The sub-Saharan African Congenital Anomalies Network: building an African birth defects registry

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WCE, Birth defects surveillance in Africa
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CIDER
Center for Infectious Disease Epidemiology and Research

Congenital anomalies in sub-Saharan Africa

- SSA the only region without a Network
- Globally, 30% of congenital anomalies (CA) occur in sub-Saharan Africa
  - High birth rates
  - Antenatal exposures
    - Infectious disease and agents for treatment & prevention
    - Non-communicable disease and agents for treatment
    - Dietary factors
    - Traditional medicine use
    - Environmental toxins
  - Health care services for diagnosis & treatment
- Benefits of participating in a Network

Networks of population-based registries

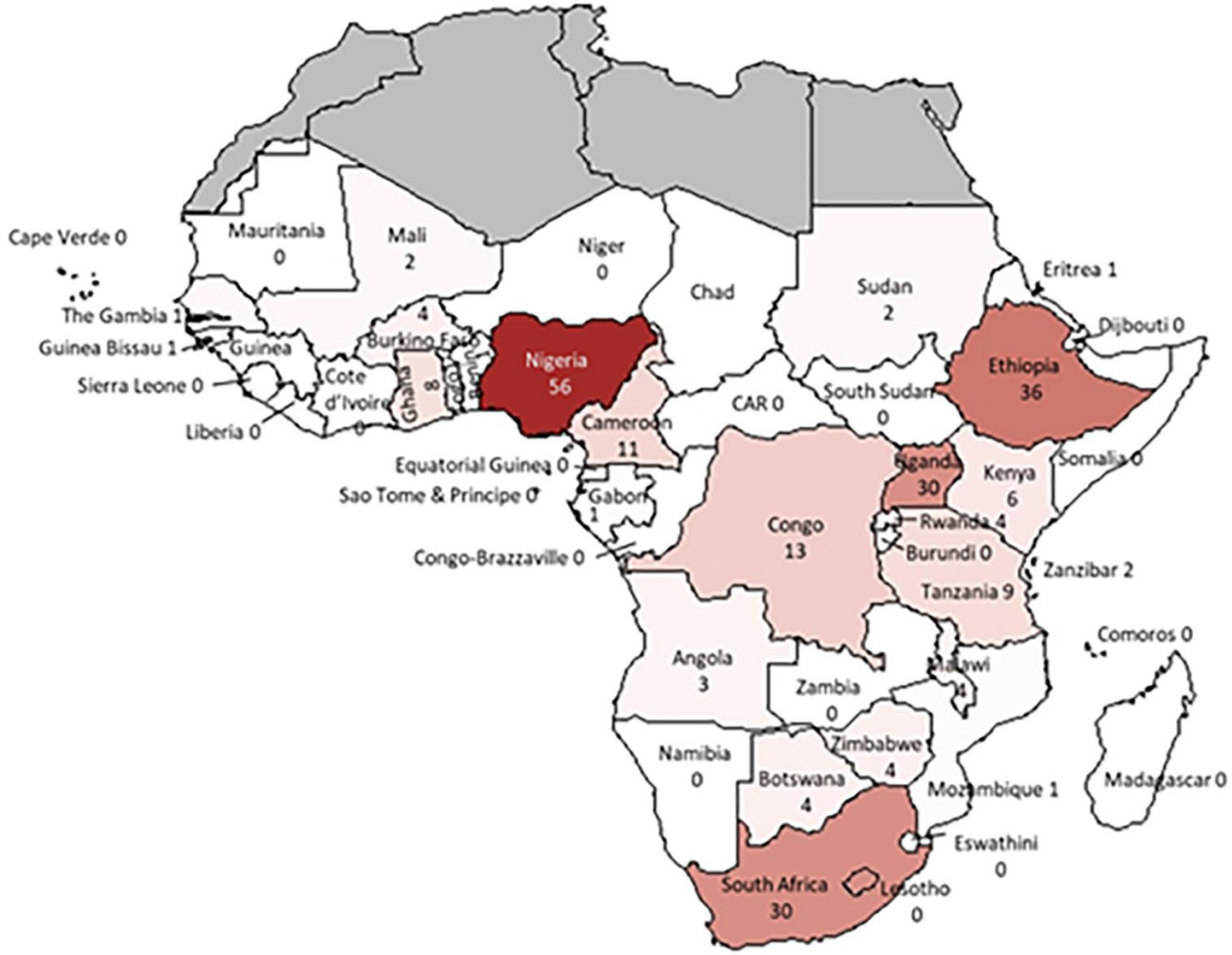
- Successful epidemiological surveillance depends on:
  - accuracy of the rates available in the base period
  - wide population coverage
  - and short periodicity of analysis

- Based on similar international networks:
  - EUROCAT in Europe
  - RELAMC in Latin America

- Networks of population-based registries for the epidemiological surveillance of congenital anomalies
- Signals of teratogenic exposures
- Information resource
- Collaborative network
- Standardised coding & classification for comparable data across registries

Congenital anomalies in sub-Saharan Africa

- sSCAN Scoping Review
  - Limited number of countries contribute to research outputs
  - 47% of countries published no CA research
  - Resources ≠ burden of disease



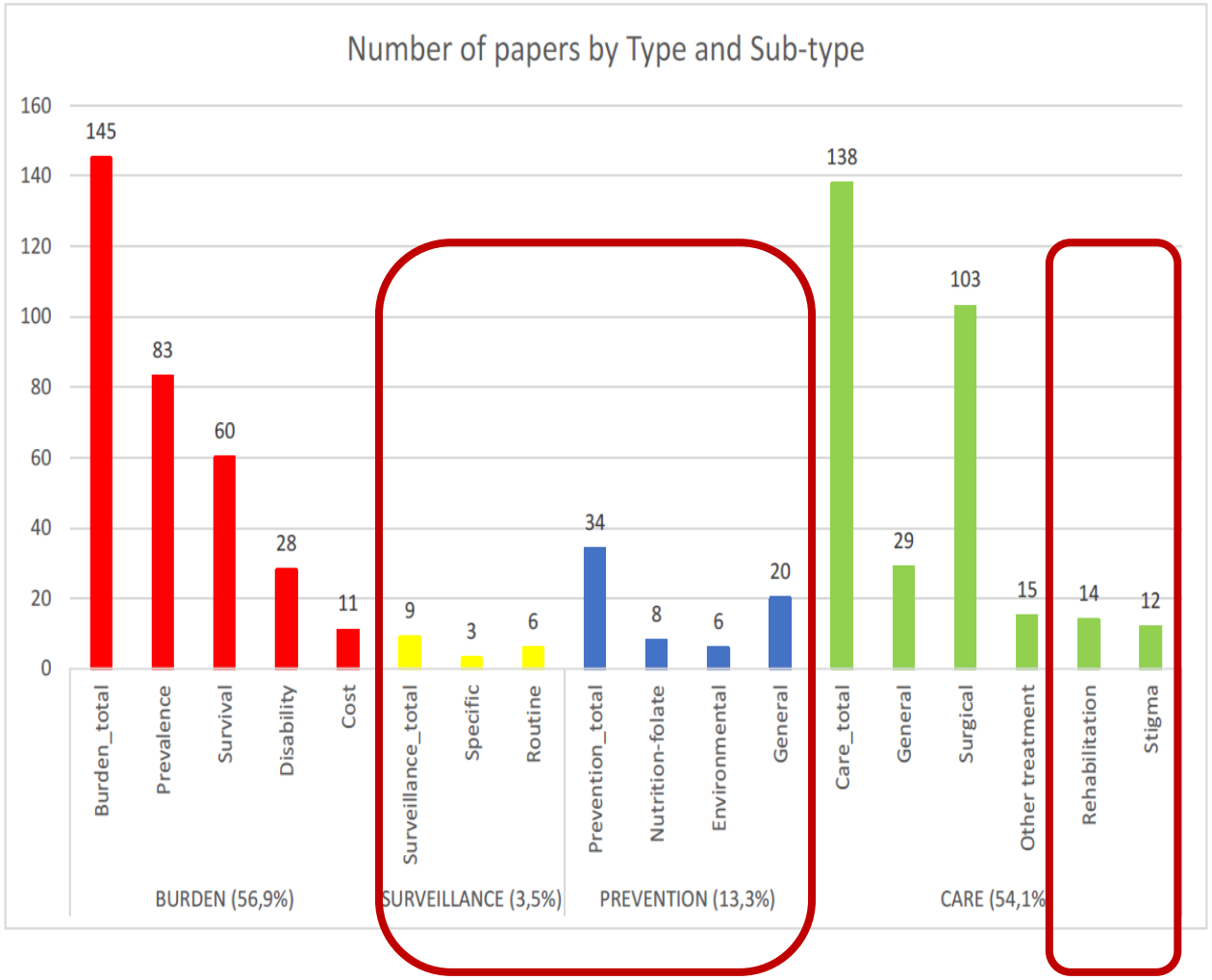
Congenital anomalies in sub-Saharan Africa

- sSCAN Scoping Review
  - Hospital-based
  - Single CA
  - Surgical treatment

Population coverage	
Single hospital	154 (60.4)
Multiple hospital	53 (20.8)
Population-based	23 (9.0)
Not given	25(9.8)
Data source	
Clinical records	143 (56.1)
Interviews with care-givers	89 (34.9)
Published literature[c]	9 (3.5)
Surveillance data	5 (2.0)
Laboratory-based (biological samples)	3 (1.2)
Smile Train database	2 (0.8)
Intervention	1 (0.4)
Recommendations	1 (0.4)
Other[b]	1 (0.4)

Congenital anomalies in sub-Saharan Africa

- Gaps:
  - Scope
  - Limited data on risk factors & prevention
  - No data on diagnosis & access to care
  - Limited population-based data
  - Antenatal diagnosis and TOPFA
  - Few functional/internal disorders (except cardiac)



Congenital anomalies in sub-Saharan Africa

- Research is fragmented

- **Insufficient data on CA to inform health policy & support services**

- Require priority research
- Appropriate to the African context
- Driven by African specialists
- Strengthen regional collaborations

Sub-Saharan African Congenital Anomalies Network

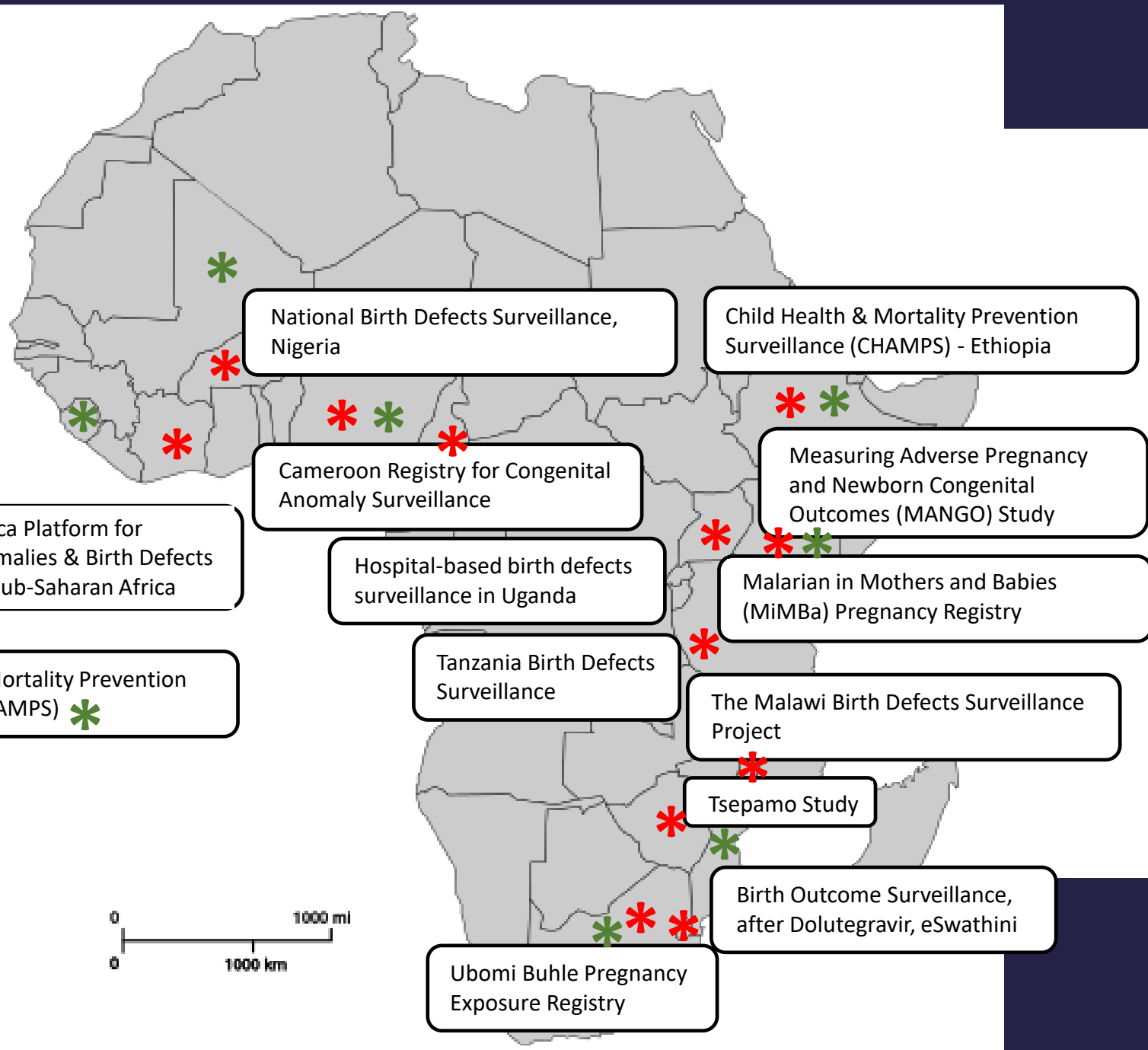
- Established 2020/2021 (COVID interruption)
- 12month UKRI seed funding (PI Dr Barlow-Mosha)
- BMGF via Ubomi Buhle in South Africa

- Multidisciplinary partnerships
  - Individual clinicians, epidemiologists, patient advocates, regulators, government representatives, researchers
  - Representing research projects, patient/family organizations, government departments, agencies
  - Supported by WHO, ICBDSR, EUROCAT, ReLAMC

- Aims
  1. Promote the prevention of CA and care for affected children & families
  2. Build an evidence base through collaborative surveillance & research
  3. Data harmonization for regional data-sharing & between-country comparisons
  4. Build capacity and strengthen health care systems
  5. Engage and support affected families & communities

Networks within sSCAN

Botswana
Burkina Faso
Cameroon
Cote d'Ivoire
eSwathini
Ethiopia
Kenya
Malawi
South Africa
Uganda
Tanzania



sSCAN
Sub-Saharan African Congenital Anomalies Network

https://sscan.tghn.org/

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Title	Date	Registered	Attended
sSCAN: Birth Defects Surveillance: why & how, the African Experience Part 1	30 June 2021	96	67
Addressing congenital anomalies and triple surveillance on the path to meet SDG3 targets	28 July 2021	73	34
sSCAN: Birth Defects Surveillance: why & how, the African Experience Part 2	25 Aug 2021	72	37
The use of new technologies for congenital anomaly surveillance, diagnosis & care	29 Sept 2021	55	27
Specialist service provision: paediatric surgery	27 Oct 2021	113	34
Teratogens and Pharmacovigilance	24 Nov 2021	204	53
Neural Tube Defects in sub-Saharan Africa	12 Oct 2022	175	98
Community Screening Strategies to Improve Equitable Access in Diagnosis and Management of Birth Defects: Lessons from Low & Middle-Income Countries	11 May 2023	60	24/21
Congenital Heart Defects in Sub-Saharan African Countries	17 July 2023	111	63/52
Advocacy for congenital disorders & rare diseases in Sub-Saharan Africa: an expert discussion	31 Aug 2023	44	34/13
Childhood Disability in sub-Saharan Africa	2 Nov 2023	368	129
Orofacial Clefts in sub-Saharan Africa: Epidemiology, Care and Prevention	30 May 2024	483	150/99
Congenital Infections associated with Congenital Anomalies in sub-Saharan Africa	25 July 2024	298	128/86

Sub-Saharan African Congenital Anomalies Network

- Scoping Review
  - Aminkeng Zawuo Leke, Helen Malherbe, Emma Kalk, Ushma Mehta, Phylis Kisa, Lorenzo D. Botto, Idowu Ayede, Lee Fairlie, Nkwati Michel Maboh, Ieda Orioli, Rebecca Zash, Ronald Kusolo, Daniel Mumpe-Mwanja, Robert Serujogi, Bodo Bongomin, Caroline Osoro, Clarisse Dah, Olive Sentumbwe–Mugisha, Hamisi Kimaro Shabani, Philippa Musoke, Helen Dolk, Linda Barlow-Mosha. **The burden, prevention and care of infants and children with congenital anomalies in sub-Saharan Africa: A scoping review.** *PLoS Global Public Health* 2023. 3(6): e0001850. https://doi.org/10.1371/journal.pgph.0001850
- Review of existing CA surveillance infrastructure in SSA
- Comparison of data dictionaries with a view to future data sharing
- Constitution and organizational structure

An African Birth Defects Registry: Data Harmonization & Data Sharing

- Registries as the core of CA surveillance
- Routine, standardized data collection
- Multiple sources

- **COMMON DATA MODEL**

- Data dictionary: core variables – standardized coding & classification
  - Compatible with WHO Special Programme for Research & Training in tropical diseases Central Registry for Epidemiological Surveillance of Drug Safety in Pregnancy
- Data collection infrastructure
- Common data platform
- Governance system for data sharing
- Protocol development: NTD already-published data

Thank you

Questions

International Clearinghouse for Birth Defects
Surveillance and Research

SAVE THE DATE

sSCAN & Rare Diseases-South Africa

51st ICBDSR conference, 2 – 5 November 2025

Mount Grace Hotel, Magaliesberg, South Africa

http://www.icbdsr.org/

https://www.rarediseases.co.za/