

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



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September 2024  
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# 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  $\neq$  burden of disease



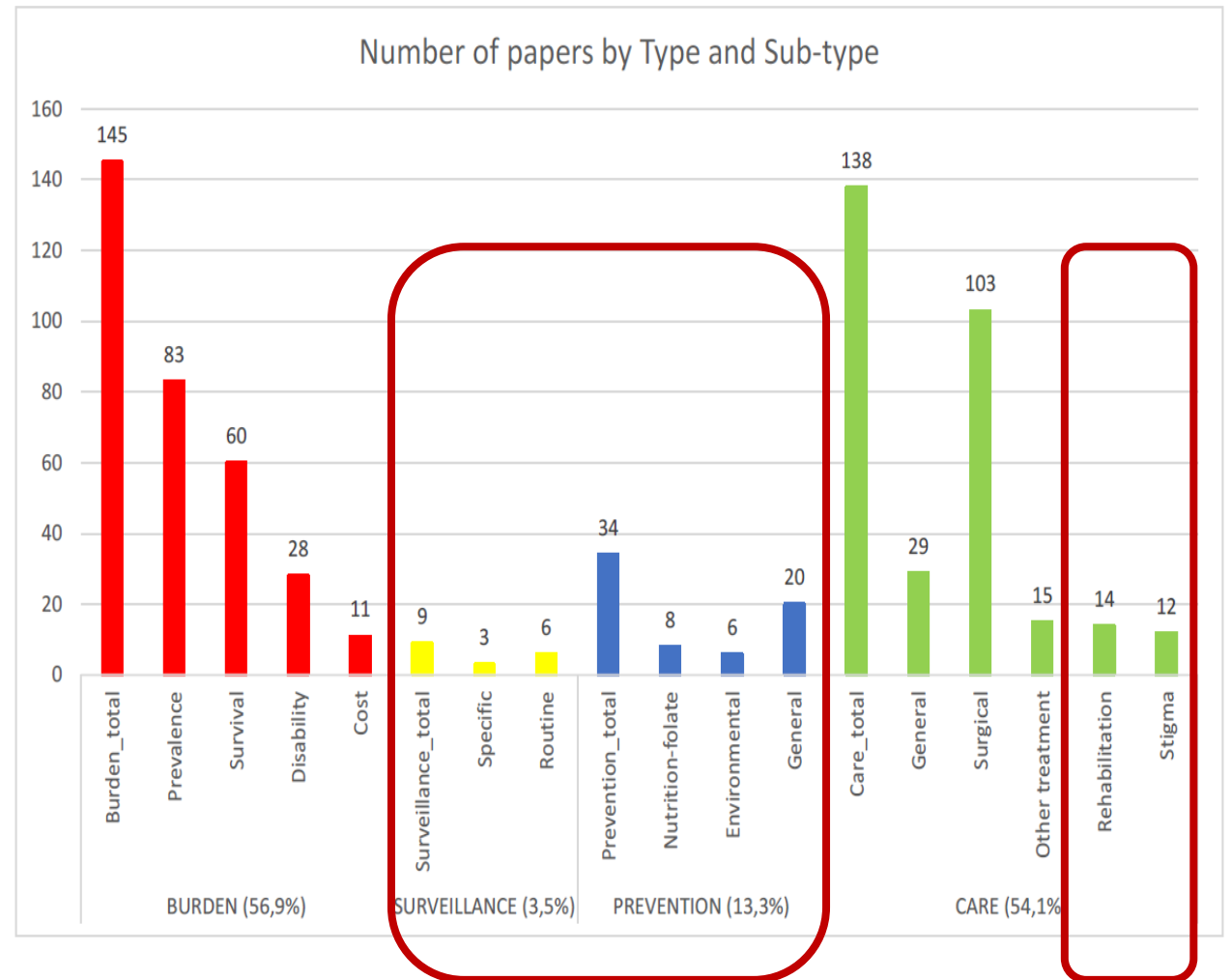
# Congenital anomalies in sub-Saharan Africa

- 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 <sup>c</sup>	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 <sup>b</sup>	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

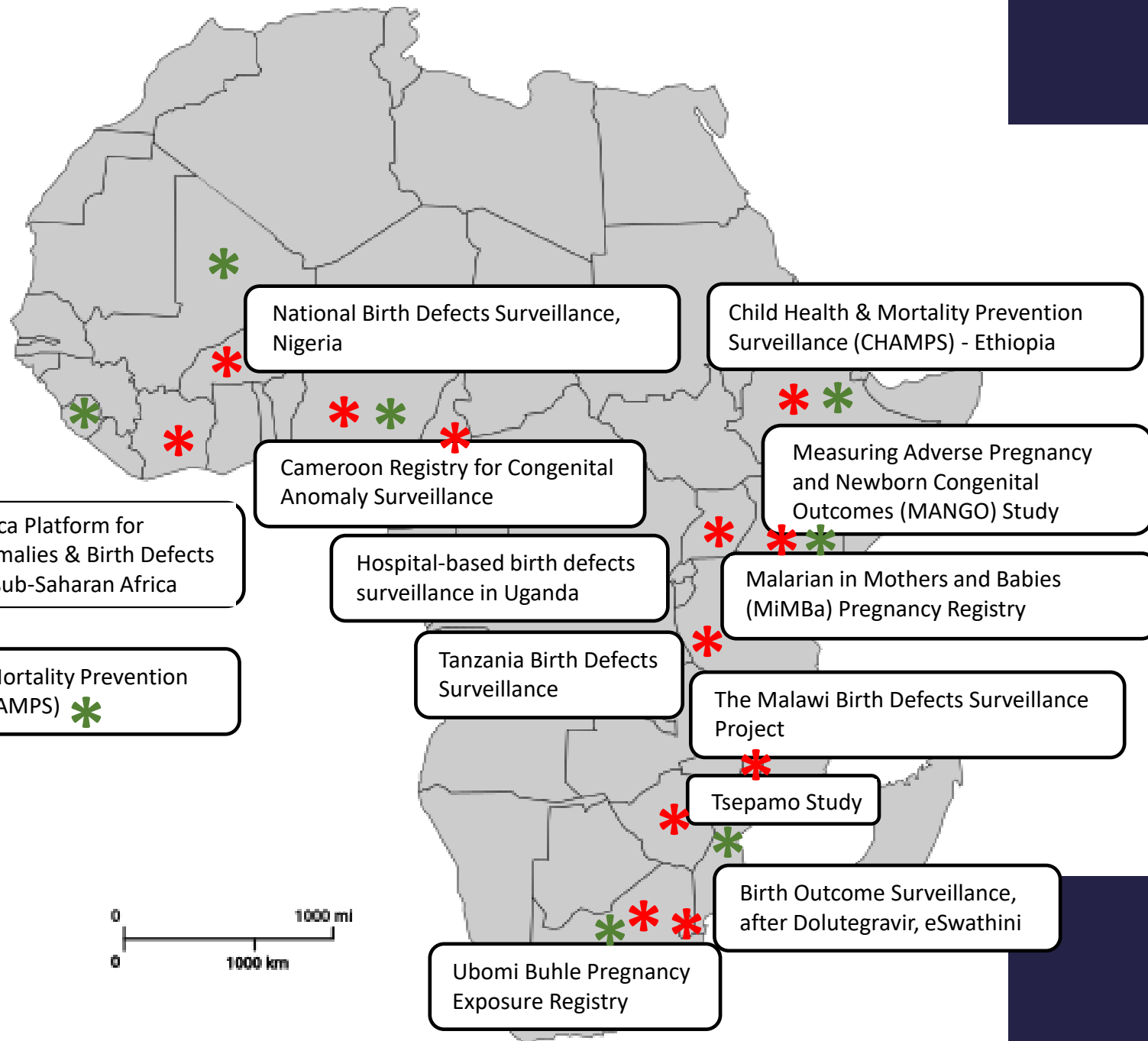
# Sub-Saharan African Congenital Anomalies Network

- 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



# https://sscan.tghn.org/

The screenshot shows the Resources page of the sSCAN website. At the top, there is a navigation bar with the logo for 'THE GLOBAL HEALTH NETWORK' and the email 'emma.kalk@uct.ac.za'. Below this is the site title 'Sub-Saharan Congenital Anomalies Network' and a search bar. The main header features the 'sSCAN' logo, which includes a map of Africa and a fetus icon, with the full name 'Sub-Saharan African Congenital Anomalies Network' underneath. A navigation menu includes 'Home', 'Get Involved', 'Webinars', 'Resources' (which is highlighted), 'Articles', 'Translate Site', 'Upcoming Events', and 'sSCAN Governance Documents'. The 'Resources' section is titled 'Resources' and contains a paragraph: 'This page provides access to a collection of internal and external documents and links to guide researchers, policy-makers, implementers, civil society and non-governmental organizations with ACAN knowledge-sharing and capacity strengthening across the globe.' Below this are three resource cards: 1. 'The Global Birth Defects Description and Coding App' with a circular icon of a fetus. 2. 'Birth Defects Surveillance: A Manual for Programme Managers [PDF, 4.4mb]' with a cover image showing a network diagram. 3. 'Birth defects surveillance: atlas' with a cover image showing a molecular structure.

The screenshot shows the Webinars page of the sSCAN website. It has the same top navigation bar as the Resources page. The main header features the 'sSCAN' logo and the full name. The navigation menu is the same, but 'Webinars' is highlighted. The 'Webinars' section is titled 'Webinars' and contains a sub-section 'Upcoming Webinar: TBC'. Below this is a section for '\*Past Webinars\*'. One webinar is listed: 'Congenital Infections associated with Congenital Anomalies in sub-Saharan Africa' dated '25 July 2024'. The description states: 'In utero exposure to certain infections is an important cause of non-genetic congenital disorders. Depending on the teratogen and timing of infection, such exposure can result in anatomical malformations, disrupted organogenesis and development, and fetal/neonatal death. Some implicated maternal infections are preventable (e.g., rubella via vaccination) or treatable (e.g., syphilis via antenatal screening and treatment). The effects of others can be diagnosed by antenatal ultrasound (e.g., Zika virus, CMV). This webinar will discuss'. To the right of the text is a video player thumbnail with a play button and a title 'Congenital Infections associated with... associated with Congenital Anomalies in sub-Saharan Africa'.

<https://sscan.tghn.org/>

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	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>](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**

**51<sup>st</sup> ICBDSR conference, 2 – 5 November 2025**

**Mount Grace Hotel, Magaliesberg, South Africa**

<http://www.icbdsr.org/>

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