SUB-SAHARAN AFRICAN CONGENITAL ANOMALIES NETWORK

GENERAL ASSEMBLY

11 – 13 SEPTEMBER, 2023

CAPE TOWN, SOUTH AFRICA

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1. Background

The sub-Saharan African Congenital Anomalies Network (sSCAN) was established in 2020/2021 to address the limited and fragmented research, surveiilance and care programmes in the field of congenital anomalies in the region.

The overall aim of the Network is to improve the diagnosis of congenital anomalies, promote the identification and prevention of the causes of these conditions and strengthen access to care for affected individuals in sub-Saharan Africa. This will be achieved by: (i) building an evidence-base through surveillance and research while strengthening service capacity; (ii) improving collaboration across research, care and advocacy groups; and (iii) actively engaging to promote policies that support these aims.

sSCAN was established in 2020 supported by UKRI MRC seed funding to Dr Linda Barlow-Mosha, then of the Makerere University-Johns Hopkins University Research Collaboration (MU-JHU) and co-investigators. Delayed by the COVID-19 pandemic, the first hybrid sSCAN General Assembly was held in Kampala, Uganda in March 2022.

2. The second sSCAN General Assembly, Cape Town, South Africa

The second sSCAN General Assembly was held between 11th and 13th September 2023 at the University of Cape Town Graduate School of Business Conference Centre in Cape Town, South Africa. Funding was secured from the Bill & Melinda Gates Foundation through their support for Ubomi Buhle, the South African Pregnancy Exposure Registry. There were 53 in-person and seven on-line attendees from 12 African counties, Argentina, Brazil and the United Kingdom representing 40 organizations (Table 1 and Appendix 1). The meeting provided an excellent opportunity for meeting and networking with others in the field, many of whom were unaware of the breadth of research on congenital anomalies in the region, and the scope of patient support and advocacy programmes. It is clear that there is a large community of practice in the region which can be brought together by sSCAN to optimize collaboration promoting robust science and quality health care in the field of congenital anomalies.

The formal programme was preceded by a half-day workshop on *Birth Defects Surveillance and Research Data* hosted by Dr Boris Groisman on behalf of the International Clearing House for Birth Defects Surveillance & Research (ICBDSR). Dr Groisman is Chair of the Executive Committee of the ICBDSR and a member of the National Network of Congenital Anomalies of Argentina (RENAC), a birth defects surveillance program covering around 230,000 births per year in that country. A medical geneticist by training, Dr Groisman's expertise include epidemiological analysis, information and communications technology, public health surveillance, and medical genetics. Thirty people attended the interactive workshop.

Table 1. Participating Countries and Organizations represented at the 2nd sSCAN General Assembly

Country	Organizations represented	Study	Delegates
Argentina	National Network of Congenital Anomalies of Argentina		1
Botswana	Botswana–Harvard AIDS Institute Partnership	Tsepamo Study	1
Brazil	Universidade Federal do Rio Grande do Sol		2 online
Burkina Faso	Centre De Recherche En Sante De Nouna	Towards an Africa Platform for Congenital Anomalies & Birth Defects Surveillance in sub-Saharan Africa	2
Cameroon	Health Research Foundation	Cameroon Registry for Congenital Anomaly Surveillance	2
Ethiopia	College of Health Sciences, Addis Ababa University		1
	Hararghe Health Research & CHAMPS Ethiopia	CHAMPS	1
Kenya	Kenya Medical Research Institute	MiMBa	2
	Moi Teaching & Referral Hospital	MANGO-Kenya	2
	Ministry of Health, Kenya	MiMBa	1
Malawi	I-TECH Malawi and Ministry of Health	Malawi Birth Defects Surveillance	1
Namibia	Ministry of Health and Social Services		1 online
Nigeria	University College Hospital, Ibadan	National Birth Defects Surveillance in Nigeria	2 online
	Aminu Kano Teaching Hospital, Kano	Aminu Kano Teaching Hospital Registry for Congenital Anomalies	2 online
	National Hospital, Abuja		1 no visa
South Africa	Groote Schuur Hospital Neonates		1
	Groote Schuur Hospital Genetics		3
	Mowbray Maternity Hospital Neonates		1
	Wits RHI	Ubomi Buhle	2
	University of Cape Town	Ubomi Buhle	6
	Western Cape Pregnancy Exposure Registry	Ubomi Buhle	2
	National Department of Health		1
	Rare Diseases: South Africa, NPC		1
	Steps Charity		1
	Robert Mangaliso Sobukwe Hospital, Kimberly		1
	National Health Laboratory Services, Limpopo		1
	Operation Smile South Africa		1
	University of Limpopo		1
	Medicines Information Centre, South Africa		1
	South African Medical Research Council		1
eSwathini	Ministry of Health, eSwathini	Birth Outcome Surveillance after Introduction of dolutegravir, eSwathini	1
Tanzania	Muhimbili Orthopaedic Institute	Tanzania Birth Defects Surveillance	1
Uganda	Makerere University - Johns Hopkins University Research Collaboration	Birth Defects Surveillance	2
	Makerere University, College of Health Sciences		2
	Makerere University, School of Public Health		1 no visa
	Busitema University		1

	Global Health, Uganda WHO Uganda Country Office AfriChild Centre		1 1 no visa 1 no visa
United Kingdom	Liverpool School of Tropical Medicine, Liverpool Ulster University, Belfast Biomedical Computing	MiMBa GBD App GBD App	1 1 1
Global	CHAMPS International Clearinghouse for Birth Defects Surveillance & Research World Health Organization US Centers for Disease Control & Prevention (KwaZulu-Natal)		1 1 1 1

CHAMPS - Child Health & Mortality Prevention Surveillance; GBD – Global Birth Defects App; I-TECH – International Training and Education Centre for Health; MANGO – Measuring Adverse Pregnancy and Newborn Congenital Outcomes; MiMBa – Malaria in Mothers and Babies; WHO – World Health Organization

3. Affiliated Research/Surveillance Groups

The collective of sSCAN affiliates has expanded from four groups since the original application. To date, 16 sub-Saharan African research or surveillance projects participate in sSCAN with the potential to contribute data to the Network. A brief summary of 14 of these projects at different stages of development was presented (Table 2). Most represent partnerships between sub-Saharan African research institutions and/or government and international research or other global funding agencies.

4. Feedback & Achievements

4.1 Website & Webinars

The original application included the establishment of the sSCAN website, supported by The Global Health Network (TGHN): https://sscan.tghn.org/. Additional funding has been secured and the website management extended to 30 April 2025. At the 2nd General Assembly in Cape Town it was decided that an interested person/people would take responsibility for updating the website (advertising webinars, uploading webinars and relevant publications; engaging with links to relevant organizations, Twitter/X and other social media); and checking and referring new members registered through the website. They will be provided with training in website management by TGHN and access to the development site.

Since its inception sSCAN has presented 10 free webinars moderated by TGHN (Table 3). The webinars are thematic and presented by regional and global experts sharing data and best practice on topics relevant to congenital anomalies in sub-Saharan Africa. The recordings are available as free resources on the sSCAN website. TGHN charges a subsidized rate per webinar and there are two remaining before April 2024. We encourage members to include funding support for the sSCAN website (£6,211 per year) and webinar/webinars at a non-subsidized rate in future funding applications (i.e., £2,422 per webinar).

4.2 Publications

Three publications were planned in the initial application, two as baseline assessments of current research and surveillance projects and one a position statement by sSCAN on congenital anomalies in sub-Saharan Africa. To date, one paper has been pulished (a scoping review of congenital anomaly research in the region led by Aminkeng Leke from the Health Research Foundation, Buea, Cameroon and Ulster University) in an international peer-reviewed journal and a second manuscript (congenital anomaly surveillance systems in sub-Saharan Africa led by Ushma Mehta from the University of Cape Town, South Africa and the Ubomi Buhle study) is under review. Published outputs are freely available on the sSCAN website.

Details of completed publications:

1. 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

2. Ushma Mehta, Daniel Mumpe-Mwanja, Modiegi Diseko, George Bello, Caroline Osoro, Adejumoke Idowu Ayede, Lee Fairlie, Ali Sie, Eric Nebié, Helen Malherbe, Rebecca Zash, Stephanie Dellicour, Philippa Musoke, Aminkeng Zawuo Leke, Linda Barlow Mosha, Helen Dolk, Emma Kalk on behalf of sSCAN. **Opportunities and Challenges for Surveillance of Congenital Anomalies in Sub-Saharan Africa**. Under review at *Birth Defects Research* 2023.

These outputs represent a collaboration between a range of African and other international experts and provide an invaluable resource in the form of baseline data for on-going and future research and funding applications in the field of congenital anomalies in sub-Saharan Africa.

Following the 2nd General Assembly in Cape Town, the preparation of a position paper/declaration situating congenital anomalies in global and African health has been prioritized. In addition, a commentary and recommendations on the advocacy landscape of congenital disorders in sub-Saharan Africa is proposed.

Members are encouraged to include their sSCAN affiliation on relevant manuscripts and other research outputs.

4.3 The International Conference on Birth Defects & Disabilities in the Developing World

sSCAN featured both as an organization and via affiliated groups at the International Conference on Birth Defects & Disabilities in the Developing World (ICBD) 1 – 4 March 2023 in Santiago, Chile (Table 4). The ICBD biennial conferences aim to enhance capacity in lower and middle-income countries to improve surveillance and diagnosis of congenital anomalies and disabilities, address related modifiable risk factors and improve the continuum of care for affected newborns and families. Through professional networking, these meetings support a more coordinated, effective and transparent global and national action on congenital anomalies. It was a wonderful opportunity to meet collaborators in person and attract new members to the Network. Unfortunately, the continuation of the ICBD is uncertain following the withdrawal of the main conference funders and organizers (March of Dimes).

Figure 1. Peer-reviewed research outputs by country, Leke A *et al.*, The burden, prevention and care of infants and children with congenital anomalies in sub-Saharan Africa: A scoping review. *PLoS Global Public Health* 2023.

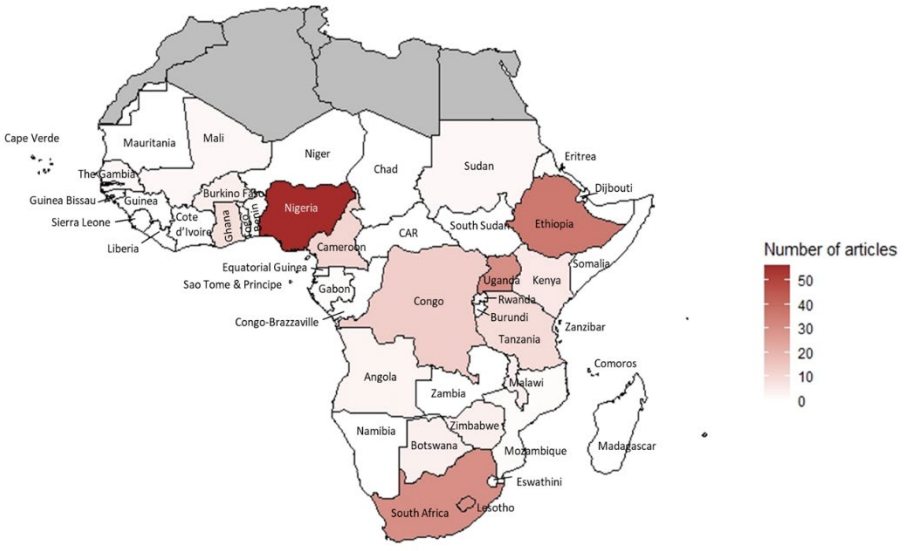


Table 2. Surveillance and Research Projects Affiliated with sSCAN by Organization and Country

Project	Organizations	Population	Congenital anomalies	Focus	Country/ies
Towards an Africa Platform for Congenital Anomalies & Birth Defects Surveillance in sub-Saharan Africa	Centre De Recherche En Sante De Nouna African Academy of Science Grand Challenges Africa	Population-based	Selected external anomalies visible on surface examination	Infectious exposures	Burkina Faso & Cote d'Ivoire
Cameroon Registry for Congenital Anomaly Surveillance	Health Research Foundation Ministry of Health	Hospital-based	Selected external anomalies visible on surface examination	Traditional medicine exposures	Buea, Cameroon
Child Health & Mortality Prevention Surveillance (CHAMPS)	Bill & Melinda Gates Foundation	Population-based (sentinel sites)	All major malformations	Mortality surveillance	Ethiopia, Kenya, Mali, Mozambique, Nigeria, Siera Leone, South Africa (Bangladesh, Pakistan)
Child Health & Mortality Prevention Surveillance (CHAMPS) - Ethiopia	Bill & Melinda Gates Foundation	Population-based (sentinel sites)	All major malformations	Mortality surveillance	Harar, Ethiopia Kersa, Ethiopia
Measuring Adverse Pregnancy and Newborn Congenital Outcomes (MANGO) Study	Moi University, Kenya NIAID	Hospital-based	All major malformations	Antiretroviral therapy (ART exposures)	Eldoret, Kenya
Malarian in Mothers and Babies (MiMBa) Pregnancy Registry	Kenya Research Institute (KeMRI) Medicines for Malaria Venture London School of Hygiene & Tropical Medicine	Population-based (district)	All external anomalies visible on surface examination and congenital heart disease	Anti-malarian exposures especially first trimester	Kisumu, Kenya (Burkina Faso)
The Malawi Birth Defects Surveillance Project	Ministry of Health US CDC	Hospital-based	Selected external anomalies visible on surface examination	Antiretroviral therapy (ART exposures)	Malawi
National Birth Defects Surveillance, Nigeria	Ministry of Health	Hospital-based	Selected external anomalies visible on surface examination		Nigeria
Aminu Kano Teaching Hospital Registry for Congenital Anomalies	Aminu Kano Teaching Hospital Bayero University, Kano	Hospital-based	All major malformations		Kano, Nigeria
Tsepamo Study	Botswana-Harvard AIDS Institute Partnership NIH	Hospital-based (75% of population)	Selected external anomalies visible on surface examination	Antiretroviral therapy (ART exposures)	Botswana
Ubomi Buhle Pregnancy Exposure Registry	University of Cape Town Wits RHI Provincial Departments of Health US CDC Bill & Melinda Gates Foundation	Population-based (sentinel sites)	Selected external anomalies visible on surface examination	Antiretroviral therapy (ART exposures)	South Africa

Hospital-based birth defects surveillance in Uganda	Makerere University-Johns Hopkins University research Collaboration & US CDC	Hospital-based	Selected external anomalies visible on surface examination	Antiretroviral therapy (ART exposures)	Kampala, Uganda
Assessment of fetal anomaly scans in Uganda	Makerere University College Of Health Sciences	Hospital-based	All major malformations	Fetal ultrasound diagnosis and referral	Kampala, Uganda
Birth Outcome Surveillance, after Dolutegravir, eSwathini	Ministry of Health, eSwathini ViiV Healthcare through EGPAF-ASPIRE project	Hospital-based	Selected external anomalies visible on surface examination	Antiretroviral therapy (ART exposures)	eSwathini
Tanzania Birth Defects Surveillance	Ministry of Health US CDC	Population-based (district)	Selected external anomalies visible on surface examination	Antiretroviral therapy (ART exposures)	Tanzania
Planned: BICON	Busitema University NEUROKIDS	Population-based (district)	Selected external anomalies visible on surface examination		Busia, Uganda

CHAMPS - Child Health & Mortality Prevention Surveillance; EGPAF-ASPIRE – Elizabeth Glaser Pediatric AIDS Foundation Attain & Sustain 95-95-95, Prevent New Infections and Reach All Populations for Epidemic Control Project; MiMBa – Malaria in Mothers and Babies; NIAID – National Institute of Allergy & Infectious Disease; NIH – National Institutes of Health; US CDC – United States Center for Disease Control & Prevention; Wits RHI – University of the Witwatersrand Reproductive Health & HIV Institute

Table 3. sSCAN Webinars

Title	Registered	Attended
sSCAN: Birth Defects Surveillance: why and how, the African Experience Part 1	96	67
sSCAN: Birth Defects Surveillance: why and how, the African Experience Part 2	72	37
Addressing congenital anomalies and triple surveillance on the path to meet SDG3 targets	73	34
The use of new technologies for congenital anomaly surveillance, diagnosis and care	55	27
Specialist service provision: paediatric surgery	113	34
Teratogens and Pharmacovigilance	204	53
Neural Tube Defects in sub-Saharan Africa	175	98
Community Screening Strategies to Improve Equitable Access in Diagnosis and Management of Birth Defects: Lessons from Low and Middle-Income Countries	60	24
Congenital Heart Defects in Sub-Saharan African Countries	111	63
Advocacy for congenital disorders and rare diseases in Sub-Saharan Africa: an expert discussion	44	13

5. Funding Opportunities

As noted, sSCAN was established by a 12-month seed grant from the UKRI MRC (Principal Investigator Dr Linda Barlow-Mosha). Since then, the Bill & Melinda Gates Foundation through Ubomi Buhle (co-Principal Investigators Prof Lee Fairlie, Wits RHI and A/Prof Ushma Mehta, University of Cape Town) has provided funding to support 1) the sSCAN website via TGHN (to April 2025) and 2) the General Assembly 2023. This included subsided travel and accommodation for regional delegates.

In 2022/2023 sSCAN submitted two funding applications out of the University of Cape Town to support the Network (both unsuccessful). Details of these include:

1. Global Challenges Research Fund Networking Grants (Academy of Medical Sciences, UK) (£25,000) to support a Common Data Platform for sSCAN

2. Applied Global Health Partnership Grant (UKRI MRC) (£1,039,728) to support the entire Network including specific projects and capacity building between some members.

Feedback suggested that support for such a Network is difficult to position within current calls and that support for specific research projects as funding components may be more successful.

There are two approaches to funding sSCAN which should be pursued concurrently.

1. Minimum support for the core functions of the Network (administration, website, webinars and on-line engagements). Specific funding will be required to support annual/biennial in-person meetings).

2. Independent research/advocacy applications leveraging the sSCAN platform and collaborators.

We will endeavor to keep the funding of the Network lean and will need to position applications to meet donor/funder requirements. sSCAN will need to produce **outputs in response to clear objectives** – peer-reviewed publications, reports, sSCAN African Congenital Anomaly Atlas, an active membership database, up-to-date website, etc. Applications related to specific congenital anomalies, therapeutics or devices, infection, climate could be considered. Support from big pharma would require more debate and clear boundaries.

Ideally, there should be a committee dedicated to fund-raising but this is not feasible at present.

In the next 12 months we will respond to the following calls:

1. Applied Global Health Research Grant (UKRI MRC) (https://www.ukri.org/councils/mrc/guidance-for-applicants/types-of-funding-we-offer/research-grant/)

2. National Institute for Health and Care Research (NIHR) Global Health Research Groups Call 5 with a UK partner (https://www.nihr.ac.uk/documents/nihr-global-health-research-groups-call-5-guidance-for-applicants/34264?pr=)

sSCAN members are encouraged to approach the Steering Committee if you would like to be included in the process and/or for networking/expertise for independent applications. Please include specific budget allocations for a sSCAN webinar/webinars in your relevant applications.

Table 4. sSCAN at the International Conference on Birth Defects and Disabilities in the Developing World

Authors	Session	Title
Helen Malherbe, Rare Diseases South Africa	Plenary 2: Improving Equitable Access: Integrating the health Systems Services for Screening, Diagnosis and Management of Birth Dfects Among Newborns and Children in LMIC Settings	Improving Equity and Access to Newborn Screening in sub-Saharan Africa and Community Genetic Services in South Africa
Claire Baginrana, AfriChild Centre, Makerere University, Uganda	Plenary 5: Eliminating Violence, Stigma and Discrimination against Persons with Birth Defects and Disabilities	Experiences and Lessons on Violence, Stigma and Discrimination against Children with Disabilities in Uganda
Helen Malherbe, Rare Diseases South Africa	S1: Global Burden of Birth Defects for 2023: Updating the Scope, Data Sources and Model Parameters	Are we talking about the same set of conditions? Setting a Standard Terminology for the Global Burden of Birth Defects
Modiegi Diseko, Botswana-Harvard AIDS Institute , Botswana	S6: Surveillance of Birth Defects in LMICs	Neural Tube Defects Surveillance in Botswana: 2014 - 2022
Dhelia Williamson, US Centres for Disease Control & Prevention	S6: Surveillance of Birth Defects in LMICs	Prevalence of Selected Birth Defects in a Hospital-Based Birth Defects Surveillance System in Kampala, Uganda, 2015 – 2021
Emma Kalk, University of Cape Town, South Africa on behalf of sSCAN	S7: Quality and Capacity Building for Birth Defects Surveillance: Data for Action	The Public Health Burden, Prevention and Care of Infants and Children with Congenital Anomalies in sub-Saharan Africa: A Scoping Review
Joyce Namale-Matovu, Makerere University-Johns Hopkins University Research Collaboration, Uganda	S7: Quality and Capacity Building for Birth Defects Surveillance: Data for Action	Strengthening Capacity of Health workers to Diagnose Virth Defects in Ugandan Hospitals, from 2015 – 2021
Robert Serunjogi, Makerere University-Johns Hopkins University Research Collaboration, Uganda	S7: Quality and Capacity Building for Birth Defects Surveillance: Data for Action	Application of Data Quality Indicators to Hospital-based Birth Defects Surveillance Data, Kampala, Uganda, 2015 – 2021
George Bello, International Training and Education Centre for Health, Malawi	S10: Understanding Birt Defects Risk Factors	Prevalence of Adverse Birth Outcomes and External Birth Defects among Women living with HIV in Malawi

Caroline Osoro, Centre for Global Research, Kemya Medical Research Centre, Kenya	S16: Technology Application in Birth Defects Surveillance	Global Birth Defects Description and Coding Application Platform Extension for Expert Panel Review in Surveillance of Congenital Anomalies to Assess Antimalarial Drugs' Potential Teratogenicity
Luke Chiwala, International Training and Education Centre for Health, Malawi	S16: Technology Application in Birth Defects Surveillance	Use of Electronic Data Collection and Web-based Portal to ensure the Quality, Timeliness and Accuracy of Final External Birth Defects Diagnosis in Malawi
Ushma Mehta, University of Cape Town, South Africa	S18: programme Development for Birth Defects and Rare Diseases monitoring and Care Intervention	The UBOMI BUHLE Pregnancy Exposure Registry in South Africa – a New Platform for Surveillance of Risk Factors for Adverse Birth Outcomes
Emma Kalk, University of Cape Town, South Africa	Poster presentation: Abstract #5	The Burden of Congenital Disorders in the Western Cape Pregnancy Exposure Registry, South Africa
Emma Kalk, University of Cape Town, South Africa on behalf of sSCAN	Poster presentation: Abstract #22	The sub-Saharan African Congenital Anomalies Network – sSCAN
Alex Kampanza, Namibia	Poster presentation: Abstract #38	A Case Report of an Infant with osteogenesis Imperfecta, Intermediate Hospital, Katutura, Namibia

6. sSCAN Structure & Leadership

Emma Kalk summarized the aims of the Network as defined in the original application and confirmed in Kampala.

6.1 Aims of the sub-Saharan African Congenital Anomalies Network

1. Provision of a collaborative research and practice forum for Network members.

2. Sharing, analysis and dissemination of harmonized surveillance data regarding the prevalence and prevention of congenital anomalies, and care of affected individuals.

3. Establishment of platforms that support cross-cutting stakeholder engagement to create effective impact pathways at local, national and regional levels.

4. Support for capacity-building relevant to diagnosis, surveillance, research, prevention, and care through training and other resources.

5. Raise awareness and address attitudinal barriers and stigma by developing and/or disseminating appropriate public communication materials.

6. Share best practice and innovative approaches to local challenges using technology and other resources.

It was agreed that these could be operationalized in the following ways:

1. The maintenance of the sSCAN website (https://sscan.tghn.org/) with links to sSCAN events and resources; and other congenital anomalies-related resources.

2. Regular webinars conducted by sub-Saharan African experts (regional research, clinical practice, public health interventions and patient support).

3. Support for networking forums (on-line and in-person) and meetings for engagement and support.

4. Development of data transfer standards and protocols to support data-sharing.

5. Position statements/publications – policy advocacy.

A draft constitution and organogram generated following discussions at the Kampala meeting was circulated to delegates before the meeting. This formed the basis for the open discussion on leadership and the structure of sSCAN.

It was felt that the organogram should be restructured situating the members (General Assembly) at the top. The General Assembly will elect/approve members of the Steering Committee. Most activities are inter-connected (research-technology-patient care-advocacy) and categories are artificial. However, for ease of operations, the Steering Committee will have three broad Portfolios: Research, Training & Capacity Building, and Community Engagement and Advocacy. Network and individual projects/sub-committees can fit into and across these portfolios and include each of them as aims within the study. Owing to time constraints and since none of these initiatives are currently funded, each Portfolio Committee should have a Chair/Champion who manages the groups and keeps members accountable for activities and outputs. Tangible outputs are important to generate funds). It is noted that while surveillance is an important element within sSCAN, the Network is more than solely a surveillance clearing house.

It was agreed that there should be tiered categories of membership based on the size of member organizations and the site of operations of organizations and individuals (i.e., low, middle, high income countries). Eligibility criteria and definitions should be clear. We are not able to administer membership fees at this stage.

The revised organogram will be recirculated and discussed as an online meeting of the General Assembly.

7. sSCAN Priority Projects

Four priority projects were presented, and delegates attended detailed discussions in breakout sessions.

7.1 The Global Birth Defects App *(facilitated by Prof Helen Dolk)*

The Global Birth Defects Coding and Description (GBDDC) App (GBD App for short) was first released in 2019, developed in the context of response to the Zika epidemic, but applicable to any congenital anomaly surveillance or research in low resource environments without ready access to diagnostic expertise at birth. The app facilitates the accurate description and ICDv10-RCPCH coding of congenital anomalies, using a pictorial guide, which is compatible with the WHO Quick Reference Guide. The Basic version can be used as a training and look-up tool, while the Surveillance version can also be used to collect data including photos/videos and upload it to a secure server en route to the surveillance program database. The app is available free from app stores, for both Android and IOS phones/tablets, in four languages: https://globalbirthdefects.tghn.org/.

At this session, Dr Lizel Jacobs who is providing support for the GBD App globally, summarized its history and current use. We heard from three SSCAN members who have formally incorporated the GBD App (Burkina Faso [in French], Ubomi Buhle in South Africa, MiMBa in Kenya). All reported very good feedback from healthcare workers and in South Africa nurses felt empowered by it. Ubomi Buhle have made a bespoke modification to incorporate a wider set of data variables. MiMBA have developed an expert review platform, now available to all users, for their panel of birth defect experts to review the uploaded data and feed back to the coordinator. We also heard from Brazil (Prof Lavinia Faccini Schuler) where the app is being used [in Portuguese], particularly in training of healthcare workers. All current users of the surveillance version of the app are participating in a validation study, assessing user friendliness and the quality of the diagnostic data collected for the first 50 cases against expert assessment. MiMBa are almost ready with validation data, the first to complete this.

At the breakout session, those with experience of using the app could exchange their experience with those who were interested in adopting it in future (e.g. Tanzania, Kenya Mango, Uganda NTD), and we also discussed some of the possible future developments.

Issues discussed included: data protection and ethics approval; the security of the central server was clarified, and the fact that it is used only as a route by which data can be immediately downloaded to the local server (and deleted from central server); linking to RedCAP and other databases; experience with offline capability while needing wifi for installing the app and uploading data periodically, and the importance of minimal data usage by healthcare workers; providing and storing phones in facilities; options for unique identifiers; minimum speed requirements; whether SSCAN could have a pool of experts for diagnostic review.

Future developments discussed included: incorporation of African images; incorporation of diagnostic videos (and associated space and translation issues); incorporation of ICD11 codes (when extra digit is

available); incorporation of a guide to referral centres to be set up locally and links to parent information; the “sandpit” version now being released which allows potential new users to test out the app with fictional example cases to see how well it fits their requirements; incorporation of pulse oximetry training and further development in relation to congenital heart disease.

7.2 The sSCAN Common Data Platform *(facilitated by Mr Robert Serunjogi)*

Sub-Saharan Africa lacks coherent congenital anomaly surveillance systems and faces ongoing challenges with diagnostic capacity, data collection and analysis. A lack of accurate data on the burden and impact of congenital anomalies undermines appropriate resource allocation and the provision of quality health services for people affected. In addition, without baseline birth data on the prevalence of congenital anomalies it is not possible to detect deviations from the norm (signals) potentially due to medicine or other environmental exposures in pregnancy.

sSCAN will work towards a Common Data Platform to allow valid comparisons and data sharing across projects. Data Sharing is specifically referred to in the ssCAN Constitution version 2.0 (sept 2023) pages 9 – 10:

Sharing data regionally is critical to the mandate of sSCAN. The types of data shared (aggregate data, individual depersonalized data, data on health services, resources and use) and methods of sharing will be decided by members on a per project basis according to the capabilities of each organisation and the legal and ethical environment of the institutions and countries involved.

Terms and conditions relating to data sharing will be signed by each Member Organization.

Data will remain under the ownership of the contributing Member Organization, whose formal permission must be obtained for each publication, whether on the sSCAN website or in journals or reports. Secure storage, analysis and dissemination of results will be according to best international practice, as agreed by the Steering Committee and in line with the data protection regulations on each contributing country and institutions and the country and institution hosting the Directorate.

Authorship of collaborative publications will be decided according to the guidelines of the International Journal of Medical Editors (IJME), but it is expected that data contributors would ordinarily meet these criteria and be co-authors.

- *Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data.*
- *Writing the work or critical review of important intellectual content; and*
- *Final approval of the version to be published; and*
- *Agreement to be responsible for all aspects of the work, ensuring that issues related to the accuracy or integrity of any part of the work are properly investigated and resolved.*

When making decisions about sSCAN data sharing, it's important to consider the objectives of different surveillance programs or studies, while also being sensitive to their individual needs. This requires a careful balance between competing priorities, such as the need for data sharing and the need for data protection. To achieve this balance, organizations should establish clear policies and procedures for sSCAN. Additionally, it's important to maintain open communication with stakeholders and to seek input and feedback from all parties involved.

When sharing surveillance data, caution should be taken to determine which variables to share. Additionally, it's crucial to consider the research outputs and funder requirements of each group

involved. There are potential risks and benefits of sharing certain variables and ensuring that data sharing is undertaken in a responsible and ethical manner. Additionally, organizations should establish clear policies and procedures within their protocols for data sharing that consider the sensitivity of the information being shared, as well as the potential risks to the funders, study personnel, and organizations, especially when it comes to writing papers.

There was a concern that some surveillance programs were not confident of the quality of their data.

At present, the operational and legislative framework for sharing/pooling data within sSCAN does not exist and is being developed. Trusting relationships require time to develop. Suggestions include reporting on each project/surveillance programme; producing an annual report of aggregate prevalence data, perhaps those already in the public domain. To create a template for the report, we need to identify the key data points that each surveillance program would need to populate. Some common data points could be the date and time of the surveillance, the location of the surveillance, the type of surveillance conducted, and any notable observations or incidents that occurred during the surveillance. Once we have identified these data points, we can create a standardized report template that each surveillance program can populate with their specific information. This will help ensure consistency and accuracy across all reports and make it easier to compare and analyze data from different surveillance programs. We should review the ICBDSR criteria for sharing data.

Clear standards and protocols should be established to ensure the quality of surveillance data, such as data cleaning and validation procedures. Reliable data collection methods and regular quality monitoring are also essential. Improving data quality can enhance the accuracy and reliability of surveillance efforts.

One possible solution is to create a "Surveillance Data Sharing Maturity Scale" that can be used to evaluate the level of confidence and readiness for sharing surveillance data. The scale could consider factors such as data quality, security, and privacy, as well as the policies and procedures in place for handling and sharing the data. This would provide a clear framework for assessing the risks and benefits associated with sharing surveillance data, and help organizations make informed decisions about when and how to share this sensitive information.

The implementation of ICBDSR Data Quality Indicators in various surveillance programs can play a vital role in improving the accuracy and quality of surveillance data. By utilizing these Indicators, surveillance programs can identify and address gaps in data quality, ensuring that the data collected are reliable and useful. Therefore, it is highly recommended to encourage the use of these Indicators across all surveillance programs.

7.3 Clinical Care and Resources *(facilitated by Dr Phyllis Kisa & A/Prof Karen Fieggen)*

sSCAN has the potential to create a Nwetwork of Expertise across disciplines with clinical relevance, providing a forum for knowledge sharing, advice and the sharing of clinical experiences. This can include laboratory sciences (advice on testing and interpretation of results), telemedicine forums, clinicians. While sSCAN can support a community of practice, clinical decisions must be made locally, and mechanisms created/maintained to support this.

1. Expert Panel/s

Having a panel of experts or a forum available via email to assist with queries will require a Champion (for management and follow-up) and cognoscence must be taken of time and other constraints. Such a multidisciplinary forum could also provide mentorship.

2. Checklists

It was noted that **checklists** have improved the quality of outcomes in obstetric and neonatal health and we suggest a sSCAN checklists for diagnosis and referral, integrated into existing programmes in resource-constrained settings (e.g., the expanded programme of immunization [EPI]) and providing care beyond the neonatal period.

a. Essential Neonatal Checklist at birth

b. Congenital Anomalies Screening Checklist at the 6week and 12-14week vaccination visit.

The aim of these checklists is to increase rates of diagnosis of congenital anomalies and referral of affected children. These resources would be available on the sSCAN website.

3. Training: Congenital Anomalies & Full Neonatal Examination

Training and support should be provided to health care workers and birth attendants to ensure a full neonatal examination is conducted on all neonates. The aim is to empower health care workers without whom this is not possible; defined referral and treatment pathways must be in place to support health care workers who identify anything of concern. The WHO neonatal examination video and a power point presentation is available on the Ubomi Buhle website (https://ubomibuhle.org.za/training-modules/). Engagement with professional bodies for the inclusion of congenital anomalies in syllabuses and Continuing Medical Education for a can be pursued.

Women should be made aware that their neonates are entitled to a full baby examination. Posters, radio inserts and should videos available via Facebook and Whatsapp could be included.

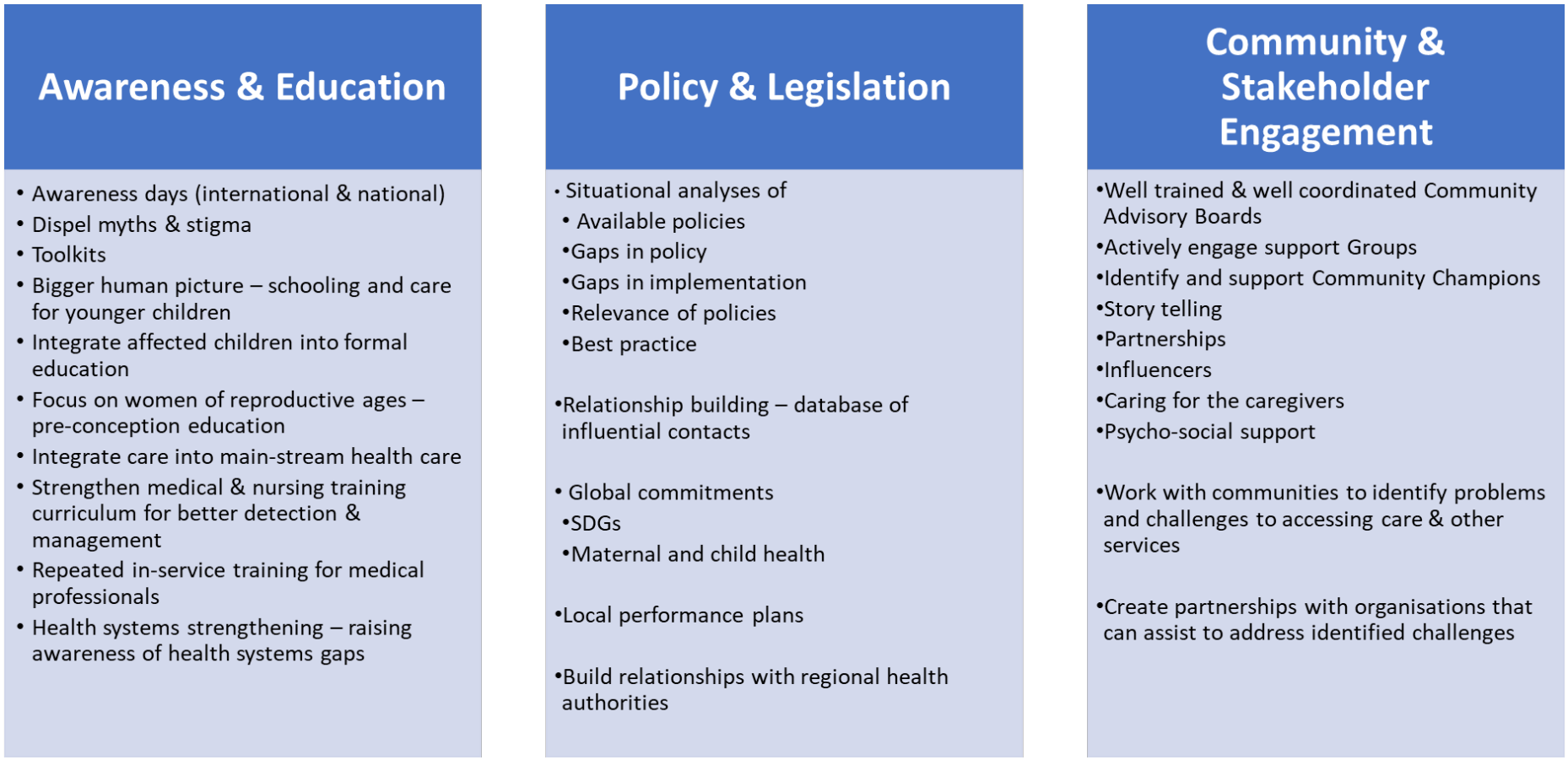
4. sSCAN as a repository for resources

The sSCAN website can serve as a repository for multiple resources. Published manuscripts of interest are already available. Checklists and training materials can be added as well as links to other resources.

7.4 sSCAN Advocacy Programme *(facilitated by A/Prof Helen Malherbe)*

The conceptual framework applied to developing a ssCAN advocacy programme included three platforms: 1) Awareness and Education; 2) Policy and Legislation; 3) Community and Stakeholder Engagement. Within each of these, broad aims can be operationalized with specific objectives and outcomes (Figure 2). Elements of these are applicable as stand-alone projects or components withing research or training initiatives. It is essential that patient engagement and policy change be integrated into all sSCAN projects. Tangible outputs include the development of Toolkits, health professional teaching (e.g., congenital anomaly modules), Community Advisory Boards and a sSCAN position paper on advocacy for individuals and families affected by congenital anomalies. The importance of a presence at conferences and stakeholder meetings and in mainstream and social media was emphasized.

Figure 2. sSCAN Advocacy Programme Conceptual Framework



8. Congenital Anomalies in sub-Saharan Africa: context, global initiatives and resources

8.1 Congenital Anomalies: the sub-Saharan African Context, *Helen Malherbe, RareDiseases South Africa, NPC and North-West University, Potchefstroom, South Africa*

There are numerous terms that are used interchangeably to describe birth defects. It is important that we are clear with respect to definitions. Congenital Disorders or Birth Defects comprise Congenital Anomalies (i.e., *structural* abnormalities) referring to the ICD10 Q chapter, chromosomal disorders and malformations as well as *functional* disorders, which are mainly monogenic disorders. Disorders caused post-conceptually, such as by teratogens, are also included in the broader collective of congenital disorders. In the future within ICD-11, the term developmental anomalies is used together with a more detailed and substantial hierarchy of conditions for this collective. The term, Rare Diseases, can include structural, functional and environmentally-caused disorders that occur at a lower birth prevalence (≤1 in 2000) (Figure 2).

The population of sub-Saharan Africa is set to double by 2050 (to 2,094 million) and 32 of least developed nations globally are in the region. The region has a high fertility rate (average of 4.6 in 2021) and represents 30% of all births globally with a high proportion of adolescent births leading to a young age distribution. A child born in sub-Saharan Africa is 20 times more likely to die than in higher-income regions. In 2019, 30% of congenital anomalies occured in sub-Saharan Africa and as advances are made against other causes of infant and child mortality, the proportion of under-5 mortality due to congenital anomalies are expected to continue to increase. The high rates of congenital anomalies can be ascribed to the high rates of both young and older mothers, consanguinity in some regions and the survival advantage of certain haemoglobinopathies coupled with high fertility and numerous high-risk environmental exposures (nutritional, infectious, medicine, pollution, climate).

The Epidemiological Transition in sub-Sharan Africa is not typical and the burden of infectious disease remains as the incidence of non-communicable diseases increases. The region has been hardest hit by HIV/AIDS which, with TB and malaria, remain important public health issues. Health services in many countries remain under-resourced with poor antenatal and perinatal care, fragmented infrastructure and a lack of universal health care.

This context has resulted in a data deficit: the true scale of congenital anomaly-related health issues remains unknown.

The WHO March of Dimes Global Report on Birth Defects 2006 provides estimates for baseline national affected births in 193 countries at a no-care baseline. The Modell Global Database estimates the prevalence and outcomes (pregnancy loss, death, disability) of selected endogenous conditions (either present at birth or with early onset) based on actual resources and then modelled in optimal scenarios. The Modell Global Database is currently being updated.

What are the characteristics of an ideal Community Genetics Service?

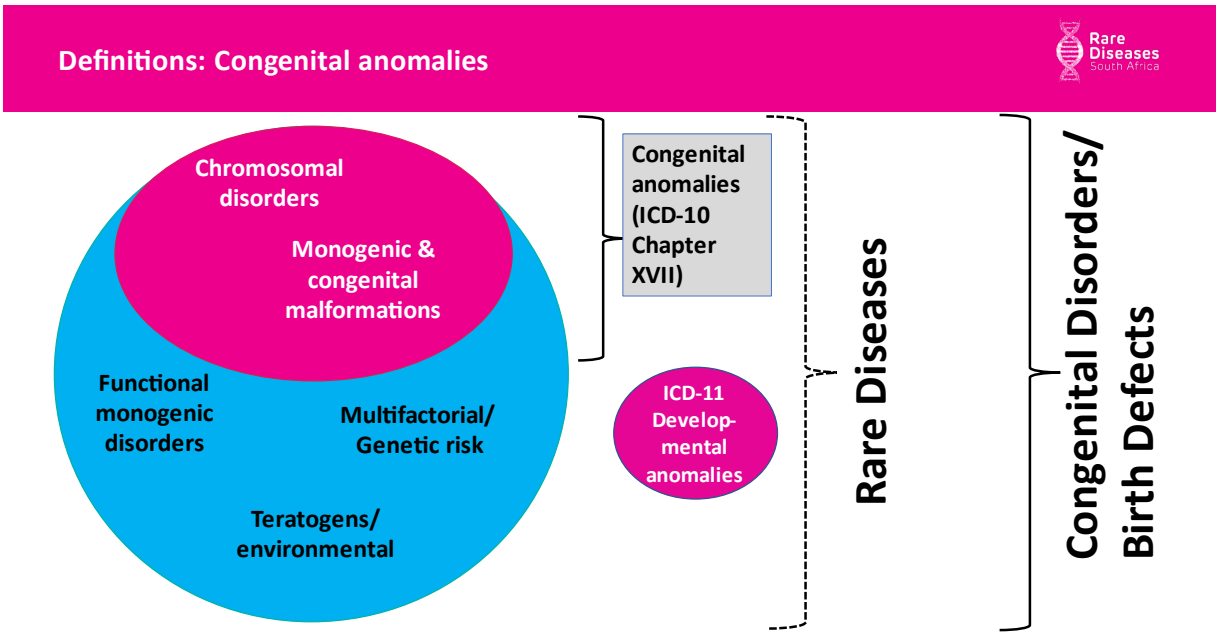
“70% of birth defects can be prevented, effectively cure and disability mitigated through optimal [community] genetic services”, Cziezel et al., 1995.

The aim is to provide the best possible care in prevailing circumstances. Services should be equitable, striving to ensure an equal outcome as opposed to ensuring equal resources; the services should be tailored to local contexts.

An accessible package of care integrated into routine services at all levels. i.e., primary, secondary and tertiary, and across the life course (pre-conception, pregnancy, birth, childhood, adolescence, adulthood.)

Leave no one behind – Sustainable Development Goals

Figure 3. Congenital Disorders Definitions (image courtesy Helen Malherbe)



Congenital disorders =Birth defects ≠ Congenital anomalies (WHO 2006, Malherbe et al 2023)

8.2 WHO's work on birth defects: the way forward for the burden of birth defects estimates 2023 – 2024

Kate Strong, Department of Maternal, Newborn, Child and Adolescent Health, World Health Organization

The WHO's approach to birth defects can be structured under three headings, Surveillance, Burden of Disease Estimates and Newborn Screening and Management.

Surveillance

Birth Defects contribute 8% of under-5 mortality globally but the true burden is under-estimated. The aetiology of contributors to neonatal and under-5 mortality in the WHO Africa region differ from other regions and birth defects are the 4th most common cause of death after prematurity, intrapartum events and sepsis. The Sustainable Development Goals to reduce neonatal (≤ 12/1000 live births) and child under-5 mortality (≤25/1000 live births) apply. Surveillance, prevention and providing care for children with birth defects are important strategies to reach these child survival targets.

The WHO has developed a Surveillance Toolkit with the US CDC and ICBDSR (updated 2022 – 2023) which comprises:

Manual for Programme Managers (https://www.who.int/publications/i/item/9789240015395)

Quick Reference Handbook (provided to all attendees)
(https://www.who.int/publications/i/item/9789240015418)

Facilitators' Guide (https://www.who.int/publications/i/item/9789241549288)

In addition, the *Birth Defects Surveillance Mobile Application Guidelines* will be published in November 2023. This is part of the Digital Adaptation Kit (DAK) initiative using evidence-based guidelines. The systems are software neutral and based on WHO clinical, health system and data use recommendations to transparently inform the design of digital systems. Those that meet WHO standards will get WHO approval.

Burden of Disease estimates

Burden of Disease estimates provide the evidence required to inform programme planning and advocacy to improve diagnosis, management and care for those born with birth defects.

The WHO has established the *Burden of Birth Defects Technical Working Group* (TWG) with 30+ members from across the WHO regions.

In addition to defining terminology, the TWG will determine the WHO Focus i.e., initially those birth defects for which prevention and care strategies exist as these are of immediate relevance to policy-makers and clinicians. They will update and use the Modell Global Database to create dynamic data resources that are updated regularly; and make use of the *BornHealthy Toolkit* (https://www.bornhealthy.org/toolkit.html). The BornHealthy Toolkit is a planning tool that allows countries to input data and create scenarios for priority setting and resource allocation. In the future, updates from the Modell Global Database will be incorporated into the Toolkit along with definitions, assumptions, methods, results and limitations to endure transparency.

Data collection is underway from registries, reports and peer-reviewed articles (from 2015) to determine the general and condition-specific burden of and mortality due to congenital anomalies. Results will be compared with those of other global efforts, namely the Institute for Health Metrics and Evaluation (IHME) Global Burden of Disease Study.

A scoping review on the contribution of birth defects to mortality across regions has been published and a cause-specific review is pending. The aim is to develop a modelling approach to update birth defects mortality data.

Newborn screening and management

Estimating the global burden and conducting surveillance for birth defects must be accompanied by action to prevent, diagnose and manage birth defects. Newborn screening includes:

1. Clinical screening by visual inspection, for structural hearing loss, congenital cataracts, pulse oximetry
2. Biochemical screening: hypothyroidism, congenital adrenal hyperplasia, haemoglobinopathies, a panel of metabolic conditions.

The WHO will develop guidelines for newborn screening under difference resource conditions. A survey to determine regional priorities for screening has been circulated.

8.3 Clinical Guidelines for Genetic Services in South Africa, 2021

Vuyiswa Lebese, South African Field Epidemiology Program Resident, National Department of Health, South Africa

Ms Lebese from the South African National Department of Health presented the newly updated Clinical Guidelines for Genetic Services in South Africa, a comprehensive set of best-practice services. The aim of the Guidelines is to provide guidance to healthcare providers to enable prevention, early recognition, screening, diagnosis, and prompt referral and care of patients requiring genetic services, in order to improve outcomes. The focus is on care across the life course (from pre-conception to adulthood) and across all levels of care, strengthening of referral pathways, patient-centred and coordinated care, and effective and sustainable surveillance and M&E systems are included. Implementation is underway. The Guidelines are available in full via:

https://knowledgehub.health.gov.za/elibrary/clinical-guidelines-genetics-services-2021

South Africa is one of the few countries in sub-Saharan Africa to offer genetic care within the public health services although specialist medical geneticists in the public sector practice only in two or nine provinces.

South Africa has a passive (spontaneous) surveillance system for reporting congenital anomalies; the system is not well utilized with significant under-reporting. However, data on neural tube defects will be included in routine national indicators.

8.4 International Clearinghouse for Birth Defects Surveillance & Research: resources for sub-Saharan Africa

Boris Groisman, ICBDSR and RENAC

The International Clearinghouse for Birth Defects Surveillance & Research (ICBDSR) is an international network of surveillance systems with the aim of investigating and preventing birth defects. Aggregated data are shared routinely. Forty-three programmes from four regions (not Africa) share data which are diverse in terms of methodology, data source and detail. Only 13 programmes are from low- or middle-income countries. The diversity ensures this is a powerful analysis database. Membership requires baseline data for at least two years using the same surveillance methodology. Affiliate Members (organization or individual) do not contribute data but can act as facilitators. **sSCAN could apply as a Network.**

Data on up to 45 selected birth defects are shared and can be viewed graphically. Members collaborate on research projects using the data. The ICBDSR has published standard data indicators that are more flexible and appropriate for use in low- and middle-income countries. This can be downloaded from http://www.icbdsr.org/data-quality-indicators-tool/.

There are four categories of Data Quality Indicators (DQI):

1. Ascertainment DQI based on that calculated from ICBDSR data; if prevalence for a specific condition falls below this 'threshold', under-ascertainment is likely.

2. Description DQI indicate the accuracy and completeness of the description and documentation.

3. Coding DQI evaluates common coding errors.

4. Classification DQI evaluates distribution as isolated, multiples or syndromes for those birth defects for which a typical distribution is already known.

The ICBDSR has a Mobile App, *Quick Reference Handbook*, which is useful for review and checklists for description. It is based on the WHO Handbook and Manual described above.

The organization hosts a Training Platform (website) with self-paced courses and pre-courses prior to in-person workshops which are tailored to the content of the workshop. There are video lectures and self-assessments. ICBDSR has been running in-person training programmes since 2011 which can be tailored to requirements. The is a Basic Course which introduces surveillance principles and best-practice and an Intermediate Course with a focus on quality improvement in existing programmes.

PEACE Population Estimate of Attributable Fraction of Congenital Conditions Everywhere calculates population attributable fraction given the prevalence of birth defects and risk factors.

9. Conclusions

The 2nd sSCAN General Assembly brought together 60 delegates from 15 countries representing 40 projects across a range of disciplines: epidemiology and public health; surveillance and project management; clinical genetics, paediatrics and surgery; nursing and midwifery; pharmacovigilance and medicine regulation; data management; computer science; patient support and advocacy groups; global organizations and government representatives. The activities and achievements of the new organization over the last year are impressive. We learnt of the scope of our community of practice in congenital anomalies in sub-Saharan Africa and the resources that can be shared across initiatives. There was input into the sSCAN Constitution and Network structure and we hope to ratify these governance documents before the next meeting. We will optimize the sSCAN website and expand it as a repository of resources on congenital anomalies. New colleagues have expressed interest and will join the Steering Committee. We continue to seek funding for the Network and affiliated projects.

Thank you to everyone how attended – it was wonderful to meet you all and has provided the momentum to expand sSCAN activities in the coming years.

Presentations will be available on the sSCAN website.

Compiled by Emma Kalk, on behalf of sSCAN, September 2023

Appendices

1. Supplementary Table 1. List of Attendees 2nd sSCAN General Assembly (alphabetical order)

Participant	Organization	Project	Role	Country
Dr Boris Groisman	International Clearinghouse for Birth Defects Surveillance & Research; National Network of Congenital Anomalies of Argentina		Medical Geneticist	Argentina
Ms Modiegi Diseko	Botswana–Harvard AIDS Institute Partnership	Tsepamo Study	Nurse Study Co-ordinator	Botswana
Prof Lavinia Schuler-Faccini	Universidade Federal do Rio Grande do Sol		Clinical Geneticist	Brazil
Mr Ayoade Desmond Babalola	Universidade Federal do Rio Grande do Sol		PhD student	Brazil & Nigeria
Dr Clarisse Dah	Centre De Recherche En Sante De Nouna	Towards and Africa Platform for Congenital Anomalies & Birth Defects Surveillance in sub-Saharan Africa	Clinician	Burkina Faso
Dr Ali Sie	Centre De Recherche En Sante De Nouna	Towards and Africa Platform for Congenital Anomalies & Birth Defects Surveillance in sub-Saharan Africa	Clinician and Director	Burkina Faso
Dr Aminkeng Leke	Health Research Foundation	Cameroon Registry for Congenital Anomaly Surveillance	Epidemiologist	Cameroon
Dr Michel Maboh	Health Research Foundation	Cameroon Registry for Congenital Anomaly Surveillance	President	Cameroon
A/Prof Abede Mekonem	College of Health Sciences, Addis Ababa University		Plastic & Reconstructive Surgeon	Ethiopia
Dr Samrawit Tegene	Hararghe Health Research & CHAMPS Ethiopia	CHAMPS Ethiopia	Clinician Research Co-ordinator	Ethiopia
Dr Audrey Chepkemoi	Moi Teaching & Referral Hospital	MANGO-Kenya	Neonatologist	Kenya
Prof Edwin Were	Moi Teaching & Referral Hospital and Moi University	MANGO-Kenya	Obstetrician	Kenya
Dr Meshack Liru	Ministry of Health, Kenya	MiMBa	Paediatrician	Kenya
Dr Caroline Osoro	Kenya Medical Research Institute (KEMRI)	MiMBa	Clinician and Senior Research Scientist	Kenya
Dr Benard Omondi	Kenya Medical Research Institute (KEMRI)	MiMBa	Clinician	Kenya
Dr George Bello	I-TECH Malawi and Ministry of Health, Malawi	Malawi Birth Defects Surveillance	Surveillance Technical Director	Malawi
Mr Alex Kapanza	Ministry of Health and Social Services, Namibia		Health Program Officer	Namibia
Dr Oluwakemi Ashubu	University College Hospital, Ibadan		Consultant Paediatric Endocrinologist	Nigeria
A/Prof Idowu Ayede	University College Hospital, Ibadan	National Birth Defects Surveillance in Nigeria	Paediatrician	Nigeria
Prof Labaran Aliyu	Aminu Kano Teaching Hospital & Bayero University, Kano	Aminu Kano Teaching Hospital Registry for Congenital Anomalies	Obstetrician	Nigeria

A/Prof Mohammed Abdulsalam	Aminu Kano Teaching Hospital & Bayero University, Kano	Aminu Kano Teaching Hospital Registry for Congenital Anomalies	Paediatrician	Nigeria
Dr Candice Afonso	Department of Neonatology, Groote Schuur Hospital, Cape Town		Senior Medical Officer	South Africa
A/Prof Karen Fieggen	University of Cape Town & Groote Schuur Hospital		Medical Geneticist	South Africa
Dr Lesego Gaotshetse	University of Cape Town & Groote Schuur Hospital		Registrar, Medical Genetics	South Africa
Dr Careni Spencer	University of Cape Town & Groote Schuur Hospital		Medical Geneticist	South Africa
Ms Nakita Laing	Groote Schuur Hospital		Genetics Counsellor	South Africa
Dr Anika van Niekerk	Mowbray Maternity Hospital, Cape Town		Neonatologist	South Africa
Dr Elizabeth Allen	The Global Health Network		Strategic Partnerships Lead	South Africa
Prof Lee Fairlie	Wits-RHI	Ubomi Buhle	Director Maternal Child Health, co-Principal Investigator Ubomi Buhle	South Africa
Dr Faeezah Patel	Wits-RHI	Ubomi Buhle	Clinician & Researcher	South Africa
Dr Lizel Jacobs	Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town	Ubomi Buhle	Senior Research Officer	South Africa
Mr Shaun Krog	Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town	Ubomi Buhle	Data Analyst	South Africa
Dr Di Lavies	Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town	Ubomi Buhle	Project Manager	South Africa
Ms Khanyisa Mandondo	Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town	Ubomi Buhle	Research Nurse	South Africa
A/Prof Ushma Mehta	Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town	Ubomi Buhle	Deputy Director; co-Principal Investigator Ubomi Buhle	South Africa
Ms Florence Phelanyane	Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town and Western Cape Government Department of Health	Ubomi Buhle	Data Analyst	South Africa
A/Prof Emma Kalk	Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town	Ubomi Buhle & Western Cape Pregnancy Exposure Registry	Chief Research Officer	South Africa
Ms Vumela Mzangwe	Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town	Ubomi Buhle & Western Cape Pregnancy Exposure Registry	Research Assistant	South Africa
Ms Vuyiswa Lebese	National Department of Health, South Africa		Assistant Director: Human Genetics	South Africa
A/Prof Helen Malherbe	Rare Diseases South Africa NPC & North West University		Director: Research & Epidemiology	South Africa
Dr Diane Morof	US Centers for Disease Control & Prevention		Associate Director of Programs-KwaZulu Natal	South Africa
Ms Karen Mara Moss	Steps Charity		Founder and Executive Director	South Africa
Dr Portia Mutevedzi	Emory University	CHAMPS	Senior Director CHAMPS	South Africa
Ms Susan Peterson	Robert Mangaliso Sobukwe Hospital, Kimberly		Registered Midwife	South Africa
Dr Tumelo Satekge	National Health Laboratory Services, Limpopo		Pathologist	South Africa
Ms Sarah Scarth	Operation Smile South Africa		Executive Director	South Africa
Prof Kathrine Scholtz	University of Limpopo		Research Associate	South Africa

Ms Annoesjka Swart	Medicines Information Centre, South Africa		Manager	South Africa
Prof Liesl Zuhlke	South African Medical Research Council		Vice President: Extramural Research & Internal Portfolio; Paediatric cardiologist	South Africa
Ms Bonisile Nhlabatsi	Ministry of Health, eSwathini	Birth Outcome Surveillance after Introduction of dolutegravir in eSwathini	Sexual Reproductive Health Program Manager	eSwathini
Dr Kate Strong	World Heatlh Organization		Department of Maternal, Newborn, Child & Adolescent Health	Switzerland
Dr Hamisi Shabani	Muhimbili Orthopaedic Institute		Neurosurgeon	Tanzania
Mr Denis Kalibbala	Global Health Uganda		Data Manager	Uganda
Dr Eric Katagirya	Makerere University		Lecturer and Researcher	Uganda
Dr Phyllis Kisa	Makerere University College of Health Sciences		Paediatric surgeon	Uganda
Dr Mwanja Daniel Mumpe	Makerere University - Johns Hopkins University Research Collaboration	Birth Defects Surveillance	Programme Manager	Uganda
Mr Robert Serunjogi	Makerere University - Johns Hopkins University Research Collaboration	Birth Defects Surveillance	Data Manager	Uganda
Ms Lydia Ssenyonga	University of Cape Town & Busitema University, Mbale		Paediatric nurse & Researcher	Uganda
Dr Stephanie Dellicour	Liverpool School of Tropical Medicine, Liverpool	MiMBa	Pharmacoepidemiologist and Principal Research Associate	United Kingdom
Prof Helen Dolk	Ulster University, Belfast	GBD App	Professor Of Epidemiology	United Kingdom
Mr Philip Whitfield	Biomedical Computing Ltd	GDB App	Software Developer	United Kingdom

2. Photographs, 2nd sSCAN General Assembly

Sub-Saharan African Congenital Anomalies Network

General Meeting

11-13 September 2023
Cape Town | South Africa

PROGRAMME

DAY 1 MONDAY 11 SEPT

CHAIRS: **A/Prof Emma Kalk** *Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town, South Africa* **Dr Phyllis Kisa** *Makerere University College of Health Sciences & Mulago National Referral Hospital, Kampala, Uganda*

VENUE: Auditorium

08h15 – 09h00	**REGISTRATION**	
09h00 – 13h00 **TEA 11h15 - 11h45**	**International Clearinghouse for Birth Defects Surveillance & Research Data Workshop**	**Dr Boris Groisman** *ICBDSR, National Network of Congenital Anomalies of Argentina (RENAC), National Center of Medical Genetics, Argentina* **FACILITATORS: sSCAN**
13h00 – 14h00	**LUNCH**	
14h00 – 16h30 **TEA 15h30 - 16h00**	**WELCOME**	**A/Prof Emma Kalk & Dr Phyllis Kisa**
	Introduction of all projects	
	Towards an African platform for congenital abnormalities and birth defects surveillance in sub-Saharan Africa	**Dr Clarisse Dah** *Centre de Recherche en Santé de Nouna, Nouna, Burkina Faso*
	The Cameroon Registry of Congenital Anomaly Surveillance (CARECAS): First steps	**Dr Aminkeng Leke** *Epidemiologist, Vice President/Co-Founder, Health Research Foundation, Cameroon*
	Child Health and Mortality Prevention Surveillance (CHAMPS) data for surveillance and child mortality prevention	**Dr Portia Makamba-Mutevedzi** *Senior Director: Impact and Engagement, CHAMPS Programme Office*
	Child Health and Mortality Prevention Surveillance (CHAMPS)-Ethiopia, Activities & Result from the Last Three Years	**Dr Samrawit Abebaw** *CHAMPS Ethiopia*
	Update on Birth defects Surveillance in Nigeria	**Dr Oluwakemi Ashubu** on behalf of Associate Prof Ayede Adejumoke Idowu *College of Medicine, University of Ibadan & University College Hospital, Ibadan, Nigeria*
	The Aminu Kano Teaching Hospital Registry for Congenital Anomalies	**Prof Aliyu Labaran Dayyabu** *Department of Obstetrics & Gynecology, Bayero University & Aminu Kano Teaching Hospital, Kano, Nigeria*
	The Malawi Birth Defects Surveillance Project	**Dr George Bello** *Surveillance Technical Director & Principal Investigator, Malawi Birth Defects Surveillance, I-TECH Malawi & Ministry of Health*
	MiMBa: Antimalarial pregnancy exposure registry	**Dr Stephanie Dellicour** *Liverpool School of Tropical Medicine, UK*
	Overview of the Birth Outcomes Surveillance in Botswana – the Tsepamo Study	**Modiegi Diseko** *Botswana Harvard Partnership (BHP)*
	Introduction to the UBOMI BUHLE Pregnancy Exposure Registry, South Africa	**A/Prof Ushma C. Mehta** *Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town, South Africa; and Co-PI of UBOMI BUHLE Pregnancy Exposure Registry*
	An overview of the Hospital-based birth defects surveillance in Kampala, Uganda	**Dr Daniel Mwanja Mumpe** *Makerere University - Johns Hopkins University (MU-JHU) Research Collaboration, Uganda*

	Proposed project to assess the current status of fetal anomaly scans in select high volume antenatal care centers in Uganda	**Dr Phyllis Kisa** *Makerere University College of Health Sciences & Mulago National Referral Hospital, Kampala, Uganda*
	Birth Outcome Surveillance after Introduction of Dolutegravir in Eswatini	**Bonisile Nhlabatsi** *Programme Manager, Sexual Reproductive Health Unit, Ministry of Health, Eswatini*
	Measuring Adverse Pregnancy and Newborn Congenital Outcomes (MANGO)-Kenya	**Prof Edwin Were** *Department of Reproductive Health, Moi University, Kenya*
	Feedback and achievements	
	sSCAN Website & Webinars	**A/Prof Emma Kalk** *Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town, South Africa* **Dr Elizabeth Allen** *Regional Faculty Lead, The Global Health Network, South Africa*
	Publications	**Dr Aminkeng Leke** *Health Research Foundation, Cameroon*
	sSCAN at the International Conference on Birth Defects and Disabilities in the Developing World, Santiago, Chile, March 2023	**Modiegi Diseko** *Botswana Harvard Partnership, Botswana*
	Funding opportunities	**A/Prof Emma Kalk**

DAY 2 TUESDAY 12 SEPT

VENUE: Auditorium

08h00 – 08h30	**REGISTRATION**	
08h30 – 10h30	**sSCAN Structure & Leadership**	**A/Prof Emma Kalk & Dr Linda Barlow-Mosha**
10h30 – 11h00	**TEA**	
11h00 – 13h00	**Introduction to sSCAN Projects**	**CHAIR: Robert Serunjogi** *Makerere University - Johns Hopkins University (MU-JHU) Research Collaboration, Uganda*
	1. Global Birth Defects App (GBDDC)	
	Overview of the GBDDC App	**Dr Lizel Jacobs** *Centre for Infectious Disease Epidemiology & Research, School of Public Health, University of Cape Town, South Africa; and UBOMI BUHLE Pregnancy Exposure Registry*
	GBDDC platform extension for expert panel review: The Kenyan experience	**Dr Benard Omondi & Dr Stephanie Dellicour** *Malaria in Mothers and Babies, Kenya Medical Research Institute, Kenya*
	Global Birth Defects App use for congenital abnormalities assessment in Burkina Faso	**Dr Clarisse Dah** *Centre de Recherche en Santé de Nouna, Nouna, Burkina Faso*
	The Global Birth Defect App – The South African experience	**Dr Lizel Jacobs** *University of Cape Town and UBOMI BUHLE Pregnancy Exposure Registry, South Africa*
	Brazilian experience with the Global Birth Defects App (remote)	**Prof Lavinia Schuler-Faccini** *Universidade Federal do Rio Grande do Sul, Rio Grande do Sul, Brazil*
	2. sSCAN Common Data Platform	**Robert Serunjogi** *Makerere University - Johns Hopkins University (MU-JHU) Research Collaboration, Uganda*
	3. Community Genetics & Clinical Resources	**Dr Phyllis Kisa** *Makerere University College of Health Sciences & Mulago National Referral Hospital, Kampala, Uganda*
	4. Proposed Advocacy Activities of sSCAN	**A/Prof Helen Malherbe** *Centre for Metabolomics, North-West University, Potchefstroom, South Africa; and Director: Research & Epidemiology, Rare Diseases South Africa (RDSA) NPC*
13h00 – 14h00	**LUNCH**	

	BREAKOUT SESSIONS | sSCAN Projects Discussion	
	1. Global Birth Defects App VENUE: Auditorium	**FACILITATOR: Prof Helen Dolk** *Epidemiology & Health Services Research Ulster University, UK*
	2. Common Data Platform VENUE: Venue 4	**FACILITATOR: Robert Serunjogi** *Makerere University - Johns Hopkins University (MU-JHU) Research Collaboration, Uganda*
	3. Community Genetics & Clinical Resources VENUE: Venue 5	**FACILITATORS: Dr Phyllis Kisa** *Makerere University College of Health Sciences & Mulago National Referral Hospital, Kampala, Uganda* **A/Prof Karen Fieggen** *Division of Human Genetics, department of Medicine, University of Cape Town; & Groote Schuur Hospital, South Africa*
	4. sSCAN Advocacy Network VENUE: Venue 6	**FACILITATOR: A/Prof Helen Malherbe** *North-West University, Potchefstroom, South Africa; and Rare Diseases South Africa*
16h00 – 16h30	**TEA**	
16h30	**Feedback**	

DINNER – Life Café, Waterfront (*Leave at 18h30*)

DAY 3 WEDNESDAY 13 SEPT

VENUE: Auditorium

08h00 – 09h00	**COFFEE & NETWORKING**	
09h00 – 11h00	**Congenital Anomalies in sub-Saharan Africa**	**CHAIR: Prof Lee Fairlie** *Director of Maternal and Child Health at Wits Reproductive Health & HIV Initiative; and Co-PI of UBOMI BUHLE Pregnancy Exposure Registry*
	Congenital Anomalies: the sub-Saharan Africa Context	**A/Prof Helen Malherbe** *RareDiseases South Africa*
	Highlights of the sSCAN scoping review on the burden, prevention and care of infants and children with congenital anomalies in sub-Saharan Africa	**Dr Aminkeng Leke** *Health Research Foundation, Cameroon*
	WHO's work on birth defects: The way forward for the burden of birth defects estimates 2023-2024	**Dr Kate Strong** *Department of Maternal, Newborn, Child and Adolescent Health, World Health Organization*
	Clinical Guidelines for Genetic Services in South Africa, 2021	**Vuyiswa Lebese** *South African Field Epidemiology Program (SAFETP) Resident, National Department of Health, South Africa*
	International Clearinghouse for Birth Defects Surveillance & Research: resources for sub-Saharan Africa	**Dr Boris Groisman** *ICBDSR*
10h30 – 11h00	**TEA**	
11h00 – 13h00	**Discussion: Development of a sSCAN Position Statement**	**A/Prof Ushma C. Mehta** *Ubomi Buhle, South Africa*
13h00 – 14h00	**LUNCH**	
	Summary & Close	**A/Prof Emma Kalk & Dr Phyllis Kisa**

DEPART

University of Cape Town · iYunivesithi yaseKapa · Universiteit van Kaapstad

CIDER

sSCAN Sub-Saharan African Congenital Anomalies Network

WORKSHOP on birth defect surveillance

Recognition, description, coding and data quality

11 September 2023

09h00 - 13h00

Dr Boris Groisman *ICBDSR, National Network of Congenital Anomalies of Argentina (RENAC), National Center of Medical Genetics, Argentina*

VENUE: Auditorium

9h00 – 9h30	**Introduction and organization**	Aims of workshop, review of tools (Quick Reference Handbook, Manual for programme Managers) Pretest
9h30 – 10h30	**Overview of birth defects surveillance**	Public health surveillance of birth defects: Definition, Processes, Methodology and Experience in Argentina
10h30 – 11h15	**Neural tube defects –case study**	Pilot neural tube case study – includes description, diagnosis, use of checklists. Brief review of risk factors (focus on folic acid)
11h15 – 11h45	**TEA**	
11h45 – 12h45	**Case study – Quality Evaluation / improvement**	Importance of data quality, appropriate development of tables
12h45 – 13h00	**Post-test, wrap up**	

Summary – aims and structure:

- By the end of the workshop, participants will be able to recognize, diagnose, and describe several major congenital anomalies of significant clinical and public health importance, using approaches and tools meant to improve efficiency and data quality.
- To improve interaction and learning, participants will work in small groups through case studies and exercises, supported by tutors.
- Participants will be provided with manuals for them to keep for future use.
- The ideal participant is an enthusiastic champion of birth defect surveillance and prevention, interested or actively engaged in surveillance or clinical activities related to congenital anomalies.

BREAKAWAY Sessions

BREAKAWAY 1:
Global Birth Defects App

FACILITATOR: Prof Helen Dolk
Epidemiology & Health Services Research Ulster University, UK

VENUE: Auditorium

Points for discussion

1. Current and future developments
2. Standard Database option: downloading to a database
3. App content:
   - Incorporation of African images, ICD11 codes, training videos
   - Healthcare uses: Initiating care, referral guidance
   - Congenital heart disease: additional modules for pulse oximetry and telemedicine
   - Clinical Genetics platform: sending data for expert review. Extension of panel review. Feedback pathway.
   - Parent Communication module
4. Other: Sandpit version, Common IOS/Android

BREAKAWAY 2:
Common Data Platform

FACILITATOR: Robert Serunjogi
Makerere University - Johns Hopkins University (MU-JHU) Research Collaboration, Uganda

VENUE: Venue 4

Points for Discussion

1. Strategic Aims of & Reasons for Data Sharing
2. Feedback from the previous sSCAN meeting held in Kampala, Uganda
3. Systematic data variables and definitions
4. Potential benefits and risks, either to individuals or to society, of sharing the Data
5. Legal Framework & Data Protection Legislation
6. Data Storage & Security
7. Use of Secondary Data
8. Development of a Data-sharing Protocol

BREAKAWAY Sessions

BREAKAWAY 3:
Community Genetics & Clinical Resources

FACILITATORS: Dr Phyllis Kisa *Makerere University College of Health Sciences & Mulago National Referral Hospital, Kampala, Uganda*
A/Prof Karen Fieggen *Division of Human Genetics, department of Medicine, University of Cape Town, South Africa; & Groote Schuur Hospital*

VENUE: Venue 5

Points for Discussion

1. Feasibility of a sSCAN Clinical Genetics Platform for the sharing expertise. There are very few Clinical Geneticists practicing in Africa, and the proposal is to develop a platform for skills transfer and mentorship.
   a) How to recruit clinical genetic experts and connect them with inexperienced clinical healthcare workers.
   b) Identification of local Congenital Anomaly Champions in strategic centers to be catalyst and how to support them.
   c) Offsite clinical support with Telehealth.
2. Raise awareness and encourage use of existing resources e.g., the Global Birth Defects App, WHO Birth Defect Toolkit.
3. Feasibility of a Paediatrics Cardiology Platform to exchange best-practice in the diagnosis (including imaging) and treatment of congenital heart defects. (OR ANY-OTHER SINGLE DEFECT THE GROUP FEELS IS PRIORITY)
4. Feasibility to create and support a multidisciplinary training Platform for Paediatric Surgery
5. Role of tele-health to establish these networks and connections and the participants' experience with tools so far.
6. What are the clinical needs regarding Congenital Anomaly detection and care?
7. Share success stories
8. Connections/partnership between research and NGO's to bridge clinical care gaps

BREAKAWAY 4:
Conceptualizing the sSCAN Advocacy Network

FACILITATOR: A/Prof Helen Malherbe, *North-West University, Potchefstroom, South Africa; and Rare Diseases South Africa*

VENUE: Venue 6

Points for Discussion

1. A sSCAN Advocacy Network: Clarifications & Expectations. How do we get there?
2. Activities & resources, toolkits (using existing resources/tailoring, role of Community Advisory Boards, recruitment/buy-in of advocates at all levels, relationships, diversity of advocacy roles, sustainability
3. Stakeholder Landscape & Linkages
4. The Way Forward: roadmap & action points, including proposed format/structure

PLOS GLOBAL PUBLIC HEALTH

RESEARCH ARTICLE

The burden, prevention and care of infants and children with congenital anomalies in sub-Saharan Africa: A scoping review

Aminkeng Zawuo Leke[1,2☯*], Helen Malherbe[3☯], Emma Kalk[4☯], Ushma Mehta[4☯], Phylis Kisa[5☯], Lorenzo D. Botto[6,7☯], Idowu Ayede[8☯], Lee Fairlie[9☯], Nkwati Michel Maboh[2☯], Ieda Orioli[10,11☯], Rebecca Zash[12☯], Ronald Kusolo[13☯], Daniel Mumpe-Mwanja[13☯], Robert Serujogi[13☯], Bodo Bongomin[14☯], Caroline Osoro[15☯], Clarisse Dah[16☯], Olive Sentumbwe–Mugisha[17☯], Hamisi Kimaro Shabani[18☯], Philippa Musoke[13☯], Helen Dolk[1☯], Linda Barlow-Mosha[13☯]

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Abstract

The aim of this scoping review was to determine the scope, objectives and methodology of contemporary published research on congenital anomalies (CAs) in sub-Saharan Africa (SSA), to inform activities of the newly established sub-Saharan African Congenital Anomaly Network (sSCAN). MEDLINE was searched for CA-related articles published between January 2016 and June 2021. Articles were classified into four main areas (public health burden, surveillance, prevention, care) and their objectives and methodologies summarized. Of the 532 articles identified, 255 were included. The articles originated from 22 of the 49 SSA countries, with four countries contributing 60% of the articles: Nigeria (22.0%), Ethiopia (14.1%), Uganda (11.7%) and South Africa (11.7%). Only 5.5% of studies involved multiple countries within the region. Most articles included CA as their primary focus (85%), investigated a single CA (88%), focused on CA burden (56.9%) and care (54.1%), with less coverage of surveillance (3.5%) and prevention (13.3%). The most common study designs were case studies/case series (26.6%), followed by cross-sectional surveys (17.6%),

Competing interests: The authors have declared that no competing interests exist.

retrospective record reviews (17.3%), and cohort studies (17.2%). Studies were mainly derived from single hospitals (60.4%), with only 9% being population-based studies. Most data were obtained from retrospective review of clinical records (56.1%) or via caregiver interviews (34.9%). Few papers included stillbirths (7.5%), prenatally diagnosed CAs (3.5%) or terminations of pregnancy for CA (2.4%).This first-of-a-kind-scoping review on CA in SSA demonstrated an increasing level of awareness and recognition among researchers in SSA of the contribution of CAs to under-5 mortality and morbidity in the region. The review also highlighted the need to address diagnosis, prevention, surveillance and care to meet Sustainable Development Goals 3.2 and 3.8. The SSA sub-region faces unique challenges, including fragmentation of efforts that we hope to surmount through sSCAN via a multidisciplinary and multi-stakeholder approach.

Introduction

Twenty-four percent of the world's under-5 population live in sub-Saharan Africa (SSA) [1], yet this region accounts for 50% of all deaths in this age group [2]. Projections suggest that the United Nations'(UN) Sustainable Development Goals (SDG) aiming to reduce the under-5 mortality rate to less than 25 per 1000 live births by 2030 (SDG-3) may not be achieved by 51 countries, two thirds of which are in SSA [3,4]. Congenital anomalies (CAs) are a major contributor to the high child morbidity and mortality in SSA. They are defined as structural anomalies that occur during intra-uterine life and can be identified prenatally, at birth, during infancy and in some cases, adulthood [5]. CAs are a sub-set of the broader birth defects collective, which also includes functional disorders [6].

Of the estimated 8.5 million new cases of CAs that occurred globally in 2019, 30% were in SSA [7]. Ranked as the 5th leading cause of death worldwide for children under-5 [4], CAs were responsible for an estimated 473,400 under-5 deaths in 2019 and represent approximately 9.4% of all under-5 deaths globally [7]. As progress continues to be made in addressing causes of infectious disease mortality in SSA, CAs will contribute greater proportion of child mortality. It is estimated that 90% of all severe CAs occur in low- and middle-income countries (LMIC) [5] and 38% of global deaths under-5 years due to CA are in SSA [7].

Despite the high burden of infant and under-5 mortality and morbidity related to CAs, these conditions appear to be a low priority on maternal and infant healthcare agendas in many SSA countries. From 2000 to 2015, the under-5 mortality rate due to CAs decreased by only 1% in SSA compared with 36% in North America and Europe [8]. There is no coordinated approach within the 49 countries of the sub-region to comprehensively address CAs and SSA remains the only region in the world without a CA surveillance network [9]. To address these gaps, SSA country representatives have established the sub-Saharan African Network for Congenital Anomaly Surveillance, Prevention and Care (sSCAN) [10]. To provide context for the activities of the Network, we conducted a scoping review to assess the current scope and depth of CA research within SSA.

Scoping reviews are a robust methodology to "systematically map the literature available on a topic" and to identify key concepts, theories and gaps in an area of research [11]. Such reviews explore the breadth and extent of available literature. They are often used to inform future research (as in this case) or as precursors to systematic reviews which are applied to more specific research questions [12–15].

The aim of this review is to determine the scope, objectives, and methodology of recent published research on CA in SSA, to categorize the focus of outputs (i.e., burden, surveillance, prevention, care) and identify potential stakeholders and researchers who may fall within sSCAN's remit.

Materials and methods

The approach used for this scoping review was based on the Arksey and O'Malley methodology [12] with modifications from the Joanna Briggs Institute [16] guided by the PRISMA-ScR via the Cochrane network [17].

Eligibility criteria

Original articles in English or French reporting on CAs in SSA as primary or secondary outcomes/objectives, focused on pregnancy (antenatal) care or involving infants or children <16 years, were included. An initial review to inform the study timeframe indicated that most articles were published in the last five years (Fig 1). Since sSCAN aims to consolidate current and future CA activities in SSA, the study period was limited to January 2016—June 2021. Systematic reviews were included to facilitate discussion. General literature reviews, editorials and letters lacking original data were excluded.

Information sources and selection of papers

A detailed search was conducted in the Medline database, divided into four major sub-sections relevant to CA: 1) Burden, 2) Surveillance, 3) Prevention and 3) Care. The search included both MeSH and text terms. The following Boolean string searches were used for each major sub-heading:

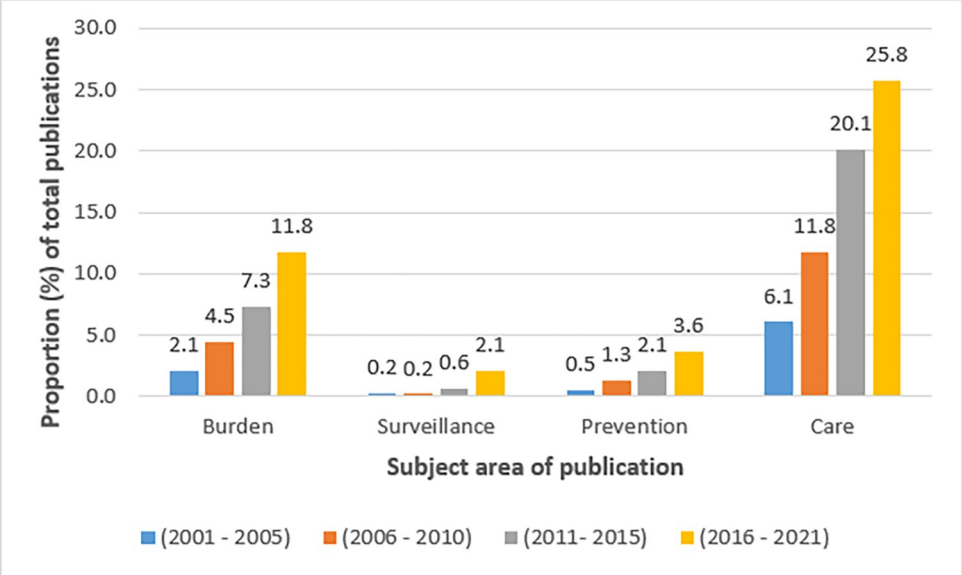

Fig 1. Trends in publication of papers related to CAs in SSA from 2001–2021, by subject area (subject areas were not mutually exclusive).

https://doi.org/10.1371/journal.pgph.0001850.g001

1. **Burden** (Burden *OR* prevalence *OR* infant/child mortality *OR* years of life lost/YLL *OR* disability adjusted life years/DALY *OR* cost of care *OR* economics *OR* survival outcome *OR* Survival) ***AND*** (congenital anomalies *OR* congenital abnormalities *OR* birth defect)
2. **Surveillance** (Population Surveillance *OR* Public Health Surveillance *OR* Surveillance *OR* Epidemiological Monitoring) ***AND*** (congenital abnormalities *OR* congenital abnormalities *OR* birth defect)
3. **Prevention** (Prevention *OR* folic acid supplementation *OR* vaccination *OR* infection *OR* nutrition, *OR* diabetes *OR* alcohol *OR* medication *OR* drugs *OR* smoking *OR* risk factors) ***AND*** (congenital anomalies *OR* congenital abnormalities *OR* birth defect *OR* Neural tube defect/NTD *OR* Congenital Rubella Syndrome)
4. **Care** (care *OR* surgery *OR* stigma *OR* neglect *OR* culture *OR* beliefs *OR* Barriers to care *OR* Rehabilitation *OR* prenatal diagnosis) ***AND*** (congenital anomalies *OR* congenital abnormalities *OR* birth defect *OR* NTD *OR* hydrocephalus *OR* cleft lip/palate *OR* CHD)

Search results from each subsection were merged and imported in Reworks where duplicates were removed. It is important to note that our search terms were in English only, although all French papers that were retrieved were evaluated.

Articles were assigned to ten pairs of sSCAN co-authors (~53 articles/pair), who evaluated eligibility using title and abstract (primary screening). Full text was obtained for eligible articles only.

Data abstraction

The co-author pairs undertook secondary screening of full-text articles and abstracted key data elements into a standardized Data Collection Form developed using Microsoft Excel and piloted and finalized by all authors (S1 Data). The co-authors categorised papers according to burden, surveillance, prevention, or care (not mutually exclusive), with sub-categories within these areas, and further classified papers by methodology. Disagreements within/between author pairs were resolved via discussion. To optimize inter-rater reliability, six articles in each pair were reviewed by all authors. See S2 Data for extracted data from papers reviewed.

The author team defined disease surveillance as "a continuous and systematic process of collecting, analyzing and interpreting health-related data in order to monitor disease progression and establish patterns in a defined population". Papers originating from an ongoing surveillance programme were classified under surveillance, where two types were distinguished: (1) Independent surveillance programmes focusing exclusively on CAs, and (2) Public health surveillance programmes which involve routine data collected by the Ministry of Health from all care facilities and included CA amongst other conditions. Studies classified as independent or public health surveillance were expected to have originated from established, ongoing initiatives.

Data analysis

Abstracted data were merged and cleaned in Microsoft Excel. Using STATA Statistical Software (Release 15. College Station, TX: StataCorp), categorical variables were described using frequency counts and proportions. Two authors conducted a thematic analysis in Microsoft Excel for descriptive, thematic presentation of the papers. Additional qualitative analysis of full-text articles was undertaken using Atlas ti Windows (Version 9) to code themes and determine the frequency of specific emerging key topics.

Results

Selection of articles

The initial search identified 532 articles published between January 2016 and June 2021. Of these, 255 [18–272] studies were included in the final review after several rounds of screening (Fig 2).

Trend of publications

The number of publications remained relatively constant between 2016 and 2020 (Fig 3), with a drop in 2021 (2 per month rather than 4 per month on average), considering the study period ending in June 2021.

Distribution of publications by country

Final papers included originated from 26 of the 49 countries in SSA, with more papers from Eastern (38.6%) and Western (29.3%) Africa compared to Southern (17%) and Central

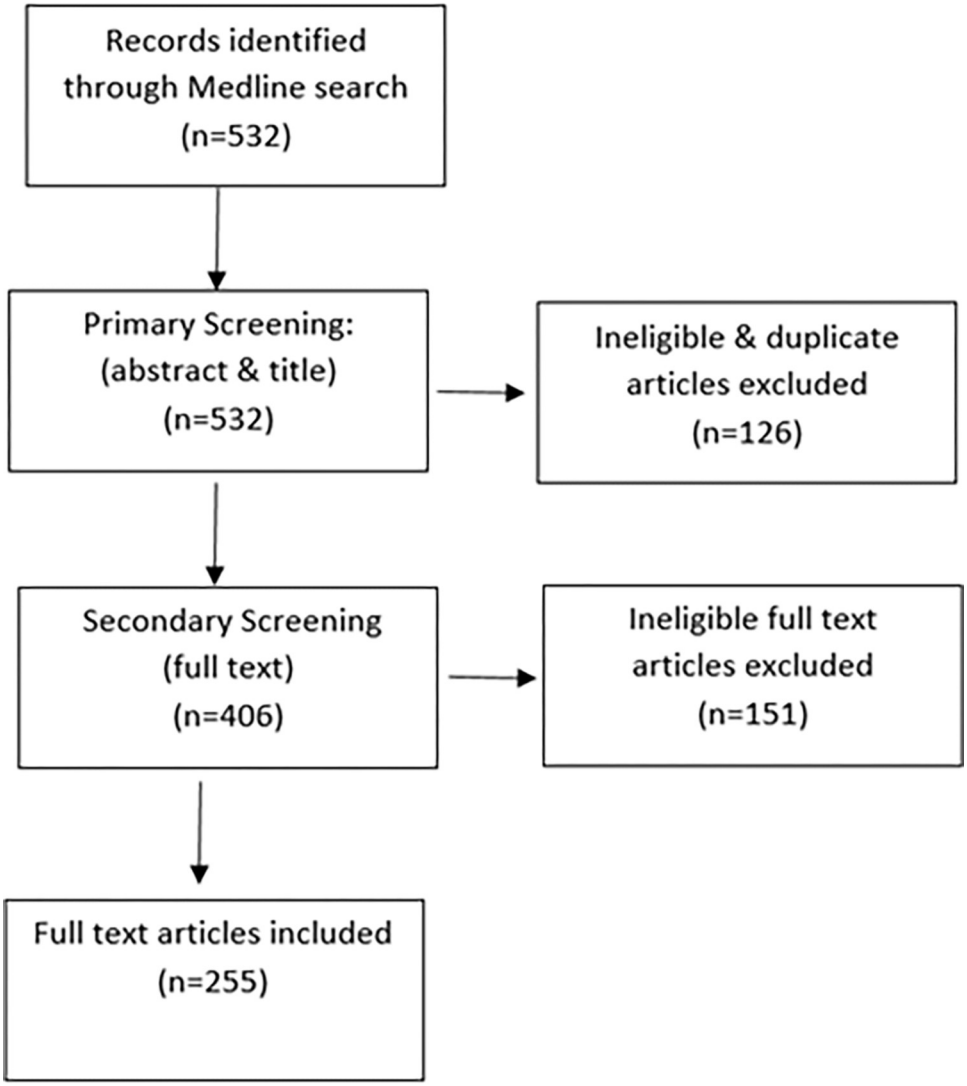

Fig 2. PRISMA study selection flow chart outlining screening process.

https://doi.org/10.1371/journal.pgph.0001850.g002

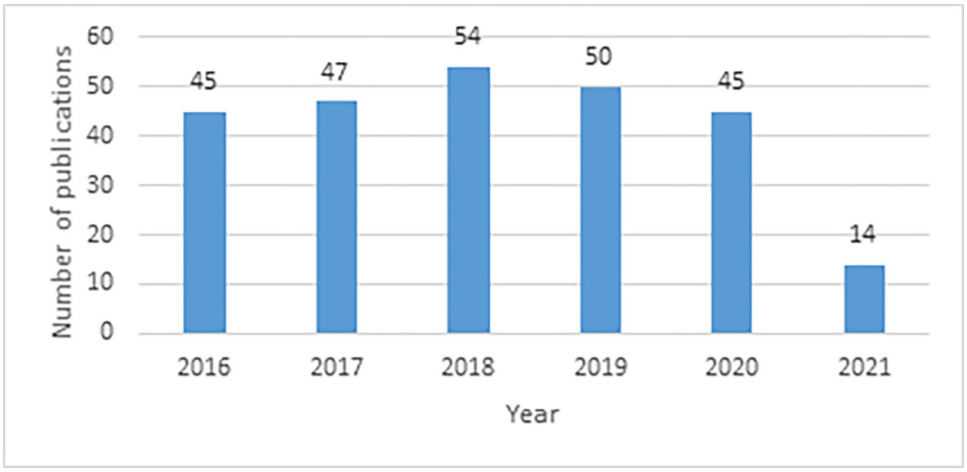

Fig 3. Number of publications per year (2016 –June 2021).

https://doi.org/10.1371/journal.pgph.0001850.g003

(10.4%) Africa (Fig 4; S1 Table). Papers from Nigeria (22.0%), Ethiopia (14.1%), Uganda (11.7%) and South Africa (11.7%) accounted for almost 60% of the total. Several papers were global reviews including some SSA countries (4, 1.6%) or studies involving multiple countries within SSA (14, 5.5%).

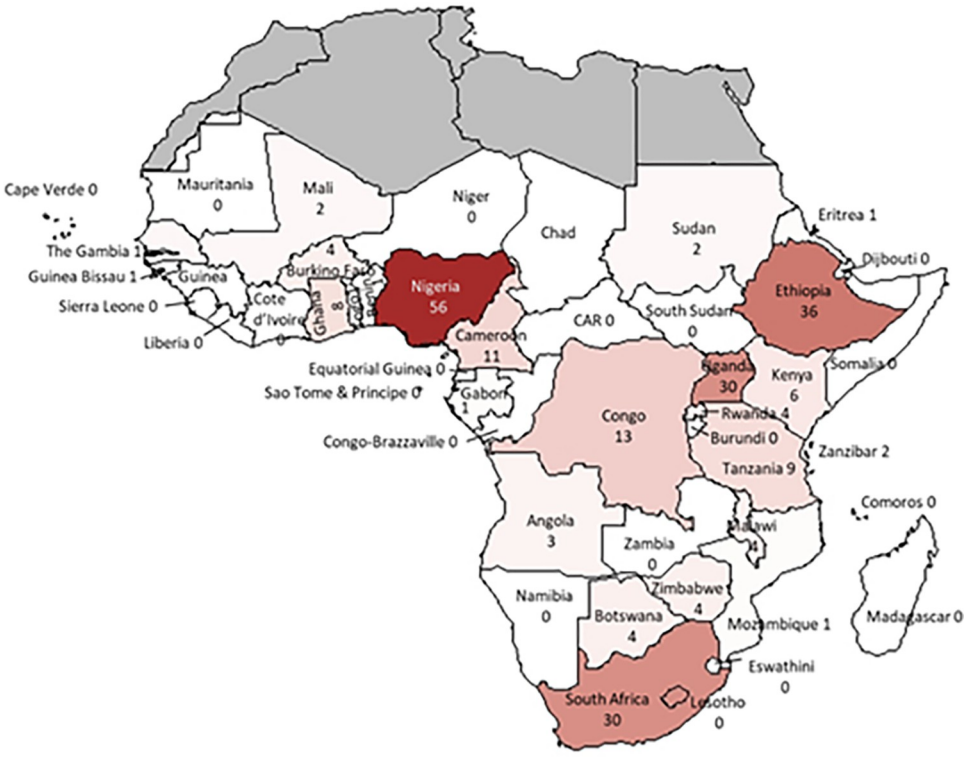

Fig 4. Number of articles reviewed by country (darker colour indicating higher number of articles). Source: Created using the R software (coordinates obtained using map_data and plotted using ggplot).

https://doi.org/10.1371/journal.pgph.0001850.g004

Types of CAs

Most of the papers reviewed had CA as their primary focus (85%) and investigated a single CA type (88%). Central Nervous System (CNS) (19%), cardiac (17%), craniofacial (15%) and gastro-intestinal (12%) anomalies were the four most investigated CAs (Fig 5). S2 Table shows breakdown of specific CA types investigated.

Focus areas and objectives

Fig 6 shows the distribution of articles across the four major subject areas (burden, surveillance, prevention, and care), with a further breakdown into sub-areas. Single case studies were excluded from the thematic analysis.

a. Burden

A total of 145 (56.9%) papers addressed issues related to burden, making it the most published topic.

i. Prevalence

Studies of prevalence (n = 83) provided data regarding the prevalence at birth or during childhood (e.g., among school children) of specific CAs (n = 60) or a range of CAs (n = 23). Most were hospital-based studies, either from a single (n = 37) or multiple (n = 27) hospitals. A few were population-based studies (e.g., [60,61,94]), and surveys of school children (e.g., [33,63,184]). Reporting on prevalence was often a secondary objective of single hospital studies addressing surgery and care, or of cohort or case-control studies of risk factors and prevention. Prevalence data were accompanied by additional descriptive epidemiology, such as sex ratio, maternal age distribution or other sociodemographic variables, and the clinical characteristics of cases.

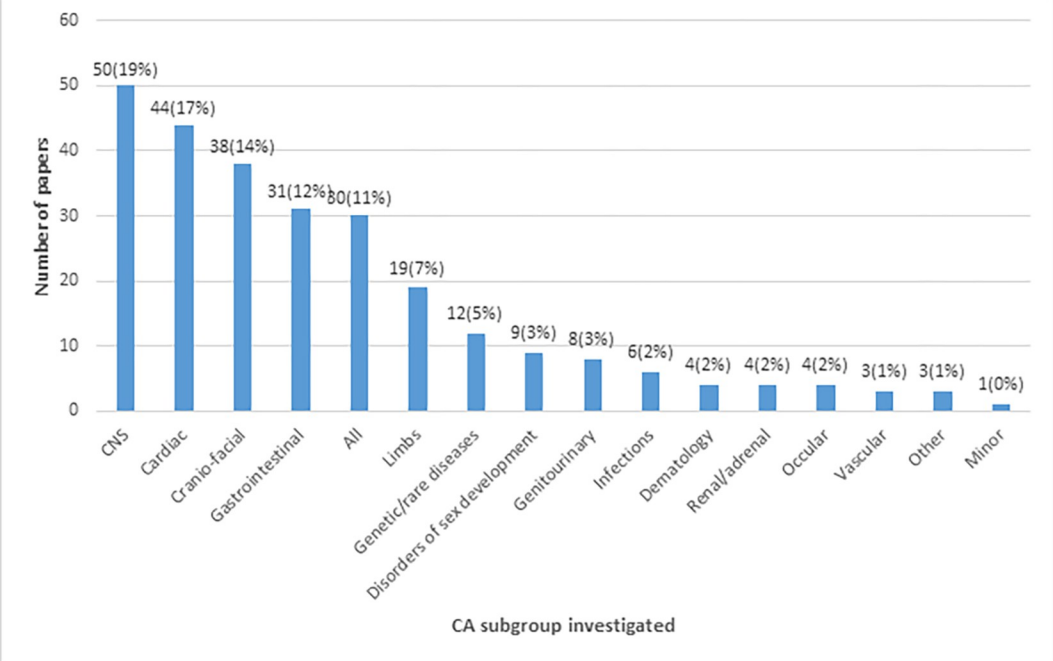

Fig 5. Number of publications per type of congenital anomaly.

https://doi.org/10.1371/journal.pgph.0001850.g005

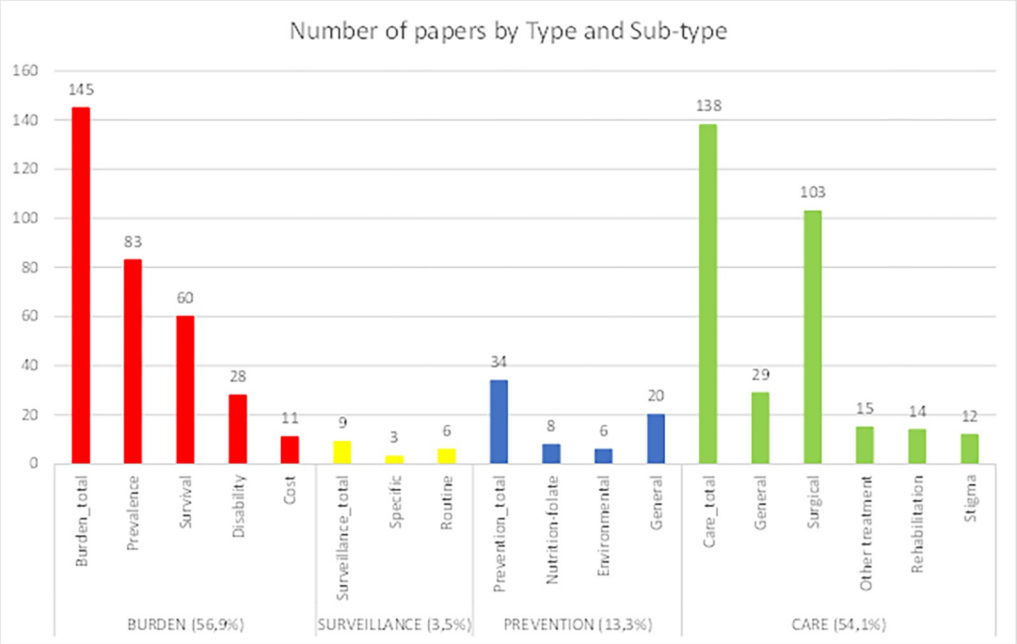

Fig 6. Distribution of papers across the four key categories.

https://doi.org/10.1371/journal.pgph.0001850.g006

ii. Survival

Survival papers mainly looked at survival of babies with CA admitted for surgical care (e.g., [19,28,54,66,76,89]). The period of survival was mainly during the first year of life, or in the days/months following surgery, with no long-term survival studies. In some studies, mortality of babies with CAs was included as part of an investigation into all causes of neonatal death (e.g., [29,150,264]). In others, mortality was reported as an outcome following implementation of a new care protocol (e.g., [54]); or as rates of termination of pregnancy for fetal anomaly following prenatal diagnosis (e.g., [84,87]). Most studies (88.3%) investigated survival for a single CA, of which neural tube defects (NTD; hydrocephalus/spina bifida (25.0%) and congenital heart disease (CHD; 18.3%) were the most common, followed by gastrointestinal anomalies such as atresias (15%) and gastroschisis (5%).

iii. Disability

Papers focusing on disability generally investigated how living with untreated CA affected physical/functional capacity (e.g., [63,103,109,134]), with some reporting on associated comorbidities (e.g., [64,75]). One paper [134] evaluated self-reported quality of life of children living with spina bifida compared to unaffected children. A few papers investigated the impact on the quality of life for mothers (e.g., [30,195,256]) and caregivers of affected children (e.g., [25,31]). One paper [214] derived disability weights, used to calculate Years Lived with Disability (YLD). Orofacial clefts (OFC) (21.4%) were the most CA investigated in relation to disability, with clubfoot (7.1%) and intestinal atresia (7.1%) also noted.

iv. Cost of Care

For the 11 papers identified for this category, the focus was upon cost of care in relation to financial challenges influencing access to care and poor outcomes (e.g., [25,31,89,236]), alongside social challenges [31,175]. Papers on cost of care primarily focused on CHD (45.5%) and

OFC (27.3%), relating to the financial burden of individuals accessing care (and the impact on care seeking) rather than the cost to the health system. A further 105 papers mentioned the financial burden of CA facing families but did not collect or analyse data on this issue.

b. Surveillance

Papers that reported on long-term ongoing collection and analysis of CA data were categorized as surveillance. These reported on prevalence (included also in Burden), or on risk factors (also included in Prevention). Surveillance data originated from the routine collection of data by the public health system across many diseases (n = 6 [60,77,78,94,129,249]), or from specific independent initiatives (n = 3 [86,99,100]). Eight of the nine surveillance papers addressed a single type of CA (spina bifida (n = 4), congenital rubella syndrome (n = 3) and microcephaly (n = 1). A further 38 (15%), mentioned surveillance, mainly in relation to the need for more comprehensive surveillance of CA.

a. **c. Prevention**

Thirty-four (13.3%) papers addressed issues related to prevention, either known risk factors such as folic acid, or other potential causes of CA.

i. Folic Acid

Eight (23.5%) of the 34 papers on prevention focused on folic acid, most commonly reporting on the use of folic acid by mothers in the context of NTD and~~/or~~ hydrocephalus (e.g., [22,105,123,124,132,164]). Four papers focused on barriers to [34], awareness of the benefit of [49], and estimation of potential reduction in the rate of NTD and hydrocephalus due to folic acid use [94]; and modelling of potential prevention of under-5 mortality [94]. A further 47 (18.4%) papers mentioned folic acid but did not collect specific data.

ii. Maternal infections including Rubella

Six papers focused solely on rubella or rubella vaccination [60,129,145,176,232,249], addressing rubella infection prevalence among women, immunity in adolescents, screening, and the baseline prevalence of congenital rubella syndrome prior to the introduction of immunization (60). A further 17 papers mentioned rubella or rubella vaccination but did not collect specific data [26,34,55,64,70,73,78,83,88,123,153,164,165,192,238,242,244]. One paper investigated the emergence and circulation of Zika virus in SSA [78].

iii. Environmental Exposures

The two main categories of risk factors investigated were medication safety in pregnancy (n = 8, [70,96,99,100,123,159,164,207]), and environmental pollution (n = 6). Most medication safety studies evaluated a series of medications (including herbal) as part of a general CA risk factor assessment [70,96,123,164], while a few evaluated the safety of a single medication type/class (antiretrovirals [99,100] and antimalarials 207) or general medication use in pregnancy [159]. There were no papers on common medicines used for non-infectious diseases, or on the impact of vaccination during pregnancy. Herbal remedies and traditional medicine featured prominently in 34 papers, including those which did not collect data.

Papers on environmental pollution focused particularly on exposure to extraction metals such as copper, cobalt, mercury and arsenic [67,70,71,95]. A further 16 papers mentioned environmental pollution, but did not collect specific data [26,34,44,50,67,70,71,88,95,96,105,132,160,164,183,216,222,227,232,237].

A cluster of 13 papers specified radiation exposure during pregnancy as a concern [19,33,34,62,70,76,105,107,132,148,188,202,203].

d. Care

Care was the second most common area investigated after burden, and the focus of 138 (54.1%) papers, mainly aimed at describing and improving treatment and care outcomes.

i. Surgical care

There were 103 papers related to surgical care, of which 36% focused on surgery outcomes. The main surgical areas were cardiac (23.4%), CNS (for NTD and hydrocephalus; 20.8%), gastrointestinal (predominantly anorectal malformations; 18.8%), OFC (14.9%) and orthopedics (predominately congenital talipes; 11%). Papers focused on different issues, including challenges faced by patients in accessing surgical care e.g. [25,35,37] (including due to COVID-19, [57]); and performing surgery for complex anomalies [37,38]; the quality of peri- and/or post-operative surgical care (e.g., [32,33]); outcome/survival after surgery (e.g., [19,89,120]); and developing cost-effective, local surgical management tools (e.g. management silos for gastroschisis [58]). Notably, late or missed CA diagnosis either due to late presentation, lack of access to care, or shortage of diagnostic expertise was addressed in several papers (e.g., [28,81,91,110,114]). For example, one paper investigating access to care by caregivers of children with congenital heart defect (CHD) concluded, "Delayed access to care was largely due to the lack of early CHD recognition and financial hardships related to the inefficient and disorganized health care system" [25]. Papers also reported case series, including patient characteristics, and clinical characteristics and complications, to aid service planning and improvement.

ii. Rehabilitative care

Papers on rehabilitation constituted 5.5% of all papers reviewed and addressed issues such as evaluation of training of rehabilitation care professionals and the quality of care provided (e.g., [20,46]), effectiveness of specific rehabilitation techniques (e.g. [91,109]), characteristics of children with untreated CA presenting for rehabilitative care (75), and opinion of caregivers regarding cosmetic care (e.g. plastic surgery) (e.g. [102]). OFC (42.9%) and clubfoot (35.7%) were the most common anomalies investigated in relation to rehabilitative care. Speech therapy and plastic surgery were common topics included for children with OFC.

iii. Stigma and related cultural issues affecting care

Papers on stigma and related cultural issues (n = 12) were often based on surveys administered to care givers (mostly mothers) of children with CAs and addressed issues such as the influence of stigma on the quality of care (e.g., [30,34]), social/cultural barriers to uptake of preventive measures [31], prenatal screening [116] and treatment [31], genital reconstruction in disorders of sex development [120,128], plastic surgery [102], community rejection and abandonment by spouse [31,175], as well as health system responsiveness [175]. Some papers documented family and community beliefs about the causes of CA, e.g., witchcraft, contraception, and the guilt of the mother [31,116,241]. Beliefs and perceptions about the efficacy of medical care, preference for traditional medicine [241], and parental/community believes on whether treatment should be sought [31,241] were also included.

iv. Other themes relating to Care

Eight of the care papers [20,46,57,72,114,154,180,258] were system-focused rather than addressing specific care, and these included training, professional development and service delivery, and multidisciplinary teams. These described how training and service organization initiatives have improved care.

Seven papers reported on the experiences of healthcare of parents and caregivers, and their healthcare-seeking behaviours [25,31,44,102,166,179,241]. These studies interviewed parents and caregivers to find out about their navigation of the healthcare system, documenting difficulties in obtaining a diagnosis, and accessing specialist care.

Fourteen papers reported on dysmorphology or genetics [42,56,59,103,120,128,133,170,210,212,224,246,271]. These studies undertook detailed examinations of babies with CA to understand the range of dysmorphologies, and the associations between different anomalies. One paper focused on ethnic differences in minor anomalies [42]. Several papers reported the genetic distribution of disorders of sex development [59,120,128,224].

Seven papers investigated the results of prenatal diagnostic services [65,84,87,116,161,188]. These addressed the problem of limited information about prenatal screening of CA via ultrasound, including how often it is conducted, role of counseling, rate of parents' acceptance of the screening and termination when a diagnosis is made, as well as its overall value supporting early diagnosis and care.

Methodologies

Six aspects of study methodology were examined: study type, population coverage, data source, type of birth, age at CA diagnosis, and expert confirmation of CA diagnosis (Table 1).

Case studies/case series (26.6%) were the most common study type with a considerable number of cross-sectional surveys (17.6%), retrospective record reviews (17.3%), and cohort studies (17.2%). For population coverage, most studies (60.4%) were conducted in a single hospital, with few population-based studies (9%). Data were mainly sourced from retrospective review of clinical records (56.1%) or via interviews with caregivers (34.9%). Very few papers included stillbirths (7.5%), TOPFA (2.4%) or prenatally diagnosed CAs (3.5%). For most papers (58.8%) the CA diagnosis was confirmed by an expert.

Discussion

Trends in CA-related publications in SSA

This scoping review revealed an increase in CA-related publications in SSA within the last decade. This may reflect increased awareness among researchers and stakeholders during this period, stemming from CA-related events such as: 2010 World Health Assembly (WHA) Birth Defects Resolution 63.17 that called for the strengthening of birth defect surveillance systems globally and nationally [273]; and the series of birth defect surveillance training sessions in SSA organized by the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) in 2014 and 2015 [274]. This publication trend mirrors the proportional increase of CA as a cause of childhood mortality and morbidity as infectious causes decline. For example, from 2000 to 2017, the number of under-5 deaths in Africa due to CAs increased by 31,000 (19%), in contrast to HIV/AIDS and measles for which under-5 deaths decreased by 144,000 (-68%) and 277,000 (86%), respectively [8].

Most studies addressing CAs included in the review were undertaken in a handful of countries, with 66% of countries in the region publishing no research on these conditions. This highlights the extent to which CA-related research is neglected in SSA despite the high disease burden. Most studies were confined to specific countries/institutions with minimal cross-border collaboration to support and strengthen surveillance and care. Disseminating research on CAs and their relative contribution to childhood mortality and morbidity is vital to provide an evidence base for investment in initiatives aimed at primary, secondary and tertiary prevention. This review highlights the importance of initiatives such as sSCAN in building awareness

Table 1. Proportion of studies across different methodologies.

Method element	n (%)
Type of study	
Case study/case series [a]	67 (26.6)
Cross-sectional survey	45 (17.6)
Retrospective record review	44 (17.3)
Cohort study	44 (17.2)
Case-control study	16 (6.3)
Descriptive Epidemiology	11 (4.3)
Diagnostic study	8 (3.1)
Systematic review	7 (2.7)
Qualitative study	6 (2.3)
Economic/costing	2 (0.8)
Modelling	2 (0.8)
Intervention	2 (0.8)
Other[b]	1 (0.4)
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	90 (35.3)
Published literature[c]	9 (3.5)
Surveillance data	5 (2.0)
Laboratory-based (biological samples)	3 (1.2)
Smile Train database	2 (0.8)
Recommendations	1 (0.4)
Other[b]	1 (0.4)
Type of birth	
Live birth	195 (76.5)
Still birth	19 (7.5)
Termination of Pregnancy	6 (2.4)
Not given	50 (19.6)
Age of diagnosis	
Any	45 (17.6)
At birth	51 (20.0)
Child	68 (26.7)
Prenatal	9 (3.5)
Not given	70 (27.5)
Expert confirmation of diagnosis	
Yes	150 (58.8)
No	12 (4.7)
Not given	79(31.0)

[a] Includes 25 single case studies.

[b] *Development of a low-cost material for the treatment of gastroschisis.*

[c] *Systematic review.*

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around the burden of CAs in the region, creating a network of support and collaboration for researchers and clinicians, and advocating for better access to care.

Delay in diagnosis and the impact on care outcomes

As expected, the majority of CAs featured in this review are visually obvious, external conditions, including NTD and other CNS conditions, cranio-facial and gastrointestinal anomalies. While CHD also featured, the burden of these internal and other less obvious anomalies and functional congenital disorders (single gene disorders and rare diseases) requiring additional diagnostic tools continue to be under-diagnosed and under-reported due to misdiagnosis and premature mortality incorrectly reported. This prevents an accurate assessment of the contribution of these conditions to the disease burden. Literature is lacking on survivorship and the proportion of those receiving an accurate diagnosis and relevant treatment and developing this baseline essential.

Lack of screening is a major contributor to the high rate of missed and delayed CA diagnosis in SSA. While conducting a surface examination of all newborns is standard practice, it requires appropriate skills and capacity. In an attempt to address this, the WHO/CDC/ICBDSR has recently launched a birth defect surveillance toolkit with checklists to improve efficiency and data quality [275]. Recent reports indicating many SSA countries are gradually implementing pulse oximetry for postnatal screening of CHD [276] is encouraging, although poor performance concerns related to use of this technology in darker-skin babies are emerging [277,278]. High resolution, prenatal ultrasound screening for CAs remains limited in LMIC due to the expensive equipment and skilled personnel required. Recent advances in technology offer low-cost, compact mobile ultrasound devices, dramatically increasing the availability of ultrasound services in LMICs [279,280]. The expertise required to perform a fetal anomaly ultrasound scan still presents a major barrier. Emerging artificial intelligence solutions, automatically detecting CAs and capturing accurate images may allow less-skilled personnel to perform the procedure in the future [281].

Training, service development and surgical care

Given the rising burden of CAs and lack of expertise in SSA, there is an urgent need to increase clinical capacity to treat correctable CAs. While the number of paediatric surgeons in SSA is increasing, numbers of other important personnel such as specialist paediatric surgical nurses, intensive care personnel, paediatric anaesthesiologists, clinical geneticists, radiologists, and neonatologists remain low.

Historically, surgical camps or global outreach teams have filled this gap, but these are less sustainable than upskilling local providers, and often reach only a few of those requiring care [282,283]. While some initiatives transfer skills and develop local expertise, many make little local impact. To succeed, such initiatives must be locally driven by individual champions in SSA with continued capacity-building of local teams following the intervention. Some collaborative efforts with HIC-based organizations have seen significant success in the treatment CAs in SSA. These are often single disease programmes, such as Smile Train (www.smiletrain.org)) which focuses exclusively on OFC.

Awareness and access to care

Poor health literacy and education across SSA is a significant barrier to navigating the health system, especially for those impacted by CA. This is compounded by the lack of well-coordinated care for babies diagnosed with CA. Knowing how, where and when to access appropriate care, especially in rural areas with vast geographical distances may be overwhelming. Specialist

treatment centers are mainly located in urban centres, significant distances away from birthing centres. Long-distance travel on poor roads with inadequate public transport infrastructure pose a risk to vulnerable infants, in addition to the cost implications for the family. Most families in SSA live below the poverty line and cannot cover out-of-pocket healthcare costs, combined with additional living costs, childcare for siblings and lost earnings. Seeking care for the child affected by a CA may require overcoming insurmountable barriers.

State-funded insurance schemes and government subsidies could dramatically improve the care of affected children combined with telemedicine to facilitate remote care, limiting costs and travel. The most pressing need is for CAs to be integrated into mainstream primary health care systems in SSA, with a well-coordinated system to promote prevention, screening, diagnostics and care. This could be championed by initiatives such as sSCAN in collaboration with governments, local organizations, patient advocacy and support groups and other external stakeholders.

Surveillance and prevalence data

Studies assessing prevalence in this review reflected the challenges faced in establishing the baseline birth prevalence of CAs in the sub-region. Most studies involved hospital-based data, predominantly in a single hospital, with only three studies [60,61,94] assessing population-based prevalence. High rates of home-based deliveries, limited diagnostic capacity and clinical expertise are only a few of the barriers researchers face in determining the true burden of CAs in SSA. The few existing surveillance projects have been driven by the need to assess medicine safety during pregnancy such as antiretrovirals and antimalarials. Surveillance systems in Botswana, South Africa, Malawi, and Uganda have focused on assessing the safety of antiretrovirals in pregnancy and birth outcomes, including CAs. As the pipeline of novel medicines, vaccines and other health technologies expands, such projects are likely to increase in the region, providing an opportunity to build capacity around CA surveillance and generate much needed empiric data on CAs [284].

Prevention

Primary prevention (i.e. preventing CA-affected pregnancies) is the ideal approach to reducing the CA burden of disease [285]. This requires optimized prenatal and perinatal nutrition (e.g., folate fortification to decrease NTD risk), reduced exposure to known teratogens (e.g. infections, alcohol, prescribed and recreational drugs), and research to establish the teratogenicity of environmental exposures where evidence is lacking or limited. A broad, integrated primary prevention strategy for CAs in SSA should be envisaged. This review revealed limited research activity in this area.

In addition to reducing risk factors (e.g. maternal diabetes, infections, toxic exposures) improving maternal folate status by food fortification is a highly effective primary prevention strategy. This has been proven to prevent a substantial fraction of severe NTDs, especially spina bifida and anencephaly, as well as addressing anaemia [286]. Six of the 18 countries identified for their potential to maximize reduction in anemia and NTD through large-scale fortification are in SSA. Encouragingly, this scoping review has identified several publications addressing aspects of folic acid-related prevention. However, much more can be done to help translate the promise of folic acid into meaningful reduction in NTDs.

Secondary prevention strategies reduce the number of CA affected births (including prenatal diagnosis, genetic counselling and option of TOPFA while tertiary prevention strategies involve the early diagnosis of CA (even prenatal) with prompt treatments to prevent complications and mitigate disability [287].

Risk factors

The limited scientific evidence-base related to CA associated with medication use in early pregnancy is a global issue, but in SSA there are additional concerns relating to the widespread use of essential medicines for the prevention and treatment of infectious diseases such as malaria and HIV [288,289], and the high prevalence of herbal medication use [290]. Inadequate research on medication safety in pregnancy may delay access by pregnant women to treatments with an optimal benefit-risk profile for both mother and baby. There is also a need to monitor and respond to the use of medicines with a known teratogenic profile.

Maternal infections are a well-established cause of CAs. However, other than rubella, the only other infectious disease related to CAs included in this review was the Zika virus. First recorded in Uganda, Zika has received global attention following an epidemic in Latin America starting in 2015, causing severe microcephaly [291]. The extent of microcephaly risk relating to Zika in Africa, where both the specific virus and mosquito differ from those in Latin America, is unknown due to the lack of functioning surveillance systems in the sub-region. Other diseases requiring more attention include congenital syphilis [292], toxoplasmosis [293,294], and cytomegalovirus [295,296], due to their higher prevalence in SSA. Compounding effects of multiple infections (co-morbidities) affecting the fetus, and interaction with malnutrition and other exposures also require consideration.

Environmental air, water and soil pollution is an ongoing concern with particularly high levels reported in African countries of heavy metals and pesticides [297]. Five studies in this review researched environmental pollutants in relation to CA risk, three of which were undertaken due to widespread contamination from mining operations [67,71,95].

No studies on dietary factors (other than folic acid) were included in this review, but several, very specific practices such as "chewing of khat" [70] were identified. While Fetal alcohol spectrum disorder (FASD) is a significant public health problem in many communities, including in SSA [298], this review did not include search criteria to identify studies addressing alcohol or smoking during pregnancy. Due to the difficulty in diagnosing FASD at birth, such a review would not be comprehensive. With the increasing prevalence of obesity and diabetes in African countries [299], periconceptional management of diabetes to prevent CHD and other CA is becoming more important. No papers in the review addressed this issue.

Although this review did not investigate the relationship between socioeconomic status and CAs, it was noted that extreme poverty is particularly prevalent in rural areas of SSA, where it is most difficult to obtain reliable data on CAs caused by a combination of nutritional deficiencies, infections, and environmental exposures. It can therefore be concluded that poverty both causes CA and is associated with poor access to treatment and poor outcomes.

Influence of culture

Few papers in this review addressed issues related to stigma and culture. SSA is one the most culturally diverse region of the world [300], with deeply rooted cultural and social underpinnings that influence health-seeking behavior. Across the region, the process of pregnancy and birth is regarded as "secret" and associated with varied cultural and spiritual dimensions. Notably, the birth of a baby with CA often carries stigma and varied cultural/social interpretations as to the cause and approaches to treatment. Strategies to address CA in SSA must therefore include robust attempts to fully understand associated cultural and social challenges and to develop mitigation frameworks that include holistic approaches involving the entire community. A starting point could be to learn from the challenges and successes of similar stigma addressing related conditions such as HIV/AIDS [301]. Particular attention must also be given to the cultural and social factors that influence the use of traditional medicines during

pregnancy and for the management of CAs. This has become even more urgent with the current WHO plan to incorporate traditional medicine into mainstream healthcare systems in SSA [302].

Health information systems

Comprehensive, formalized and centralized electronic health record (EHR) systems are scarce in SSA, seriously impacting the availability of empiric surveillance data for CAs. This is highlighted by the limited literature reporting on surveillance systems and the dominance of hospital record reviews and interviews as data sources. The lack of EHR systems makes wide-scale linkage of pregnancy exposures and neonatal outcomes extremely challenging. There is a need to build awareness around the importance of accurate, quality data as an evidence-base to better inform resource allocation and clinical decisions, and to motivate for investment in EHR systems in the region.

The high rates of out-of-facility deliveries in some countries, fragmented obstetric services and resource constraints with respect to expertise, funding, and information and communication technology (ICT) challenge the implementation and maintenance of EHRs [303,304]. In the last 20 years there has been remarkable improvement in the ICT infrastructure across SSA, and the proliferation of mobile devices [304]. Recently, the African Union expanded its Digital Transformation Strategy for Africa for a further 10 years. These developments present an exciting opportunity to improve upon EHR data capture. Within such a resource-constrained environment even minimal expansion of system coverage could be implemented for targeted disease areas, as has been the case with HIV/AIDS [305]. Uptake of innovative tools such as the new Global Birth Defects app specifically designed to facilitate diagnosis of CAs for surveillance programs operating in low resource settings such as SSA [306], should be maximized.

Strengths and limitations

This is the first scoping review investigating recent literature on CA in SSA. It was conducted to inform the activities of the newly established sSCAN and designed to maximise network involvement evaluating and interpreting the literature. This approach may have led to inconsistencies in the categorization of papers between data abstractor groups. While this was mitigated as far as possible via the use of a standardized data extraction form accompanied by specific instructions and training, misclassification remains a possibility.

The results of the literature search were dependent upon the inclusion of CA and associated MESH terms as key words in the literature. Some papers on risk factors may have been missed if they were not specifically related to CA. For example, whereas maternal infections are risk factors for CA, but papers on maternal infections would only be included in this review if they related this risk factor to CA.

To facilitate reporting, papers were categorized into four main groups identified by author consensus. This categorization may be perceived as being arbitrary. For example, papers on stigma were allocated to a sub-category under Care but may just as easily be considered to relate to the sub-category of disability under burden. Similarly, cost of care was categorized under burden, but many papers related to financial costs to the patient/family and were a major element in papers regarding Care. This was mitigated by describing details on the objectives of papers and concerns of the authors in each category. The categories were also not mutually exclusive, and so papers could be allocated to multiple categories.

The timeframe of this review was limited to a five-year period to represent the "current" situation regarding research activity relating to CA in SSA, and the situation following the 2010 WHA Resolution 63.1. It was not our purpose to review all literature regarding CA in SSA.

Additionally, the focus on obvious CA, a sub-set of congenital disorders, excluded less obvious structural anomalies as well as functional conditions, including most single gene disorders [6].

Conclusion

There is increasing awareness and recognition among researchers in SSA of the growing contribution of CAs to under-5 mortality and morbidity in SSA together with the need to address diagnosis, prevention, surveillance and care of these conditions to meet SDG3.2 and 3.8 2030 targets [3]. SSA has specific challenges in relation to CAs and needs to formulate an approach to address these. The newly formed sSCAN can champion this course through a comprehensive, multidisciplinary and multi-stakeholder approach that involves national governments, local institutions, patient organizations, and relevant international organizations such as WHO, to ensure that opportunities for primary prevention are fully implemented and those impacted by CA receive optimal care and are not left behind.

Supporting information

S1 Table. Regional distribution of studies across sub-Saharan Africa.
(DOCX)

S2 Table. Congenital Disorders (not mutually exclusive).
(DOCX)

S1 Data. Data extraction template.
(XLSM)

S2 Data. Data extracted from papers reviewed.
(XLSX)

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