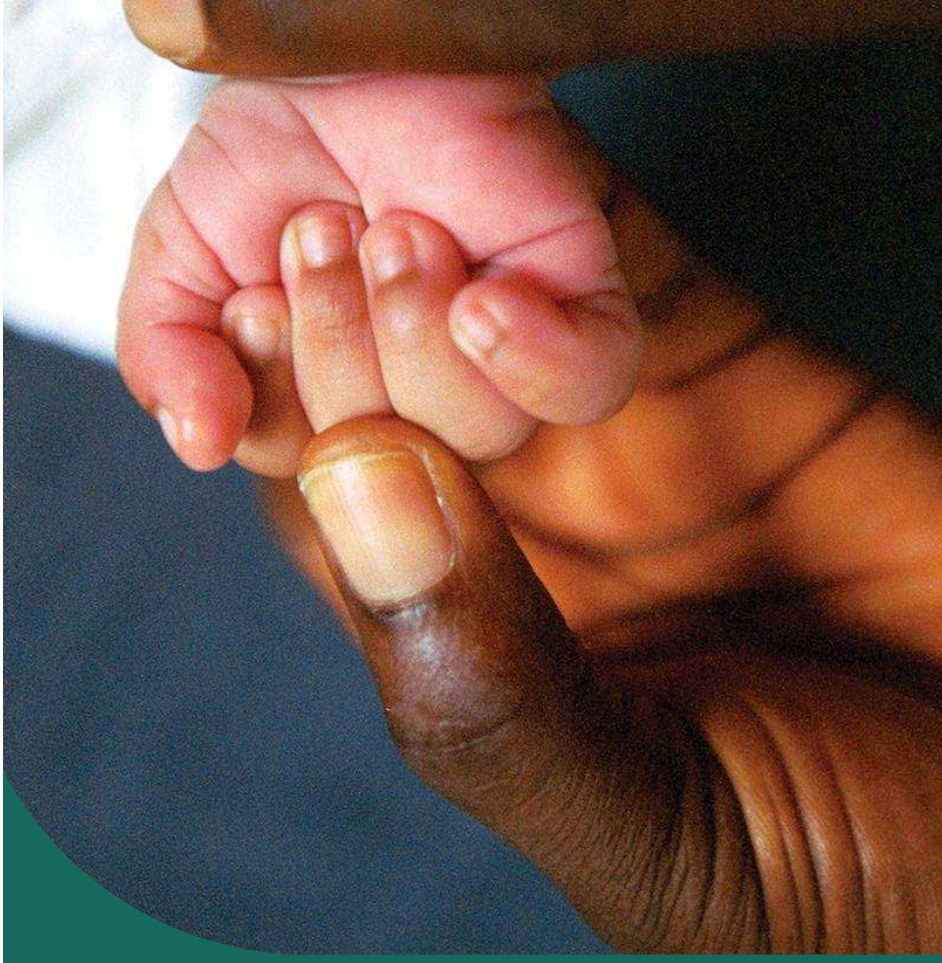




Counting 2 million stillbirths: seizing missed opportunities for impact and investment

July 29, 2021



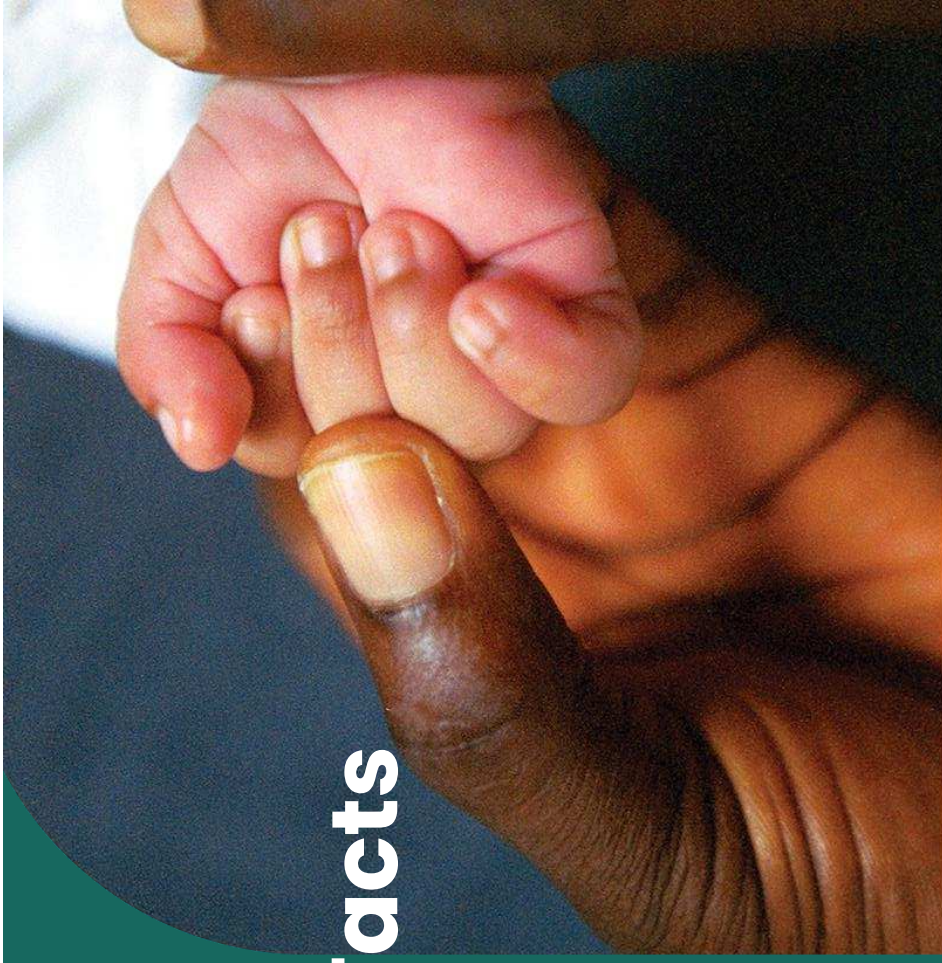
STILLBIRTH

Fake news & Facts



Professor Joy Lawn,
*Professor of Maternal Reproductive and Child Health
Epidemiology,
Director of MARCH Centre, London School of Hygiene
& Tropical Medicine
@joylawn*

July 29, 2021



STILLBIRTHS: Fake news & Facts

GFF Stillbirths Count Webinar

Professor Joy Lawn BM BS, MPH, PhD, FRCPCH FMedSci
London School of Hygiene & Tropical Medicine

With Dr Hannah Blencowe



MARCH
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& CHILD HEALTH



@MARCH_LSHTM | march.lshtm.ac.uk

@joylawn

#EveryNewborn

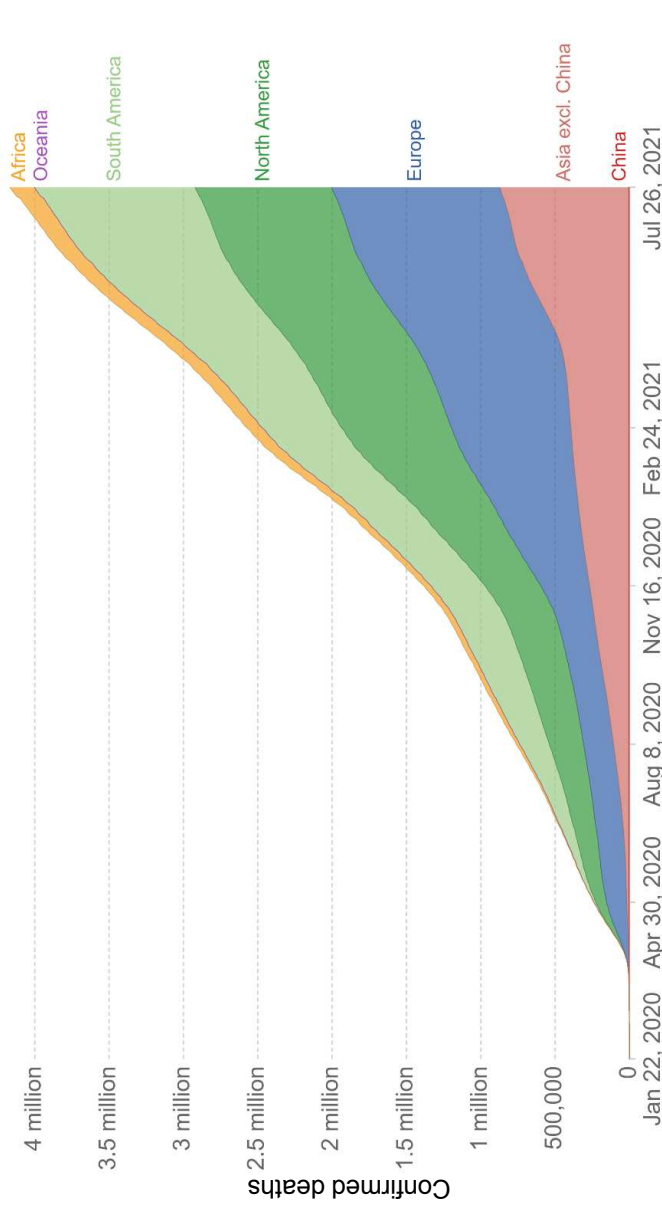


17 months of COVID-19 pandemic

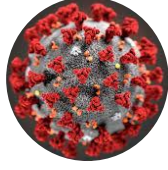
Disease + deaths

Cumulative confirmed COVID-19 deaths

Limited testing and challenges in the attribution of the cause of death means that the number of confirmed deaths may not be an accurate count of the actual number of deaths from COVID-19.

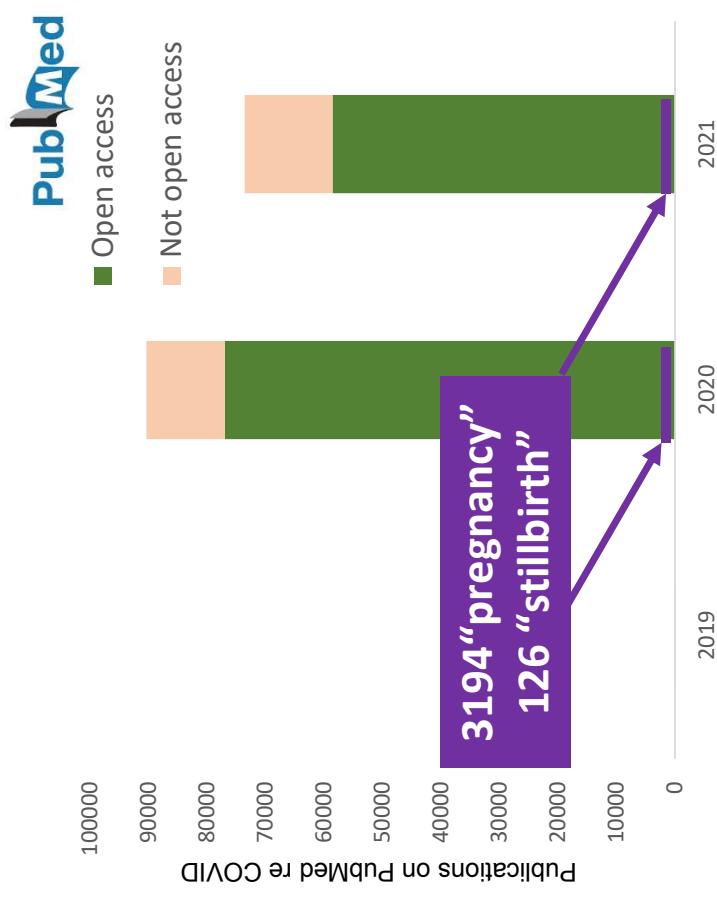


Source: Johns Hopkins University, ECDC COVID-19 Data. Last updated: 07 July 2021 (16:00 UTC). OurWorldinData.org/coronavirus • CC BY




>193.3 million confirmed cases
>4.14 million known deaths

Data + science




>157,600 publications,
77% open access (4% in 2019)
>100 vaccines developed/in process

9 years to meet Sustainable Development Goals ...




No woman
should die
giving life

0.3 mill die



No
baby
stillborn

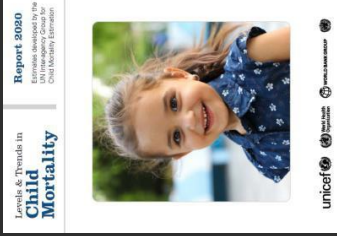
>2 mill die



ENDING PREVENTABLE
NEWBORN DEATHS and STILLBIRTHS
BY 2030

No
newborn
born to die

2.5 mill die



Levels & Trends in
**Child
Mortality**
Report 2020
Estimates developed by the
UN Inter-agency Group for
Child Mortality Estimation

Every child surviving
and thriving to age of
20 years

5.1 mill die

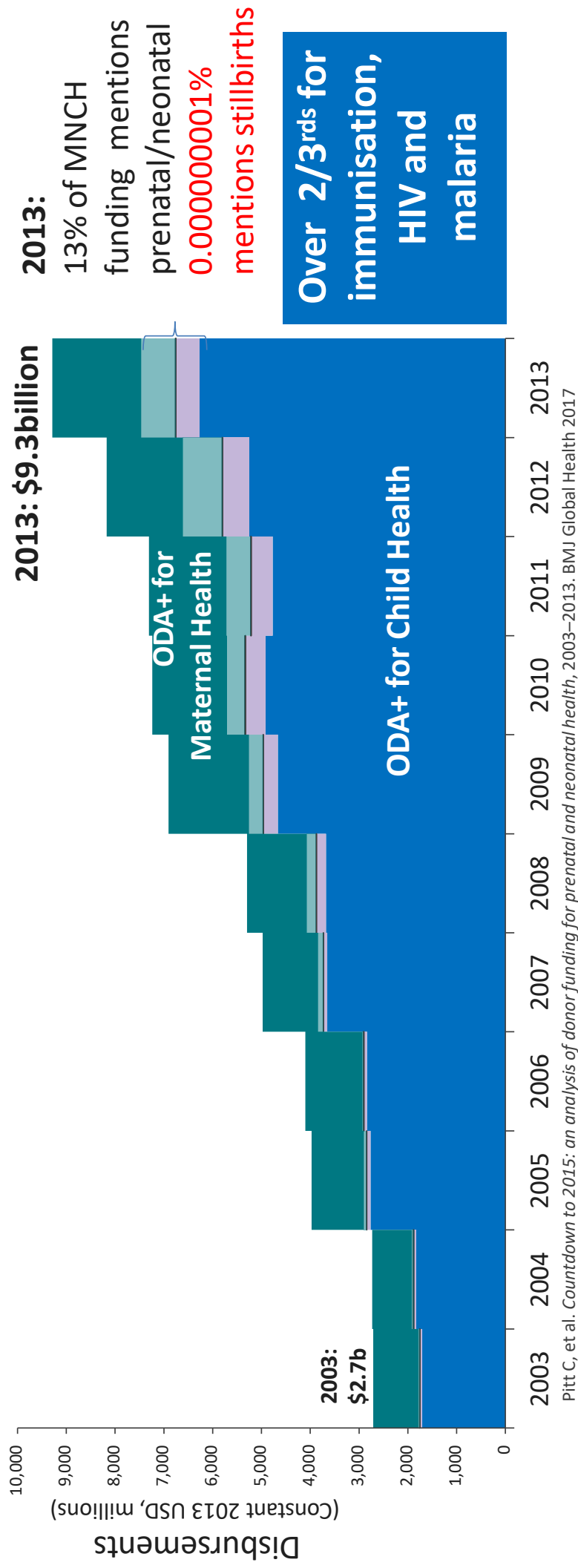
TIME: > 50% related to birth, slower progress

PLACE: Africa 13% of global population, yet by 2030 Africa predicted >66% of these deaths

~10 million deaths of women & children per year, progress threatened by pandemic

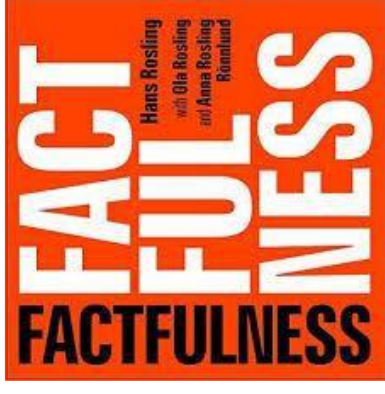
Does data influence donor funding?

RMNCH funding Tracked by Countdown to 2030 (note national funding more important but harder to track)



Despite almost 300 million stillbirths in 10yrs (2003-2013) the words “stillbirth”, “miscarriage”, “fetus” occurred only 9 times amongst >2 million donor disbursements ... new analyses in progress on stillbirth/newborn in GFF investment cases





Fake news = deliberate [disinformation](#) or [hoaxes](#) spread via [news media](#) or [online social media](#).

Fake news is published with the intent to mislead in order to damage an agency, entity, or person, and/or gain financially or politically, often using sensationalist, dishonest, or outright fabricated [headlines](#).

Fake news differs from [satire](#) or [parody](#), intended to amuse not mislead.

Science moves on and “facts” you learnt may be proven false
Most crucial learning is critical thinking skills, and how to fact check

Fake news about stillbirths

4

Stillbirth FACTS

- 1 Women forget they had a stillbirth
- 2 No target for stillbirths, countries not interested
- 3 Not preventable, “meant to happen”
- 4 Unclear definitions, no data, all based on “estimates”, untrackable

THE LANCET

@joylawn

#IPA2019

#EveryNewborn

1 Stillbirths do count for women

Stillbirth
FACT

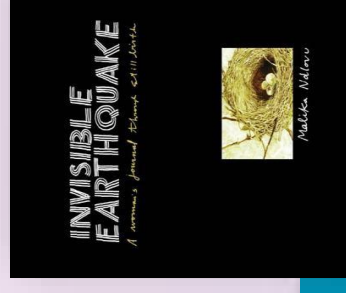
THE LANCET

THE LANCET

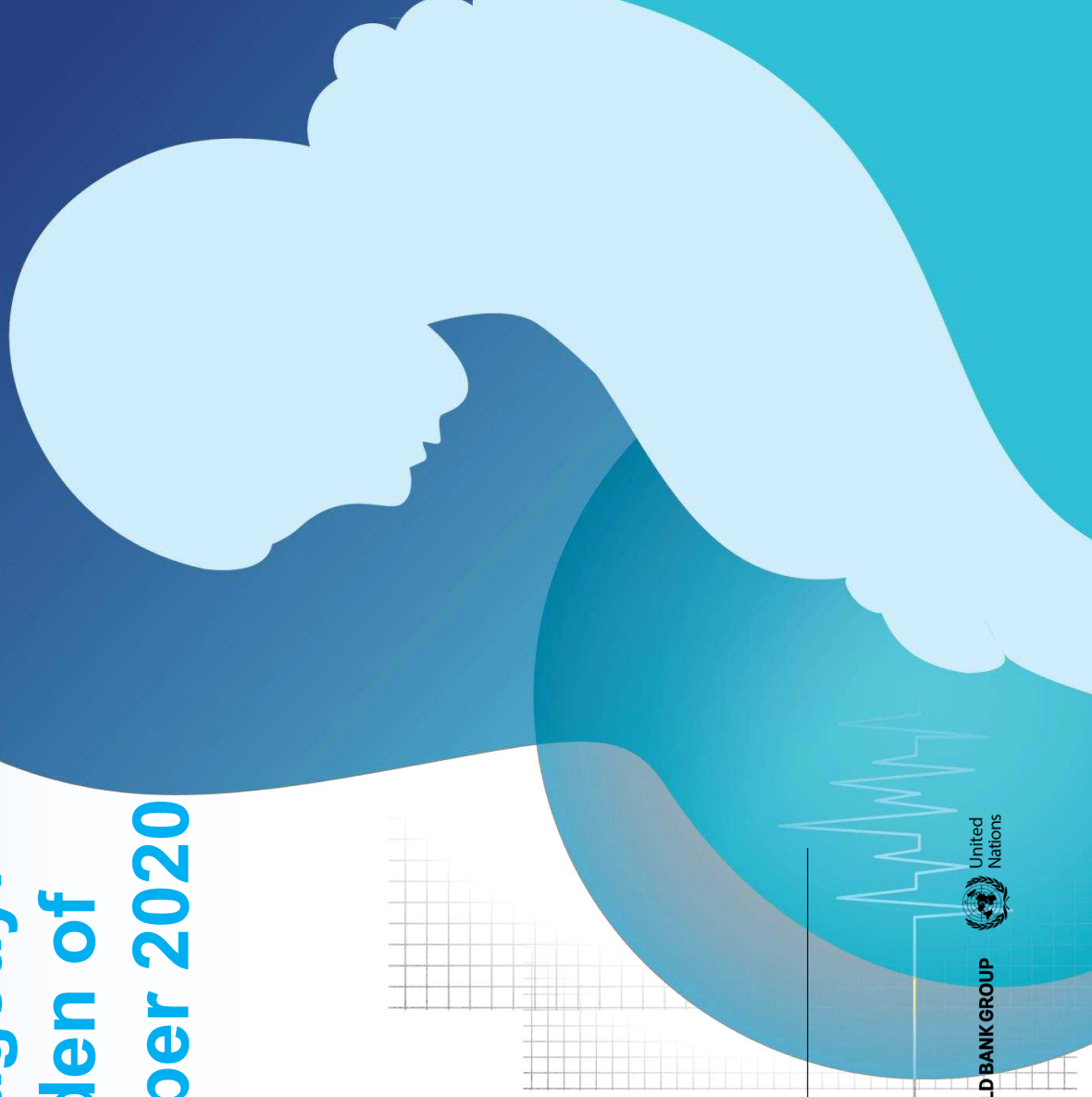
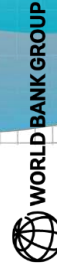
“No fetal heartbeat. These three words began the surreal journey of inducing labour and finally my daughter’s stillbirth... For weeks I waded through each day trying to keep my head above an ocean of sorrow.

I just wanted to stop breathing, to stop time moving me forward...”

Malika Ndlovu, South African artist



A Neglected Tragedy: The global burden of stillbirths October 2020



Unnecessary
Unseen
Unrecognised
Underprioritised
Underfinanced

Taboo
Stigma
Misconception

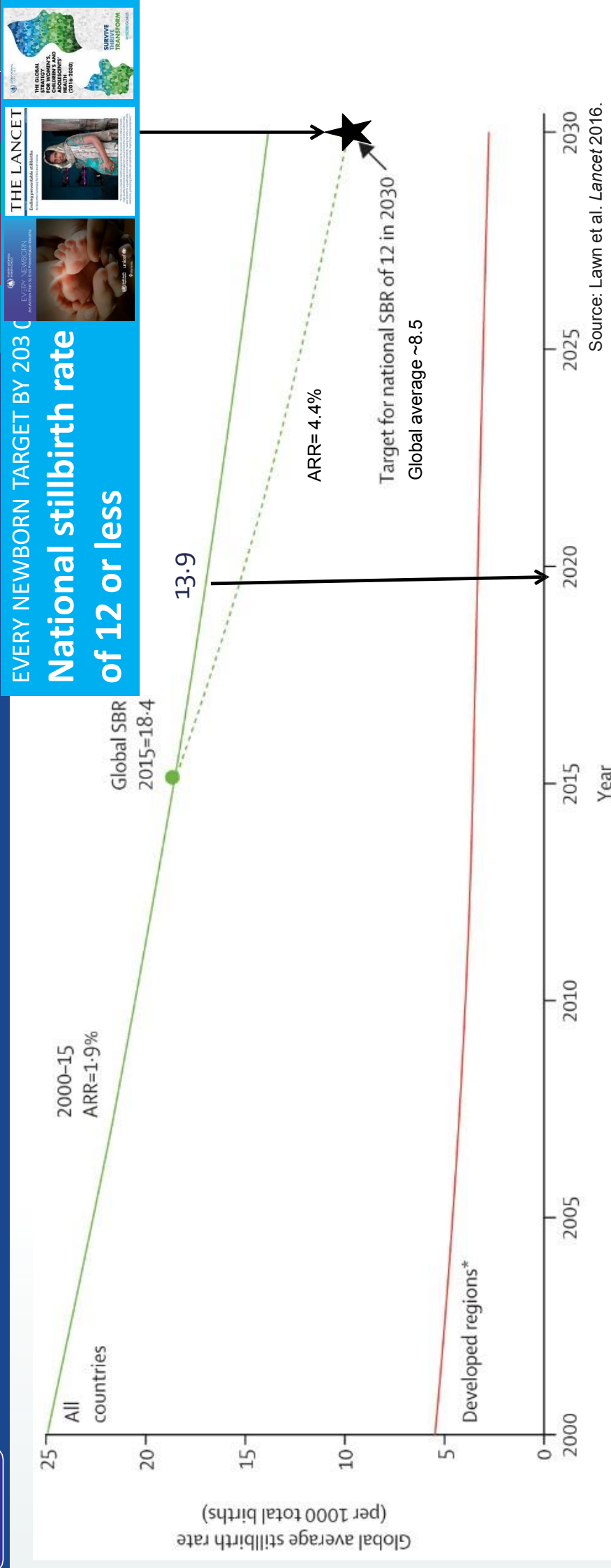
TARGET for ending preventable stillbirths

THE LANCET

2

Stillbirth
FACT

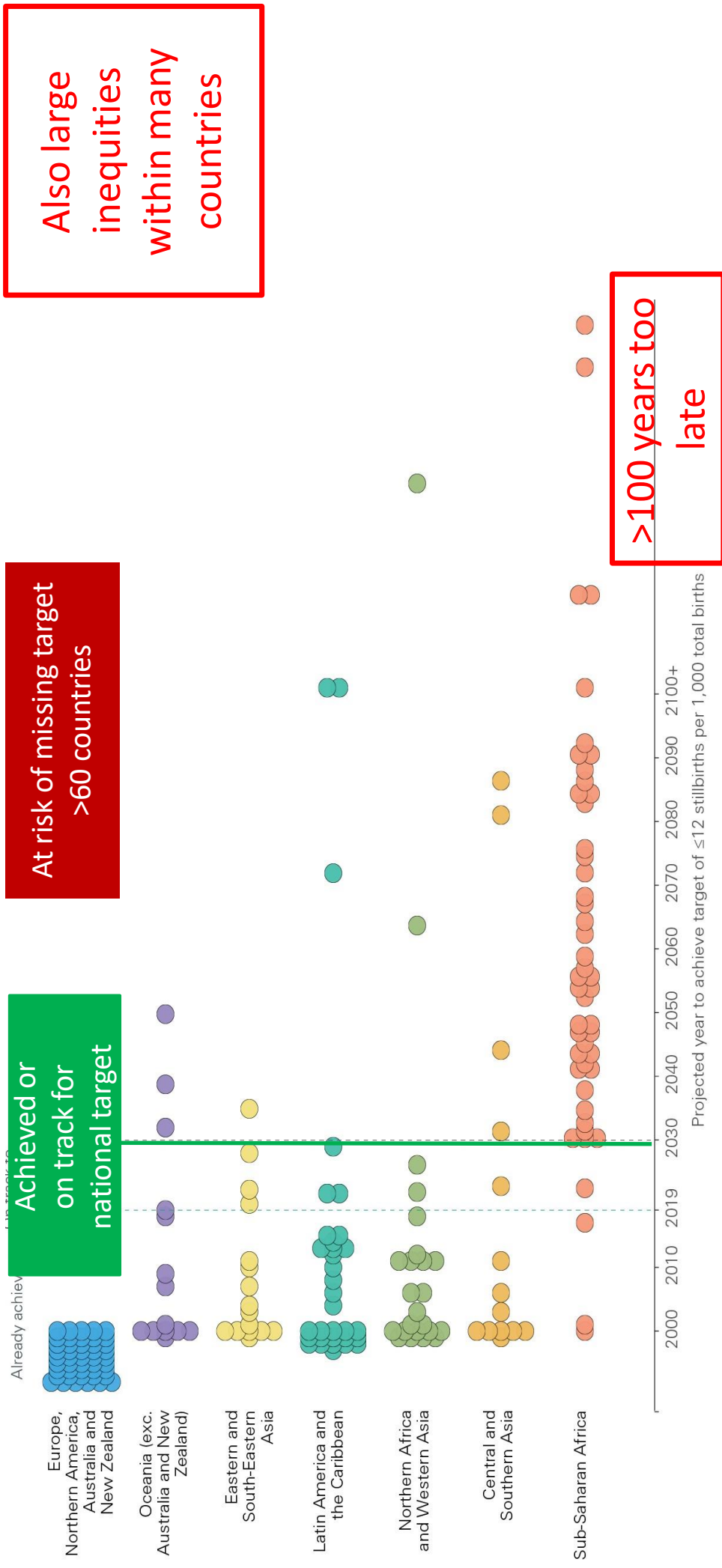
Global Strategy and Every Newborn Action Plan



Need to at least double the average annual rate of progress...

So far 30/93 high burden countries have set stillbirth targets (78/93 for newborns)

Projected year to achieve ENAP stillbirth target if current trends continue



Source: UN-IGME 'A Neglected Tragedy. The global burden of stillbirths 2020

Most stillbirths are preventable



Estimates are impeded by >35 classification systems

The “big five” causes:

1. Childbirth complications (>1 million)
2. Maternal infections in pregnancy eg syphilis, malaria, Group B Strep
3. Maternal chronic conditions, eg hypertension and diabetes
4. Fetal growth restriction
5. Congenital abnormalities (few)

Source: Lawn JE, Blencowe H, Pattinson R, et al, Stillbirths: Where? When? Why? How to make the data count? *Lancet* 2011.

Perinatal Audit data from high income countries

Sub-optimal care contributes to around 30% of stillbirths

Unexplained stillbirth often due to poor investigation

Majority of stillbirths are preventable NOW

Universal coverage of high quality care including:

ANTENATAL CARE

- Detection and management of maternal conditions in pregnancy e.g. infections (esp. syphilis & malaria), hypertension, diabetes etc..
- Detection and management of fetal growth restriction

CARE AT BIRTH

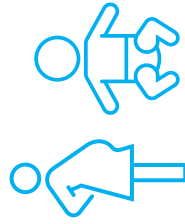
- Fetal monitoring and response
- Induction of labour for pregnancies > 41 weeks

PRE and INTER-CONCEPTION CARE

- Family Planning
- Folic acid fortification



Stillbirths are a sensitive and measurable outcome indicator of equity, quality of care and COVID-19 pandemic disruptions



Meta analyses 28% increased risk in stillbirth rate 1.28 (1.07–1.54)

B Chmielewska, et al Lancet GH 2021, Effects of the COVID-19 pandemic on maternal and perinatal outcomes: a systematic review and meta-analysis



An additional 200,000 babies could be stillborn in 2020 due to health service disruptions (around 50% closures), in 117 LMICs
(Lives Saved Tool Analysis).

News

2 million stillbirths every year, pandemic might worsen toll

The World Health Organization and partners say there are about 2 million stillbirths every year, according to its first-ever global estimates

Via AP news wire | Wednesday, 07 October 2020 23:47



4 Definition clear and data now

THE LANCET

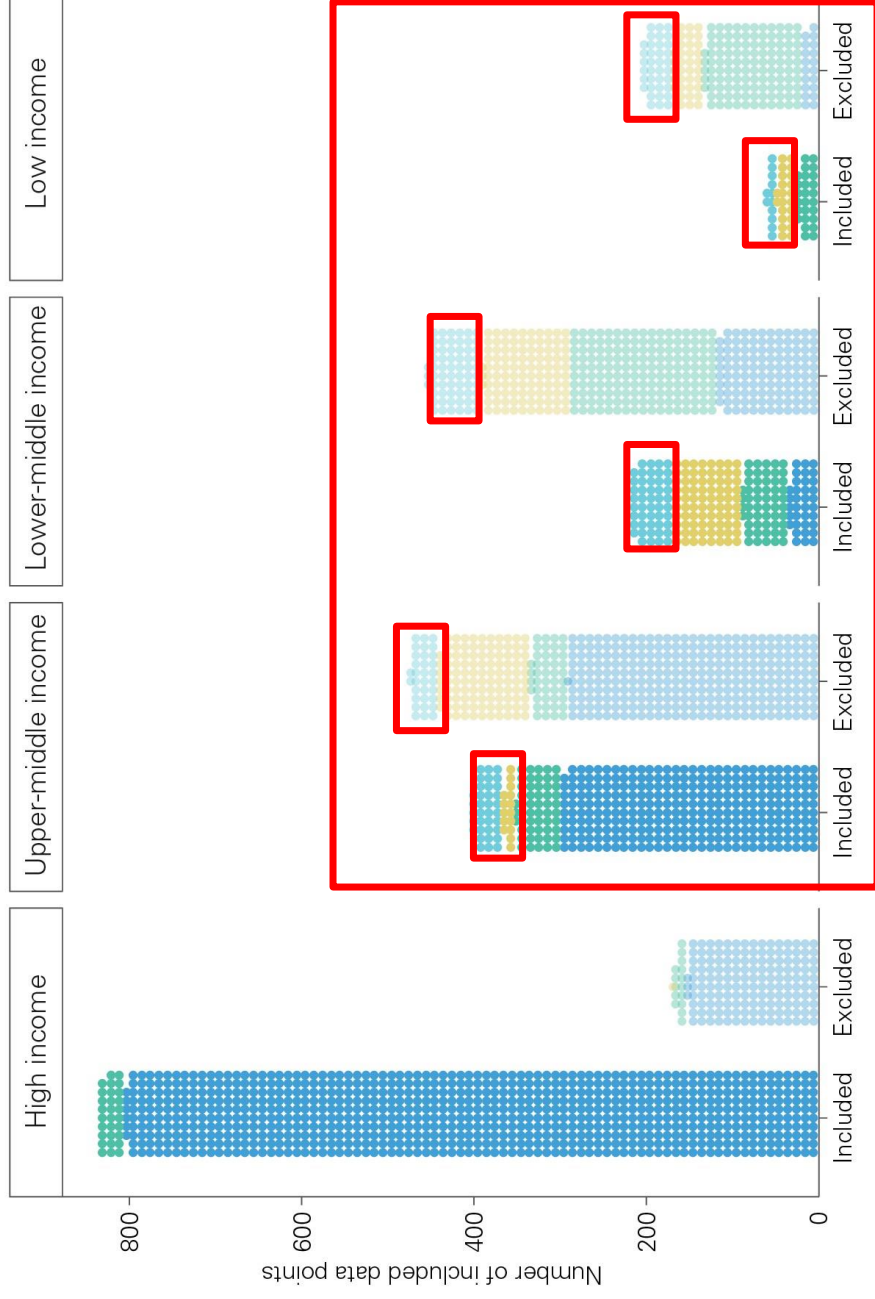
Stillbirth
FACT

- **WHO definition for international comparison is clear:**
Baby born with no signs of life & gestational age of ≥ 28 weeks (birthweight of $\geq 1000\text{g}$)
Also each country to track all fetal deaths from >22 weeks gestation (birthweight $\geq 500\text{g}$)
- **Stillbirth rate data available from most countries:**
 - NEWs!! WHO/UNICEF working with >100 countries to routinely report stillbirth data every year and UN IGME doing stillbirth estimates every ~ 2 years
 - Data availability more than doubled compared to our first estimates for WHO in 2011
 - For 2019 estimates more than 132 of 195 countries have stillbirth data
 - High income countries – 87% have national data, mostly CRVS
 - LMIC - \sim two thirds have national data
 - many still reliant on surveys
 - scope for HMIS especially once national facility birth $>80\%$

Clear definition – issue is application, high-income country variability
Data quantity is high and increasing, data quality needs work

Data to inform stillbirth rate estimates

Too much data from LMICs did not meet inclusion criteria – CAN and MUST improve!!



Not just moan about bad data! Improve it!
Two important Every Newborn studies funded by CIFF

- Administrative
- HMIS
- Survey
- Population-based study

EVERY NEWBORN INDEPTH STUDY

Improving measurement of stillbirths in household survey



#everynewborn #endstillbirths

Stillbirth measurement in surveys



- Randomised comparison in 5 countries showed Full Pregnancy History (FPH) potential to better capture stillbirth rates (SBR 21% higher in FPH vs FBH+)
- DHS-8 standard questionnaire in 2020 has replaced FBH+ with FPH

Akuze et al, Lancet GH, 2020

Measurement of stillbirth care

- Women with stillbirths previously excluded from survey questions on maternity care – INDEPTH study found women do report care
- DHS-8 removed previous skip patterns – stillbirth affected women included
- Health cards have potential to improve survey data, e.g. birthweight & GA but need to be completed, legible & available at time of survey

Blencowe et al: Stillbirth outcome capture and classification in population-based surveys

- Di Stefano et al: Stillbirth maternity care measurement and associated factors in population-based surveys



- **Use in surveys now: need to address barriers to reporting especially if more stigma**
Miscarriage or termination > Stillbirth > Neonatal death > Child deaths

#EN_INDEPTH TEAM 12 papers in BMC with 79 authors! Includes paper on birth registration and stillbirth/neonatal death certificates Also main results paper in Lancet GH

Films and summaries at <https://www.lshtm.ac.uk/research/centres/march-centre/en-indepth>

#EN-INDEPTH
#everynewborn #endstillbirths



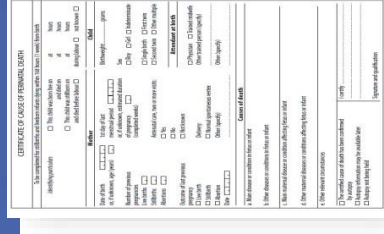
Funded by
CHILDREN'S
INVESTMENT FUND
FOUNDATION

Population
Health Metrics



Data to inform stillbirth cause of death

- **Civil Registration and Vital Statistics (CRVS):** from Medical Certificate of Cause of death (2016 version includes stillbirths and neonatal deaths)
 - New UN guidance on how to – countries advancing birth registration can also advance deaths registration for stillbirths and neonatal deaths
- **Perinatal Audit/ Review:** important role at a local level and for quality improvement
- **ICD-PM (2016):** classification system suitable for classifying deaths: by timing, but revisions planned for the fetal or neonatal cause of death and/or contributing maternal conditions
- **Verbal autopsy:** Commonly used in surveys to attribute probable cause of death but many tools omit stillbirth and the IP/AP classification has low accuracy



CERTIFICATE OF CAUSE OF PERINATAL DEATH

1. Name of the deceased: _____ Sex: Male Female

2. Date of death: _____ Time of death: _____

3. Place of death: _____

4. Age at death: _____

5. Date of birth: _____ Time of birth: _____

6. Sex of the deceased: Male Female

7. Date of stillbirth: _____ Time of stillbirth: _____

8. Place of stillbirth: _____

9. Age at stillbirth: _____

10. Date of delivery: _____ Time of delivery: _____

11. Place of delivery: _____

12. Date of registration: _____

13. Time of registration: _____

14. Place of registration: _____

15. Name of the registrar: _____

16. Signature of the registrar: _____

17. Date of signature: _____

18. Name of the doctor: _____

19. Signature of the doctor: _____

20. Date of signature: _____

21. Name of the pathologist: _____

22. Signature of the pathologist: _____

23. Date of signature: _____

24. Name of the coroner: _____

25. Signature of the coroner: _____

26. Date of signature: _____

27. Name of the registrar: _____


28. Signature of the registrar: _____

29. Date of signature: _____

30. Name of the registrar: _____

31. Signature of the registrar: _____

32. Date of signature: _____



Making Every Baby Count
Audit and review of stillbirths and neonatal deaths



The WHO application of ICD-10 to deaths during the perinatal period:
ICD-PM



ICD-11
International Classification of Diseases 11th Revision
The global standard for diagnostic health information



Actions!

Our generation has
potential to transform
health of next
generation

Will we deliver?

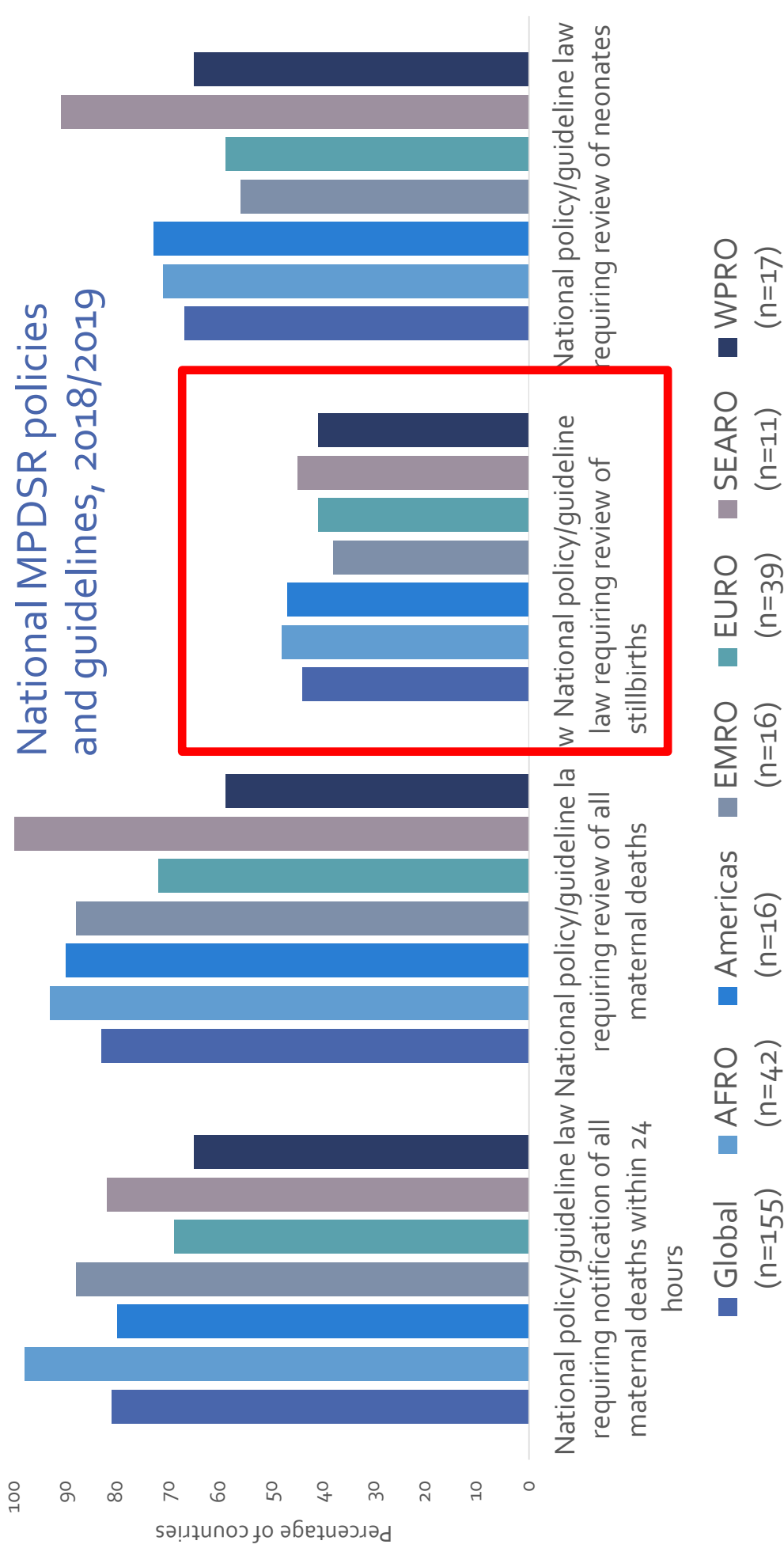
@joylawn

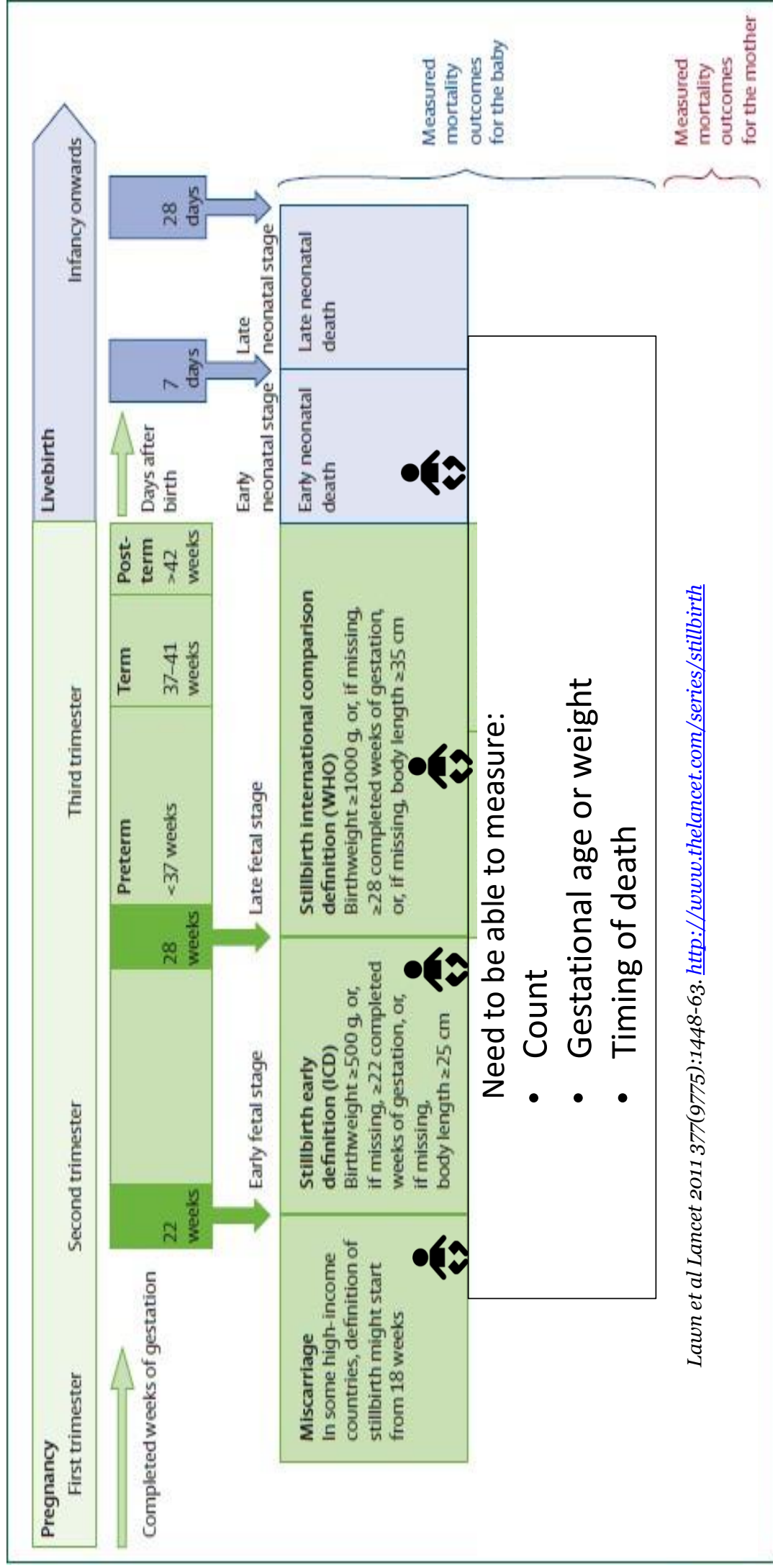
Actionable facts on stillbirths

1. Stillbirths count to families and society
2. 2030 target is **URGENT!** 9 years to national target of SBR of 12, need to double progress
3. Stillbirths are preventable, especially with high quality Antenatal and Intrapartum care (major return on investment)
4. Stillbirths can be counted
 - Surveys
 - CRVS
 - Routine data

Improve and use the data – including in GFF
investment cases

Stillbirth audit/review: lagging behind maternal & newborn deaths





Need to be able to measure:

- Count
- Gestational age or weight
- Timing of death

Lawn et al Lancet 2011 377(9775):1448-63. <http://www.thelancet.com/series/stillbirth>

Figure 1: Defining stillbirths and associated pregnancy outcomes for international comparison
Definitions from ICD, tenth revision. ICD-International Classification of Diseases.

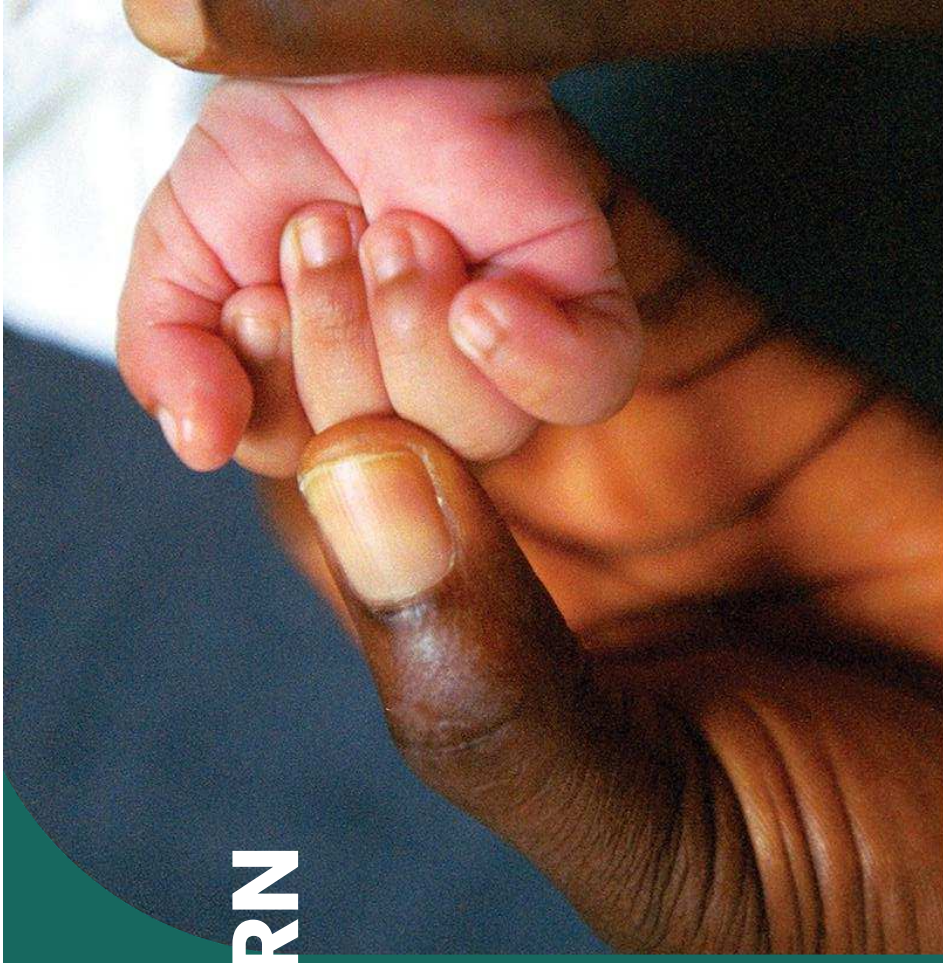


EVERY NEWBORN *birth study*



Dr Louise-Tina Day
EN-BIRTH Research Manager at London
School of Hygiene and Tropical Medicine
[@LouiseTinaDay](#)

July 29, 2021



EVERY NEWBORN **BIRTH STUDY** Summary of findings for **stillbirth** data

#EN_BIRTH
#everynewborn
#endstillbirths

Presenter: **Louise Tina Day**

LSHTM on behalf of the EN-BIRTH study group, Kimberly Peven lead author



Pregnancy & Childbirth



LONDON
SCHOOL OF
HYGIENE
& TROPICAL
MEDICINE



MARCH
MATERNAL
ADOLESCENT
REPRODUCTIVE
& CHILD HEALTH



icDDR, b:ih!

IFAKARA
HEALTH
INSTITUT



UPPSALA
UNIVERSITET

Funded by



CHILDREN'S
INVESTMENT FUND
FOUNDATION

EN-BIRTH team

Country team leads & organisations

Bangladesh:

Dr Shams El Arifeen (icddr,b)

Nepal:

Dr Ashish KC,
(Uppsala University, with implementing partner Golden Community)

Tanzania:

Dr Honorati Masanja and the late Dr Mbaruku Godfrey, (Ifakara Health Institute)

London School of Hygiene &

Tropical Medicine (LSHTM):

Joy E. Lawn

EN-BIRTH Study Group

Bangladesh: Qazi Sadeq-ur Rahman, Ahmed Ehsanur Rahman, Tazeen Tahsina, Sojib Bin Zaman, Shafiqul Ameen, Tanvir Hossain, Abu Bakkar Siddique, Aniq Tasnim Hossain, Tapas Mazumder, Jasmin Khan, Md. Taqbir Us Samad Talha, Rajib Haider, Md. Hafizur Rahman, Anisuddin Ahmed, Shams El Arifeen.

Nepal: Omkar Basnet, Avinash K Sunny, Nishant Thakur, Rejina Gurung, Anjani Kumar Jha, Bijay Jha, Ram Chandra Bastola, Rajendra Paudel, Asmita Paudel, Ashish KC.

Tanzania: Nahya Salim, Donat Shamba, Josephine Shabani, Kizito Shirima, Menna Narcis Tarimo, Godfrey Mbaruku (deceased), Honorati Masanja.

LSHTM: Louise T Day, Harriet Ruysen, Kimberly Peven, Vladimir S Gordeev, Georgia R Gore-Langton, Dorothy Boggs, Stefanie Kong, Angela Baschieri, Simon Cousens, Joy E Lawn.

EN-BIRTH validation collaborative group:

Bangladesh: Md. Ayub Ali, Bilkish Biswas, Rajib Haider, Md. Abu Hasanuzzaman, Md. Amir Hossain, Ishrat Jahan, Rowshan Hosne Jahan, Jasmin Khan, M A Mannan, Tapas Mazumder, Md. Hafizur Rahman, Md. Ziaul Haque Shaikh, Aysha Siddika, Taslima Akter Sumi, Md. Taqbir Us Samad Talha

Tanzania: Evelyne Assenga, Claudia Hanson, Edward Kija, Rodrick Kisenge, Karim Manji, Fatuma Manzi, Namala Mkopi, Mwifadhi Mrisho, Andrea Pembe
Nepal: Jagat Jeevan Ghimire, Regina Gurung, Elisha Joshi, Avinash K Sunny, Naresh P. KC, Nisha Rana, Shree Krishna Shrestha, Dela Singh, Parashu Ram Shrestha, Nishant Thakur,

LSHTM: Hannah Blencowe, Sarah G Moxon

EN-BIRTH Expert Advisory Group:

Agbessi Amouzou, Tariq Azim, Debra Jackson, Theopista John Kabuteni, Matthews Mathai, Jean-Pierre Monet, Allisyn Moran, Pavani Ram, Barbara Rawlins, Jennifer Requejo, Johan Ivar Sæbø, Florina Serbanescu, Lara Vaz

National Advisory Groups:

Bangladesh: Mohammad Shahidullah, Khaleda Islam, Md Jahurul Islam.

Nepal: Naresh P KC, Parashu Ram Shrestha.

Tanzania: Muhammad Kambi, Georgina Msemo, Asia Hussein, Taihiya Yahya, Claud Kumalija, Eliudi Eliakimu, Mary Azayo, Mary Drake, Honest Kimaro.

Finally, and most importantly, we thank the women, their families, the health workers and data collectors





EN-BIRTH study

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



#everynewborn #endstillbirths



EN-BIRTH study

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



#everynewborn #endstillbirths



Every Newborn Action Plan



Ending preventable deaths for 2.4 million newborns and >2 million stillbirths each year

Strategic objective 5:

Count every newborn through measurement, programme-tracking and accountability



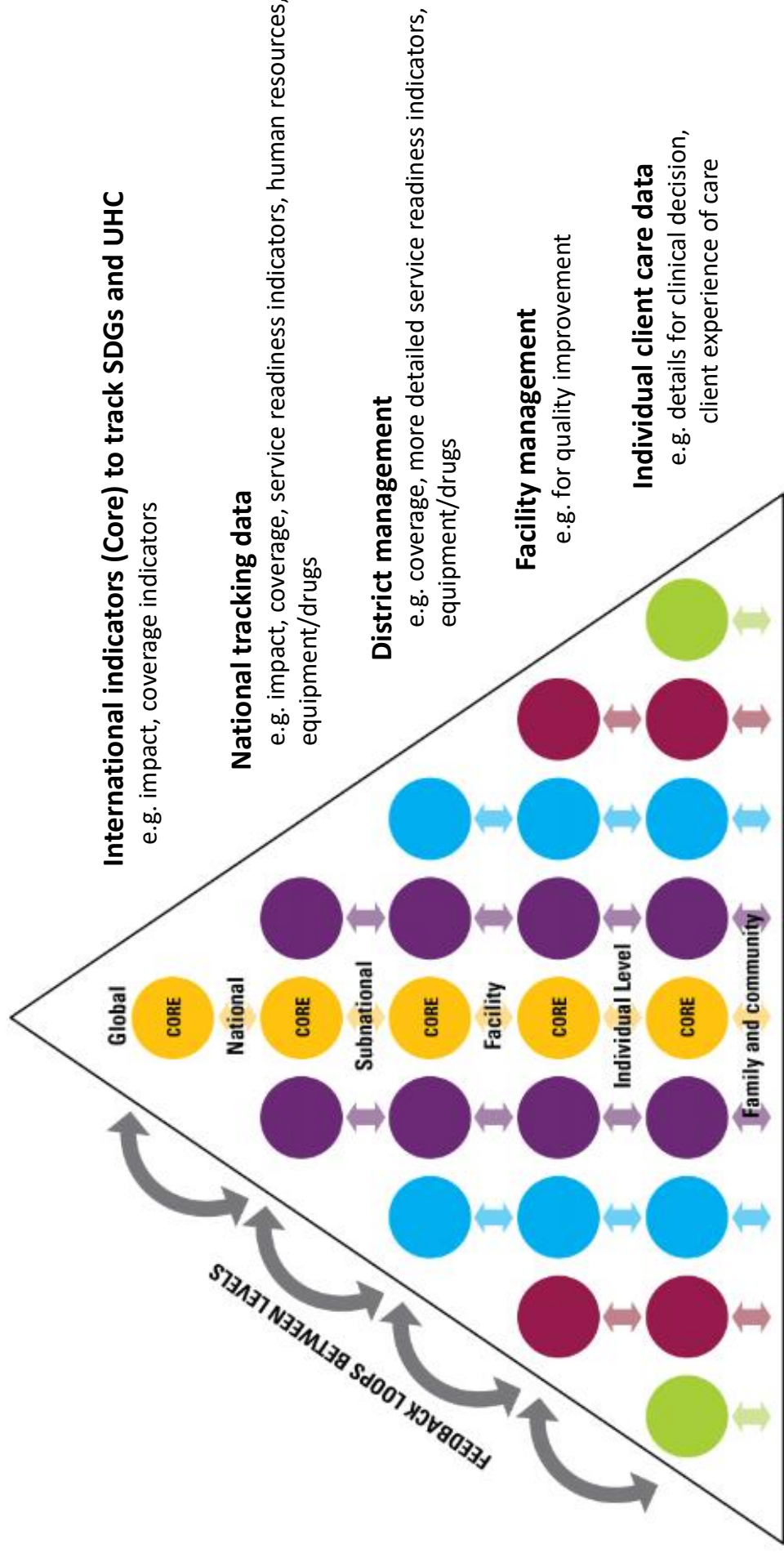
Ambitious WHO measurement improvement roadmap
2015-2020

based on evidence for selected priority gaps.....

- *Improve metrics* nationally and globally
- Drive change towards Sustainable Development **Goal 3**



Core indicators



What was known already?



MEASUREMENT

- In low- and middle-income countries aggregated routine register data are usual source for health management information systems
- Lack of trust in register data quality impedes use

Labour ward register data has potential to close gap for data around the time of birth

EN-BIRTH Study



Every Newborn Birth Indicators Research Tracking in Hospitals”

Aimed to
assess validity of measurement
of selected newborn and maternal
health indicators
in hospitals
to inform prioritisation
and selection for use
in routine health information systems
and population-based surveys
for national and global tracking



EN-BIRTH study

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



Day LT, Ruysen H, Gordeev VS, et al: "Every Newborn-BIRTH" protocol: observational study validating indicators for coverage and quality of maternal and newborn health care in Bangladesh, Nepal and Tanzania. *Journal of Global Health* 2019, 9(1).

#everynewborn #endstillbirths

EN-BIRTH = Every Newborn-Birth Indicators Research for Tracking in Hospitals

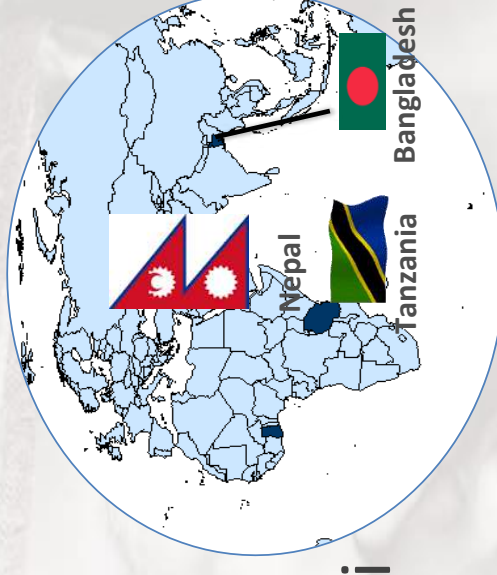
To test validity of coverage metrics for high impact care for every mother, every newborn

WHERE?

Bangladesh – icddr, b sites in Kushtia District and Dhaka

Tanzania – Ifakara Health Institute, sites at Muhimbili and Temeke

Nepal – UNICEF/Golden Community in Pokhara



Total of ~20,000 births



CHILDREN'S
INVESTMENT FUND
FOUNDATION

EN-BIRTH Objectives



| | |
|--|--|
| 1 NUMERATOR | To determine validity for selected facility-based interventions for mothers and newborns (numerator) in terms of accuracy for recording in routine registers and for women's report in maternal survey |
| 2 DENOMINATORS | To compare different denominator options for each of the interventions |
| 3 CONTENT & QUALITY OF CARE | To evaluate priority questions for each intervention with respect to coverage (e.g. content, timing, etc.) |
| 4 BARRIERS AND ENABLERS | To assess barriers and enablers to routine register documentation |

Rigorous science to validate, not just adding multiple new indicators
Keeping end in mind focus on use in HMIS and digital systems such as

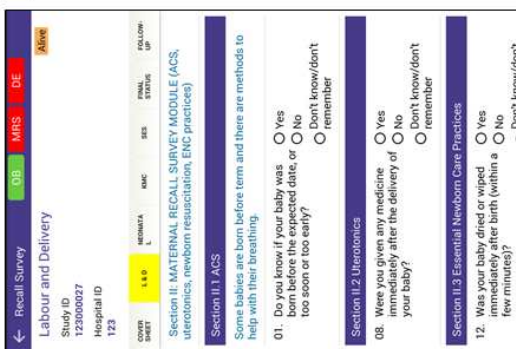


Bangladesh



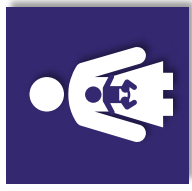
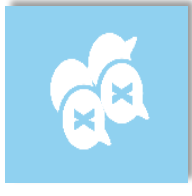
EN-BIRTH Tablet Application

Customised Android based Time stamped entries





Tanzania



Qualitative work – Barriers and enablers to routine register recording Kangaroo Mother Care lead





Nepal



Neonatal Resuscitation lead Experience of care - Respectful Maternal and Newborn Care lead



UPPSALA
UNIVERSITET





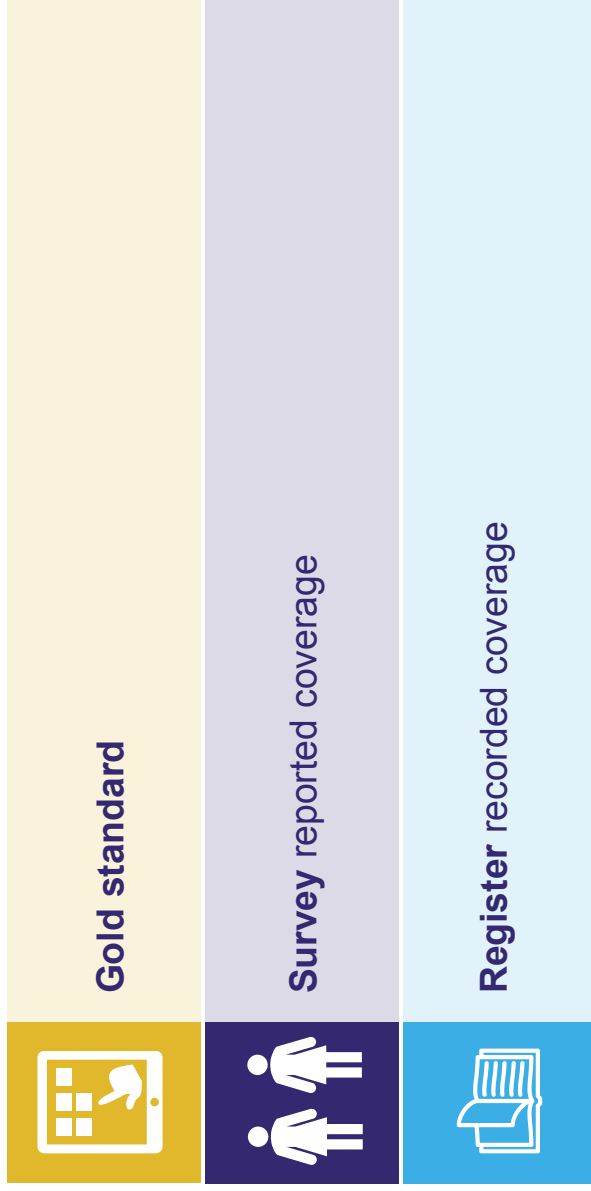
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Rigorous science to validate, not just adding multiple new indicators
Keeping end in mind focus on use in HMIS and digital systems such as



What was done?



EN-BIRTH study: "Gold standard" or "true" coverage assessed by trained clinical data collectors

OBSERVATION or **VERIFICATION** of intervention from patient case notes:

- antibiotics for presumed severe infection

Research question: Do women's report survey questions give a valid representation of observed maternal and newborn interventions?

FACILITY REGISTER DATA

Routinely aggregated as source data for HMIS e.g. DHS2

EN-BIRTH study: intervention/practices data extracted by trained data collectors:

- Yes +/- details
- No
- Not recorded (blank)
- Not readable

Research question: Do women's report survey questions give a valid representation of observed maternal and newborn interventions?

WOMAN'S REPORT EXIT SURVEY

Population-based survey commonly used source for LMIC e.g. DHS and MICS

EN-BIRTH study: intervention/practices report from women at facility exit interview by trained data collectors:

- Yes +/- details
- No
- Don't know/remember

Research question: Do women's report survey questions give a valid representation of observed maternal and newborn interventions?



#everynewborn #endstillbirths



EN-BIRTH study

1. Why?
2. What was done?
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Day LT, Ruysen H, Gordeev VS, et al: "Every Newborn-BIRTH" protocol: observational study validating indicators for coverage and quality of maternal and newborn health care in Bangladesh, Nepal and Tanzania. *Journal of Global Health* 2019, 9(1).

#everynewborn #endstillbirths



Every Newborn – BIRTH

EN-BIRTH key links

- Study protocol →
- Baseline analysis →
- Lancet GH paper →
- BMC supplement papers →

Meet the teams involved

At the end of the study, we asked all teams to reflect on highlights, collaborative learning, and significance of the results. Hear what they had to say below.

About EN – BIRTH

The Every Newborn Action Plan

Each year,

- 2.5 million newborns die in first 28 days accounting for 47% of under-5 child deaths.
- More than 2 million are stillborn, 50% during labour.

99% of these deaths happen in low & middle income countries, especially for the poorest families, are preventable.

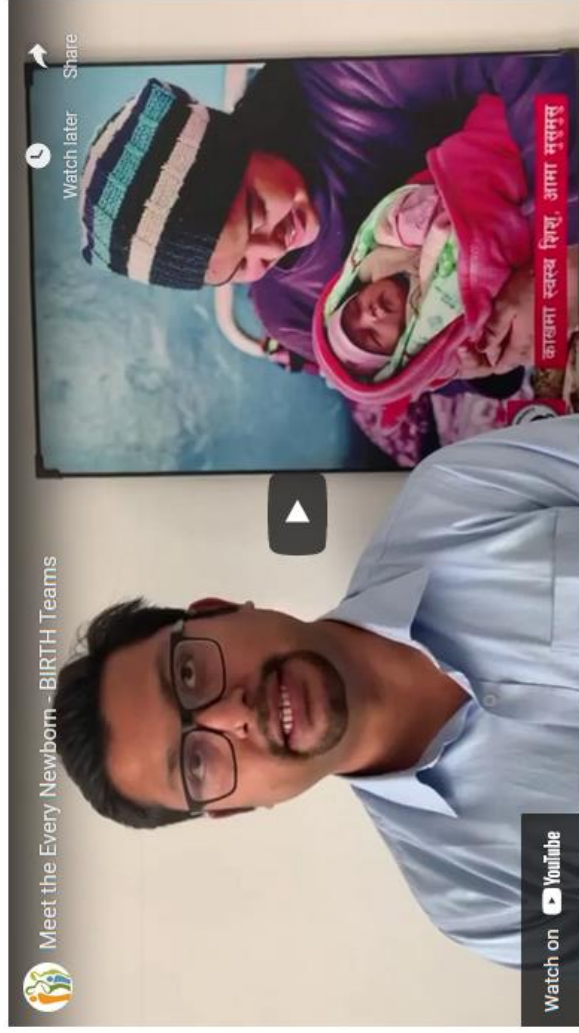
In response to this, the Every Newborn Action Plan was developed with the aim to end preventable setting the first ever national mortality targets:

- ≤ 12 neonatal deaths per 1000 live births
- ≤ 12 stillbirths per 1000 total births

EN-BIRTH

EN-BIRTH study involved observing >23,000 births using an innovative tablet-based system to valid from routine facility registers and women's survey report.

The study was conducted in five hospitals in Bangladesh, Nepal and Tanzania, coordinated by a team and funded by the Children's Investment Fund Foundation (CIFF).





Labour Ward

5 public district/ tertiary hospitals:
2 in Bangladesh, 1 in Nepal, 2 in
Tanzania

23,015 births observed

6,698 Caesarean sections

550 Stillbirths

Labour and delivery ward

Clinical observation (gold standard)

23811 women identified for clinical observation

87 consent not given

23724 women consented

709 not observed

23015 women observed
6698 caesarean section
16030 vaginal birth
287 missing data
23471 babies observed
22242 single
852 twin
45 triplet
332 missing

1013 women register data not extracted
1078 babies register data not extracted

22002 women with register-recorded data
22393 babies with register-recorded data

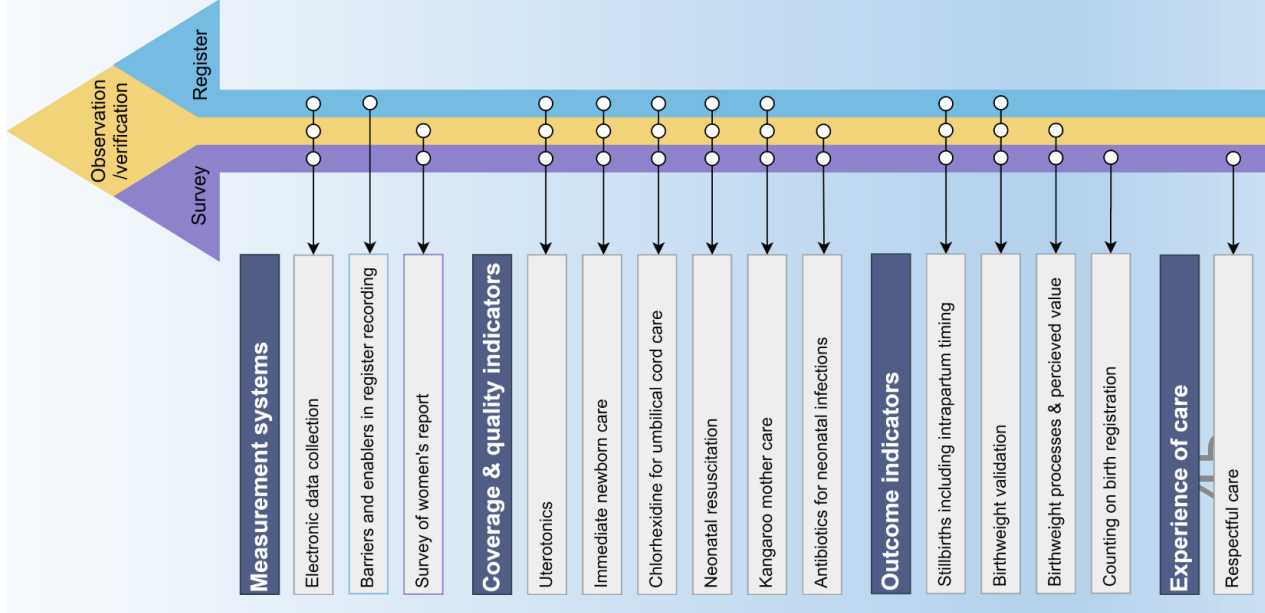
1967 not approached for survey
416 consent not given

20632 women with survey-reported data

Register-recorded data

Survey-reported data

EN-BIRTH Analysis



PhD linkage

EN-BIRTH multi-country validation study

observation
verification

survey

register

Measurement systems

Coverage & quality
indicators

Outcome indicators

Stillbirths including
intrapartum timing

Birthweight validation

Birthweight processes &
perceived value

Counting on birth registration

Experience of care

Peven et al. *BMC Pregnancy and Childbirth* 2021, **21**(Suppl 1):226
<https://doi.org/10.1186/s12884-020-02238-7>

BMC Pregnancy and Childbirth

From *Every Newborn BIRTH* multi-country validation study, informing measurement of coverage and quality of maternal and newborn care

RESEARCH

Open Access



Stillbirths including intrapartum timing: EN-BIRTH multi-country validation study

Kimberly Peven^{1,2}, Louise T. Day¹, Harriet Ruysen¹, Tazeen Tahirov³, Adish KC⁴, Josephine Shaban⁵, Stefanie Kong¹, Shafiqul Ameen³, Omar Basnet⁶, Rajib Halder³, Qazi Sadequr Rahman³, Hamah Blencowe^{1*}, Joy E. Lawn^{1*} and EN-BIRTH Study Group

Abstract

Background: An estimated >2 million babies stillborn around the world each year lack viability. Low- and middle-income countries carry 64% of the burden yet have the least data. Most births are now in facilities, hence routine register-recording presents an opportunity to improve counting of stillbirths, but research is limited, particularly regarding accuracy. This paper evaluates register-recorded measurement of hospital stillbirths, classification accuracy, and barriers to routine recording.

Methods: The EN-BIRTH mixed-methods, observational study took place in five hospitals in Bangladesh, Nepal and Tanzania (2017–2018). Clinical observers collected time-stamped data on perinatal care and birth outcomes as gold standard. To assess accuracy of routine register-recorded stillbirth rates, we compared birth outcomes recorded in labour ward registers to observation data. We calculated absolute rate differences and individual-level validation metrics (sensitivity, specificity, percent agreement). We assessed misclassification of stillbirths with neonatal deaths. To examine stillbirth appearance (fresh/macerated) as a proxy for timing of death, we compared appearance to observed timing of intrauterine death based on heart rate at admission.

Results: 23,072 births were observed including 550 stillbirths. Register-recorded completeness of birth outcomes was > 90%. The observed study stillbirth rate ranged from 3.8 (95%CI = 2.0, 7.0) to 50.3 (95%CI = 43.6, 58.0)/1000 total births and was underestimated in routine registers by 1.1 to 73 /1000 total births (register: observed ratio 0.9–0.7). Specificity of register-recorded birth outcomes was > 99% and sensitivity varied between hospitals, ranging from 77.7–86.1%. Percent agreement between observer-assessed birth outcome and register-recorded birth outcome was very high across all hospitals and all modes of birth (> 98%). Fresh or macerated stillbirth appearance was a poor proxy for timing of stillbirth. While there were similar numbers of stillbirths misclassified as neonatal deaths (17/430) and neonatal deaths misclassified as stillbirths (21/36), neonatal deaths were proportionately more likely to be misclassified as stillbirths (58.3% vs 4.2%). Enablers to more accurate register-recording of birth outcome included supervision and data use.

(Continued on next page)

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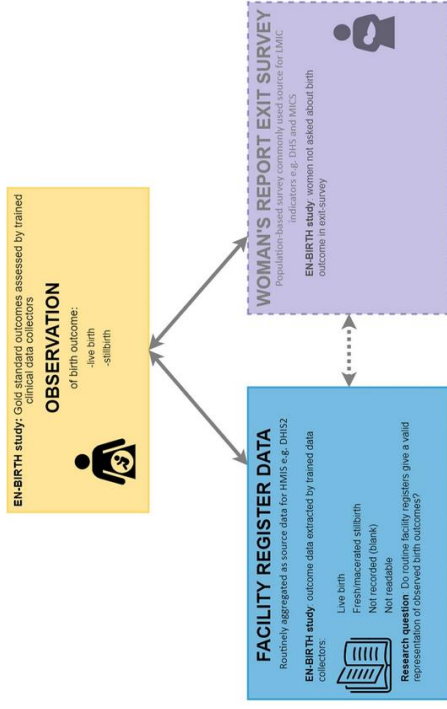
¹Hamzah Blencowe and Joy E. Lawn are joint senior authors, ²Maternal, Adolescent, Reproductive & Child Health (MARCH) Centre, London School of Hygiene & Tropical Medicine, Keppel Street, London, WC1E 7HT, UK. Full list of author information is available at the end of the article



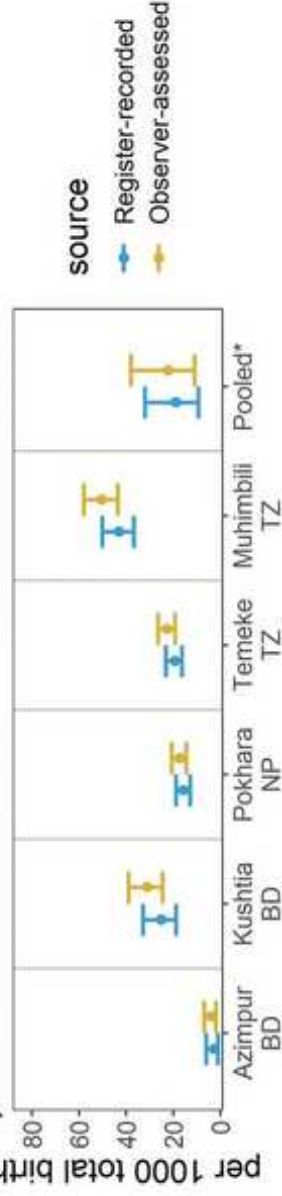
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#everynewborn #endstillbirths

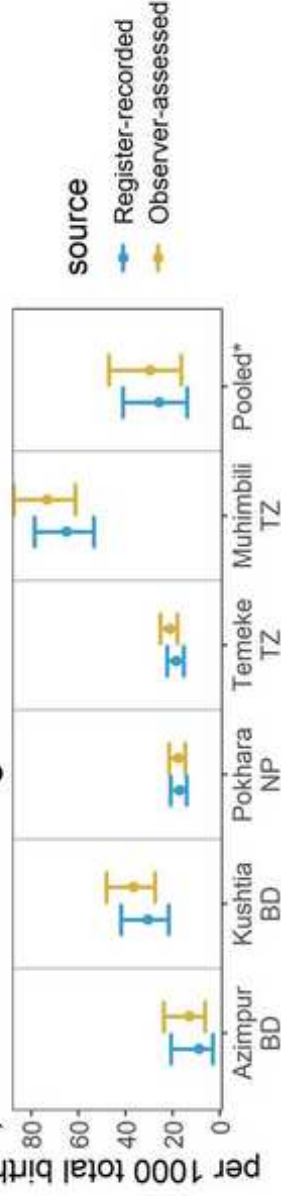
Stillbirth



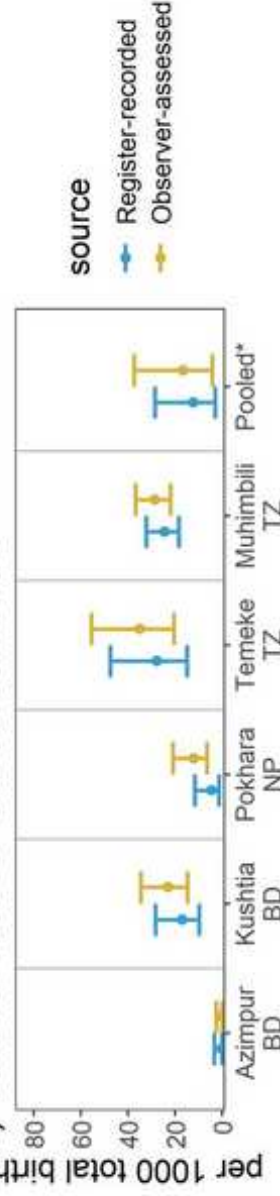
a) Stillbirth rate for all modes of birth



b) Stillbirth rate for vaginal births



c) Stillbirth rate for Caesarean births

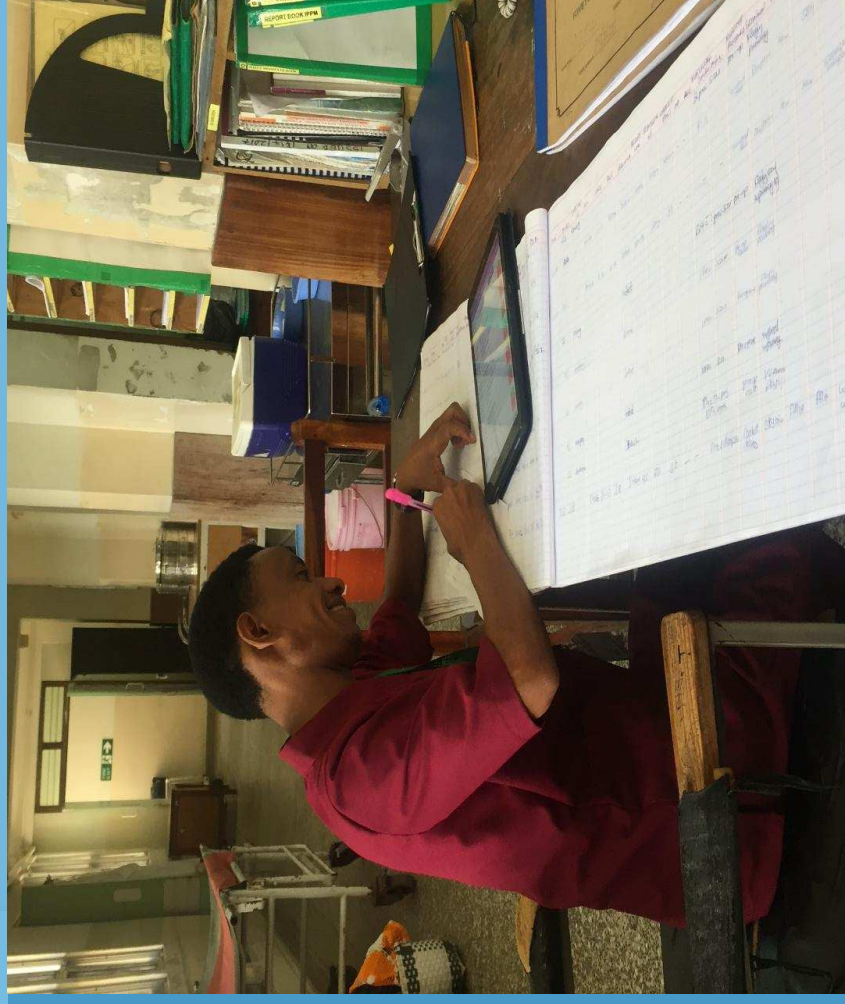


Hospital Stillbirth rate:
5.8 – 50.3/ 1000 total births



Routine labour ward register data on stillbirths

- Data completeness high in all five hospitals, >90%
- Registers under-estimated the observed stillbirth rate by 1.1 to 7.4 per 1000 total births.
- High percent agreement (> 98%) and specificity (> 99%) with variable sensitivity (77.7–86.1%)



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EN-BIRTH Objectives

| | |
|--|--|
| 1 NUMERATOR | To determine validity for selected facility-based interventions for mothers and newborns (numerator) in terms of accuracy for recording in routine registers and for women's report in maternal survey |
| 2 DENOMINATORS | To compare different denominator options for each of the interventions |
| 3 CONTENT & QUALITY OF CARE | To evaluate priority questions for each intervention with respect to coverage (e.g. content, timing, etc.) |
| 4 BARRIERS AND ENABLERS | To assess barriers and enablers to routine register documentation |

Rigorous science to validate, not just adding multiple new indicators
Keeping end in mind focus on use in HMIS and digital systems such as



Misclassification in the register?

Neonatal Death or Stillbirth?

- Only 38 misclassified register record
 - 17 of 430 stillbirths (4.0%) recorded as neonatal deaths
 - 21 of 36 neonatal deaths recorded as stillbirths.

Intrapartum/ Antepartum stillbirths?

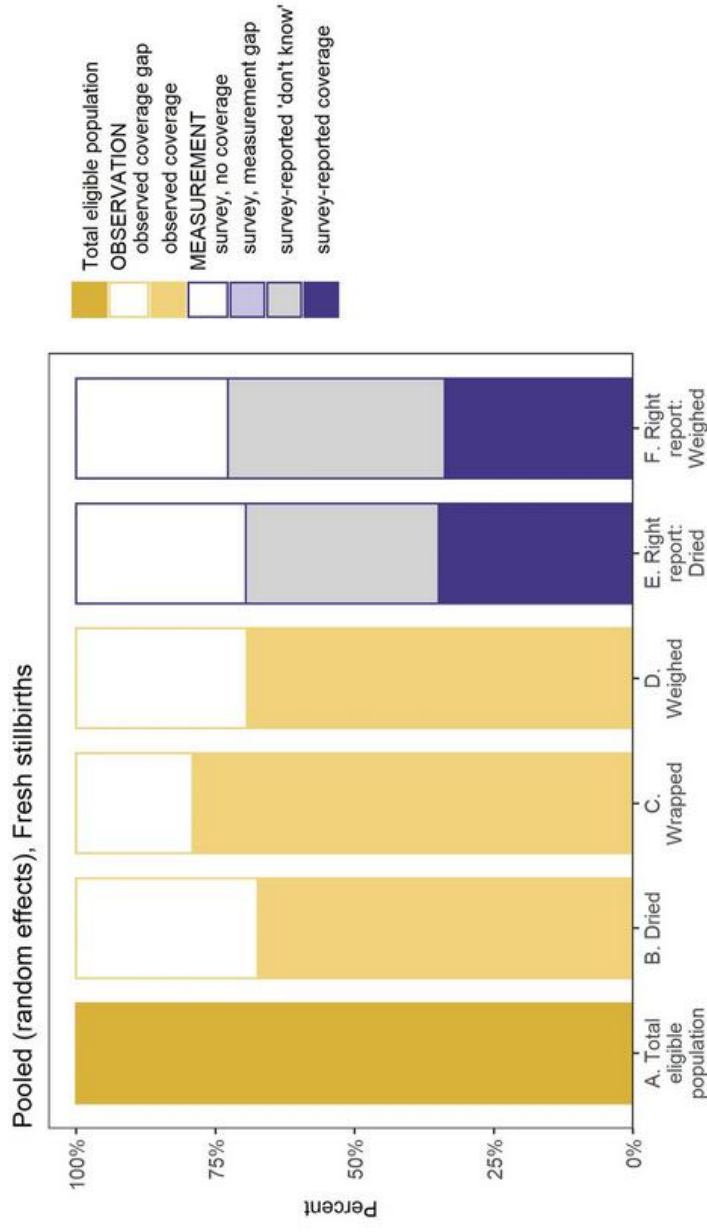
- Intrapartum - fetal heart heard on admission – 5 - 41% were recorded as macerated stillbirths

Fresh / macerated stillbirths inaccurate for intrapartum/ antepartum



Respectful care

- Livebirths all hospitals dried (>98%) wrapped (>98%) weighed (>98%)
- Stillbirths in Bangladesh dried (31.3–42.9%) wrapped (28.6–35.5%) weighed (21.9–28.6%)



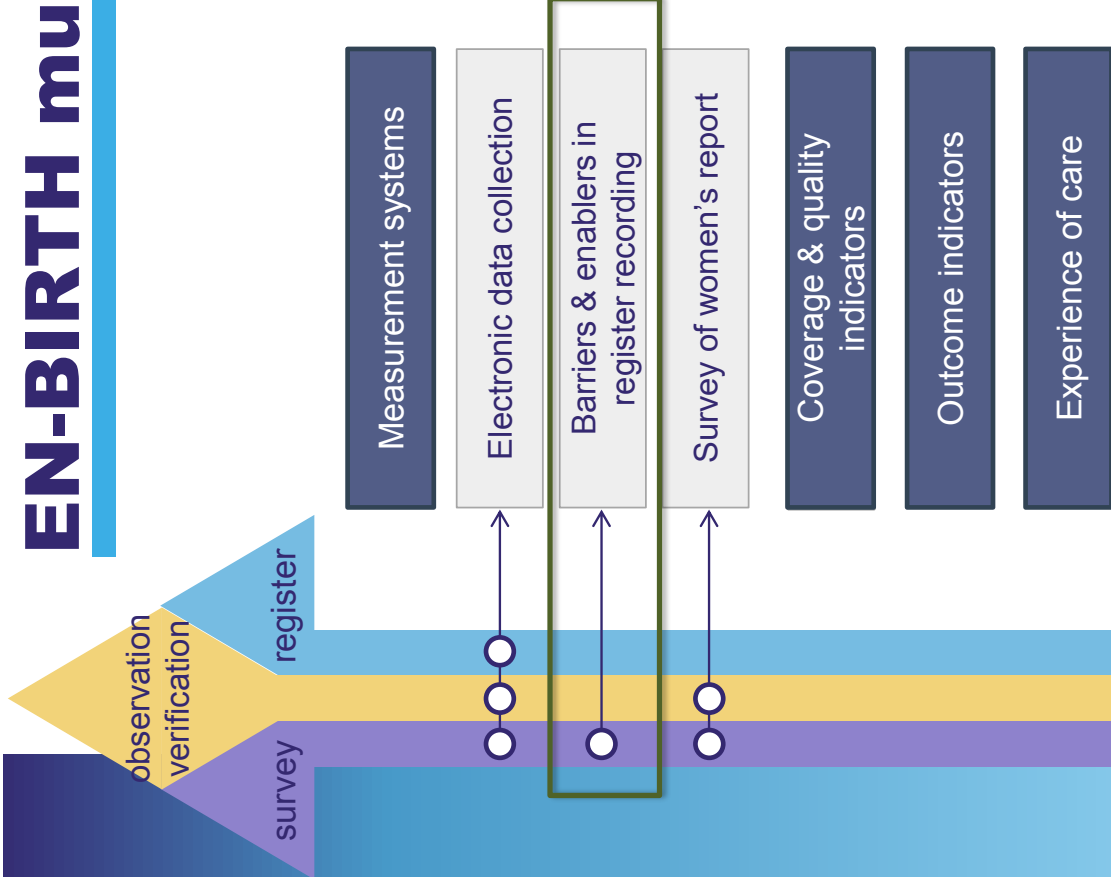


Objectives

| | |
|--|--|
| 1 NUMERATOR | To determine validity for selected facility-based interventions for mothers and newborns (numerator) in terms of accuracy for recording in routine registers and for women's report in maternal survey |
| 2 DENOMINATORS | To compare different denominator options for each of the interventions |
| 3 CONTENT & QUALITY OF CARE | To evaluate priority questions for each intervention with respect to effective coverage (e.g. content, timing, completion rates, etc.) |
| 4 BARRIERS AND ENABLERS | To assess barriers and enablers to routine register documentation |

Rigorous science to validate, not just adding multiple new indicators
Keeping end in mind focus on use in HMIS and digital systems such as

EN-BIRTH multi-country validation study



Informing measurement of coverage and quality of maternal and newborn care



What was found?

Barriers and Enablers



Each country had a different labour ward register design.
Coverage indicator data elements captured in 2 of the 3



Recording burden

Routine register data

- Multiple documents in which care is documented



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Register structure

Printed formal

Many columns:

- Nepal = 35
- Tanzania = 48
- Bangladesh = 58

Statistika za ululatio, Mafokero za Uzoazi na Hali za Maendeleo ya Mwanadamu

| Mwaka wa ujuzi (Year) | Mwaka wa ululatio (Year of survey) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) | Mwaka wa maendeleo (Year of development) |
|-----------------------|------------------------------------|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|
| 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 | 2017 |

Hand-written informal

Many registers

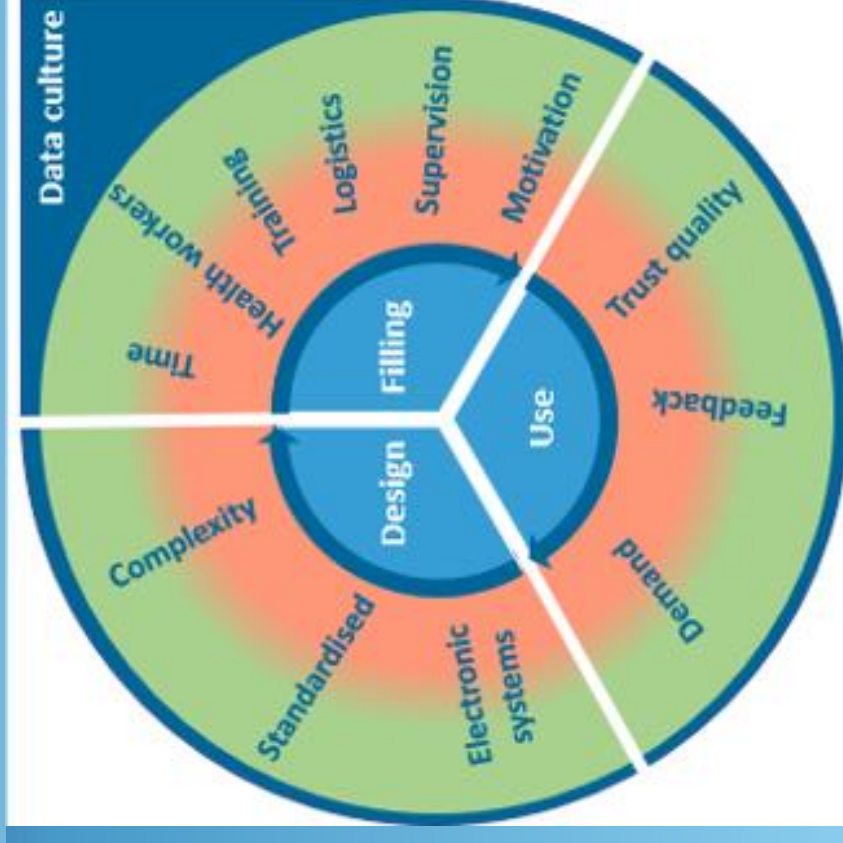
| PROCEEDURE | RX | OUTCOME | OUTCOME ACTION | DISPOSE DEL BY |
|-----------------------------------|------------------|---------|----------------|----------------|
| Conducting delivery through stork | - | Alive | Wanted stork | 38 Billed |
| Use of bare placental | Use of placental | Alive | Wanted | 32 Reported |
| Conduct oxytocin | oxytocin | Alive | Wanted | Used in 2017 |

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Barriers and Enablers

- Hospitals with identical register design differed in completeness and accuracy.
- Stillbirth qualitative findings suggest supervision, perceived usefulness of data and feedback contribute to improved quality of register data.



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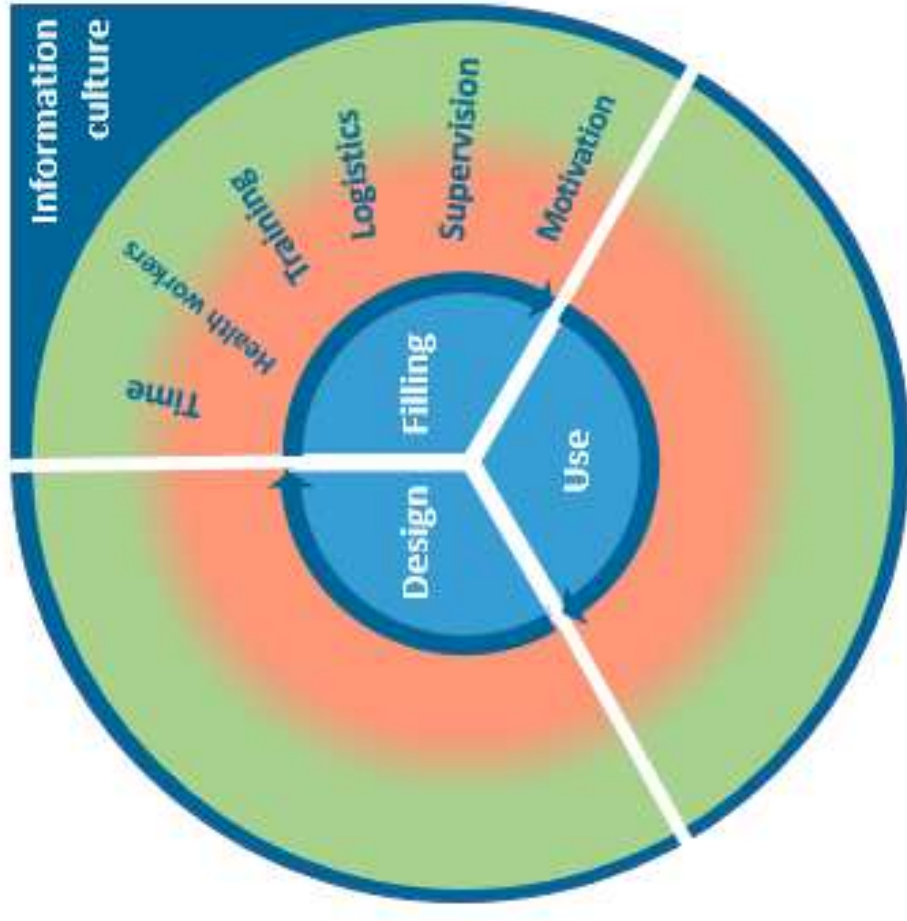


Register filling

Barriers and Enablers

Time

*“In an eight hour shift,
if I have a large number of
patients,
I may spend more time in
documentation than the time I
spend
in attending the patients”
[IDI_L&D_Nurse, MNH, TZ]*



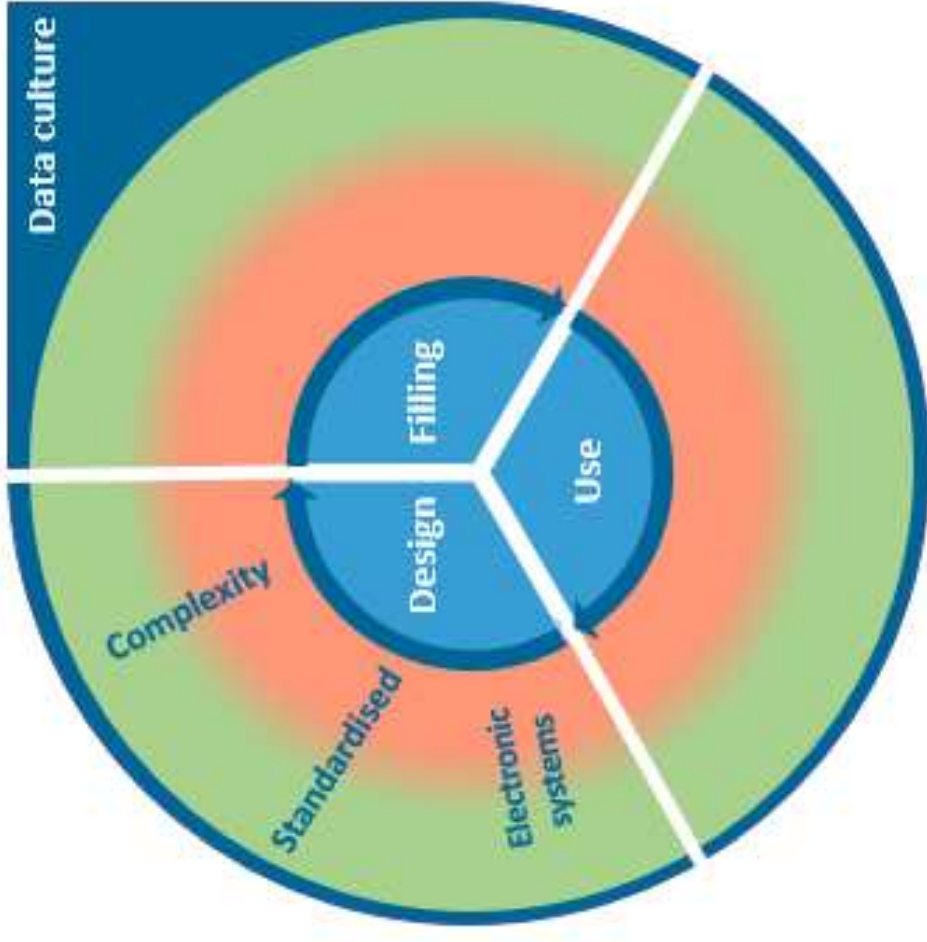


Register Design

Standardisation

“I enter entire patient’s information....sometimes I have to add some columns where I can include some data that I know is important.....to help me with my end of the month report. So if I were to just follow the register it means some data could be missed and that’s the challenge that I encounter”

Barriers and Enablers





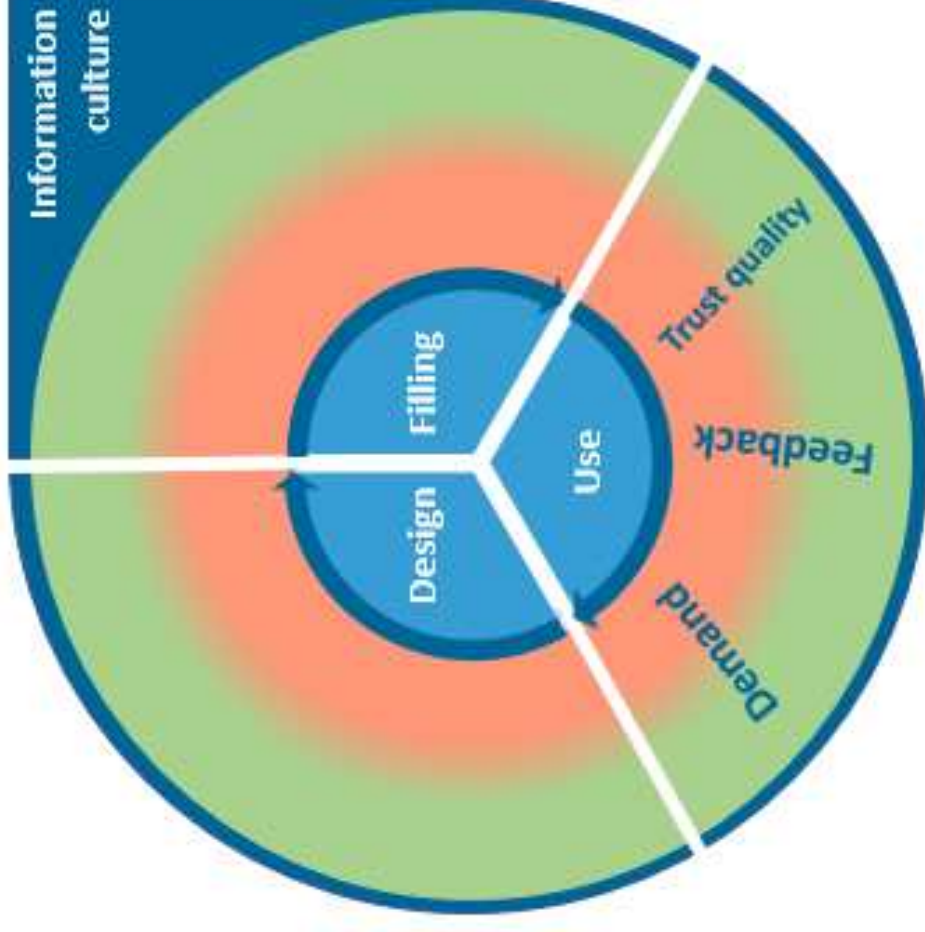
Register Use

Barriers and Enablers

Feedback

“I haven’t got any feedback from them (HMIS) about documentation. There sits monthly meeting in hospital with data people. We don’t usually participate in that meeting.”

[IDI_L&D_Nurse, BD]





EN-BIRTH study

1. Why?
2. What was done?
3. What was found?
Survey
Register
4. What next in
measurement and research?



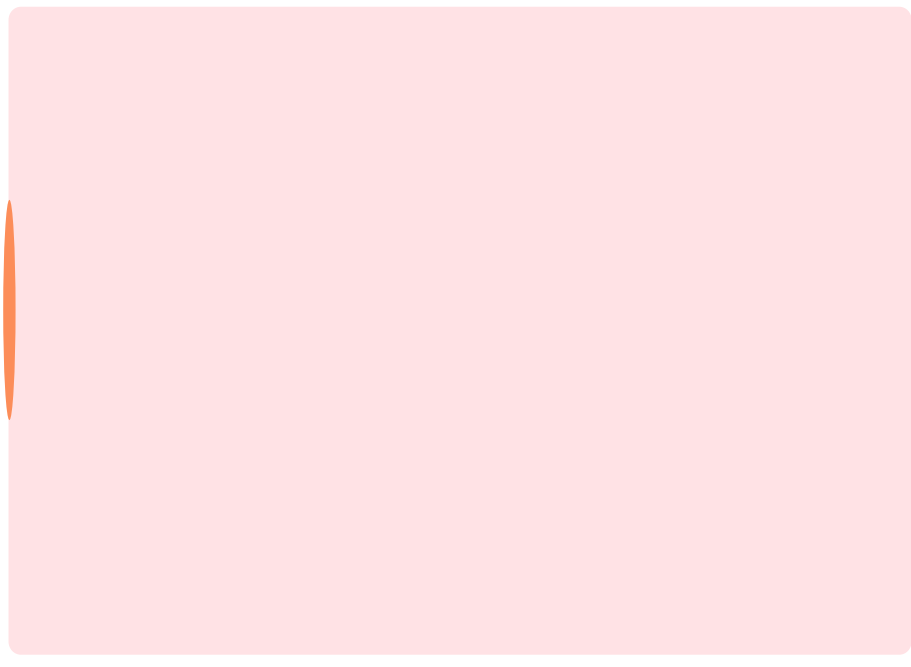
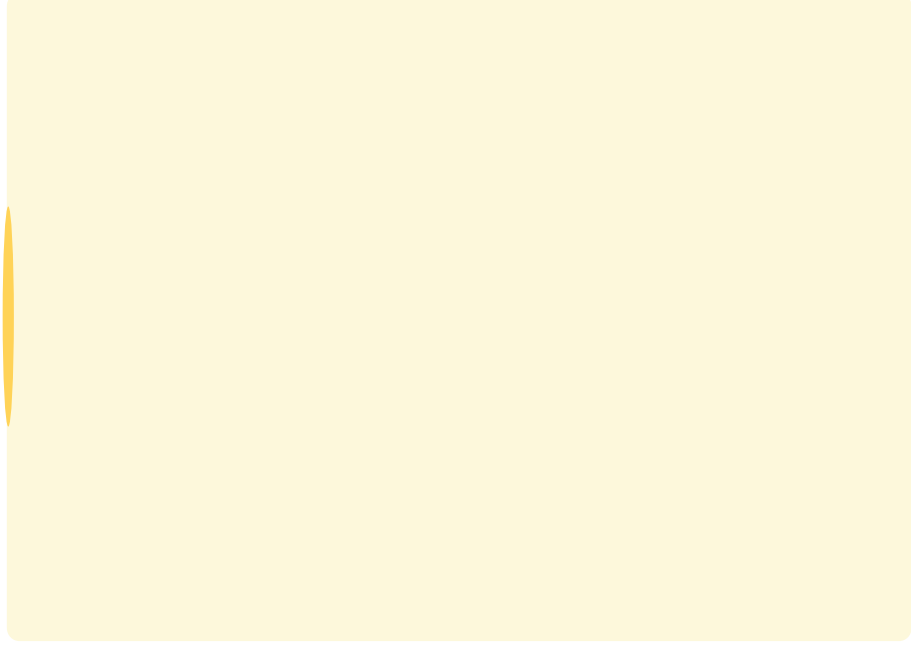
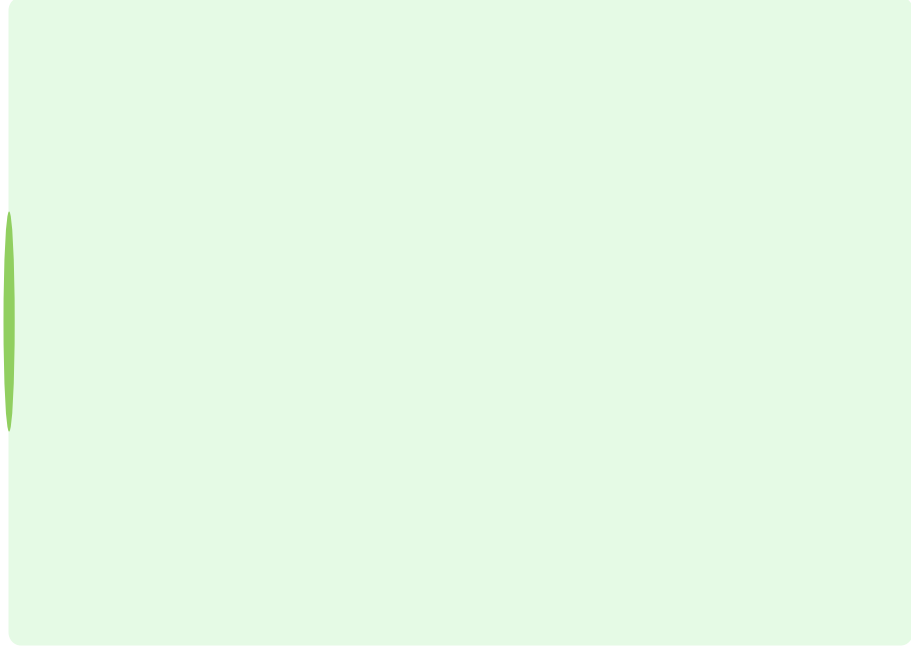
Day LT, Ruysen H, Gordeev VS, et al: "Every Newborn-BIRTH" protocol: observational study validating indicators for coverage and quality of maternal and newborn health care in Bangladesh, Nepal and Tanzania. *Journal of Global Health* 2019, 9(1).

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What next register data?

Routine register data



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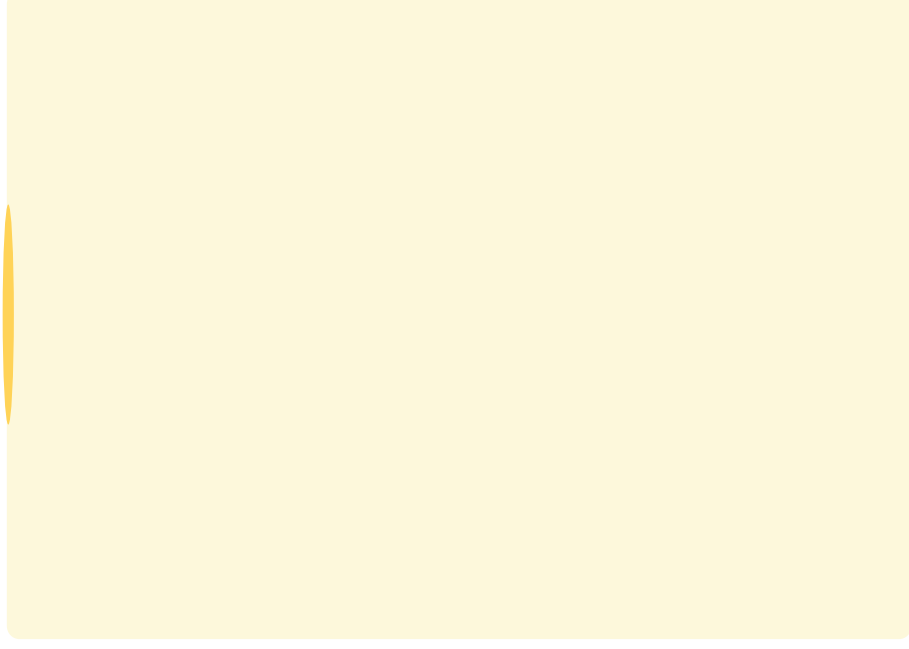
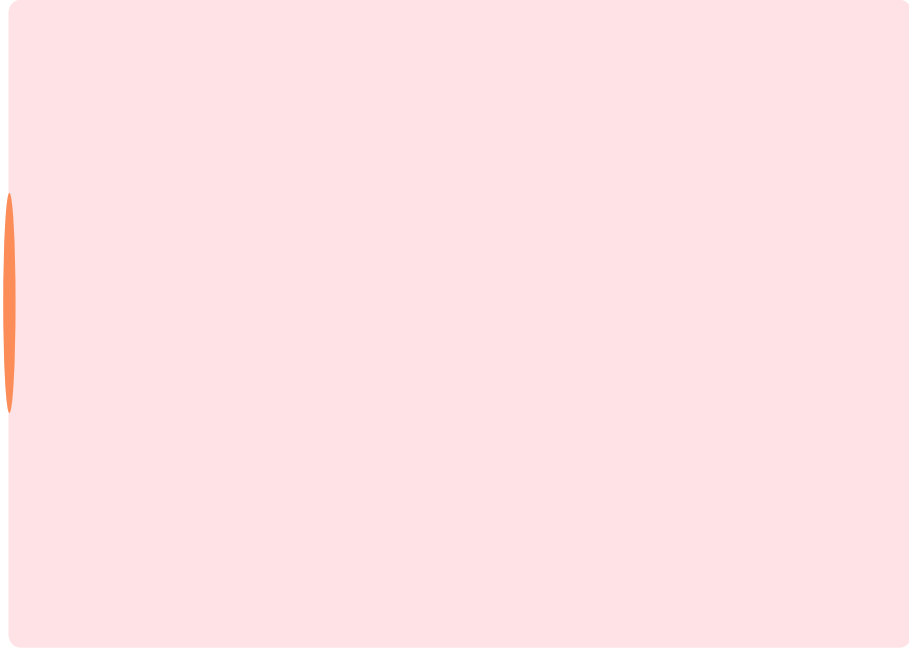


What next register data?

Routine register data

Now

Start using register data
with feedback loops



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What next register data?

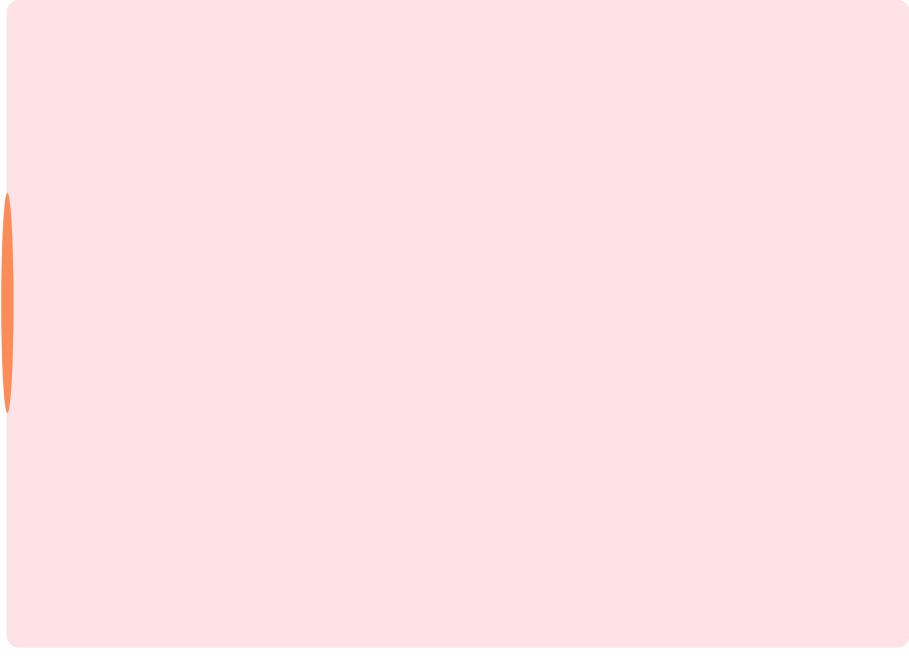
Routine register data

Now

Start using register data
with feedback loops

Next in
research

Improve data quality



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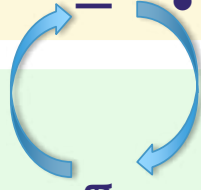


What next register data

Routine register data

Now

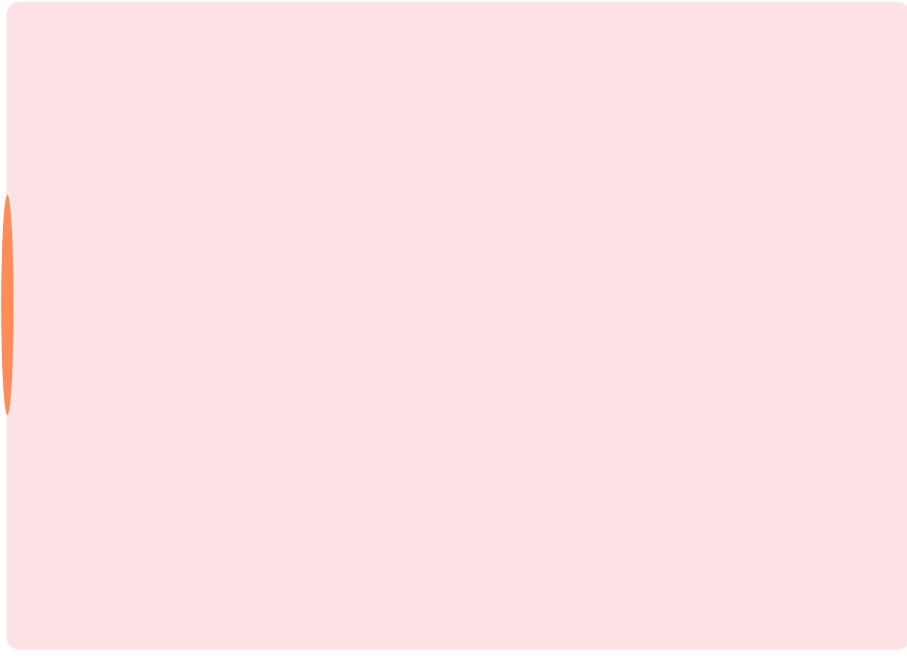
Start using register data with feedback loops



Next in research

Improve data quality

- Register standardised design, optimising results
- Implementation research to improve data quality and use



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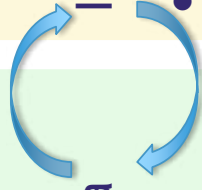


What next register data

Routine register data

Now

Start using register data with feedback loops



Next in research

Improve data quality

- Register standardised design, optimising results
- Implementation research to improve data quality and use

Not useful

Blanks

Too much burden on health workers

Non standardized

#everynewborn #endstillbirths



Stillbirth - What next and research gaps?

- Linkages to:
 - Civil and vital registration systems (CRVS) (birth/death certificates)
 - Maternal and Perinatal Death Surveillance and Response (MPDSR)
- Bereavement support is understudied in LMIC, but important to care for affected families, communities, and caregivers.



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Stillbirth - What next and research gaps?

- Reducing stillbirth/neonatal death misclassification requires:
 - devices and systems to easily measure and record heart rate
 - training in timely newborn care, recognising signs of life, and resuscitation
- Recording fetal heart rate on admission is crucial for every woman and her baby
 - Fresh/macerated inaccurate



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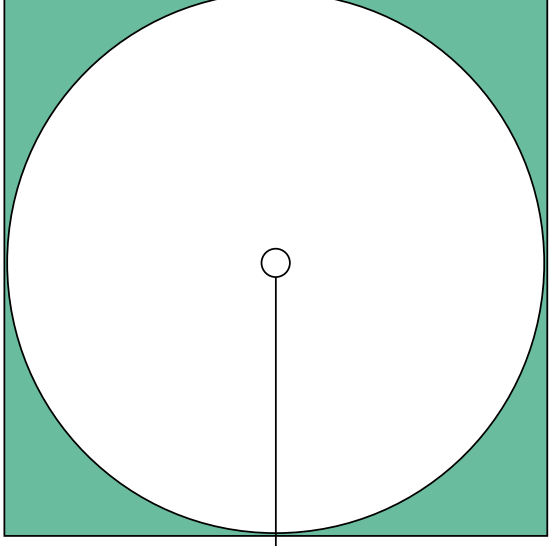


Stillbirth - What next and research gaps?

- Facility-stillbirths were accurately captured, but under-used for national and global accountability.
- Register design, staff training, supervision and data culture could further improve data quality
- Implementation research is required including flow in Health Management Information Systems (HMIS).



#everynewborn #endstillbirths



Advancing Routine Health Management Information Systems (HMIS) to Deliver for Every Newborn

Data for Impact
With LSHTM
With icddr,b





Every Newborn BIRTH Indicators Research Tracking in Hospitals (EN-BIRTH) Phase 2

LSHTM, icddr, IHI July 2021





Bangladesh

Tanzania

EN-BIRTH Phase 2

Data for Impact

With LSHTM

With icddr,b



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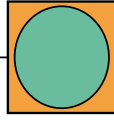
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Data for Impact / UNC

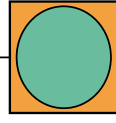
Dr Kavita Singh Ongechi
Ms Gabriela Escudero



EN-BIRTH Phase 2 purpose

- EN-BIRTH Phase 2 study will assess whether the validated indicators are feasible to implement as the next step to promote broad HMIS uptake in low- and middle- income countries (LMIC).

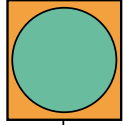
- The main output of this work will be a toolkit to enable other high-burden countries to implement and use selected newborn indicators in national HMIS/DHIS2.



EVERY NEWBORN PROGRESS REPORT

90 ENAP countries to use
data to drive change
towards SDG 3.2

2019



For those 34 countries with the highest burden of newborn mortality and stillbirths, only two countries report having all four indicators in HMIS: the Democratic Republic of the Congo and Togo. Ethiopia, India and Nigeria report that work is underway to include all four indicators.

Table 13 shows the status of HMIS indicators in high burden countries.

Table 13. Status of HMIS research in the 34 highest burden countries

| Highest burden countries | Indicator for newborns that benefited from KMC | Indicator for use of antenatal corticosteroids for fetal lung maturation | Indicator for newborn resuscitation performed | Indicator for treatment of neonatal sepsis |
|----------------------------------|--|--|---|--|
| India | In process | Yes | Yes | Yes |
| Nigeria | Yes | In process | In process | In process |
| Pakistan | No | Yes | No | Yes |
| Democratic Republic of the Congo | Yes | Yes | Yes | Yes |
| Ethiopia | Yes | In process | Yes | Yes |
| China | No | No | No | No |
| Indonesia | No | No | No | No |
| Bangladesh | Yes | No | Yes | No |
| United Republic of Tanzania | Yes | No | Yes | Yes |
| Afghanistan | No | No | No | Yes |
| Sudan | In process | No | In process | Yes |
| Uganda | In process | In process | Yes | In process |
| Angola | No | No | No | No |
| Philippines | Yes | No | No | No |
| Kenya | In process | No | In process | In process |
| Mozambique | No | No | Yes | No |
| Cote d'Ivoire | No | No | Yes | No |
| Egypt | Yes | No | No | No |
| Mali | Yes | No | Yes | Yes |
| Niger | No | No | No | Yes |
| Somalia | No | No | No | No |
| Central African Republic | No | No | No | No |
| South Sudan | In process | No | Yes | Yes |
| Lesotho | No | No | No | Yes |
| Guinea-Bissau | No | No | No | No |
| Chad | No | No | No | No |
| Mauritania | No | No | No | No |
| Sierra Leone | Yes | No | No | No |
| Benin | No | No | Yes | No |
| Djibouti | No | No | Yes | Yes |
| Comoros | No | No | No | No |
| Equatorial Guinea | No | No | No | No |
| Togo | Yes | Yes | Yes | Yes |
| Yemen | In process | In process | In process | In process |

HMIS: health management information systems



What next and research gaps?

Barriers and Enablers



Routine labour ward register data can be used now to contribute vital data around the time of birth.

Overcoming barriers to register recording would enable frontline health workers, especially midwives, be valued for the register data they collect, to improve data quality and importantly also use those data to improve quality of care for the women and babies they care for.



Caesarean section negatively affected accuracy of both survey-reported and register-recorded coverage.

Further research is required regarding the measurement implications of increasing caesarean section rates.



What next and research gaps?



Valid data alone will not save lives.

Data need to be used by health-care professional caring for women and their babies and by policy makers and governments to invest and transform care, enabling universal health coverage as a reality that can be measured and improved.



Two-way feedback between HMIS levels is critical to improve performance and accurately track progress towards agreed health goals.

Implementation research is required on interventions to standardise labour ward register designs, and the processes for filling them with regular data quality review.

EN-BIRTH team

Country team leads & organisations

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Nepal:

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(Uppsala University, with implementing partner Golden Community)

Tanzania:

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Tropical Medicine (LSHTM):

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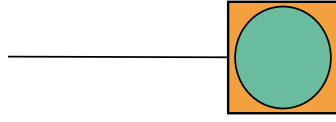
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Finally, and most importantly, we thank the women, their families, the health workers and data collectors





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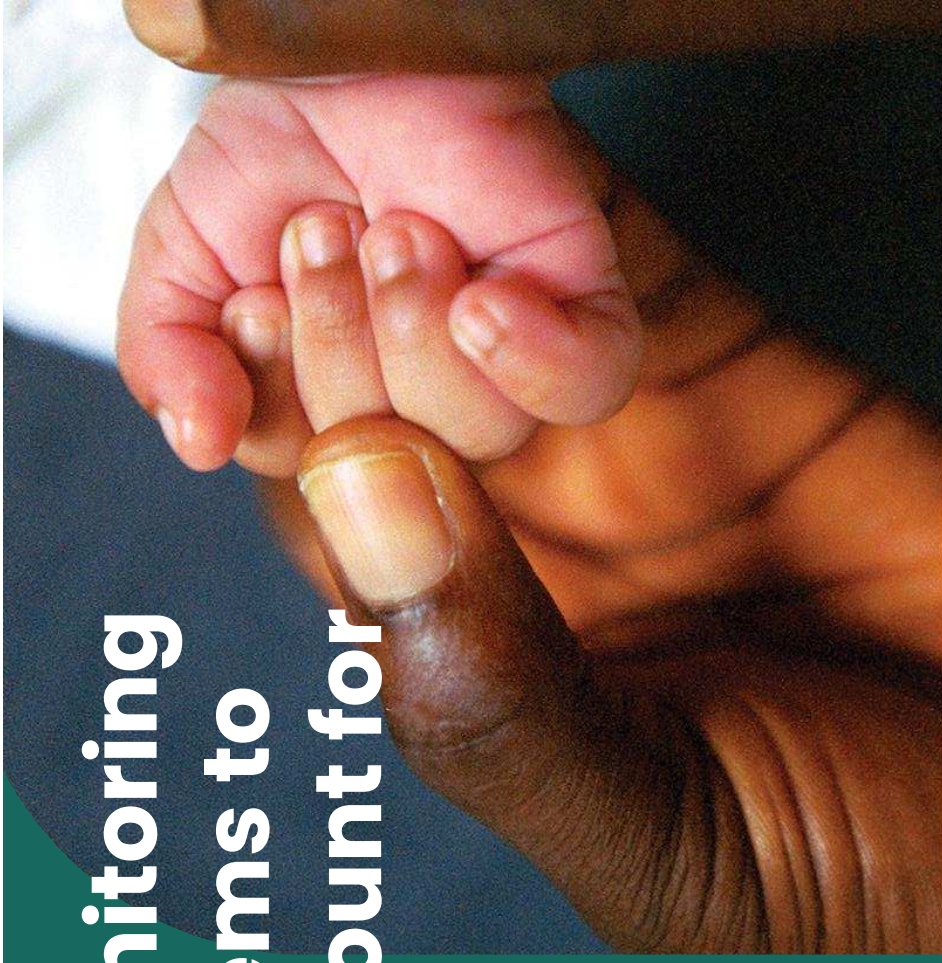


Improving monitoring and data systems to count and account for stillbirths



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July 29, 2021



Importance of counting stillbirths

- 56 countries are not on track to reach the stillbirth target (≤ 12 per 1,000 total births)
- Recommended as a high priority vital event, as are live births & deaths
 - Recognized as a preventable public health problem
 - Assists in determining health conditions and risk factors that may affect pregnancy outcomes
 - Recommended that both stillbirth and perinatal death rates are tracked alongside neonatal mortality rates
 - Important to collect data that will enable the burden of stillbirths to be more accurately estimated
- Considerations on definitions: country, sources

Stillbirths can be counted

- Country systems
 - Population-based surveys
 - Routine systems:
 - (Maternal and) Perinatal Death Surveillance and Review systems (health facility & community events)
 - Health Management Information System, Stillbirth Registers
 - Civil Registration and Vital Statistics, Sample Registration System, including Health and Demographic Surveillance Systems
- Other sources
 - Report of the UN Inter-agency Group for Child Mortality Estimation
- Determination of causes of death (more challenging)
 - Medical certification of causes of death
 - Verbal autopsy, social autopsy

Stillbirths in the GFF agenda

- 30 GFF-supported countries are off track to reach the stillbirth targets
- Reducing preventable stillbirths included in some RMNCAH-N Investment Cases (e.g., Kenya)
 - The vision of the RMNCAH investment framework is:
A Kenya where there are no preventable deaths of women, new-borns or children and; no preventable still-births, where every pregnancy is wanted, every birth celebrated and accounted for; and where women, babies, children and adolescents are free of HIV/AIDS, survive, thrive and reach their full social and economic potential.
- Currently not a prioritized vital event in the CRVS agenda, and no GFF supported country reports data on stillbirths from the CRVS system
 - Nigeria: compulsory to register stillbirths; Sierra Leone: stillbirths must be notified to the civil registration authority; Rwanda: stillbirths not to be declared to civil registrar; Uganda: stillbirths not covered in civil registration laws
- GFF has initiated activities to revitalize and highlight the importance of stillbirths

GFF results strategy

Vision: Help strengthen country systems, sharpen focus on measurable outcomes, generate learning, inform improvements and strengthen accountability

GFF activities build upon country systems and aim to contribute to strengthening them

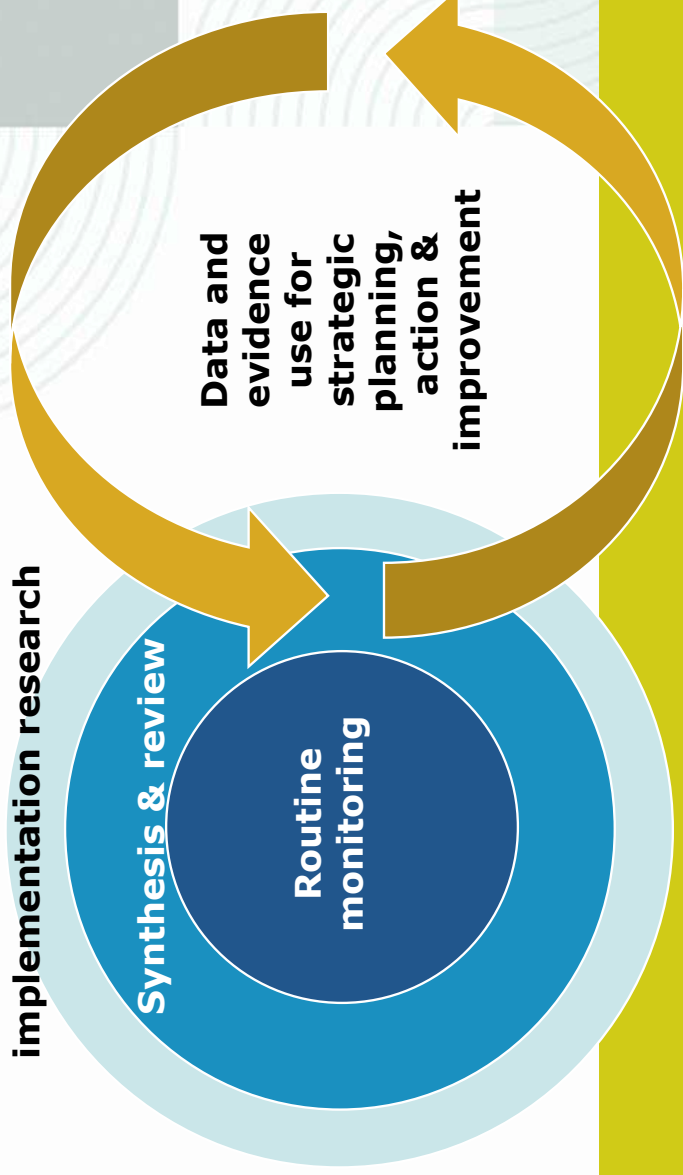
Evaluation & implementation research

Synthesis & review

Routine monitoring

Data and evidence use for strategic planning, action & improvement

Country data sources, systems, and capacities



Roadmap for stillbirth reporting

- Through the Country Platform, undertake dialogue and stakeholder mobilization on the importance of prioritizing:
 - Reducing preventable stillbirths;
 - Improvements in data systems for reporting and monitoring stillbirths
- Including stillbirths in RMNCAH-N Investment Cases and other country-specific priorities
 - Situational analysis of the status of stillbirths, perinatal and neonatal mortality (trends, subnational data, gender)
 - Assessment of data sources on stillbirth
 - Prioritization of activities to improve availability, quality and use of data quality on stillbirths in national reporting systems

Roadmap for stillbirth reporting and responding

- ❖ Country context specific:
 - ❖ *Where no reporting is happening:*
 - ❖ Support national guidelines for stillbirth inclusion,
 - ❖ amend laws to incorporate stillbirths in the CRVS system,
 - ❖ look for opportunities to integrate stillbirth reporting in existing systems (e.g., MPDSR, HMIS,)
 - ❖ *Where stillbirth reporting is routine:*
 - ❖ Strengthen quality, completeness, analysis and use of the data
- ❖ All settings
 - ❖ Data use to determine causes of stillbirths, monitor and prevent future stillbirths (MPDSR, health service quality, supporting families who have experienced stillbirth

Interlinking actions – from measuring to managing



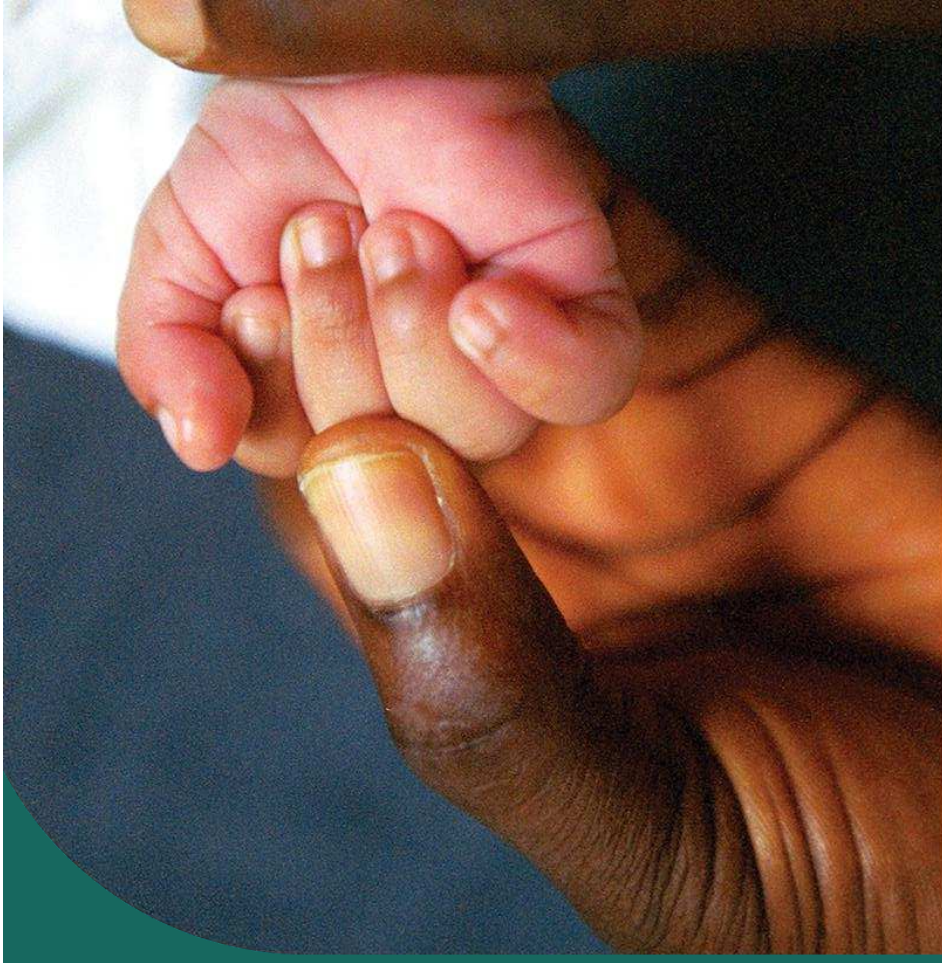
Want more resources?

1. [UN IGME stillbirth estimates 2020](#)
2. [Lancet Ending preventable stillbirth series](#)
3. [EN BIRTH study](#)
4. [WHO health sector contributions to civil registration \(June 2021 and includes a chapter on stillbirth\)](#)
5. [CRVS toolkit with chapter on stillbirth](#)



Counting 2 million stillbirths **annually**: seizing missed opportunities for impact and investment

July 29, 2021



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