Congenital Anomaly Surveillance Systems in Africa: A practical overview

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I have no conflicts of interest to declare

Key concepts

- Congenital anomalies comprise a wide range of abnormalities of body structure or function that are present at birth and are of prenatal origin

- Most surveillance systems focus on major anomalies

- Major Congenital Anomalies: Structural changes that have significant medical, social or cosmetic consequences for the affected individual, and typically require medical intervention.
  - E.g. cleft lip and spina bifida.
  - These account for most of the deaths, morbidity and disability related to congenital anomalies

Burden of Congenital Anomalies in Africa

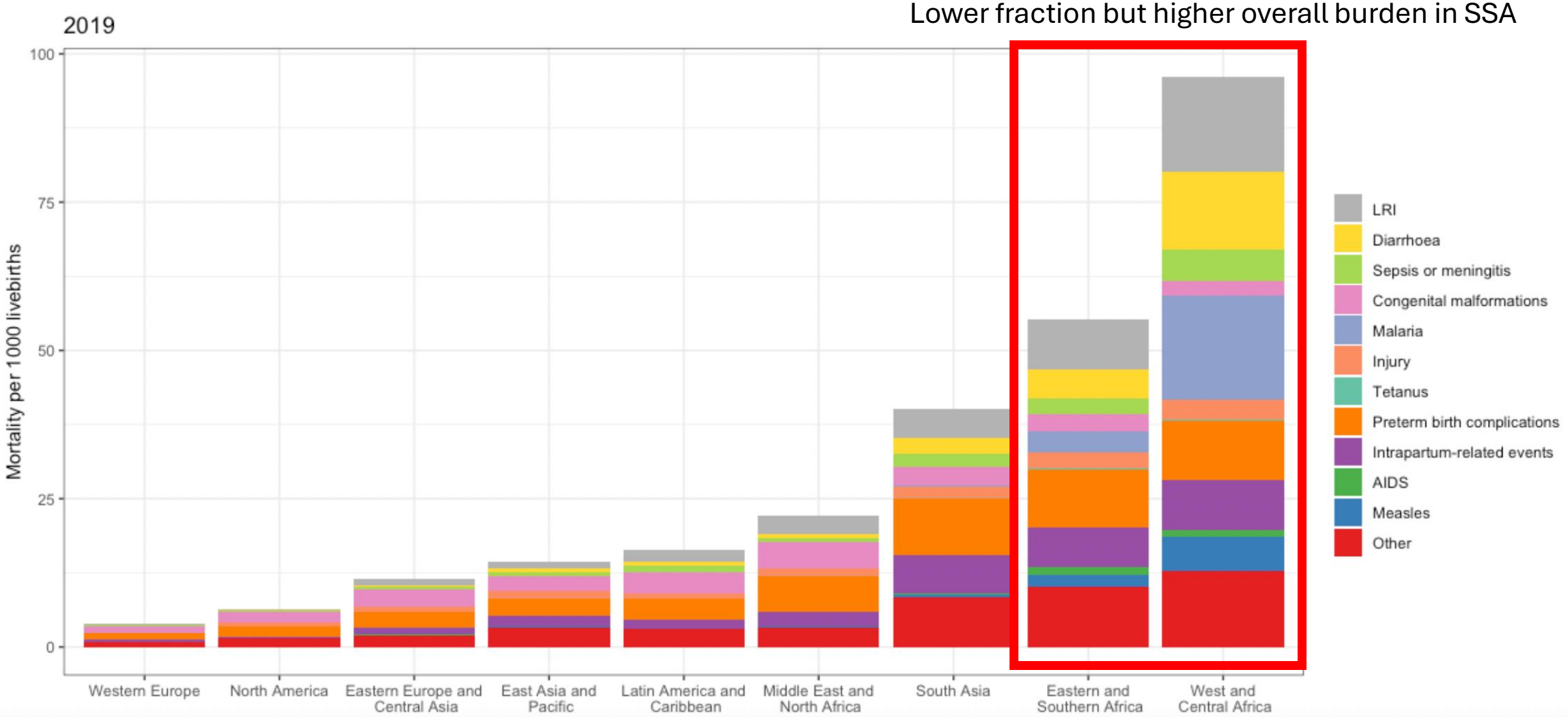
- Globally – 5th leading cause of mortality in children under 5 years (±400k deaths p.a.) and 3rd leading cause of neonatal mortality (240k p.a.).
- No decline between 2000-2019.
- >90% of mortality from CA's occur in LMICs, with Africa holding the highest burden.
- Also among top ranked causes of years lost to disability among non-fatal morbidities in children and adolescents, especially under 5 years.
- Regions with highest estimated burden have the greatest knowledge gaps especially Africa.

Gaps in Knowledge  Gaps in Care

Perin et al, Lancet Child and Adolescent Health 2022; 6(2): 106–115

Webappendix 7. Cause-specific mortality fractions (CSMFs) by UNICEF region in 2000 and 2019

Lower fraction but higher overall burden in SSA



Perin et al, Lancet Child and Adolescent Health 2022; 6(2): 106–115

Potential Objectives of Congenital Anomaly Surveillance

- monitor trends i… …es among a defined pop…
- detect cl…
- re…
- disse… …and gov…
- provide a bas… …and prevention programmes; a…
- allow evaluation of prevention programmes.

The key objectives of the surveillance system determines its design in terms of

1) Setting (hospital or population)

2) Type of anomalies to monitor (targeted CAs or all)

3) Population (only livebirths? Stillbirths? All pregnancies?)

4) Method employed (active/passive, prospective or hospital-based, sentinel sites or national)

WHO/CDC/ICBDSR. Birth defects surveillance: a manual for programme managers. Geneva: World Health Organization; 2014.

Calculating Prevalence of specific CA

System can focus on selected anomalies or open to all major anomalies

FORMULA for birth prevalence (expressed as cases of defect A per 10,000 live births):

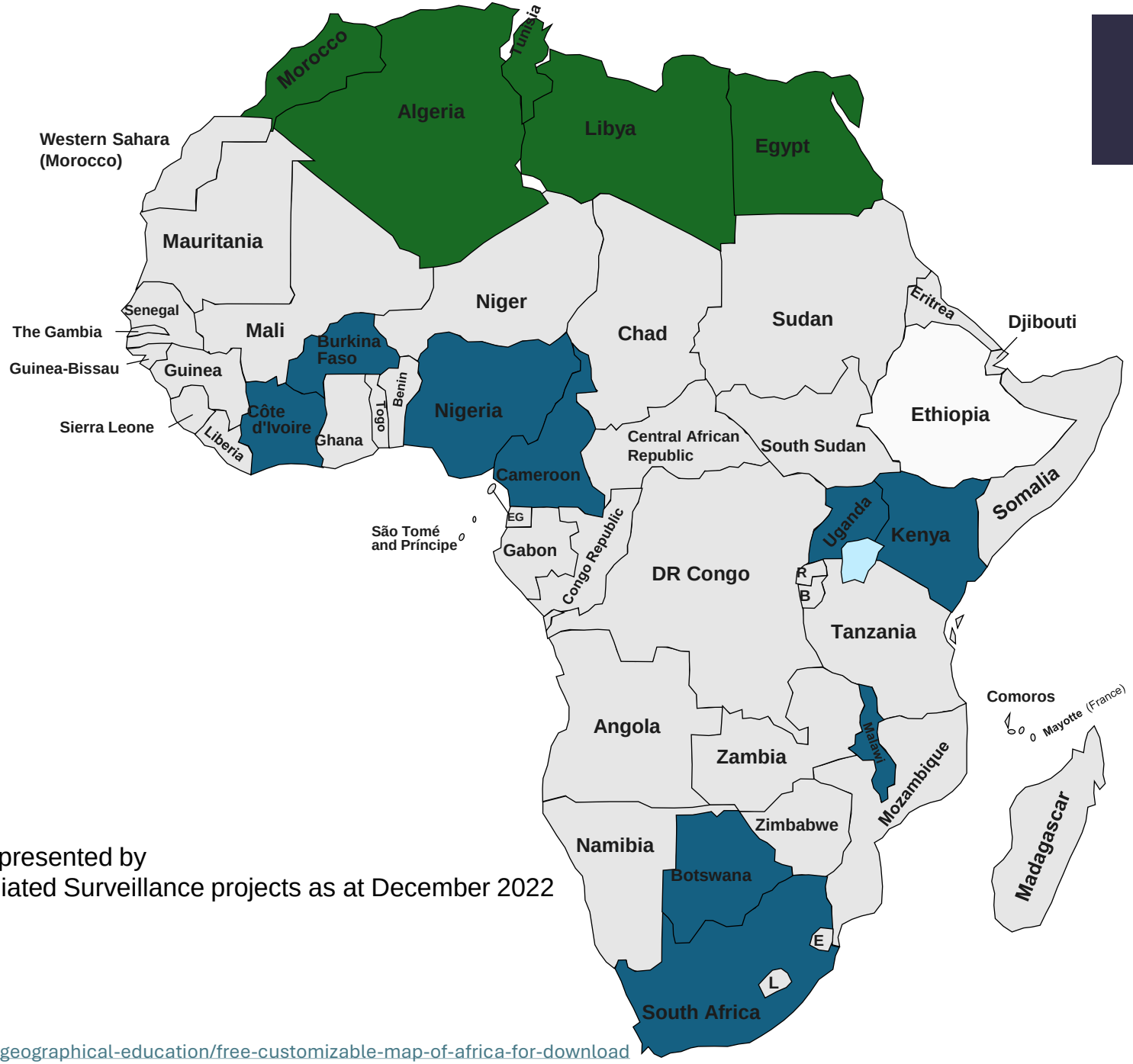
$$\frac{\text{the number of cases with birth defect A in an area and time period}}{\text{the number of live births in that area and time period}} \times 10\,000$$

Denominator can include Livebirths, stillbirths and induced abortions (< or > 20 weeks)

EXAMPLE from Missouri:

$$\frac{\text{193 cases with Tetralogy of Fallot statewide delivered in 1989-1995}}{\text{532,592 live births}} \times 10\,000 = 3.62 \text{ cases per } 10{,}000 \text{ livebirths}$$

National Birth Defects Prevention Network (NBDPN). Guidelines for Conducting Birth Defects Surveillance. Sever, LE, ed. Atlanta, GA: National Birth Defects Prevention Network, Inc., June 2004.



Countries represented by
sSCAN*-affiliated Surveillance projects as at December 2022

B=Burundi

EG=Equatorial Guinea

L=Lesotho

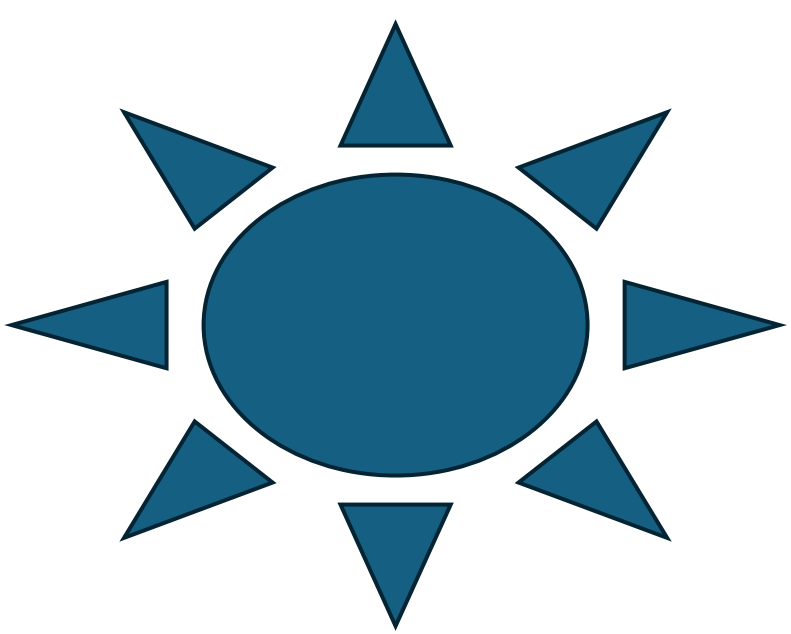
R=Rwanda

E=Eswatini

Map adapted from:
https://www.geocurrents.info/geographical-education/free-customizable-map-of-africa-for-download

sSCAN surveillance projects

Surveillance Project	Country/ies	Type of surveillance	About
Ugandan BDS	Uganda	Hospital—based	50 000 births p.a. ; Major external visible anomalies, photos, ICD10 codes, international expert review
Tsepamo	Botswana	Hospital-based	35 000 births p.a.; focus on ARV exposures, photos, international expert review
Cameroon registry of CA Surveillance (CARECAS)	Cameroon	Hospital-based	Estimate 18 000 births p.a., focus on herbal medicine exposures
Malawi BDS	Malawi	Hospital-based, nested case control	40 000 births p.a., major external anomalies at birth, photo, international expert review. Focus on ARVs
UBOMI BUHLE	South Africa	Prospective Pregnancy Registry	15 000 births p.a., GBDDC App, ICD10, local remote expert review, focus on ARVs
MiMBA Antimalarial pregnancy registry	Western Kenya, Burkina Faso	Prospective Pregnancy Registry	6000 p.a. Kenya and 2200 Burkina Faso, GBDDC App ICD10, remote international review on app review platform
Côte d'Ivoire, Burkina Faso	Côte d'Ivoire, Burkina Faso	Pilot cohort study recruiting antenatally with screening tests at birth	Microcephaly and other congenital anomalies at birth, Zikavirus and prevalence of CAs



Quality clinical Care

Quality Data

Access to source documents and labs

Gestational dating of exposures of interest and outcomes

Incomplete birth outcome ascertainment

Cultural factors and health-seeking behavior (Access to care and Stigma

Incomplete exposure ascertainment

Key challenges

Legal and ethical challenges around data collection and sharing

Limited access to technology and expertise to diagnose CAs identified

Some Mitigating Strategies

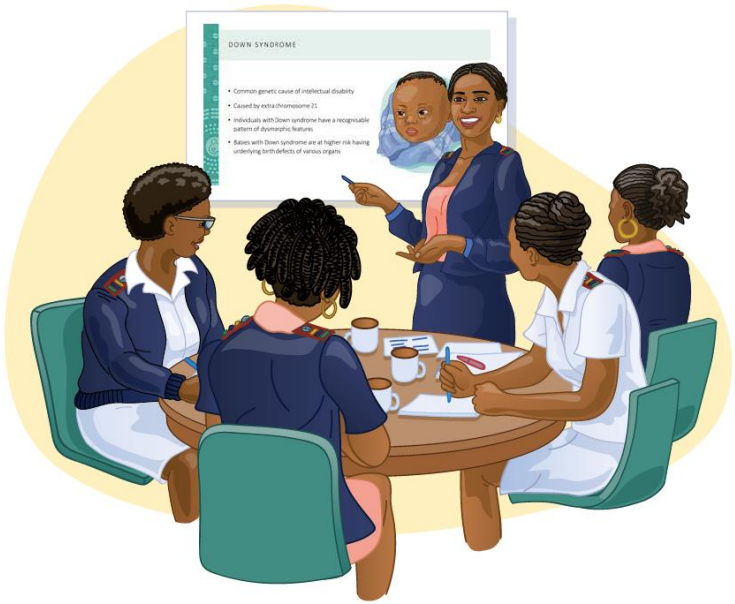
- Strong partnership with department of health, facility managers and staff
- Ongoing training of staff
- 24/7 surveillance coverage
- Global Birth Defect App and review platform
- Support access to ultrasound at sites
- Directly support improved care at sites
  - e.g. training in bereavement services, support genetics counselling
  - Establish linkage with national referral centres and not-for-profit programmes (e.g. Operation Smile, Hope Walk etc.)
- Confine data collection to consistently collected concurrent disease and exposures (e.g., exclude over-the-counter, traditional and herbal medicines).
- Consented photos, secure storage, limited access to data, pseudonymization
- Equitable data sharing – encouraging local capacity for review and analysis

Training Modules

ubomi buhle
Life is beautiful

https://ubomibuhle.org.za/training-modules/

1. Exposures ✓
2. Outcomes ✓
3. Gestational age assessment ✓
4. Clinical record-keeping ✓
5. Other ✓

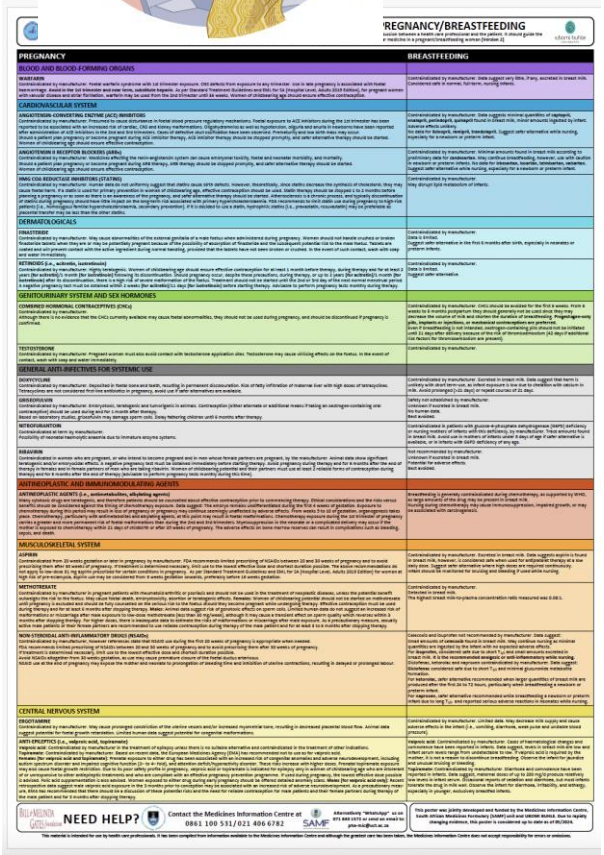


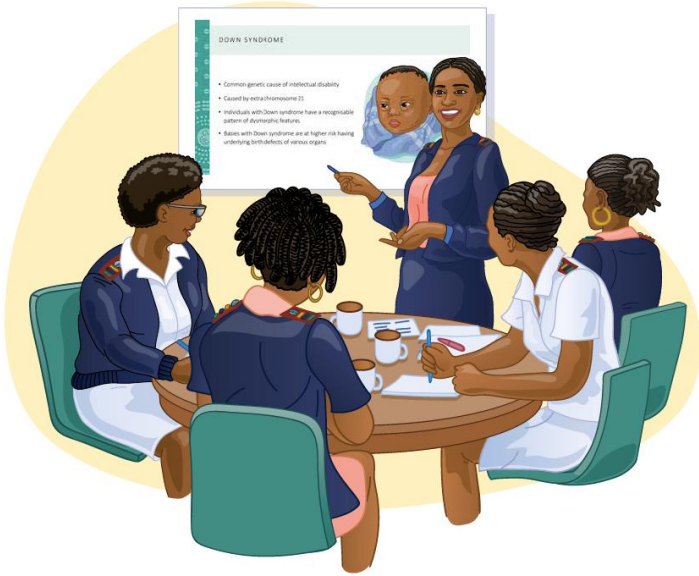
Facility nurse training

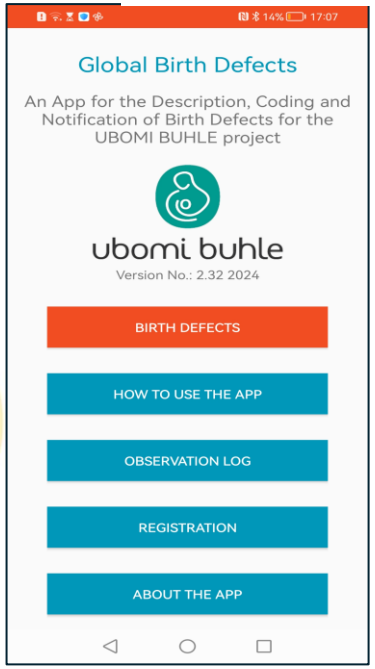
1. Introduction to UBOMI BUHLE (South African Pregnancy Exposure Registry)
2. How to take an accurate pregnancy exposure history and complete the MCR
3. Safer prescribing in pregnancy and common teratogens
4. Methods of gestational dating
5. Congenital disorders
6. How to examine a newborn or stillborn baby and record in the MCR
7. Introduction to counselling and bereavement support
8. Basic version of Global Birth Defects App

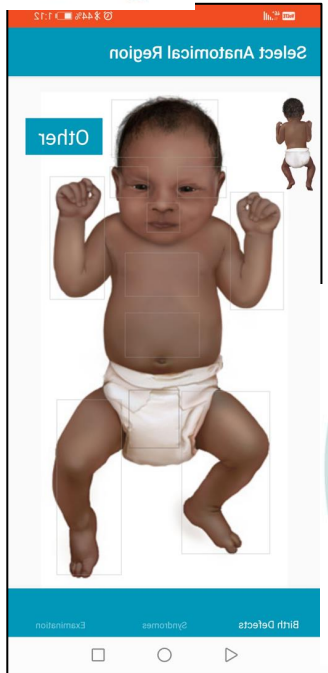
Initiatives to support improved data quality from sites

1. Exposures
2. Outcomes
3. Gestational age assessment
4. Clinical record-keeping
5. Other









The Global Birth Defect APP DESIGN

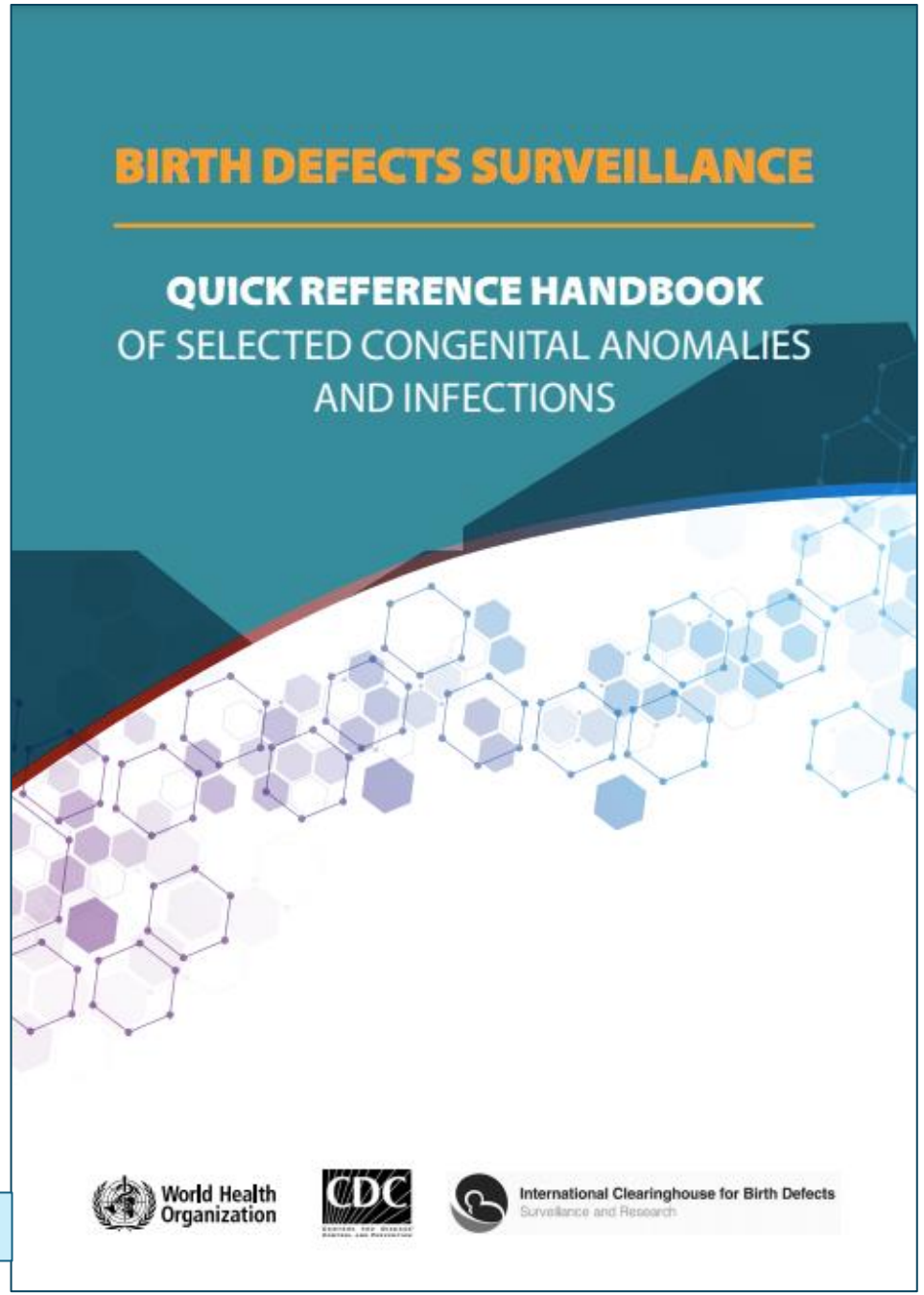
- About 120 common major external congenital anomalies
  10 minor anomalies
  4 internal anomalies (congenital heart defect, oesophageal atresia/trachea-oesophageal fistula, large intestine atresia/stenosis, renal hypoplasia/agenesis)

- Photos and pictures to assist with most likely diagnosis with ICD10 code

- Now with greater compatibility with the "WHO/ICBDSR/CDC Birth Defects Surveillance Quick Reference Handbook" (WHO QRH)

- App contains some links to the relevant WHO QRH pages

https://globalbirthdefects.tghn.org/download-birth-defects-surveillance-app/

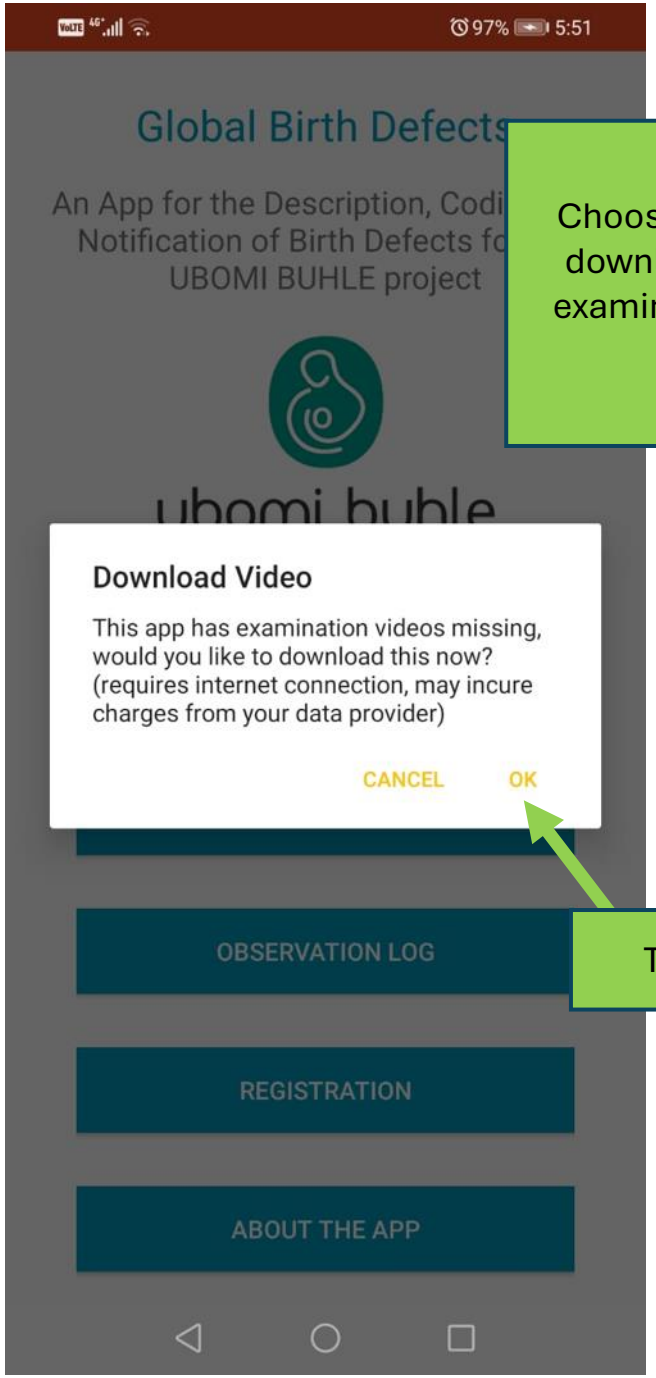


Dolk H, et al, Birth Defects Research 2021, 113 (14): 1057-1073

Global birth defects App –

GET IT ON Google Play

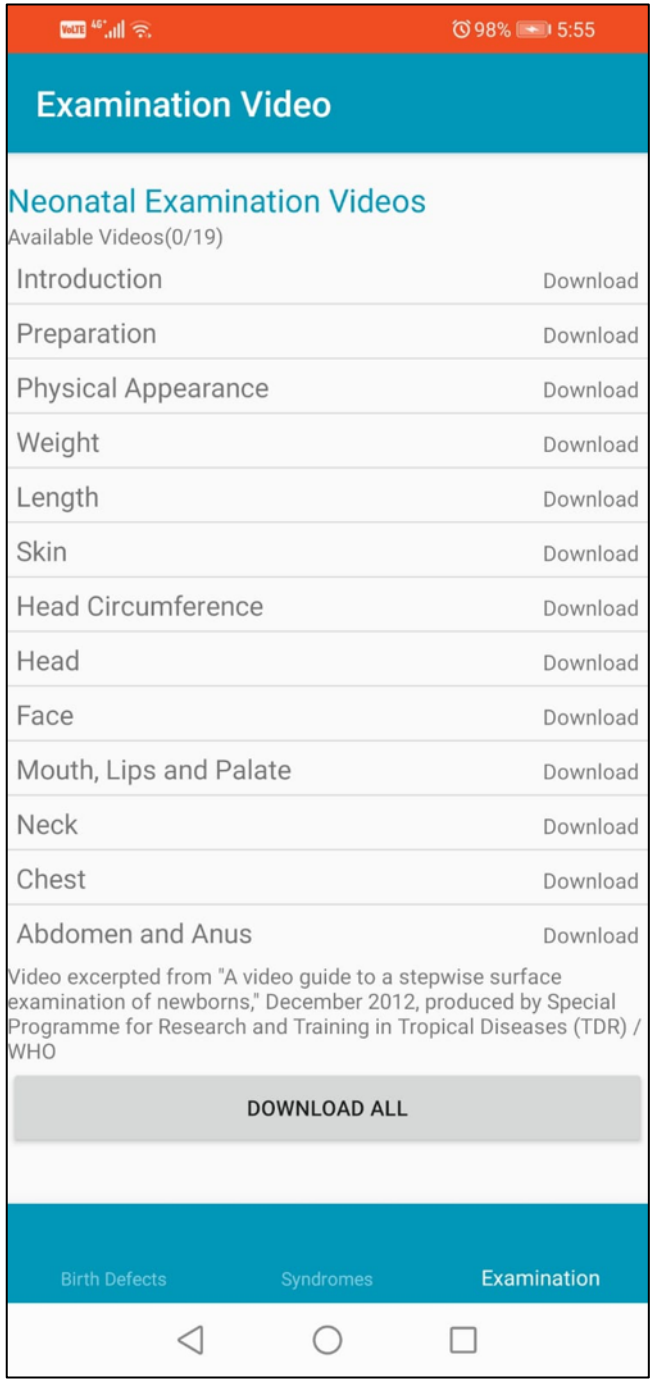
Basic and Surveillance versions

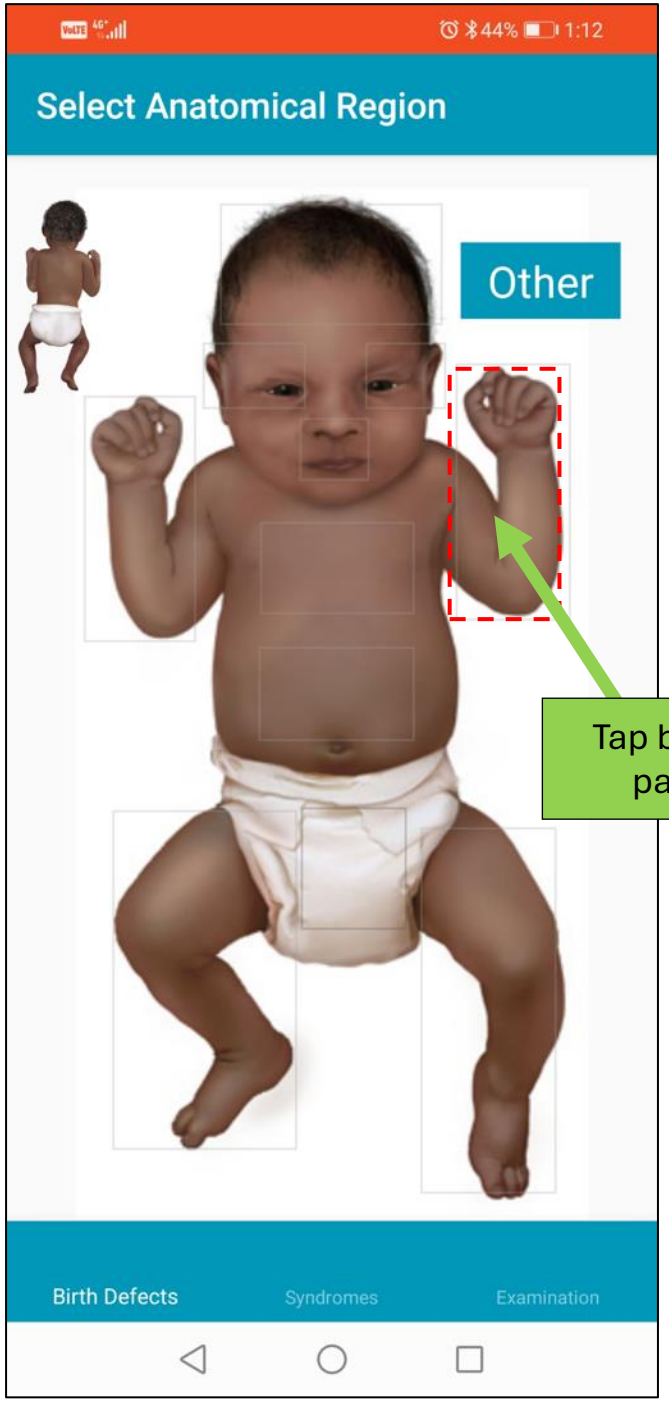


Choose whether to download surface examination videos now

Tap

Heavy on data

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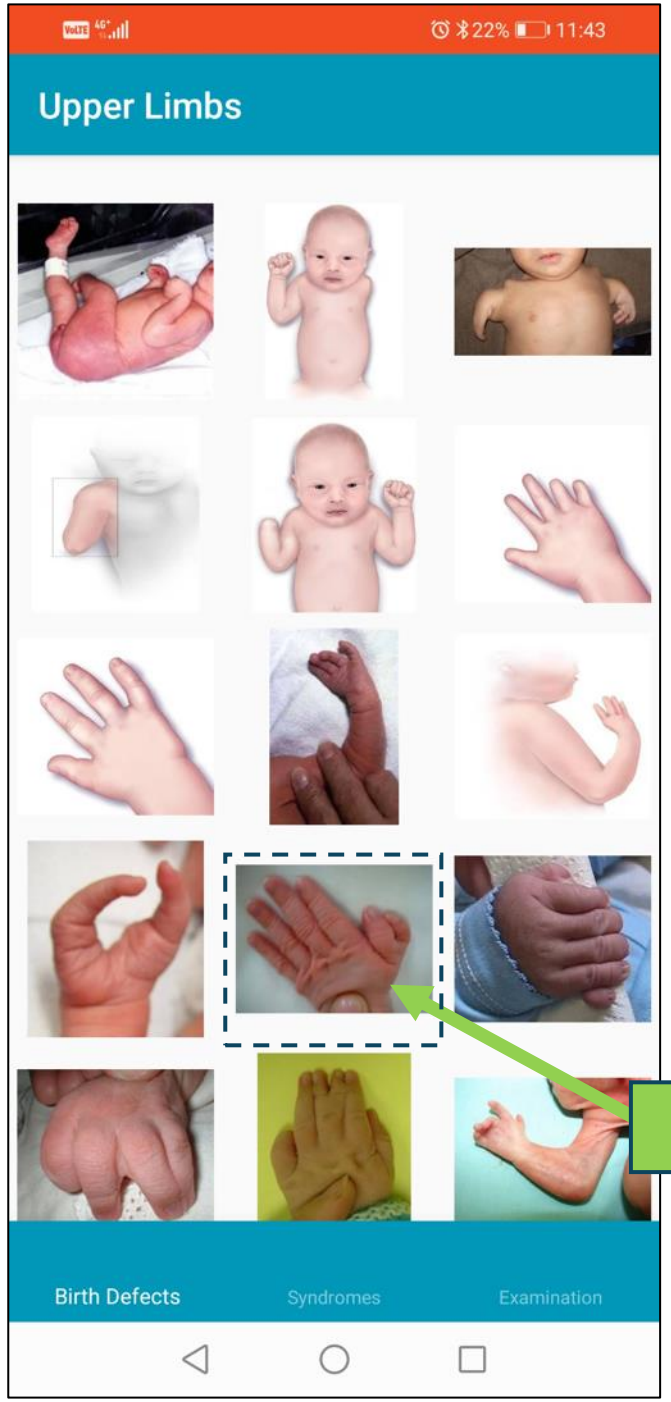
Other
Tap body part
Birth Defects
Syndromes
Examination


Upper Limbs
Tap
Birth Defects
Syndromes
Examination


Upper Limbs
CLOSE
SELECT
Tap
Birth Defects
Syndromes
Examination

Flow diagram for GBD app CD review platform

Central Server

Triage medical officer checks server weekly for new cases

Case requires specialist review?

Yes

No

Email sent to 3 CD specialists for review

Concordance of diagnosis between reviewers?

No

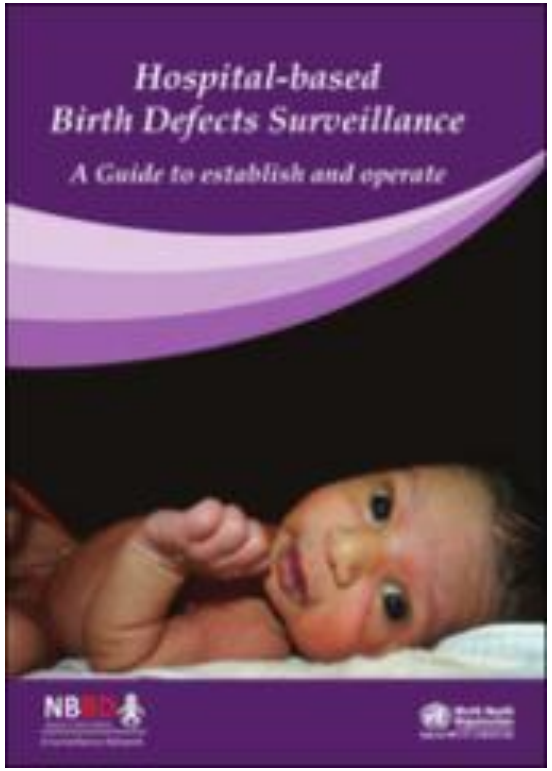
Yes

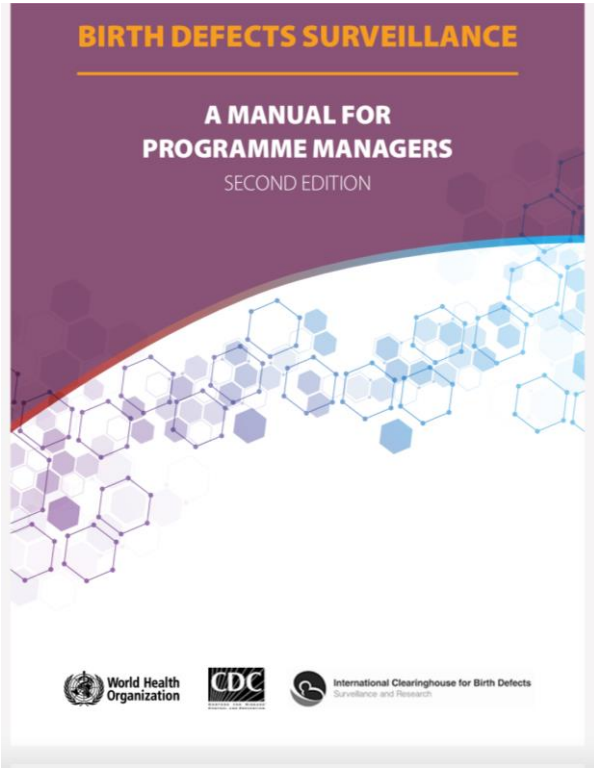
Moderator facilitates discussion between 3 reviewers until consensus reached

Case is closed

Triage officer downloads all cases for a particular research site and emails the cases in Excel table with photos/videos, to the site lead (password-protected)

UB staff from sentinel site takes consented photos/ videos and uploads case





Other Useful resources

Summary

- Congenital anomaly surveillance remains a neglected area of maternal child health surveillance especially in Africa
- Most current surveillance projects are focused on assessing the safety of medicines in pregnancy
- Key surveillance challenges can be addressed through sound investment in
  - health systems strengthening
  - capacity development
  - bespoke digital technologies,
  - advocacy and
  - regional collaboration

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