EVERY NEWBORN
INDEPTH STUDY

Why? What? Where?

BMC
Population Health Metrics
biomedcentral.com
Part of Springer Nature

Presenter: Hannah Blencowe LSHTM team, United Kingdom

#everynewborn
#endstillbirths
#EN_INDEPTH

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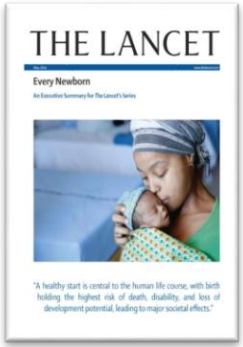
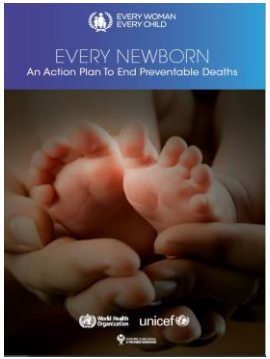
Opportunity & imperative for better measurement

BURDEN: ~4.5 million mostly in LMICs

~2 million stillbirths,
~2.4 million neonatal deaths,
~0.3 million maternal deaths





OPPORTUNITY: 1st ever global goal for reducing neonatal deaths by 2030 and more focus on stillbirths

CHALLENGE: measurement gap

AMBITIOUS measurement improvement plan 2015-2020 led by WHO with LSHTM to improve metrics based on evidence for selected priority gaps so findings can be used to drive change towards SDG targets

Supplement papers available here

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Population based surveys

MEASUREMENT OPPORTUNITY:

- DHS and MICS major data sources for LMICs for national and global estimates on
  - Neonatal deaths
  - Stillbirths
  - Low birth weight

IMPERATIVE TO IMPROVE

- Especially for stillbirth capture surveys may underestimate
- No rigorous comparison of survey-based measurement approaches especially maternity histories
- Research regarding question design and performance regarding pregnancy outcomes lacking
- No multi-country standardised qualitative assessments of barriers and enablers to capturing pregnancy outcome data

Aim & objectives

AIM: To improve measurement of pregnancy outcomes in population-based surveys especially large scale platforms like DHS and MICS

OBJECTIVES:

1. **Randomly compare** two maternity history approaches for the capture of stillbirths and neonatal deaths, and time taken (Published Lancet GH, April 2020).
2. **Evaluate use of existing/modified survey questions** to capture fertility intentions and selected pregnancy outcomes (TOP, miscarriage, birthweight, gestational age), as well as birth and death certification.
3. **Compare EN-INDEPTH survey & routine HDSS** capture of pregnancy outcomes
4. To identify **barriers and enablers** to the reporting of pregnancy and adverse pregnancy outcomes

Baschieri et al "Every Newborn-INDEPTH" (EN-INDEPTH) study protocol for a randomised comparison of household survey modules for measuring stillbirths and neonatal deaths in five Health and Demographic Surveillance sites. J Global Health 2019 Jun;9(1):010901. doi: 10.7189/jogh.09.010901.

Methods

Household survey of 69,176 women with electronic data collection using the World Bank's Survey Solutions software

Time taken to administer questions assessed using **paradata**

Community perceptions and barriers/enablers to reporting of pregnancy and adverse pregnancy outcomes explored in **Focus Group Discussions with women & interviewers**

Baschieri et al "Every Newborn-INDEPTH" (EN-INDEPTH) study protocol for a randomised comparison of household survey modules for measuring stillbirths and neonatal deaths in five Health and Demographic Surveillance sites. J Global Health 2019 Jun;9(1):010901. doi: 10.7189/jogh.09.010901.

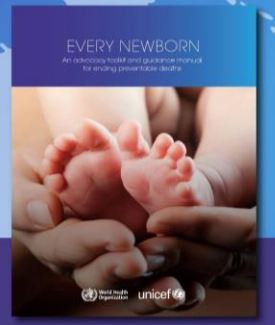
Bandim (Guinea-Bissau)	
Start year	1978
En-INDEPTH survey number of births	12,282

Dabat (Ethiopia)	
Start year	1996
En-INDEPTH survey number of births	8,380

Matlab (Bangladesh)	
Start year	1966
En-INDEPTH survey number of births	21,319

Kintampo (Ghana)	
Start year	1994
En-INDEPTH survey number of births	16,046

IgangaMayuge (Uganda)	
Start year	2004
En-INDEPTH survey number of births	8,622



En-INDEPTH Study Team, facilitated by the London School of Hygiene & Tropical Medicine and Makerere University School of Public Health in partnership with the Every Newborn Movement, co-chaired by WHO and UNICEF

Supplement papers available here

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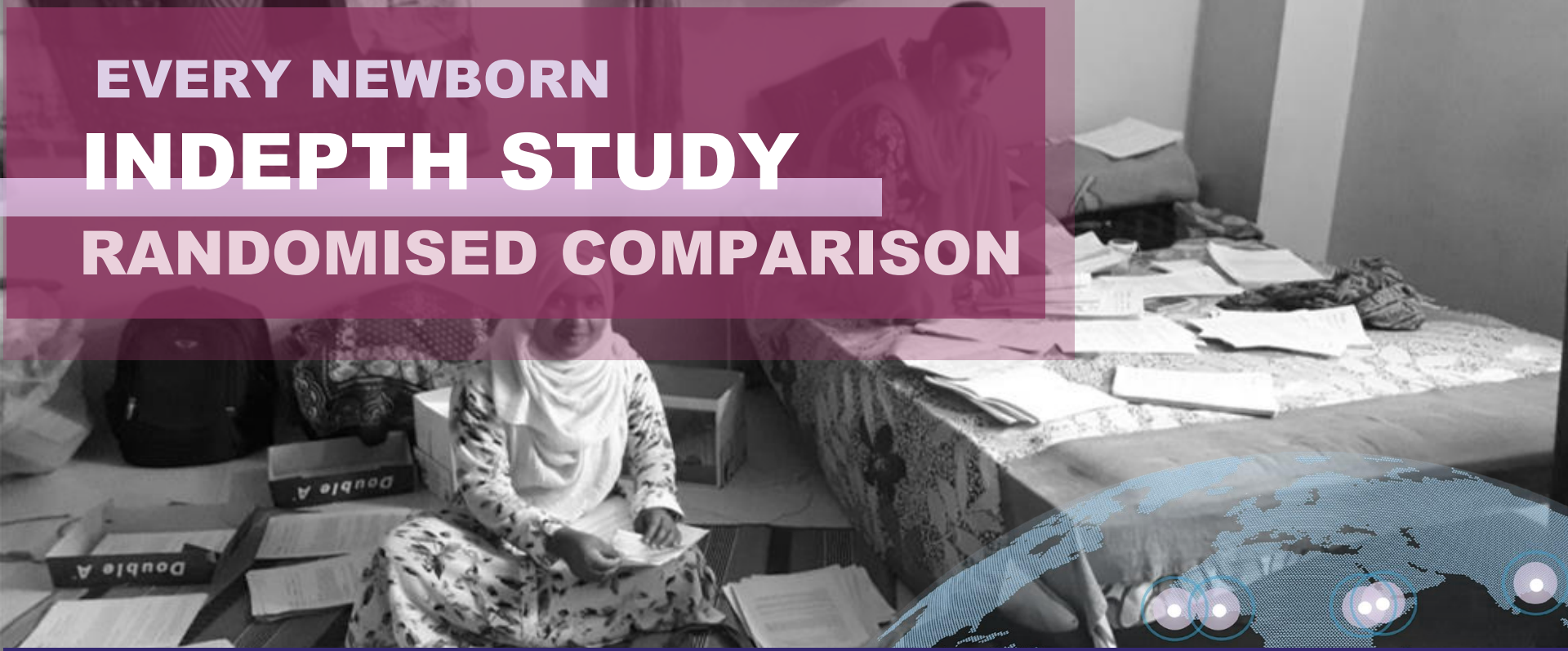

EVERY NEWBORN
INDEPTH STUDY
RANDOMISED COMPARISON

Presenter: Joseph Akuze

J Akuze, H Blencowe, P Waiswa, …Je Lawn, Cousens. Randomised comparison of two household survey modules for measuring stillbirths & neonatal deaths in 69,176 pregnancies in five countries: Every Newborn-INDEPTH study. Lancet Global Health 2020. **Paper available here**

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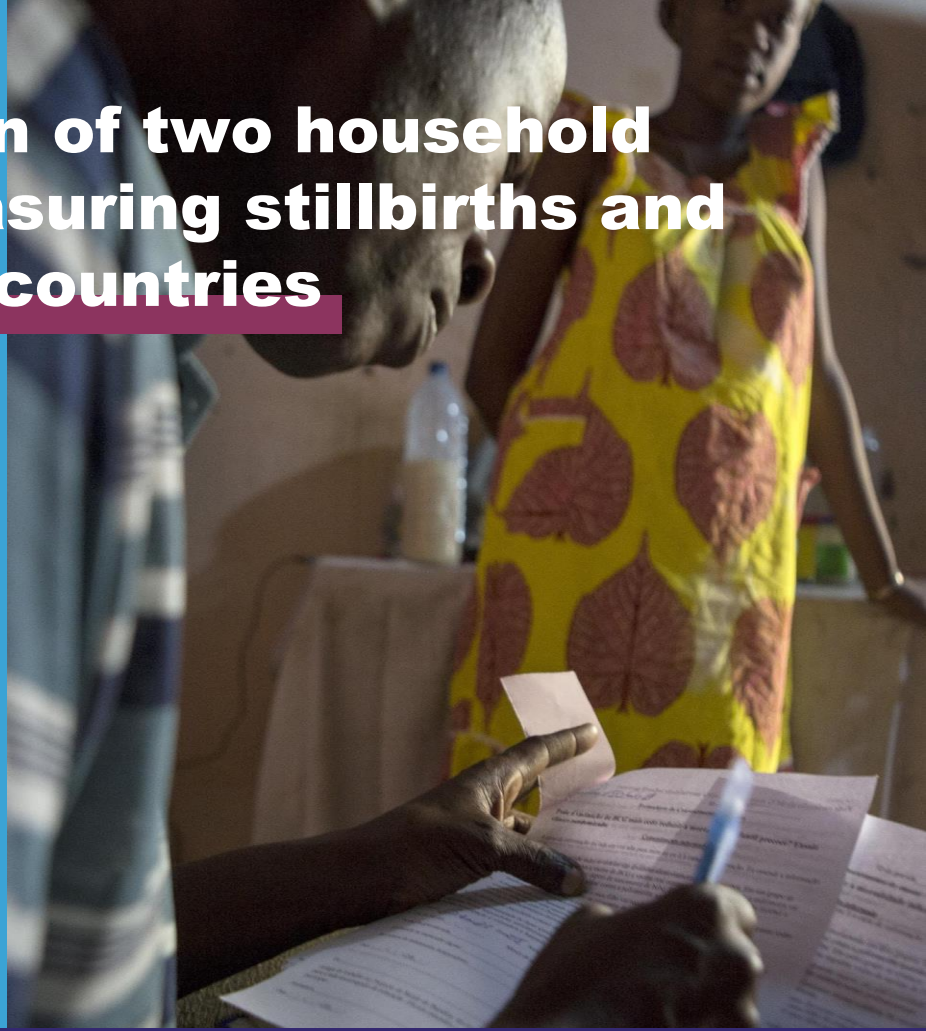
LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE · MARCH Maternal Adolescent Reproductive & Child Health · Projecto de Saúde BANDIM · icddr,b · Makerere University · Uganda Virus Research Institute GHS-MOH · CIFF CHILDREN'S INVESTMENT FUND FOUNDATION

Randomised comparison of two household survey modules for measuring stillbirths and neonatal deaths in five countries

1. What was known already?
2. What was done?
3. What was found?
4. What next in measurement and in research?



Akuze et al:Randomised comparison of two household survey modules for measuring stillbirths and neonatal deaths in five countries: the Every Newborn-INDEPTH study. Lancet Global Health 2020

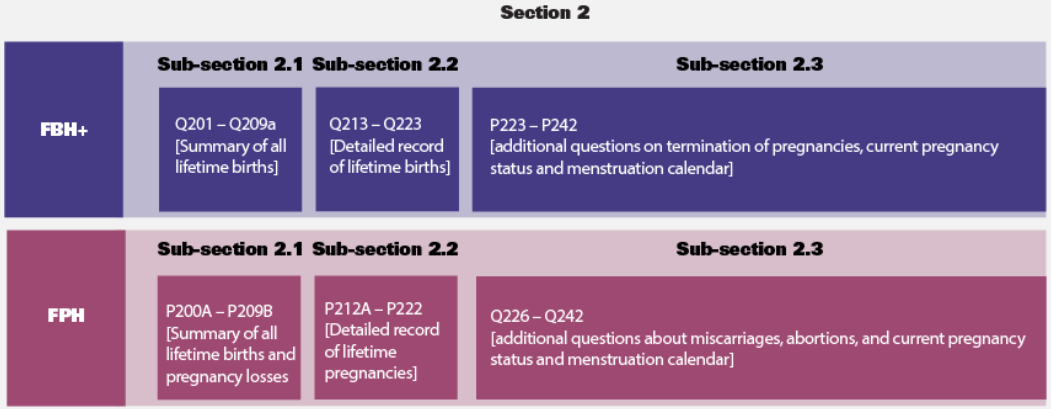
What was known already about counting >5 million stillbirths and neonatal deaths?

High income countries <1% of the deaths	Reliable data in registries, Civil and Registration Vital Statistics systems (CRVS)
Low-Middle-Income Countries Majority of the deaths	Data gaps and still reliant on population based surveys especially: • Demographic and Health Surveys (DHS) >90 countries over the last 4 decades • Multiple Indicator Cluster Surveys (MICS) Both rely on a visit to a household every usually every 3-5 years and asking a maternity history

Maternity Histories in surveys

- **Two methodologies:**
  - **FBH+** Full live birth histories with pregnancy loss questions (calendar histories, last 5 years)
  - **FPH** Full pregnancy history (all live births and pregnancy losses)

No direct comparison made between these approaches



What was done?

Household survey of 69,176 women aged 15-49 years in 5 sites

Electronic data collection using **Survey Solutions** platform

Women **individually randomised** to either FPH or FBH+

Additional questions on pregnancy, postnatal care & fertility preferences

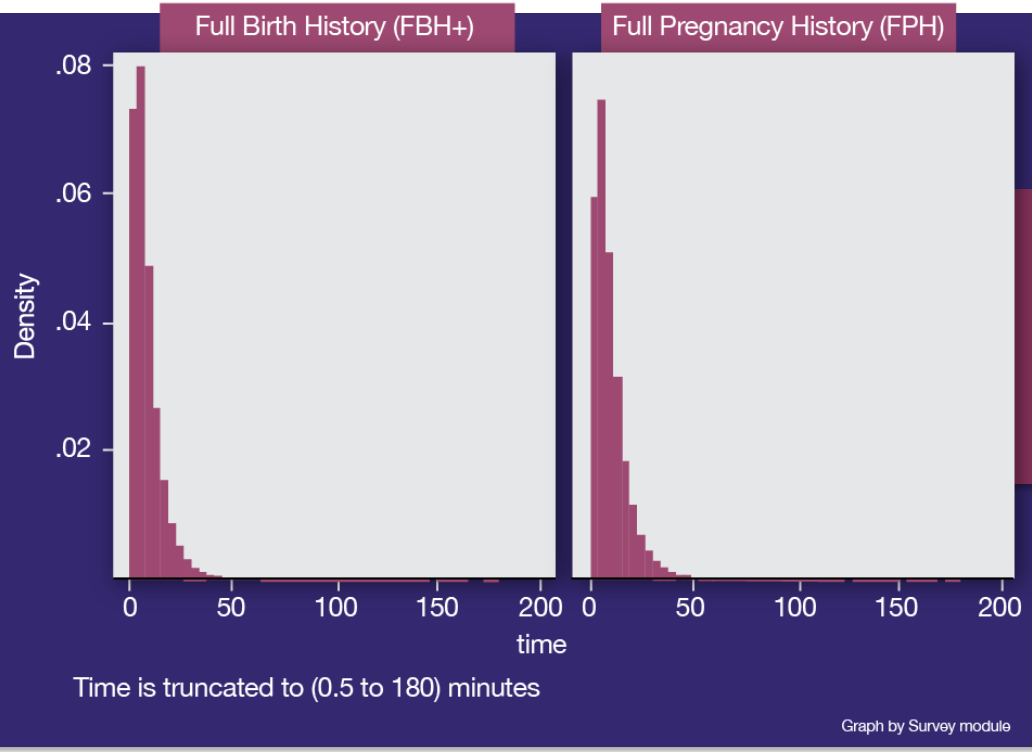
Data collection: July 2017 - August 2018 by 117 predominantly female interviewers

Compared FPH and FBH+ in terms of:

Capture of stillbirths and neonatal deaths

Time taken to administer

What was found re time taken?



Little difference in mean time

FBH+:9.1 mins (9.0-9.3)

FPH:10.5 mins (10.4-10.6)

What was found re neonatal deaths?

Sample size = 1,656 neonatal deaths reported in last 5 years

- FBH+ : n = 839 deaths | 33,020 livebirths
- FPH: n = 817 deaths | 32,546 livebirths

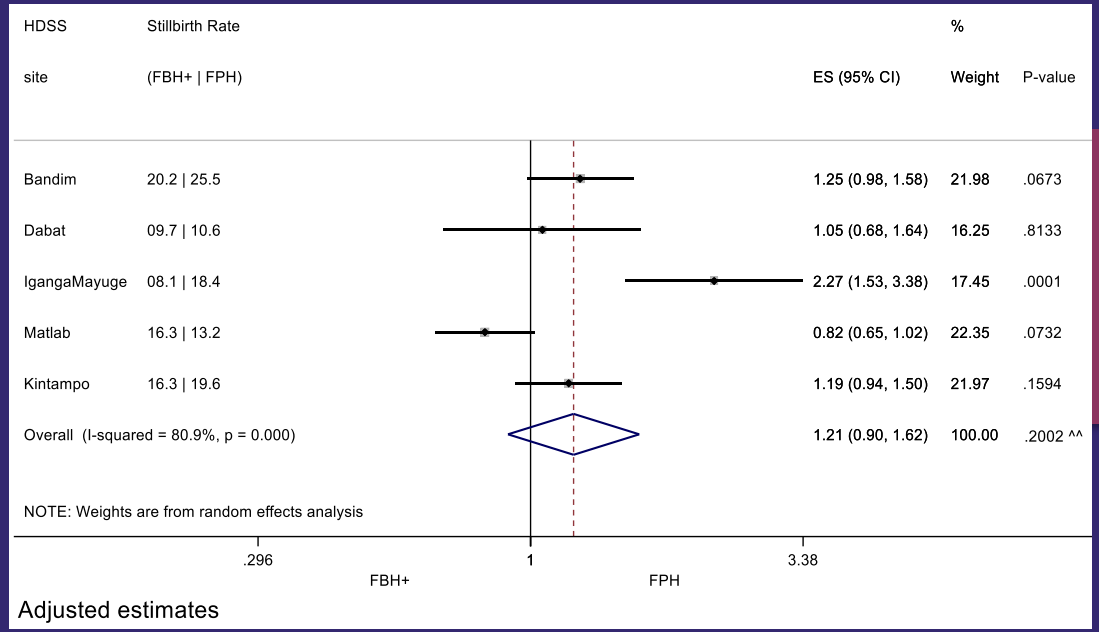
BUT NO DIFFERENCE DETECTED BETWEEN FBH+ vs FPH

FBH+ 25.4 (23.7 – 27.1) vs FPH 25.1 (23.4 – 26.8) aOR 1.0 (0.9 – 1.1)

Little difference between crude analysis or adjusted for neonatal deaths clustering by individual women

NMR PLAUSIBLE compared to data/estimates for all 5 countries

What was found re stillbirths

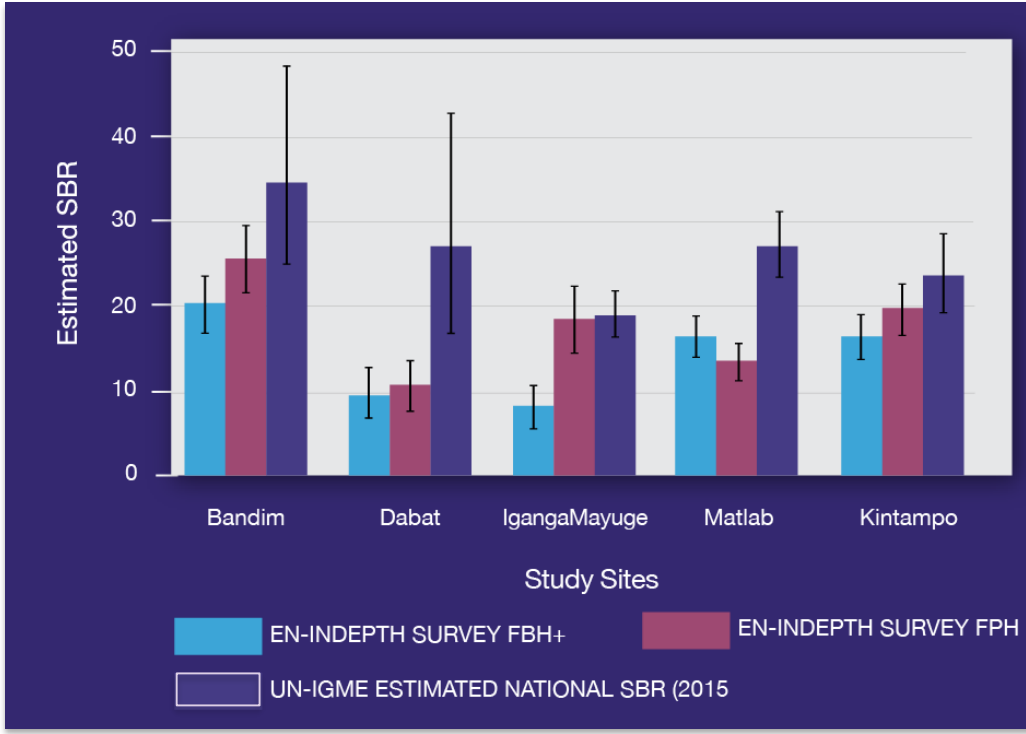


Sample size = 1,083 stillbirths reported in last 5 years

DIFFERENCE DETECTED

Overall SBR **21% higher** in FPH vs FBH+ (95%CI -10 – 62%)

What was found re stillbirths?



SBR higher using FPH in 4 sites

BUT

- SBR in survey remains lower than expected
- Heterogeneity between sites

WHY?

- Omission & misclassification?
- Differences in survey implementation ?

.

RANDOMISED COMPARISON

What next: in measurement & research?

Measurement now

- FPH has potential to increase stillbirth capture in surveys
- DHS-8 has now got FBH + with FPH in standard questionnaire
- Standardised guides needed for implementation of FPH; including translations, software, training materials, interviewer prompts

Research

- Further research to understand omission & misclassification of stillbirths in surveys
- Paradata analyses to improve question structure and software design
- Barriers and enablers to capturing information on pregnancy outcomes, and implementation research to address these

Akuze et al:Randomised comparison of two household survey modules for measuring stillbirths and neonatal deaths in five countries: the Every Newborn-INDEPTH study. Lancet Global Health 2020

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EVERY NEWBORN
INDEPTH STUDY
BARRIERS & ENABLERS

Presenter: **Doris Kwesiga**- Analysis and paper writing led by **multi-site qualitative working group**

Authors: Kwesiga D, Tawiah C, Imam AMd, Adane KT, Nareeba T, Enuameh Y, Biks GA, Manu G, Beedle A, Delwar N, Fisker AB, Waiswa P, Lawn JE, Blencowe H

Paper available here

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BARRIERS & ENABLERS TO REPORTING PREGNANCY & ADVERSE PREGNANCY OUTCOMES

- What was known already?
- What was done?
- What was found?
- What is next in measurement and research?

What was known already?

- **BURDEN:** Each year there are > 5.4 million stillbirths, newborn and maternal deaths
- **MEASUREMENT:** Surveys like DHS are main way to measure pregnancy & adverse pregnancy outcomes (APOs) for the highest burden countries
- **BARRIERS:** Data quality challenges to survey capture of pregnancy outcome data include omission & misclassification[1] Social norms influence reporting yet this has not been studied in multi-country qualitative research
- Barriers and enablers to reporting pregnancy and adverse pregnancy outcomes in population-based surveys

[1]Johnson K, Grant M, Khan S, Moore Z, Armstrong A, Sa Z. Fieldwork-related factors and data quality in DHS program. DHS Analytical Studies. 2009;19.

What was done?

- **Qualitative study** as part of EN-INDEPTH study in all 5 HDSS sites Focus Group Discussions (28):
  - Women (172)
  - Survey interviewers (82)

- **Community perceptions and barriers/enablers** to reporting of pregnancy including miscarriages, stillbirths and neonatal deaths (APOs)

What was found?

- **METHODOLOGICAL** barriers to reporting **pregnancies and APOs** in surveys
  E.g tools, training, local understanding, Interviewer skills & knowledge

- **SOCIOCULTURAL** barriers to reporting **pregnancy and APOs**
  Similar across 5 settings, including religious and cultural beliefs and stigma.
  Barriers greatest for adolescents and young women

- **GRIEF**
  Psychosocial trauma associated with loss means that many mothers do not want to recount these negative experiences, especially for a purpose they do not understand.

"Dose response"

More barriers to reporting APOs at earlier gestations, with more stigma

Miscarriage > Stillbirth > Neonatal death > Child death

What next: measurement & research?

What is needed to improve the data?

Tools/questions: Cultural and contextual adaption, translation

Strengthening interviewer soft skills: Rapport building, probing and empathy
Interviewers with adequate knowledge & ability to communicate

Approaches to contextualization?

Evaluation of enhanced training materials and supervision

Thanks to #EN_INDEPTH collaborative group

Read papers and summaries at bit.ly/EN_INDEPTH

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EN-INDEPTH collaborative group

Bandim: Ane B Fisker (PI); Justiniano SD Martins; Amabelia Rodrigues; Sanne M Thysen

Dabat: Gashaw Andargie Biks (PI); Solomon Mokonnen Abebe; Tadesse Awoke Ayele; Telake Azale Bisetegn; Tadess Guadu Delele; Kassahun Alemu Gelaye; Bisrat Misganaw Geremew; Lemma Derseh Gezie; Tesfahun Melese; Mezgebu Yitayal Mengistu; Adane Kebede Tesega; Temesgen Azmeraw Yitayew

IgangaMayuge: Simon Kasasa (PI); Edward Galigawango; Collins Gyezaho; Judith Kaija; Dan Kajungu; Tryphena Nareeba; Davis Natukwatsa; Valerie Tusubira

Kintampo: Yeetey AK Enuameh (PI); Kwaku P Asante; Francis Dzabeng; Seeba Amenga Etego; Grace Manu; Alexander A Manu; Obed Ernest Nettey; Sam K Newton; Seth Owusu-Agyei; Charlotte Tawiah; Charles Zandoh

Matlab: Nurul Alam (PI); Nafisa Delwar; M Moinuddin Haider; Md. Ali Imam; Kaiser Mahmud

LSHTM/ Makerere School of Public Health: Joy Lawn (PI), Peter Waiswa, Joe Akuze, Angela Baschieri; Hannah Blencowe, Simon Cousens; Vladimir S. Gordeev; Victoria Ponce Hardy; Doris Kwesiga; Kazuyo Machiyama, Judith Yargawa

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EVERY NEWBORN
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BMC Supplement

Presenter: Judith Yargawa, LSHTM team on behalf of the EN-INDEPTH team

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Population Health Metrics
BMC

Summary

Huge team effort:

Active **core paper writing group** with representation from each HDSS site, Makerere & LSHTM for each paper

EN-INDEPTH collaborative group contributions

Papers launching today:

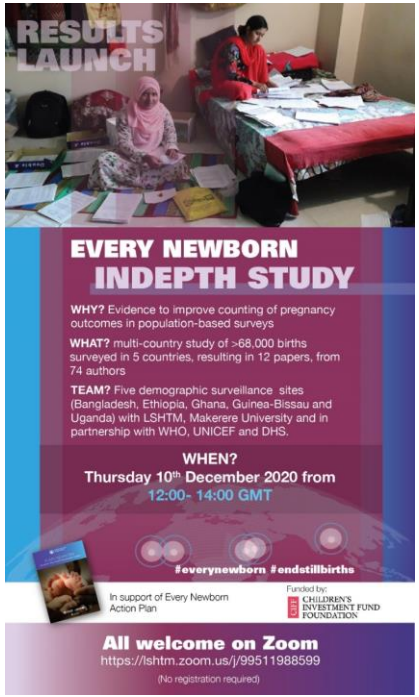
4 papers on measurement processes

2 led by PhD students based at Makerere

8 papers on pregnancy outcomes (& intention)

5 led by the HDSS site teams

Results on comparison between survey & HDSS to follow.



Summary of the EN-INDEPTH papers in BMC

MEASUREMENT PROCESSES

History of DHS capture of stillbirth & neonatal deaths 1
- Changes in DHS relevant systems over time
- Changes in mortality measurement over time

Barriers and enablers to reporting 2
- To reporting pregnancy
- To reporting adverse pregnancy outcomes

Electronic survey data collection 3
- Lessons learnt from study system
- Perspectives from fieldworkers and supervisors

Paradata to improve survey function 12
- Differences in timestamped entries (FPH vs FBH+)
- Question characteristics vs answer correction rates
- New classification of answer correction types

Linking with demographic surveillance
- Comparison of methods and processes in 5 HDSS sites
- Comparison of population level SBR and NMR in 4 HDSS sites
- Individual linkage of pregnancies in HDSS and survey data

PREGNANCY OUTCOMES

Pregnancy Intention 4
- Data completeness
- Data quality (level of agreement)
- Data utility

Termination of pregnancy 5
- Data completeness
- Data utility
- Barriers and enablers to reporting

Stillbirth 6 7
- Outcome measurement (capture, classification, perceived value of birthweight and barriers to reporting)
- Care measurement (data completeness, associated factors)

Gestational age 8
- Data completeness
- Data quality and validity
- Perceived value and barriers to reporting

Birthweight 9
- Data completeness
- Data quality
- Perceived value and barriers to reporting

Birth and death registration 10
- Data completeness
- Data quality
- Data utility

Neonatal and child mortality 11
- Reported precision
- Data quality
- Capture

KEY:

Colours at edges signify methodology in each paper:

- Quantitative
- Qualitative
- Mixed Methods
- Review

Numbers signify paper order in supplement.

Abbrev:
SB= stillbirths
NND= neonatal deaths
SBR= stillbirth rate
NMR= neonatal mortality rate
HDSS= Health & demographic surveillance system

Supplement papers available here

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EN-INDEPTH papers in BMC

Measurement processes papers

ELECTRONIC DATA CAPTURE

Why? electronic systems increasingly used for surveys, but limited research on process

What was found? even with standard tool and software and training guides, there was variation in approach especially in one site

What next? Need more research on survey implementation

(Thysen, Tawiah et al.)

PARADATA

Paradata = timestamped records tracking the process of electronic data collection, but limited research on use in survey performance esp for pregnancy outcomes

What was found? From 3.6 million timestamped entries in 65,768 interviews, 84% of interviews had at least one corrected answer

What next? Results show which questions and practices can be improved to reduce corrections, save time and enhance data quality

(Gordeev et al.)

Thysen et al: Electronic data collection in a multi-site population-based survey: EN-INDEPTH study
Gordeev et al: Paradata analyses to inform population-based survey capture of pregnancy outcomes: EN-INDEPTH study

Pregnancy intention

Why?	Surveys are the major source of data on pregnancy intention in LMICs, however few studies have evaluated the actual questions used.
What was done?	Evaluated two sets of questions on pregnancy intention (pregnancy-specific intention and desired-versus-actual family size); assessed additional questions; investigated associations between pregnancy intention and maternal health service utilisation, and adverse pregnancy outcomes.
What was found?	• Near universal completeness of responses, but >10% 'don't know' responses for desired-versus-actual family size questions. • Desired-versus-actual family size assessment was inconsistent with future fertility desire. • Women with unintended pregnancies were less likely to have four ANC visits, start ANC in the first trimester, and report stillbirths and neonatal deaths.
What was next?	Additional questions could complement current survey questions, although not the only possibilities. Further research needed to advance methods to prospectively establish intention prior to pregnancy. Implementation research needed to improve coverage and quality of maternity care for women with unintended pregnancies.

Thanks to #EN_INDEPTH collaborative group

Read papers and summaries here

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EVERY NEWBORN
INDEPTH STUDY
TERMINATION OF PREGNANCY

Presenter: Yeetey Enuameh. Analysis and paper writing led by Kintampo HDSS team, Ghana

Authors: Enuameh YAK, Dzabeng F, Blencowe H, Thysen SM, Abebe SM, Asante KP, Tawiah C, Gordeev VS, Adeapena W, Kwesiga D, Kasasa S, Zandoh C, Imam MA, Amenga-Etego S, Newton SK, Owusu-Agyei S, Lawn JE, Waiswa P, Cresswell JA

Paper available here

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TERMINATION OF PREGNANCY

DATA COMPLETENESS & FEASIBILITY

1. What was known already?
2. What was done?
3. What was found?
4. What next in measurement and in research?

Enuameh et al:Termination of pregnancy data completeness and feasibility in population-based surveys: EN-INDEPTH study

What was known already?

- **BURDEN:** There are an estimated 73.3 million Termination of pregnancies (TOP) each year[1]
- TOP, especially if unsafe, remains an important cause of maternal death, especially in LMICs
- **MEASUREMENT:** TOP is included in some household surveys but are known to under-capture events

[1]Bearak, et al: **Unintended pregnancy and abortion by income, region, and legal status of abortion: estimates from a comprehensive model for 1990–2019** *Lancet GH* 2020.

What was done?

Roster and New/ modified survey questions on TOP & Menstrual restoration asked to women in FPH arm of study

Completeness of responses & data utility assessed

Time taken to respond to questions assessed

Community perceptions, practices and barriers/enablers to reporting TOP in household surveys explored

3 TYPES OF SURVEY QUESTIONS:

1. ROSTER TOP Questions

(Bandim, Dabat, IgangaMayuge, Kintampo, Matlab)

Directly eliciting information on lifetime pregnancy losses including TOP (n=6044)

2. Menstrual restoration questions NEW!

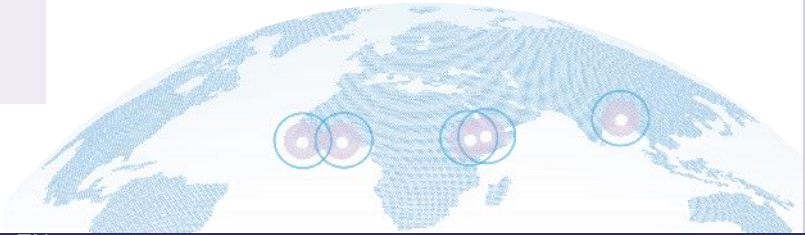
(Dabat, IgangaMayuge and Kintampo)

Actions taken to resume missed periods (n=3505)

3. TOP questions NEW!

(Dabat, Kintampo and Matlab)

For women not reporting TOP in Roster (n=17,038)



Completeness & data utility

Completeness of responses high: Roster, Menstrual Restoration and new TOP questions all **>90%**

ROSTER question

TOP rates over the five years preceding the study ranged from 0.3 (Dabat – Ethiopia) to 19.3 (Kintampo – Ghana) TOPs per 1,000 women aged 15 – 49 years

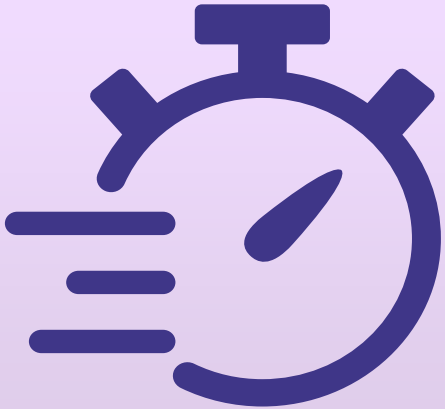
Menstrual restoration questions (NEW)

6.0% of women in Dabat, 12.0% in Kintampo and 17.2% in IgangaMayuge reported having used this during their lifetime

TOP questions (NEW)

Elicited extra lifetime TOPs of 2.0% (Dabat), 11.5% (Kintampo) and 15.5% (Matlab) from women who did not report TOPs in response to Roster questions

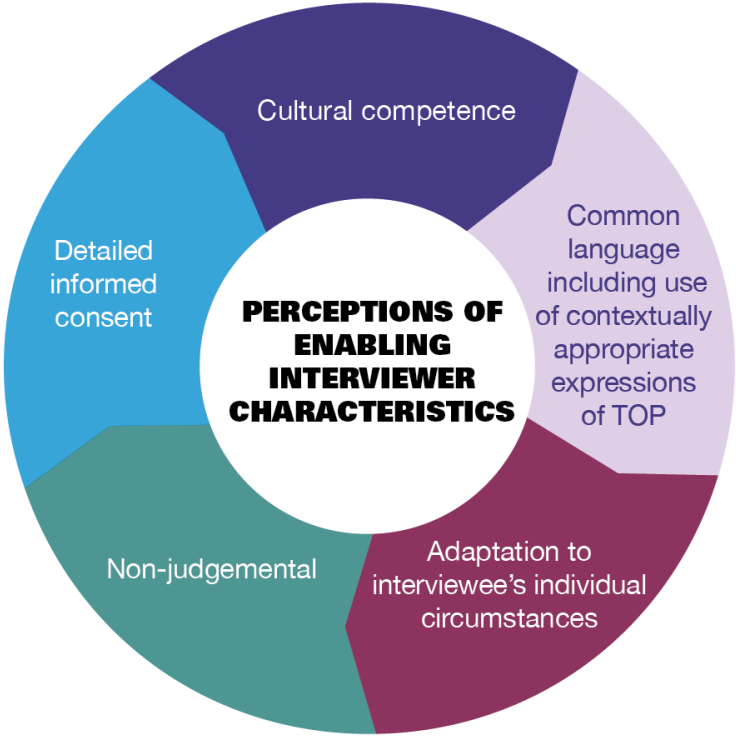
Median time taken to answer Roster questions?



<1.3 minutes

Barriers & Enablers to reporting

Community perceptions of barriers:
TOP difficult and uncomfortable to disclose. Perceived as immoral, inhumane, or shameful making it a secret to be kept by women.



TERMINATION OF PREGNANCY

What next: measurement & research?

What is needed to improve the data?

Improve survey processes: interviewer use of non-judgemental language in translations of questions and prompts

Standardise interviewer training: focus on interview techniques to address stigma and contextual barriers to reporting

Adequately powered studies to validate the use of new TOP questions in eliciting information on TOP to improve monitoring of this outcome in surveys.

Enuameh et al:Termination of pregnancy data completeness and feasibility in population-based surveys: EN-INDEPTH study

Thanks to #EN_INDEPTH collaborative group

Read papers and summaries here

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EVERY NEWBORN
INDEPTH STUDY
GESTATIONAL AGE

Presenter: **M Moinuddin Haider** - Analysis and paper writing led by **Matlab HDSS team, Bangladesh**

Authors: Haider MM, Mahmud K, Blencowe H, Ahmed T, Akuze J, Cousens S, Delwar N, Fisker AB, Ponce Hardy V, Hasan TSM, Imam MA, Kajungu D, Khan MAF, Martins JSD, Nahar Q, Nettey OEA, Tesega AK, Yargawa J, Alam N, Lawn JE **Paper available here**

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GESTATIONAL AGE

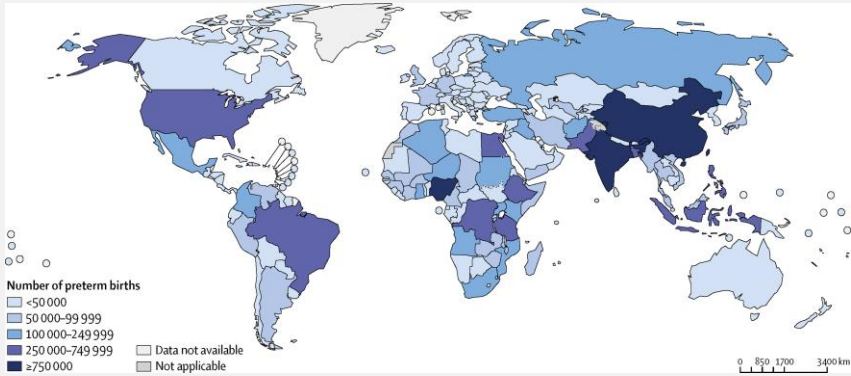
DATA COMPLETENESS, QUALITY & VALIDITY

1. What was known already?
2. What was done?
3. What was found?
4. What next in measurement and in research?

What was known already?

- **BURDEN:** Preterm birth is the leading cause of child deaths worldwide.
- **MEASUREMENT:**
  - Gestational age (GA) is key to identify preterm births
  - Household surveys rarely include GA
  - Barriers and enablers to GA data collection in surveys has not been studied.

15 million preterm births worldwide in 2014



[1]Chawanpaiboon S et al: Global**, regional, and national estimates of preterm birth in 2014: a systematic review and modelling analysis.** *Lancet Glob Health* 2019, **7:**e37-e46.

What was done?

Novel survey gestational age questions asked to 69,176 women for all livebirths in the 5 years preceding the survey

Completeness, data quality & validity assessed

Community perceptions and barriers/enablers to reporting accurate gestational age information in household surveys assessed (Focus Group Discussions with women and interviewers)

What affected data quality?

Completeness:

- GA in months reported for **>99% of births** in all sites.
- With interviewer prompting GA weeks available for **56-98% of births** (4 sites)
- With no prompting only **6%** were able to report GA weeks (Bandim).

What affected data quality?

Heaping:

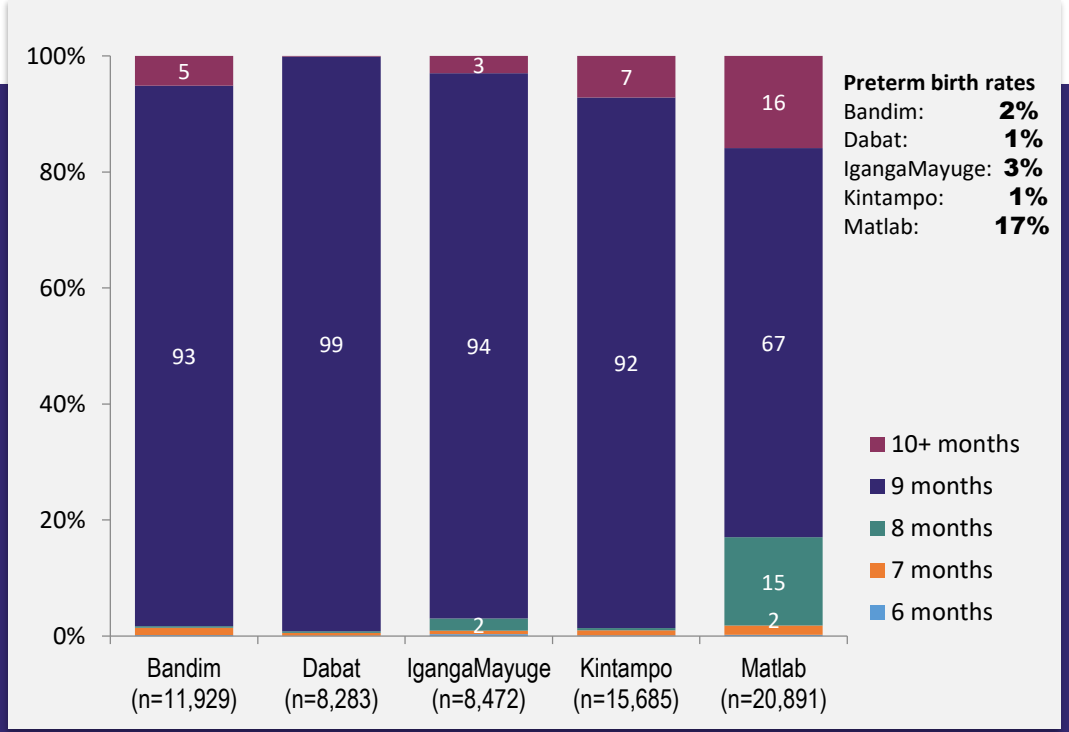
Matlab:

Less heaping of GA months and GA weeks

Reported GA in months and weeks give similar preterm birth rates

4 other sites:

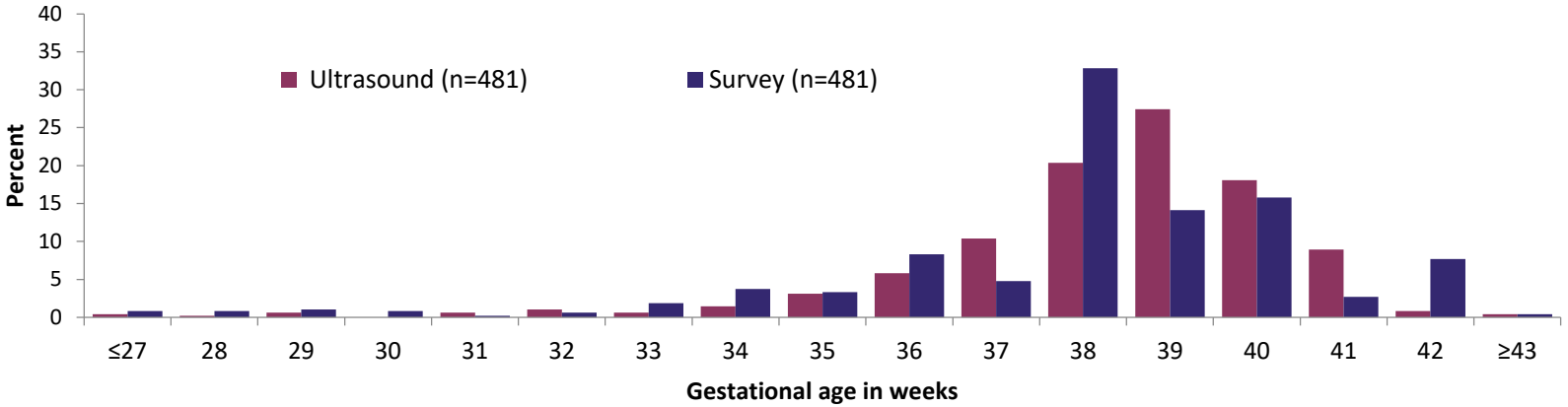
- >90% of births reported at 9 months GA
  ► low preterm birth rates
- GA weeks heaped on 36 weeks
  ►high preterm birth rates



Distribution of reported gestational age <u>in months</u> by HDSS site, EN-INDEPTH survey (five sites, n= 65,260)

Survey data validity (Matlab)

GA weeks (early pregnancy ultrasound) versus EN-INDEPTH survey, and HDSS data, last five years, Matlab (n=481)



Compared to early pregnancy ultrasound (n=481):
20.4% of survey GA weeks exactly the same as ultrasound GA
Sensitivity of survey GA weeks to detect preterm birth was **60% with specificity of 93%.**

What next: measurement & research?

In all sites, **gestational age was perceived** as valuable by women and interviewers

What is needed to improve the data?

Investment and innovation to improve the measurement of GA for every baby.

Improve communication of GA to every mother – including recording in health cards

…suggest adding GA questions to surveys.

Revised set of GA survey questions proposed.

Research to refine GA survey questions, improve consistency and link to health cards.

Improve community awareness of menstrual cycles and importance of GA.

Address barriers to reporting such as fear of social stigma and witchcraft.

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Matlab: Nurul Alam (PI); Nafisa Delwar; M Moinuddin Haider; Md. Ali Imam; Kaiser Mahmud

LSHTM/ Makerere School of Public Health: Joy Lawn (PI), Peter Waiswa, Joe Akuze, Angela Baschieri; Hannah Blencowe, Simon Cousens; Vladimir S. Gordeev; Victoria Ponce Hardy; Doris Kwesiga; Kazuyo Machiyama, Judith Yargawa

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EVERY NEWBORN
INDEPTH STUDY
BIRTHWEIGHT

Presenter: **Bisrat Misganaw** - Analysis and paper writing led by **Dabat HDSS team, Ethiopia**

Authors: Biks GA, Blencowe H, Ponce Hardy V, Misganaw B, Angaw DA, Wagnew A, Abebe SM, Guadu T, Martins JSD, Fisker AB, Imam MA, Nettey OEA, Kasasa S, Di Stefano L, Akuze J, Kwesiga D, Lawn JE

Paper available here

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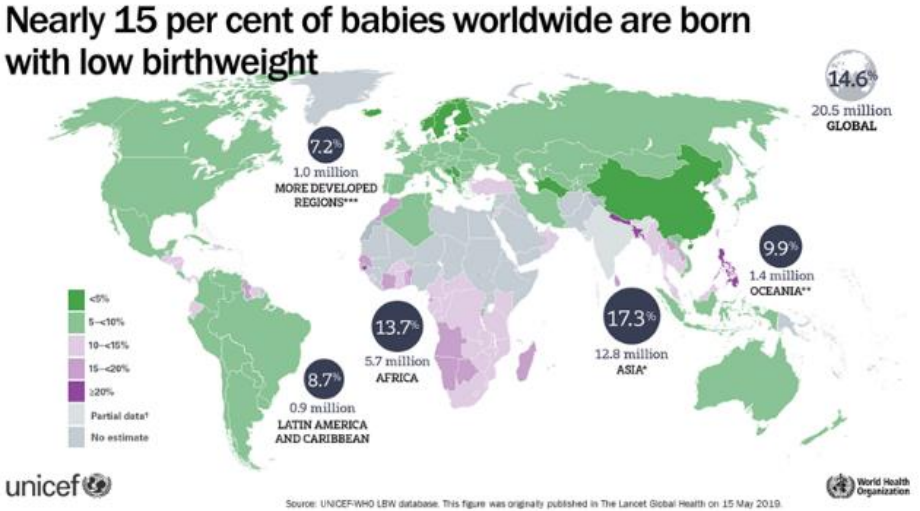
BIRTHWEIGHT

DATA COMPLETENESS & QUALITY

1. What was known already?
2. What was done?
3. What was found?
4. What next in measurement and in research?

What was known already?

- Around 20 million LBW babies/year, 80% in LMICs[1]
- Birthweight key indicator for SDGs, Every Newborn and nutrition plans
- Household surveys are major sources of birthweight data in LMICs
- Data quality issues affect global estimates - missing data and heaping



[1]Blencowe H, Krasevec J, de Onis M, Black RE, An X, Stevens GA, Borghi E, Hayashi C, Estevez D, Cegolon L, et al: **National, regional, and worldwide estimates of low birthweight in 2015, with trends from 2000: a systematic analysis.** *Lancet Glob Health* 2019, **7:**e849-e860.

What was done?

Survey birthweight questions asked for 14,411 livebirths since 1st January 2012 (Standard DHS/ MICS questions)

Completeness & data quality analysed

Time taken for birthweight questions assessed

Community perceptions and barriers/enablers to reporting accurate birthweight information in household surveys assessed (Focus Group Discussions with women and interviewers)

Whose weight did not count?

62% of babies reported to be weighed

Babies born at home

97% less likely to be weighed than facility births

aOR:0.03 (95%CI 0.02-0.03)

Neonatal deaths

81% less likely to be weighed compared to surviving babies

aOR 0.19 (95%CI: 0.16-0.24)

Low education

No education vs primary

aOR 1.43 (95%CI: 1.20-1.71)

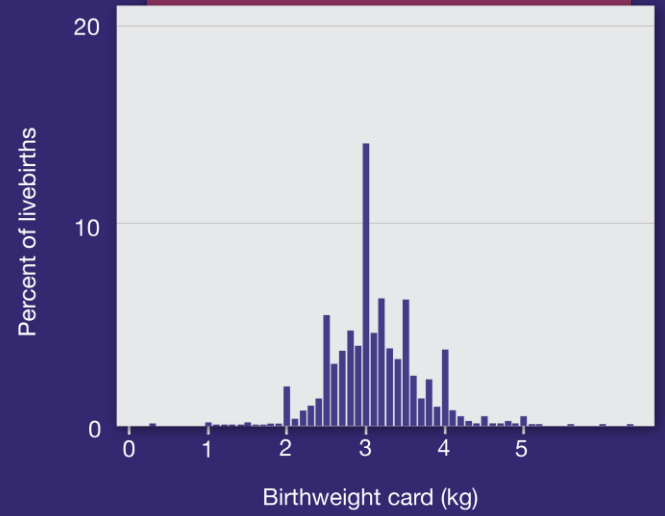
Poorest

Wealthiest 53% more likely to be weighed compared with poorest

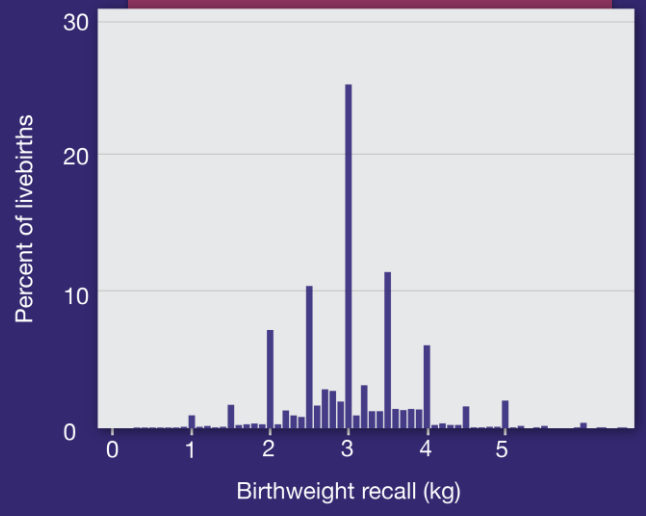
aOR 1.53 (95%CI: 1.24-1.86)

What affected data quality?

33% of all birthweights were from card:
Some heaping

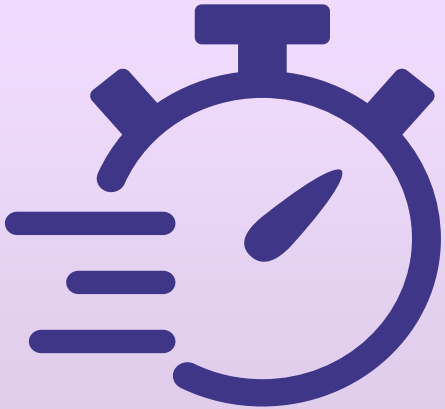


67% of all birthweights from recall:
Very marked heaping



Heaping of reported birthweight by card (n=3,057) and recall (n=4,702)

Time taken to answer questions?



0.2 minutes

What next: measurement & research?

In all sites, **birthweight was perceived** as valuable by women and interviewers

What is needed to improve the data?

Accurate scales to weigh every baby everywhere….

… including sick newborns, stillborn or born at home

Communicate birthweight to every mother…

…provide legible information in child's health card.

Encourage retention of cards by women

Improve interviewer training in reviewing health cards

Address barriers to reporting such as social perceptions and spiritual beliefs about birthweight e.g. fear of the 'evil eye'

Thanks to #EN_INDEPTH collaborative group

Read papers and summaries here

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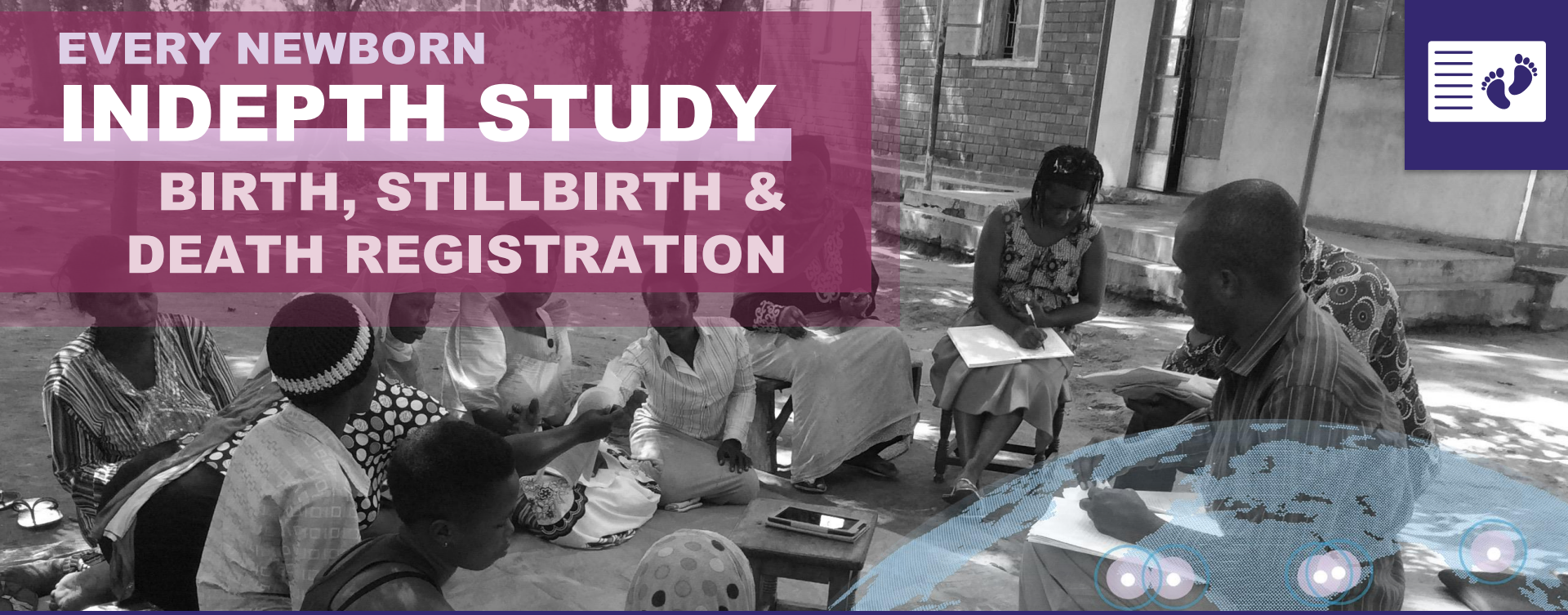
EVERY NEWBORN
INDEPTH STUDY
BIRTH, STILLBIRTH & DEATH REGISTRATION



Presenter: **Simon Kasasa** - Analysis and paper writing led by **IgangaMayuge HDSS team, Uganda**

Authors: Kasasa S, Natukwatsa D, Galiwango E, Nareeba T, Gyezaho C, Biks GA, Fisker AB, Mengistu MY, Dzabeng F, Haider MM, Yargawa J, Akuze J, Baschieri A, Cappa C, Jackson D, Lawn JE, Blencowe H

Paper available here

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BIRTH, STILLBIRTH & DEATH REGISTRATION

DATA COMPLETENESS & QUALITY

1. What was known already?
2. What was done?
3. What was found?
4. What next in measurement and in research?

Kasasa et al: Birth, stillbirth and death registration data completeness, quality and utility in population-based surveys: EN-INDEPTH study

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What was known already?

- **RIGHTS:** Birth registration is a civil right
- **LOW REGISTRATION**: of live births, stillbirths and deaths is low in many LMIC
- **INVESTMENT**: receiving increased investment
- **MEASURING PROGRESS:**
  - Birth registration is in household surveys but data quality is unknown.
  - Stillbirth registration or neonatal/child death registration are not measured in DHS or MICS surveys.

What was done?

New/ modified survey questions on birth & death registration asked to mothers of 13,058 babies in 4 African HDSS sites

Completeness, data quality & utility analysed

Time taken for birth & death registration questions assessed

Kasasa et al: Birth, stillbirth and death registration data completeness, quality and utility in population-based surveys: EN-INDEPTH study

Completeness & data quality

Questions **almost universally answered** (>99% of births in all sites with <5% don't know responses)

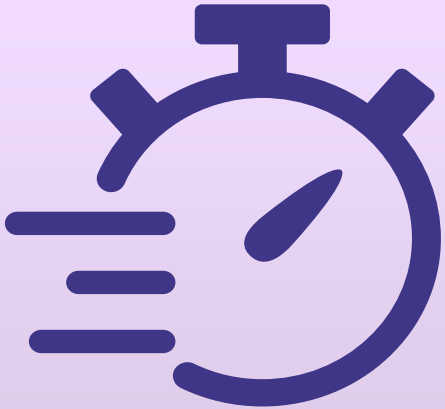
Completeness of birth registration: Varied by site and outcome. 6.1% - 53.5% of surviving livebirths; just 0.4% – 5.7% of neonatal deaths

Completeness of neonatal death registration: 1.2%

Completeness of stillbirth registration: 2.5%

Data quality: Child's age at birth registration reported for 93.6% of registered children surviving the neonatal period, with a plausible distribution of age at registration, but some heaping at 6-month intervals.

Time taken to answer questions?



<1 minute

Which births are not registered?

30.7% of live births registered

BUT ONLY

1.7% of neonatal deaths registered

Babies born at home

43% more likely to go unregistered than facility births

aOR:1.43 (95%CI 1.27-1.60)

Adolescent mothers

Babies of mothers over 35 are 50% less likely to go unregistered compared to those of mothers aged 15-19

aOR:0.50 (95%CI 0.36-0.69)

Low education

Babies of mothers with secondary education 30% less likely to go unregistered compared to those with no education

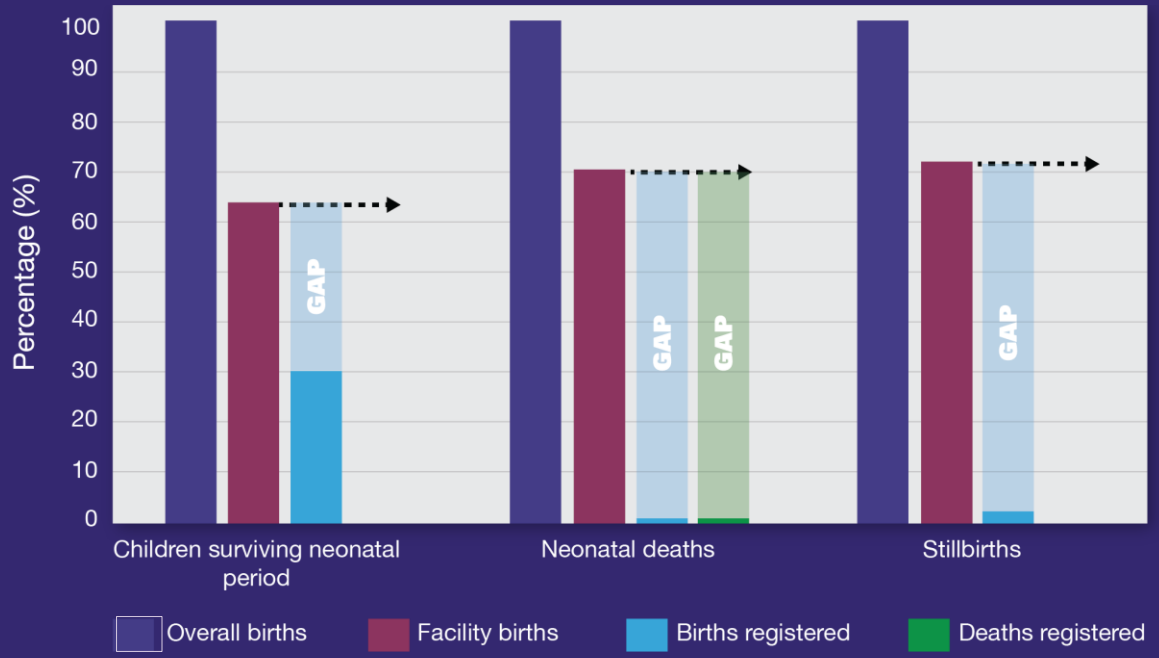
aOR:0.70 (95%CI 0.60-0.81)

Poorest

Wealthiest 61% less likely unregistered compared with poorest

aOR 0.39 (95%CI: 0.33-0.46)

Gap analysis for facility births

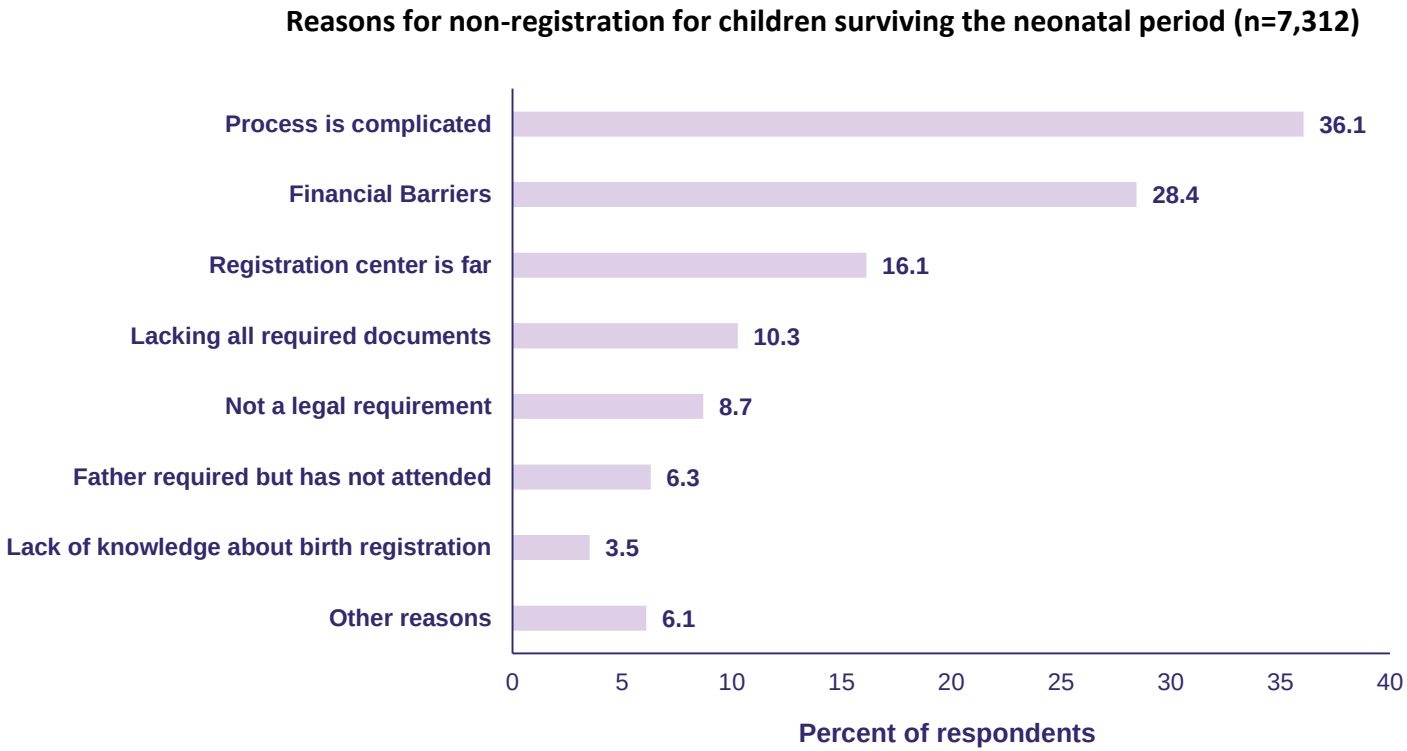


Gap analysis for birth, stillbirth and neonatal death registration, EN-INDEPTH survey (n=13,058)

Includes births in EN-INDEPTH survey since 1st January 2012

Kasasa et al: Birth, stillbirth and death registration data completeness, quality and utility in population-based surveys: EN-INDEPTH study

Why were babies not registered?



BIRTH & DEATH REGISTRATION

What next: measurement & research?

What is needed to improve the data?

Registration for all facility births, stillbirths and deaths….

With 80% of all births now in facilities will led to…

…improved tracking of registration completeness through routine data

Survey approached to track birth registration completeness and identify who is left left behind as a marker for child rights.

Identify solutions to close these gaps

Research needed to understand barriers to registration for stillbirths and neonatal deaths..

…and identify solutions in facility and community systems

Kasasa et al: Birth, stillbirth and death registration data completeness, quality and utility in population-based surveys: EN-INDEPTH study

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EVERY NEWBORN
INDEPTH STUDY
CHILD MORTALITY

Presenter: Ane B Fisker - Analysis and paper writing led by Bandim HDSS team, Guinea-Bissau

Authors: Nareeba T, Dzabeng F, Alam N, Biks GA, Thysen SM, Akuze J, Blencowe H, Helleringer S, Lawn JE, Mahmud K, Yitayew TA, Fisker AB

Read the paper here

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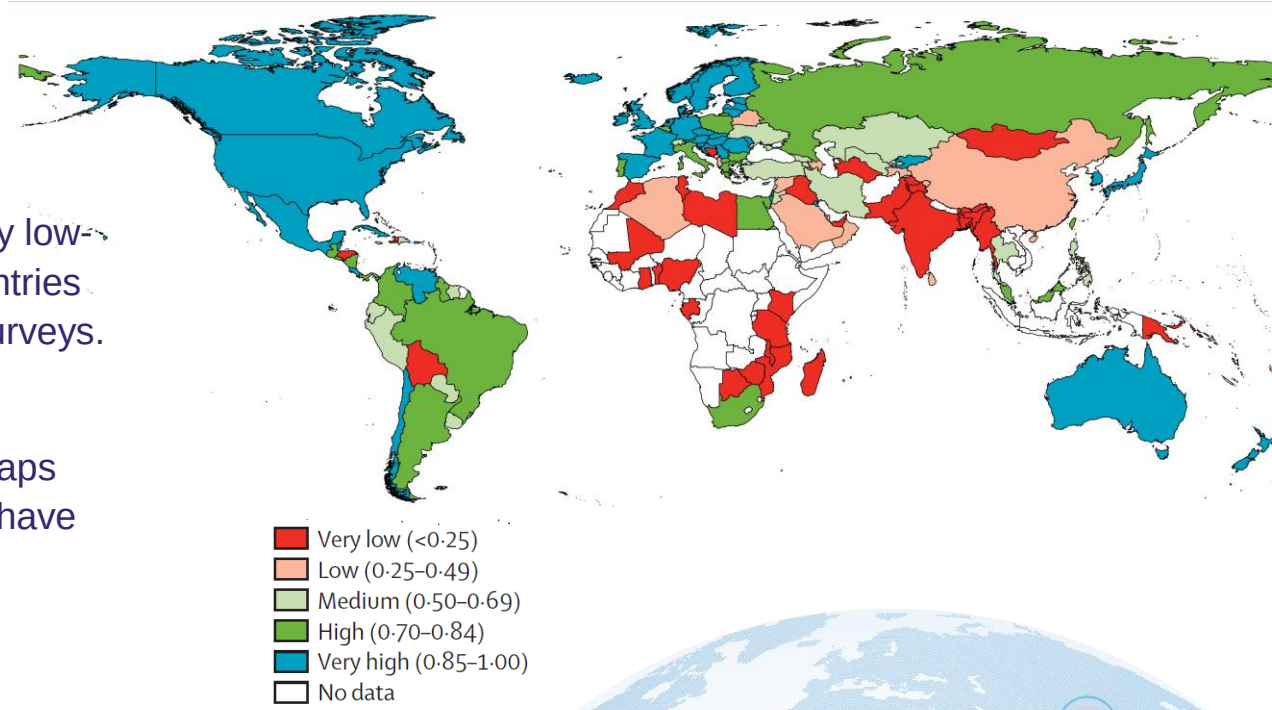
MORTALITY
SURVEYS VS PROSPECTIVE SURVEILLANCE

- What was known already?
- What was done?
- What was found?
- What affected data quality?
- What is next in measurement and research?

Nareeba et al: Neonatal and child mortality data in retrospective population-based surveys compared with prospective demographic surveillance: EN-INDEPTH study

What was known already?

- Mortality data from many low- and middle-income countries remain dependent on surveys.
- Since surveys fill data gaps validation opportunities have been limited.



[1]Mikkelsen L, Phillips DE, AbouZahr C, Setel PW, de Savigny D, Lozano R, Lopez AD: **A global assessment of civil registration and vital statistics systems: monitoring data quality and progress.** *Lancet* 2015, **386:**1395-409.

What was done?

Survey in five Health and Demographic Surveillance System (HDSS) sites

EN-INDEPTH Survey Dataset
n=69,176

Women with children
n=56,568

Children < 5 years
n=109,817

Children surviving
n=106,753

<5 death
n=3064

1) **Reported precision** of date of birth and death

2) **Consistency** of mortality estimates: levels and age distributions of child mortality

HDSS Datasets

Women with children
n=52,125

Children < 5 years
n=83,768

Children surviving
n=81,433

<5 death
n=2335

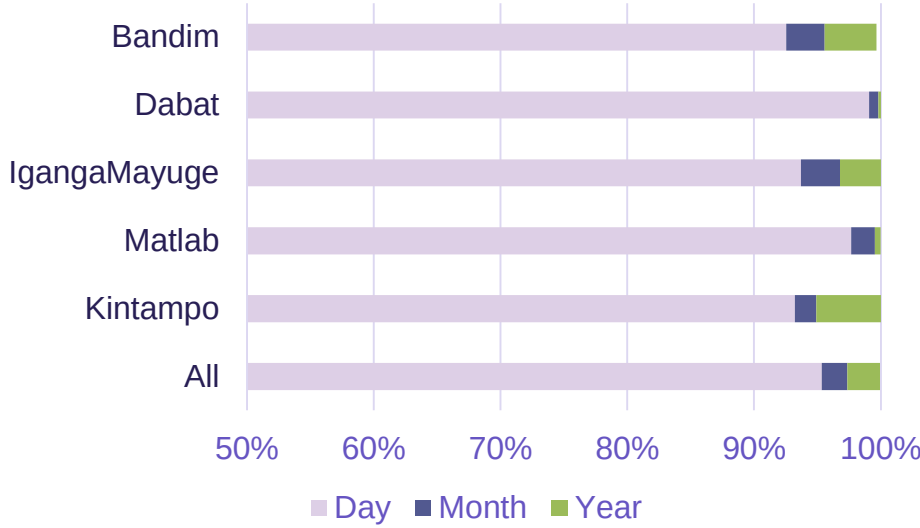
3) **Capture** of births: identify factors associated with capturing an HDSS-recorded birth in the EN-INDEPTH survey data

What was found?

Reported incomplete date of birth

Birthdates were more likely to be incomplete for

- >2 years prior to the survey: RR=4.08 (3.67–4.55)
- Children who had died: RR=5.82 (5.42–6.24)
- Higher parity: RR=2.33(1.95–2.79) for 2 vs 1
  RR=3.52 (2.95–4.20) for 3 vs 1
  RR=4.41 (3.67–5.29) for 4 vs 1
  RR=6.00 (5.05–7.14) for 5+ vs 1
- Children born to women with no formal education
  RR=0.47 (0.44–0.51) for primary vs none
  RR=0.15 (0.13-0.17) for secondary vs none
  RR=0.04 (0.02–0.06) for tertiary vs none.
- Sex of the child was not associated with whether a date-of-birth was recalled.



What was found?

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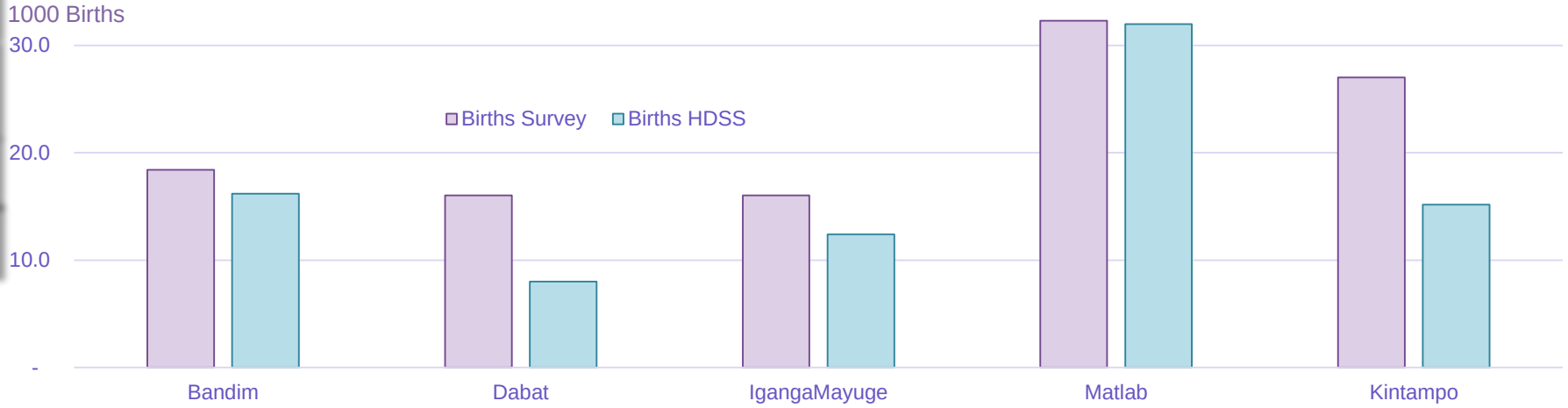

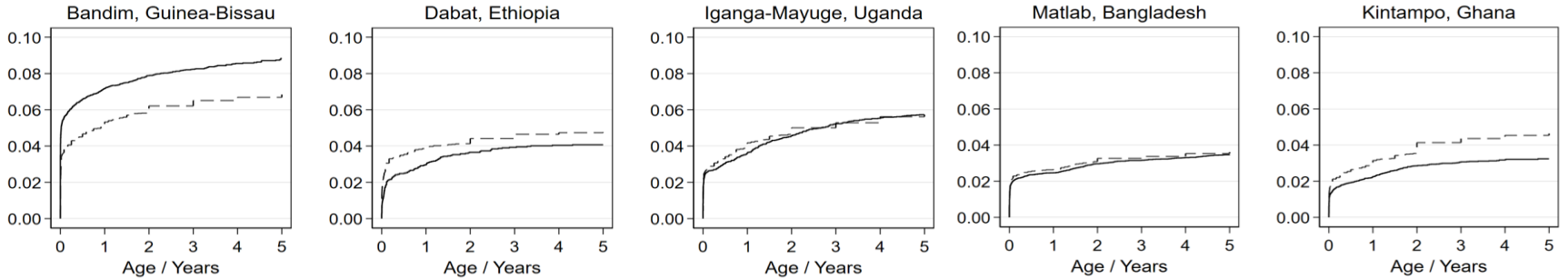

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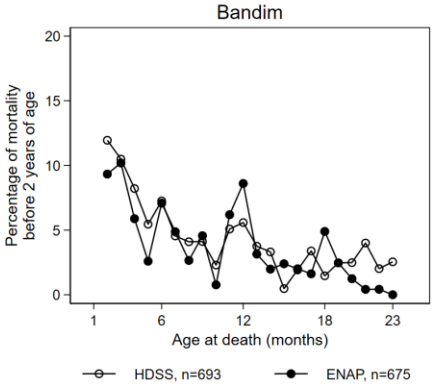
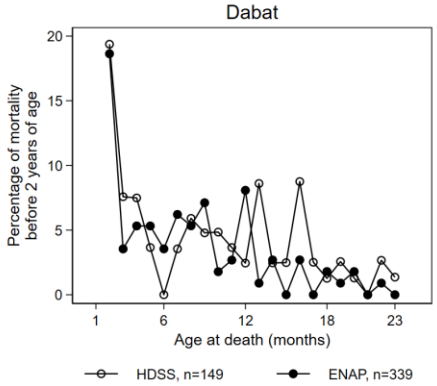
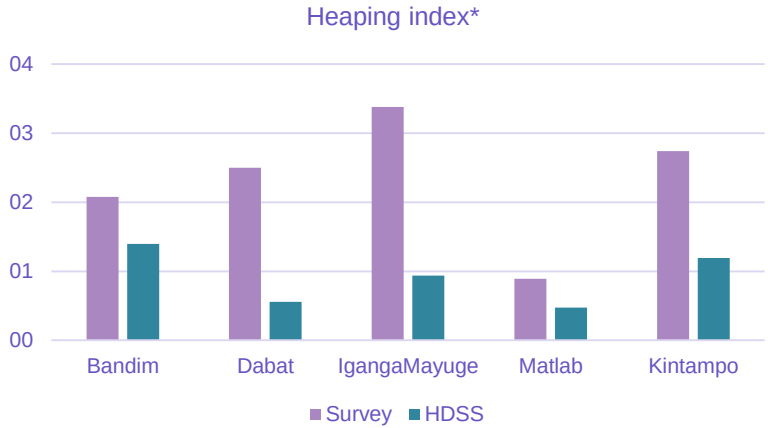
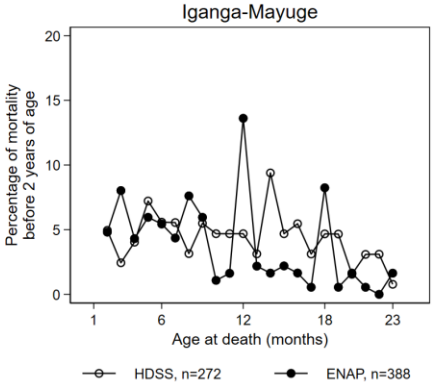
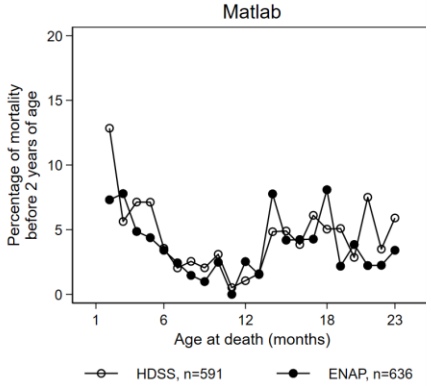
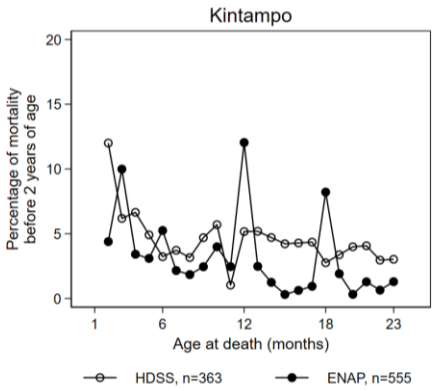












*N_{deaths} at 12 mo. / (N_{deaths} at 10-14m/5)

What was found?

HDSS Datasets

↓

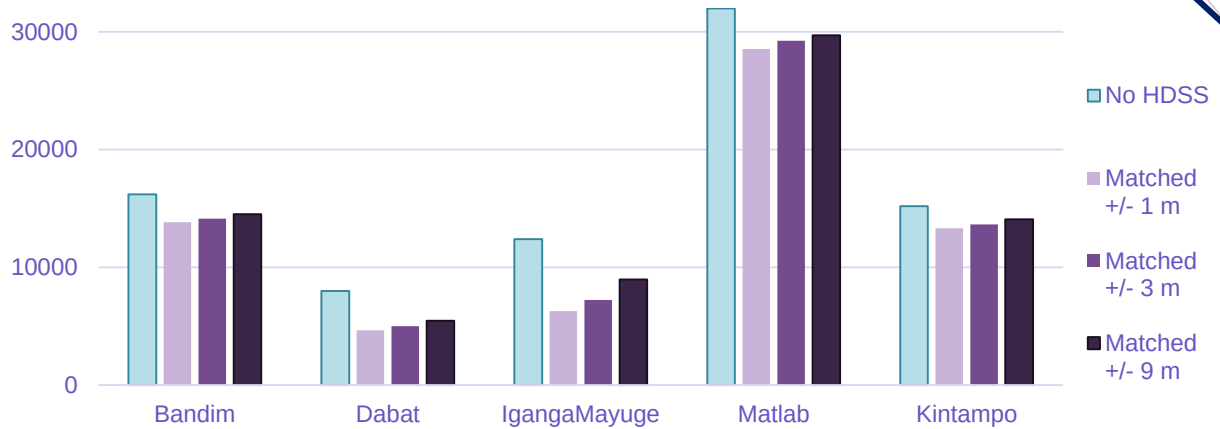
Women with children
n=52,125

↓

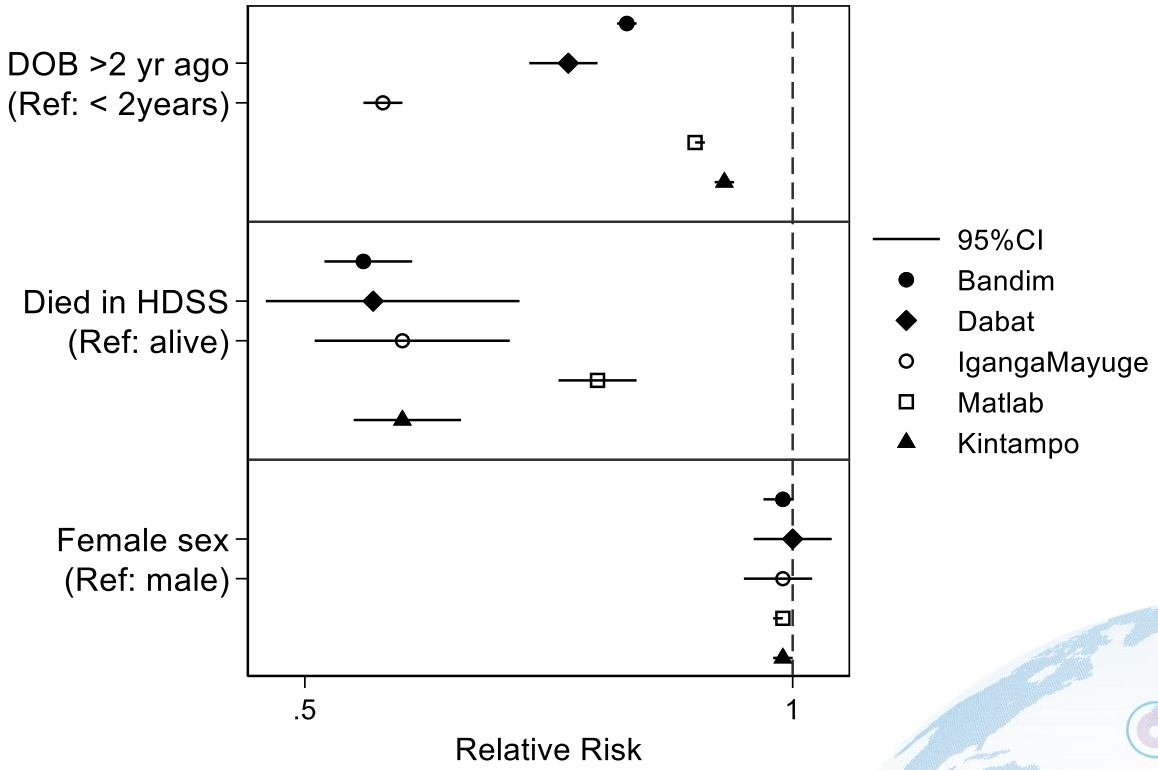
Children < 5 years
n=83,768

Mother ID	Child DOB
A	12-03-2014
A	17-12-2016
B	13-04-2013
B	24-01-2016

Mother ID	Child DOB
A	??-01-2011
A	12-03-2014
A	17-12-2017
B	??-01-2010
B	??-01-2016



What affected matching?



What is next in measurement and research?

- Levels similar – but:
  - Missing births and especially deaths in both HDSS and survey data
- These data gaps may lead to under-estimation of child mortality

- Research needed:
  - Further investigation of accuracy, omissions and associated factors.
  - Comparisons of HDSS data

Thanks to
#EN_INDEPTH
collaborative group

Read papers and summaries here

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EVERY NEWBORN
INDEPTH STUDY

Implications & next steps

Presenter: Hannah Blencowe LSHTM team, United Kingdom

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Stillbirths count and can be counted

Stillbirth measurement

What was found? Random comparison showed FPH has more potential for stillbirth capture

What has been done in DHS-8? DHS has replaced FBH+ with FPH in its DHS-8 standard questionnaire

Additional paper on stillbirth measurement: suggests other questions that could be considered in DHS, however more research is needed to address stigma & perceptions around stillbirth, improving communication of information to women & in implementing these questions in surveys

Stillbirth care

Why? Women with stillbirth were excluded from DHS questions on pregnancy care

What was found? Women can accurately report care.

What has been done in DHS-8? Removing skip patterns for maternity care questions for women with stillbirths can provide important information for this high-risk group

What next? Use population-level data on stillbirth care & factors associated with stillbirth from surveys to inform action to end preventable stillbirths & improve care for affected women & families.

Blencowe et al:Stillbirth outcome capture and classification in population-based surveys: EN-INDEPTH study
Di Stefano et al: Stillbirth maternity care measurement and associated factors in population-based surveys

From all papers implications now

Improving survey data for pregnancy outcomes is feasible now

- **Tools and questions**
- **Translations & adaptation to context** by using local words for stillbirth or preterm birth and considering the cultural and societal barriers to reporting of pregnancies and adverse pregnancy outcomes including termination of pregnancy
- **Health cards** have potential to improve survey data, e.g. birthweight & GA but need to be completed, legible & available at time of survey

But will require adapted interview training resources and ongoing supervision

EN-INDEPTH IMPLICATIONS

What next in research?

1

Data quality for pregnancy outcomes

- Develop ***robust data quality assessments*** for stillbirths and neonatal deaths needed: incl. accuracy, omission & misclassification
- ***Improve assessment*** of birthweight & gestational age for every baby coupled with measures to ***minimise heaping***

2

Survey content and structure

- Improve understanding of question performance e.g. using paradata to inform survey design, with linked qualitative assessments

Papers available here

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EN-INDEPTH IMPLICATIONS

What next in research?

3

Implementation research including communities

- ***Understand and address barriers to reporting*** e.g. stigma, certain spiritual beliefs etc…
- How to increase use of ***handheld cards***, and data quality on these
- Which ***training methods and supervision models*** are most effective to achieve/ maintain quality?
- Use of dashboards routinely to ***optimise local data collection feedback loops***

4

Linkage to facility data

- Improved facility measurement of key outcomes (e.g. birthweight, GA, stillbirth) must link to ***improved communication to women*** e.g. verbal & handheld cards

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