structures to develop a feasible and sustainable intervention to improve newborn care practices through routine home visits in pregnancy and the first week of life. Results will be available this year.

UNEST trial overview – Peter Waiswa

A Summary of Uganda Newborn Survival Study (UNEST) at the Iganga/Mayuge HDSS, Uganda was presented by Peter Waiswa. This is an ongoing interventional study with the aim of developing and costing an integrated maternal-newborn care package that links community and facility care that informs programs and policy.

Discussion – led by Alexander Manu of Kintampo HDSS

Consensus: It was agreed that this group on newborn research within the INDEPTH Network is *necessary* and has a unique opportunity to move the newborn agenda forward.

Alexander used the template of key indicators requested from all the sites earlier by Peter and Kate as basis for this plenary discussion to look at what data already exist at various DSS sites and how sites could share their experiences regarding the collection of certain data that have been identified as pivotal to bridging the gaps in knowledge.

The following table summarizes the outcome of the discussion:

Level of data collection currently being undertaken at HDSS

Indicator	Remarks
Pregnancy surveillance	All sites conducting pregnancy surveillance with a specific pregnancy form at intervals of between 3-6 months.
Neonatal death	All sites. It was remarked that specific perinatal and infant causes of deaths are not well covered in the current VA tools and there was the desire that the forum could explore generating a standard version which will group deaths in a way that will be programmatically friendly.
Stillbirths	All (except Ifakara?)
Maternal deaths	All adult deaths are code but there aren't standard codes for maternal deaths in the sites
Gestational age at birth	This is not routine surveillance but Chakaria, Bangladesh have LMP and date of delivery included. Kilifi does LMP**.** Cultural barriers were cited as potential concern for collecting such information; ICCDRB solved this by replacing male interviewers with female interviewers. Ifakara extracts LMP from ANC cards.

Birth weight	Only hospital births have this recorded; in Kilifi, Kenya 40% births are in hospital and so this information is linked back to DSS. In Kintampo, this is recorded only in research settings, but as facility deliveries have increased to nearly 70%, linking DSS to the health system will also give better data.
PDA use	Used in Kemri/Cdc and Iganga. Ifakara and Kintampo are doing some roll out.
Neonatal morbidity data	This data is very lacking but it was realized that this sort of data lends itself mainly to facility level collection Manochi collects from facility but not community and tool is in Portuguese.
Neonatal Verbal autopsy	All using standard WHO module
Neonatal Social Autopsy	Being conducted at Iganga, Dodowa, ICCDRB
Unique tools	Mostly using WHO VA. There is not much customization. Ifakara is to share post partum interview tool.

NB. 'All' does not include KEMRI/MCTA, West Kisumu site whose DSS is soon to be launched.

Concerns raised:
- The difference in the number of times the surveillance is carried out at different sites makes different sites have different error margins especially with regard to the collection of neonatal mortality and morbidity data. The longer the intervals between rounds, the poorer the data quality and the higher the recall bias.
- The reliability of gestational age when baby is born at home
- Stillbirths are not always reported
- Standardization of how cause of death is ascribed across the sites-: need to use the Hierarchical model which ascribes programmatically relevant causes of newborn deaths and stillbirths
- Coding problems - adapting codes for newborn deaths or stillbirths at the sites - no site is yet doing any coding for causes of stillbirths

Other important issues:
- Capacity building in other African countries: Sierra Leone for instance was cited even though the country is not represented in the INDEPTH network.
- Taking advantage of mobile phone technology to improve health: This was discussed extensively and members felt there was an opportunity to use the mobile phone technology to improve services to reach to mothers and their newborn children.

Way forward – led by Peter Waiswa

Coordination: This is to begin by setting up a mailing group with the suggested name "INDEPTH newborn group" with the INDEPTH Secretariat kept in the loop. The designated key

contact person at the INDEPTH Secretariat was identified as Dr. Agaya Bawa. Peter was asked to continue with the coordination of the group and he requested support from Alex and Kate who both agreed.

Start up actions:
- Circulate minutes (action by Janet)
- Write up and circulate a **Concept note** (Action by Peter, Alex and Kate)
- The participants will use the minutes and concept note to introduce and get consensus on participation in the working group at the various home sites
- Participants to determine the level of commitment for this work at their sites and give feedback communication within two months
- **Start looking at the data at the individual sites to determine what we know at present, what we would like to know, and think about the indicators to use to determine newborn health.**
- Collect and share local indicators. To begin with each site is to compile and share a 'Newborn health profile' which is to include the following indicators among others (see Annex 2. Newborn profile):
    - Birth rate
    - Fertility rate
    - Fresh still birth rate
    - Neonatal Mortality rate
    - Early Neonatal mortality rates
    - Day of death
- Questionnaires in use or potentially in use to be shared for the sake of uniformity across sites to facilitate potential cross site data analysis.

Plan for next meeting:
- The next meeting is tentatively planned for September/October 2011 to coincide with the 2011 INDEPTH AGM.
- By then we should be a working group with preliminary data to present and a brochure on the group's membership and potential activities in order to attract funding.

Potential partners:
- INDEPTH has start up money for worthwhile endevours ($25000)
- Child Health Epidemiology Reference Group (CHERG). Dr. Joy Lawn of save the Children to help make the links.
- JICA - if the group meets their objectives for receiving support. Requests for support go through Dr. Osman Sankor the INDEPTH Network Executive Director. JICA would also like to receive the Concept note when it is ready.
- Saving Newborn Lives, Save the Children – this grant phase is coming to an end but will be a key activity to consider if SNL continues.
- DFID consortium

Conclusion: The meeting ended on a positive note with what started out as a loosely organized group becoming a group with a definite plan of action.

Annex 1. List of participants

	NAME	HDSS CENTRE	Address (email, PO Box, Tel, Fax)
1	Alexander Manu	Kintampo HDSS, Ghana	Makmanu128@gmail.com; Alex.manu@kintampo_hrc.org
2	Charlotte Tawiah	Kintampo HDSS, Ghana	Charlotte.tawiah@kintampo_hrc.org
3	Daniel Azongo	Navrongo, Ghana	dazongo@navrongo.mimcom.org; kdazongo@gmail.com NHRC Box 114 Navrongo, Ghana Tel+233 244997666
4	David T Kangoye	SAPONE, Burkina Faso	tigakd@yahoo.fr CNRFP, BP 2208 Onagadongon, Burkina Faso
5	Evasius Bauni	KEMRI-WELLCOME TRUST, EDI-DSS, Kilifi	ebauni@kilifi.kemri-wellcome.org PO Box 230 Kilifi, Kenya
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7	Janet Oyieko	MCTA/Kisumu West HDSS	joyieko@wrp-ksm.org KEMRI PO Box 54- 40100 Kisumu Tel +254 733777928, +254721996988
8	Kate Kerber	Save the Children Cape Town, South Africa	kkerber@savechildren.org
9	Kenji Shibuya	University of Tokyo	shibuyak@m.u-tokyo.ac.jp
10	Lucy Linda Yevoo	Dodowa Health Research Centre	lyevoo@gmail.com
11	Mathew Alexander	Ifakara HDSS	malexander@ihi.or.tz PO Box 53 Ifakara, Morogoro, Tanzazia
12	Mohammed Iqbal	Chakaria, Bangladesh	miqbal@icddrb.org ICDDRB. Mohakhali, Dhaka, 1212
13	Peter Waiswa	Iganga/Mayuge	pwiswa@musph.ac.ug Makerere University school of public health, PO Box 7072, Kampala, Uganda. Tel + 256772405357
14	Sabine Gabrysch	Heidelberg University (Naouna Kintampo Cooperation)	Sabine.gabrysch@gmx.de
15	Sayako Kanamori	Ministry of Foreign affairs, Japan	sayakokanamori@mofa.go.jp
16	Terhi Lohela	Heidelberg, Germany	Terhi.lohela@helsinki.Fi
	Absent at the meeting but interested		
17	Paschal Ssebowa	Rakai HSP, Uganda	pssebbowa@rhsp.org
18	Sacoor, Charfudin Nicos Jussub	Manhica HDSS, Mozambique	charfudin.sacoor@manhica.net

Annex 2: HDSS Newborn profile template

INTEREST GROUP FOR NEWBORN HEALTH RESEARCH IN THE INDEPTH NETWORK

Name:
Email contact:
HDSS name:

1. What is the population of your HDSS?
2. Are you currently undertaking research relevant to neonatal health outcomes?
3. Are you conducting pregnancy surveillance? How often?
4. Are you collecting neonatal mortality outcomes?
5. Are you collecting data on stillbirths?
6. Are you collecting maternal mortality outcomes?
7. Are you collecting data on gestational age?
8. Are you collecting birthweight information?
9. Are you collecting neonatal morbidity data?
10. Are you conducting neonatal verbal autopsy?
11. Are you conducting neonatal social autopsy?

Key indicators (past three years)
1. Annual number of births
2. Total Fertility Rate
3. SBR (%fresh?)
4. Neonatal mortality rate
5. Early neonatal mortality rate
6. Distribution of day of death (0-28 days)

Pregnancy and newborn-relevant tools available (please share if available):

Tool	Format	Available to share?
Pregnancy surveillance		
Neonatal verbal autopsy module and hierarchy		
Social autopsy module relevant to neonatal		
Other (specify)		

Please send responses to Peter Waiswa at pwaiswa2001@yahoo.com.