Federal Ministry of Health and Social Welfare

NATIONAL BIRTH DEFECT
SURVEILLANCE GUIDELINE 2025

October 2025

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Foreword

Birth defects constitute a major yet often under-recognized cause of neonatal and under-five morbidity and mortality globally. Each year, an estimated eight million (8,000,000) babies are born with serious congenital anomalies, and approximately three hundred thousand (300,000) of these infants die within the first twenty-eight (28) days of life, predominantly in low- and middle-income countries (LMICs) where preventive, diagnostic and rehabilitative services remain inadequate (WHO, 2023).

In sub-Saharan Africa, congenital anomalies are responsible for on estimated nine percent (9%) of all neonatal deaths. Survivors frequently endure lifelong physical, cognitive, and social challenges (WHO, 2016). In Nigeria, available data indicate a rising trend in the burden of birth defects. Findings from the Verbal and Social Autopsy (VASA) Surveys show that the proportion of neonatal deaths attributable to congenital anomalies increased from one percent (1%) in 2014 to three percent (3%) in 2019 (FMoH, 2019). Furthermore, hospital-based studies across the six geopolitical zones have reported prevalence rates ranging between 2.3 and 39.9 per 1,000 live births, underscoring variations in detection capacity, regional risk factors, and reporting practices.

It is in response to this emerging public health challenge that the National Birth Defects Surveillance Guideline (NBDSG) 2025 has been developed. The Guideline provides the first national standardized framework for the systematic collection, validation, and utilization of data on birth defects in Nigeria. It seeks to facilitate early detection, strengthen case management, and inform evidence-based prevention and intervention strategies. The Guideline institutionalizes a hospital-based sentinel surveillance system in twelve (12) tertiary health facilities nationwide to generate reliable, representative, and actionable data for policy formulation, planning, and implementation.

Beyond its technical content, this Guideline represents a reaffirmation of the Federal Government's commitment to equity, inclusion, and social justice in health service delivery aligns with the Nigeria Health Sector Renewal Investment Initiative (HSRII), Every Newborn Action Plan (ENAP), and the overarching pursuit of Universal Health Coverage (UHC). It also contributes directly to the attainment of the Sustainable Development Goals (SDGs), particularly SDG 3, which calls for ending preventable deaths of newborns and children under five years of age.

The successful implementation of this Guideline will enhance Nigeria’s public health surveillance architecture, promote early intervention and timely response, and ensure that children born with birth defects receive the attention and care necessary to survive and thrive. It is therefore imperative that all relevant stakeholders including Federal and State health authorities, professional bodies, academic institutions, and development partners demonstrate sustained commitment to its operationalization.

It is my expectation that this Guideline will serve as a vital national tool for strengthening the country's capacity to detect, manage, and prevent birth defects, thereby contributing to improved neonatal outcomes and advancing the broader goal of national health security.

Muhammad Ali Pate, CON,
Coordinating Honorable Minister of Health and Social Welfare

Acknowledgement

The National Birth Defects Surveillance Guideline (NBDSG) was developed to address the critical need for a robust data repository on children born with birth defects, a major contributor to neonatal and under-five morbidity and mortality. Until now, there has been no routine national data, aside from a few surveys such as VASA, to guide effective interventions.

The Federal Ministry of Health and Social Welfare extends its deepest appreciation to the Paediatrics Association of Nigeria (PAN), the Nigeria Society of Neonatal Medicine (NISONM), members of the National Child Health Technical Working Group, the Birth Defects Surveillance (BDS) Core Teams across the twelve (12) sentinel sites, and the Children with Special Needs Subcommittee for their commitment and clinical guidance, on the development of the NBDSG.

The Department of Family Health acknowledges the invaluable contribution of Prof. Isa Abdulkadir for developing the zero draft, we also acknowledge the great contributions of the twelve (12) sentinel tertiary institutions for piloting BDS and generating evidence-based insights that have informed the development of this guideline.

Special recognition goes to our dedicated development and implementing partners for their unwavering support through effective collaboration, resources and technical support.

Our profound gratitude goes to our professional bodies, academia, and participating institutions continue to champion inclusive policies and services for children with birth defects.

I commend to the Child Health Division under the leadership of Dr. Amina Mohammed, and the dedicated efforts of the Head of Children with Special Needs and her team, for their commitment and hard work in ensuring a quality document.

Finally, I recommend that both states and non-states actors in the child health space, should make use of this document in tracking all birth defects that occur in Nigeria, follow-up responses and document impacts.

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List of Abbreviations

BDS	Birth Defect Surveillance
CDC	United States Centers for Disease Control and Prevention
CHD	Congenital Heart Defect
ETOPFA	Elective Termination of Pregnancy for Fetal Anomaly
FMoHSW	Federal Ministry of Health and Social Welfare
HC	Head Circumference
HLHS	Hypoplastic Left Heart Syndrome
ICBDSR	International Clearinghouse for Birth Defects Surveillance and Research
ICD-11	International Statistical Classification of Diseases and Related Health Problems, Eleventh Revision
LMIC	Low and Middle-Income Country
MCA	Multiple Congenital Anomalies
MRI	Magnetic Resonance Imaging
NBDS	National Birth Defect Surveillance
NBDSG	National Birth Defect Surveillance Guideline
NCBDDD	National Center on Birth Defects and Developmental Disabilities
NTD	Neural Tube Defect
SOP	Standard Operating Procedure
TEV	Talipes Equinovarus
WHO	World Health Organization

Executive Summary

The National Birth Defect Surveillance Guideline (NBDSG) 2025 has been developed by the Federal Ministry of Health and Social Welfare (FMoHSW) as part of Government's strategic response to the rising burden of birth defects in Nigeria. According to the Verbal and Social Autopsy (VASA) surveys, the contribution of birth defects to neonatal mortality increased from 1% in 2014 to 3% in 2019, highlighting the urgent need for a coordinated, systematic, evidence-based national response.

This Guideline provides a national framework for standardized surveillance of birth defects across the country. It establishes an active, hospital-based sentinel surveillance system beginning with twelve (12) tertiary institutions across the six geopolitical zones, with the aim of generating reliable national data to guide policy formulation, planning, prevention, and management strategies.

Key Provisions of the National Birth Defect Surveillance Guideline include:

Surveillance Framework: A structured hospital-based system focusing on selected External and internal birth defects readily identifiable at or shortly after birth, utilizing internationally accepted definitions and diagnostic standards.

Data Management: Adoption of standardized data abstraction forms, electronic reporting, and ICD-11 coding for uniformity, accuracy, and comparability.

Programmatic Approach: Clear processes for case identification, validation, quality assurance, and timely reporting from sentinel hospitals to the centralized, national repository, housed within the FMoHSW for data collation, analysis, and dissemination.

Roles and Responsibilities: Defined mandates for Federal, State, and Local Governments, health institutions, caregivers, professional associations, CSOs, and development partners.

Ethical and Legal Authority: Assurance of confidentiality, data ownership by the FMoHSW, and adherence to ethical standards in data collection and reporting.

Strategic Importance

The Guideline will:

- Enable evidence-based policy and planning for the prevention and management of birth defects.
- Strengthen child health systems and reduce neonatal and under-five mortality in line with Nigeria's Every Newborn Action Plan.
- Enhance early detection, treatment, and linkage to services for affected children and families.
- Promote capacity building, community engagement, and multisectoral collaboration across health and allied sectors.
- Advance Nigeria's commitments to Universal Health Coverage (UHC), the Sustainable Development Goals (SDGs), and the principle of "Leaving No Child Behind."

The National Birth Defect Surveillance Guideline represents a landmark achievement for Nigeria's health system. Through its full implementation, the Federal Ministry of Health and Social Welfare reaffirms its commitment to safeguarding the rights, survival, and development of all Nigerian children, including those born with birth defects.

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Definitions of terms

Abstraction: The act or process of extracting necessary information from hospital logs or medical records for the identification and classification of congenital anomalies in a case. An abstraction form is used for the purpose of data collection.

Abstraction form: A tool or instrument used in data collection.

Anencephaly: A neural tube defect characterized by partial or complete absence of the brain and skull (14).

Ascertaining: In birth defects surveillance, the process of identifying embryos, fetuses, neonates, infants and children who have a congenital anomaly, using existing sources and case definitions.

Association: In birth defects surveillance, a pattern of multiple anomalies that occur with a higher than random frequency, and that is not a sequence or a syndrome.

Autopsy: A postmortem examination to determine the cause of death.

Birth defect: A structural or functional anomaly of organs, systems, or parts of the body that occurs during intrauterine life and is caused by genetic or environmental factors (e.g. exposure to toxic substances, micronutrient deficiencies or maternal diseases), or both.

Birth defect Surveillance: An ongoing, systematic collection, analysis and interpretation of

health data on birth defect essential to the planning, implementation and evaluation of public health practice

Birth outcome: A group of indicators that help measure the health and well-being of a neonate.

Birth weight: The first weight of the fetus or neonate obtained after birth; for live births

Capture: When used in the context of surveillance, indicates that a case has been identified, abstracted and coded.

Case: In epidemiological terms, an individual who meets the criteria for inclusion in a surveillance programme.

Case definition: The criteria used for inclusion of a case in a surveillance programme.

Chromosomal abnormality: The excess or absence (whether total or partial) of a chromosome, or structural changes in the chromosome that most commonly produce a set of intellectual and physical problems (congenital anomalies).

Cleft lip: A partial or complete fissure of the upper lip; it can be either unilateral or bilateral, and can be associated with a cleft of the gum.

Cleft palate: Fissure of the palate, which can affect the soft and hard palate, or only the soft palate.

Clubfoot: A congenital deformity in which the foot is turned downwards and inwards.

Confidentiality: An individual's right to have their personal, identifiable medical information kept secure.

Consanguinity: The relationship among people who descend from a common ancestor.

Craniorachischisis: Anencephaly with a contiguous spine defect without skin and meninges covering the neural tissue (rachischisis); it can be limited to the cervical region or affect the entire spine.

Deformation: The abnormal form, shape, or position of a part of the body caused by mechanical forces; these forces affect structures after their initial development.

Disability: A restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being (12).

Disorder of sexual differentiation also known as disorder of sexual development (DSD) is a condition where there is a discrepancy between the genetic, gonadal and phenotypic sex Disorder of sexual differentiation also known as disorder of sexual development (DSD) is a condition where there is a discrepancy between the genetic, gonadal and phenotypic sex of an individual, e.g. ambiguous genitalia.

Disruption: A structural defect of an organ, part of an organ, or a larger region of the body, resulting from the extrinsic breakdown of, or an interference with, an originally normal developmental process.

Dysplasia: An abnormal organization of cells into tissue(s) and its morphologic results, which most often affect skin, brain, cartilage, or bone.

Encephalocele: A pedunculated or sessile cystic lesion protruding through a defect in the skull; it can contain herniated meninges and brain tissue (encephalocele or meningoencephalocele) or only meninges (cranial meningocele); the vast majority of these defects are covered by skin.

Epidemiology: The study of the frequency and distribution of health events and their determinants among human populations, and the application of such research to the prevention and control of health problems.

Gastroschisis: A congenital fissure of the anterior abdominal defect lateral to the umbilicus, accompanied by herniation of the small intestine and part of the large intestine, and occasionally other abdominal organs.

Gestational age: The duration of a pregnancy, measured in weeks, from the first day of the woman's last menstrual period (LMP) to the current date. The duration of a normal pregnancy can range from 38 to 42 weeks.

Hospital-based surveillance programme: A programme aimed at capturing all birth outcomes with congenital anomalies that occur in selected birthing hospitals.

Hypoplasia: The underdevelopment or incomplete development of a tissue or organ.

Hypospadias: A common congenital defect of the male external genitalia in which the urethral meatus opens in the ventral side (underside) of the penis.

Incidence: The number of new cases of a disease among a given population and over a given time frame; not used when reporting congenital anomalies (see Prevalence).

Infant mortality: A demographic indicator that shows the number of deaths among children in their first year of life out of every 1000 live births registered.

Informed consent: An agreement to participate in a study or procedure after receiving and understanding full disclosure of the risks and benefits of participation.

International Classification of Disease 11th Edition:

International Clearinghouse on Birth Defects Surveillance and Research (ICBDSR): An international non-profit organization affiliated with WHO, whose mission is to bring together birth defects programmes from around the world, with the aim of conducting worldwide surveillance and research to prevent birth defects and to ameliorate their consequences.

International Statistical Classification of Diseases and Related Health Problems: The standard diagnostic classification tool for epidemiology, health management and clinical purposes.

LAMA: Left against medical advice

Live birth: The complete expulsion or extraction of a product of conception from a woman's body, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached.

Logic model: A visual element depicting how a programme operates, including the theories and assumptions underlying the programme; a logic model links outputs (both short- and long-term) with programme activities and the theoretical assumptions of the programme.

Major congenital anomaly: A structural change that has significant medical, social or cosmetic consequences for the affected individual; this type of anomaly typically requires medical intervention.

Malformation: A structural defect of an organ, part of an organ, or a larger region of the body that arises during organogenesis (initial formation of a structure).

Meningocele: A type of spina bifida characterized by herniation of the meninges through a spine defect, forming a cyst filled with cerebrospinal fluid. It does not contain the spinal cord, but can have some nerve elements.

Meningomyelocele: a protrusion of the meninges and the spinal cord through an opening in the vertebral column, and most frequently is located in the lumbosacral area. It is also referred to as myelomeningocele.

Microcephaly: A disorder in which the head circumference is two or more standard deviations smaller than the average for sex and age, associated with microencephaly and, in some cases, with altered structure of the brain and neurodevelopmental problems.

Minor congenital anomaly: A structural change that poses no significant health problem and tends to have limited social or cosmetic consequences for the affected individual.

Miscarriage: A spontaneous loss for a clinical pregnancy before 28 completed weeks of gestational age or, if gestational age is unknown, the loss of an embryo or fetus of less than 500g

Monitor: In birth defects surveillance, to watch, observe or check for the presence of congenital anomalies or diseases over a period of time.

Morbidity: The incidence or prevalence of a disease, or of all diseases in a population, in a given space and over time

Mortality rate: A demographic indicator that shows the number of deaths within a population per each 1000 inhabitants during a given time frame (generally one year).

National Birth Defect Surveillance Date Base (NBDSDB): the national central platform housed in the federal ministry of health for pooling all information/ data from the sub national hospitals for the purpose of BDS in the country.

Neonatal death: Deaths among liveborn infants during the first 28 days of life; it can be early (0-7 days) or late (8-28 days).

Neonatal period: The period that commences at birth and ends 28 completed days after birth.

Neural tube: The part of the embryo from which the brain and spinal cord develop.

Omphalocele: A congenital defect of the anterior abdominal wall in which the intestines and abdominal organs are herniated through an enlarged umbilical ring, usually covered by a membrane consisting of peritoneum and amnion.

Pathogenesis: The mechanisms or cellular events in the development of a pathologic condition or disease.

Perinatal period: The period that commences from the age of viability (at 28 completed weeks or 196 days) of gestation (the time when birth weight normally is 1000 g) and ends seven completed days after birth (12).

Population-based surveillance programme: A collection of data about a population residing in a defined geographical area.

Preconception care: Health care received before a woman becomes pregnant, with the purpose of helping reduce her risk for adverse pregnancy outcomes.

Prenatal screening: A systematic search for a specific condition among a large, asymptomatic subpopulation of pregnant women selected by personal or family history, or by demographic characteristics such as age and ethnicity; typically, it identifies at-risk groups for further diagnostic testing.

Pregnancy outcome: The result of conception and ensuing pregnancy, including live birth, stillbirth, spontaneous abortion and induced abortion.

Prevalence: A measure of the total number of existing cases of a condition, known as prevalent cases, for a given point in time or period, and among a given population, regardless of whether or not they are new cases. It is also an indicator of the magnitude of the occurrence of a disease or other health event in the population.

Live birth prevalence of congenital anomalies: Measures the number of cases with congenital anomalies among live births and is defined as number of cases of live births with any congenital anomaly (numerator) among a defined cohort of live births (denominator). For example, the live birth prevalence of congenital anomalies in 2014 is computed as live births born with any congenital anomaly in 2014 divided by all live births born in 2014.

Birth prevalence of congenital anomalies: Measures the number of cases with congenital anomalies among live births and fetal deaths (stillbirths), and is defined as number of cases of live births and fetal deaths (stillbirths) with any congenital anomaly (numerator) among a defined cohort of live births plus fetal deaths (stillbirths) (denominator). For example, the birth prevalence of congenital anomalies in 2014 is computed as live births plus fetal deaths (stillbirths) with any congenital anomaly in 2014 divided by all live births plus fetal deaths (stillbirths) in 2014.

Total prevalence of congenital anomalies: Measures the number of cases with congenital anomalies in live births, fetal deaths (stillbirths), plus elective terminations of pregnancy for fetal anomaly, and is defined as number of cases of live births, fetal deaths (stillbirths), elective terminations of pregnancy for fetal anomaly (numerator) among a defined cohort of live births, fetal deaths (stillbirths) and elective terminations (denominator). For example, the total birth prevalence of congenital anomalies in 2014 is computed as live births and fetal deaths (stillbirths) with any congenital anomaly plus elective terminations of pregnancy for fetal anomaly in 2014 (numerator) divided by all live births and fetal deaths (stillbirths) in 2014 plus all elective terminations of pregnancy for fetal anomaly occurring in 2014.

Privacy: An individual's right to control the acquisition, use and disclosure of their identifiable health information.

Public health: The discipline responsible for protecting the health of a population; its purpose is to improve population health and to control and eradicate diseases.

Public health surveillance: The systematic, continuous, timely and reliable collection of relevant and necessary data regarding certain health conditions among a population; analysis and interpretation of the data must provide grounds for decision-making and be disseminated.

Reproductive age: The age at which a woman is biologically capable of becoming pregnant. WHO characterizes this as being 15 to 49 years of age.

Risk factor: A characteristic, attribute, circumstance or exposure that is detectable among individuals or groups and is associated with an increased likelihood of a disease, congenital anomaly or other health problem.

Security: The technological and administrative safeguards and practices designed to protect data systems against unwarranted disclosure, modification or destruction.

Sentinel surveillance programme: A collection of data generally set up at one or a few sites, to obtain rapid estimates of the occurrence of a birth outcome.

Sequence: A pattern of multiple anomalies derived from a single known or presumed primary anomaly or mechanical factor.

Spina bifida: a congenital defect of the spine caused by a failure of the posterior elements of the vertebrae to close, resulting in exposure of the meninges, with or without associated spinal cord herniation.

Stillbirth: a foetal death after the gestational age of viability, which is variable among countries. In Nigeria, the age of viability is 28 weeks.

Surveillance programme: A public health programme that collects, monitors, analyses, interprets and disseminates data systematically in a timely manner, and that allows for planning, implementation and evaluation of health strategies.

Syndrome: A pattern of multiple anomalies thought to be pathogenetically related and not representing a sequence; it is due to a single cause – genetic or environmental – or to gene–environment interactions.

The guideline: a constellation of technical resources that make up this document to guide and provide a way of improving the quality of birth defects surveillance data documentation and collation.

Teratogen: An agent capable of interrupting or altering the normal development of an embryo or fetus, often resulting in a congenital anomaly or embryonic or fetal death.

Validation: In surveillance, a process to evaluate surveillance data, using a quality control protocol that covers the integrity, consistency, uniformity and reliability of the data.

Vital records: Records of life events kept under governmental authority, including fetal death certificates, birth certificates, adoption records, legitimation, marriages, divorces and death certificates.

World Health Organization (WHO): The directing and coordinating authority for health within the United Nations system, responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing health trends.

Chapter 1

1.0 Introduction

Birth defects are defined as functional or structural abnormalities of the body that are present at birth. These abnormalities are of prenatal origin and can involve almost any organ or systems of the body. They may be clinically obvious at birth or may be diagnosed later in life. Other terms used as synonyms of birth defects are congenital anomalies or congenital malformations. [1-4]. Birth defects that result from alteration of the form, shape, or position of a normally formed body part by mechanical forces are termed as deformation. Disruption, on the other hand, results from external interference with an originally normal developmental process.[5] Birth defects contribute to a significant proportion of perinatal, neonatal and under-five morbidity and mortality.[6]

1.1 Situation analysis

It is estimated that globally, about 8 million infants are born with serious birth defects every year, of which several hundreds of thousands are caused by teratogens such as alcohol, rubella, syphilis and iodine deficiency. About three million infants with birth defects will eventually die, while another 3.2 million will survive with severe disability. [7] There are however, compelling evidence, that up to 70% of birth defects can be prevented or adequately managed. [8] The causes of congenital anomalies are many and complex; with approximately 50 percent of them being idiopathic. [9] It is expected that the percentage of congenital anomalies of unknown causes will decrease in the future, as more causes are identified. [10] However, known causes can be divided into two broad groups: genetic and partially genetic causes, and causes developing after conception [4].

About 94% of the births with serious defects occur in low and middle - income countries where up to 95% of these cases end up dying. The World Health Organization (WHO) estimated that 3.2 million birth defect-related disabilities occur every year. Of the 1 million neonatal deaths reported in 2012 in the South-East Asia Region, about 46,000 (4.6%) were caused by birth defects.

The prevalence of birth defects among newborn infants varies widely in sub-Saharan African countries. It was found to be 1.43 per 1000 in Gabon [11] and 11.87 per 1000 in South Africa. [12]

In Nigeria, data on pooled national prevalence or incidence on birth defects is grossly lacking. However, available data on regional burden have been reported in some hospital-based studies. For example, incidences per 1000 live births ranged from 4.2-39.9 in South-East, 2.3 - 20.7 in South-South, 14.8 in North-Central, 28.2 in North-West, 6.9-11.5 in South-West and 9.16-31.8 in North-East respectively. [13-26] The contribution of birth defects to neonatal mortality in Nigeria rose from 1% in 2014 to 3% in 2019 according to the verbal and social autopsy (VASA) reports. [6]

Birth defect surveillance is described as the ongoing, systematic collection, analysis and interpretation of health-related data essential to planning, implementation and evaluation of public health policies strongly integrated with the opportune dissemination of these data responsible for prevention and control. [27] It can be categorized into two main types: population-based, which investigates birth defects among the whole population residing in a delimited geographic area, or hospital-based, which investigates birth defects in selected health facilities whose coverage corresponds to births or hospital admissions in these places [28].

Case detection can be active case-finding, which requires systematic screening and clinical evaluation of children; passive case-finding, when affected individuals have access to health facilities and are recognized; or a hybrid case-finding system [29].

Globally, several countries have well established birth defect surveillance programmes following the policy implementation call from the World Health Assembly in 2010. Consequently, the WHO in 2019 conducted a training-of-trainers workshop in Kampala, Uganda in order to increase awareness among key opinion leaders and programme managers in selected African countries. Some countries including Kenya, Uganda and Botswana have established country-wide birth defect surveillance programmes, effort is ongoing to establish same in Nigeria. [30]

1.2 Rationale for the Guideline

In Nigeria, the verbal and social autopsy survey in 2014 and 2019 showed a substantial increase in the burden of neonatal mortality for birth defects from 1% to 3%. [6] As part of the effort to comprehensively understand the dynamics and epidemiology of birth defects, generate evidence for strategic planning and implementation of intervention, the Federal Ministry of Health and Social Welfare (FMoHSW) through its 'Children with Special Needs branch' under the Child Health Division was saddled with the responsibility to establish the National Birth Defects Surveillance Committee. The overall aim of the committee is to midwife the birth of the National Birth Defect Surveillance Programme. This comprehensive national birth defect surveillance document herein referred to as the 'National Birth Defect Surveillance Guideline (NBDSG)' was developed towards fulfilling this aim.

The main objective of the National Birth Defect Surveillance Programme is to generate a national repository for birth defects. This calls for a well-defined systematic process and system of generating and collation of information from the various healthcare facilities where these cases are seen and managed. The data generated are then pooled into the central registry of the FMoHSW and subsequently analyzed and interpreted to guide planning and policies.

1.3 Scope of the Guideline

This maiden guideline will serve to standardize the documentation process of birth defects to ensure high quality of data in terms of accuracy, completeness, comparability, and timeliness. In addition, it will help for early detection, prompt and appropriate treatment, research, capacity building, and monitoring of burden and outcomes of birth defects.

For sustainability and scalability, if fully integrated into the National Health Strategic Plan, this guideline intends to:

- Promote the use of a uniform tool across subnational units.
- Enhance the usefulness of data from subnational units for research on the/pattern and etiology of birth defects.
- Promote the use of data for the purpose of linking affected children with services across subnational units.

1.4 Target audience

This guideline is designed for use by subnational governments, healthcare institutions, healthcare workers, policy-actors and programme managers.

1.5 The structure of the Guideline

The guideline is structured to provide a template for healthcare institutions to develop birth defect surveillance and link up with the national system. The guideline is organized into chapters including: introduction, overview of birth defects, birth defect surveillance, programmatic approach, roles and responsibilities of members, monitoring and evaluation, and references.

Chapter 2

2.0 Overview of Birth Defects

Birth defects comprise a wide range of abnormalities of body structure or function that are present at birth and are of prenatal origin. Major birth defects (Box 2.1) are defined as structural or functional anomalies that have significant medical, social or cosmetic consequences for the affected individual. They require medical or surgical intervention. They account for most of the birth defect - related morbidities, disabilities and deaths.

BOX 2.1 A list of Common major structural external and internal birth defects

Common Major Birth Defects	
External	**Internal**
Neural tube defects: • Anencephaly • Craniorachischisis • Encephalocele • Spina bifida Microcephaly Macrocephaly (hydrocephalus) Microtia/Anotia Orofacial clefts: • Cleft lip only • Cleft palate only • Cleft lip and palate Exomphalos (omphalocele) Gastroschisis Hypospadias	Congenital heart defects; • Hypoplastic left heart syndrome • Common truncus • Interrupted aortic arch • Transposition of great arteries • Tetralogy of Fallot • Pulmonary valve atresia • Tricuspid valve atresia Esophageal atresia/tracheoesophageal fistula Intestinal atresia/stenosis Anorectal atresia/stenosis Renal agenesis/hypoplasia

Reduction defects of upper and lower limbs Talipes equinovarus/club foot	
Chromosomal defects - Trisomy 21 (Down syndrome)	

Minor birth defects on the other hand are structural or functional changes that pose no significant medical, social or cosmetic problem for the affected individual. They are more prevalent among the population and are often captured only when associated with any of the major anomalies under surveillance. Examples are as shown in box 2.2

Box 2.2: Minor Birth Defects

Minor birth defects

- Absent nails
- Accessory tragus
- Anterior anus (ectopic anus)
- Auricular tag or pit
- Bifid uvula or cleft uvula
- Branchial tag or pit
- Camptodactyly
- Clinodactyly
- Cutis aplasia (if large, this is a major anomaly)
- Ear lobe crease
- Ear lobe notch
- Ear pit or tag
- Extra nipples (supernumerary nipples)
- Lop ear
- Micrognathia
- Natal teeth
- Overlapping digits
- Plagiocephaly
- Polydactyly type B tag, involves hand and foot
- Preauricular appendage, tag or lobule
- Redundant neck folds
- Rocker-bottom feet
- Single crease, fifth finger
- Single transverse palmar crease
- Single umbilical artery
- Small penis (unless documented as micropenis)

Facial asymmetry

Hydrocele

Hypoplastic fingernails

Hypoplastic toenails

Iris coloboma

Syndactyly involving second and third toes

Tongue-tie (ankyloglossia)

Umbilical hernia

Undescended testicle

Webbed neck (pterygium colli)

This document focuses on major structural birth defects. The birth defects spectrum may involve any organ or system and there may be single or multiple organ or system involvement. The most common structural birth defects are congenital heart diseases (CHD), neural tube defects (NTDs), digestive tract defects, musculoskeletal disorders and Down syndrome, while haemoglobinopathies are common functional birth defects. The prevalence and spectrum of birth defects vary across national and subnational units depending on the prevailing risk factors in the community.

Risk factors associated with birth defects include socioeconomic and demographic factors (advanced maternal age, consanguinity, low-income countries), environmental factors (maternal infections-rubella, maternal nutritional deficiencies-folate and iron deficiency, maternal alcohol consumption, anti-epileptic drugs such as phenytoin) and genetic (chromosomal abnormalities e.g Down Syndrome). Many of these factors are preventable, and a wide range of preventive approaches are possible through legislation and policies. Some of the effective interventions are vaccinations, pre-conception folic acid supplementation, food fortification with micronutrients (iodine and folic acid), prevention and management of maternal infections and chronic illnesses. Other interventions include controlling exposure to toxins, timely identification of family risk of inherited diseases, and genetic screening with counselling.

The knowledge of the prevailing types of birth defect, burden and risk factors is important for the enactment of policies and planning of interventions. This is only possible with the availability of comprehensive and qualitative information, which is mostly lacking in Nigeria. To improve data and information, there is a need to develop a National Birth defect surveillance system**.**

Chapter 3

3.0 National Birth Defect Surveillance

Generally, there are two major types of birth defect surveillance systems; population- and hospital-based surveillance systems. The type of surveillance system to be established is influenced by a number of factors including the aim and objectives of the surveillance and the resources to be utilized in the surveillance process.

Population-based birth defect surveillance captures birth outcomes with birth defects that occur among a population that is resident in a defined geographical area.

Hospital-based birth defect surveillance captures birth outcomes with birth defects that occur in selected hospitals called sentinel sites. Sentinel sites birth defect surveillance programmes are generally set up in one or a few hospitals to obtain rapid estimates of the occurrence of an adverse birth outcome.

It is considerable to commence hospital-based surveillance for birth defects in sentinel sites with a high load of childbirths. Subsequently, this can be expanded to other hospitals, so that the data collected would be representative of most regions in the country. A population-based surveillance may later be considered depending on the availability of resources.

3.1 The National birth defect surveillance in Nigeria

For the purposes of efficiency, practicability and consensus based on preliminary reviews of available in-country data, the current birth defect surveillance focuses on common major external and internal defects. These are defined as structural anomalies that have significant medical, social or cosmetic consequences for the affected individual, and typically require medical or surgical intervention. These defects are readily identifiable and easily recognizable on physical examination at birth. The defects can be diagnosed at or shortly after birth based on the protocol and standard diagnostic tools and equipment available across tertiary level hospitals in Nigeria.

The National birth defect surveillance is a hospital-based surveillance which began with an initial six tertiary hospitals and currently has 12 hospitals spread across the six geo-political zones of the country. The estimates of the prevalence of birth defects in this surveillance, is determined by the number of affected live and still-births as the numerator and the total births occurring in the participating hospitals as the denominator. Data captured on all outborns (birth outside the hospital facilities) will not be included in calculation of the prevalence.

The aim of the birth defect surveillance is to create a comprehensive surveillance system on birth defects for strategic policy action and effective management in Nigeria

The objectives are to:

1. Establish a national birth defect repository.
2. Determine the distribution and outcome of birth defects.
3. Provide data for service planning.
4. Provide basis for prevention strategies.

3.2 Approaches to the National birth defect surveillance

3.2.1 Case definition

This refers to the criteria the national birth defect surveillance (NBDS) programme uses to define and include a case in the National hospital- based birth defect surveillance. Selected, tabulated major external and internal birth defects (Box 3.1) will be included in the surveillance where the following criteria are met:

1. **Place of delivery:** neonate delivered in and outborns referred to the participating hospital
2. **Pregnancy outcome:** live births and stillbirths
3. **Time of diagnosis:** birth defects identified at birth until the first 28 days of life (neonatal period)
4. **Gestational age:** neonates delivered at 28 weeks gestation and above or a birth weight of 1000 g and above where the gestational age is not ascertained.

Data will be collected on all selected defects from all pregnancies including pregnancies resulting from assisted reproductive technology.

Diagnosis: initial focus is on the following major external and internal birth defects

Box 3.1: A list of Selected External and Internal Birth Defects for surveillance in Nigeria

1. Gastrointestinal defects
    a. Omphalocele
    b. Gastroschisis
    c. Imperforate anus
    d. Intestinal obstruction
    e. Tracheoesophageal fistula
2. Conjoined twins
3. Central Nervous System defects
    a. Neural Tube defects
    b. Hydrocephalus
4. Cardiac defects
5. Orofacial malformations – Cleft lip and Palate
6. Eye defects (congenital cataract, aniridia, microphthalmos, macrophthalmos, anophthalmos)
7. Genitourinary system defects

a. Meatal opening malformations – Hypospadias, epispadias

b. Ambiguous genitalia (DSD)

7. Musculoskeletal: limb deformity (congenital clubfoot (talipes) and others)

3.2.2 Birth Defect Case Determination

Case determination can be active, passive or hybrid (Fig. 3.1).

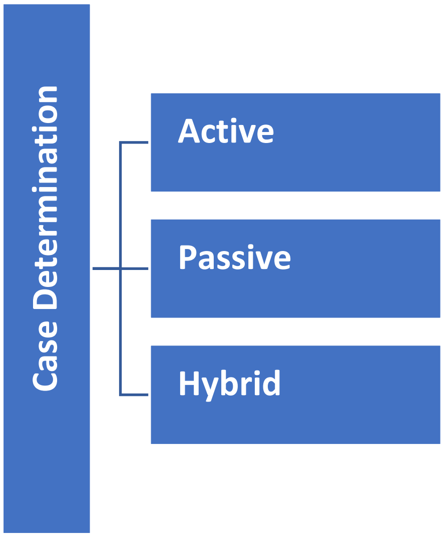

Fig 3.1 Case Determination

Active case determination

The surveillance engages personnel that are hired and trained to conduct data extraction. Medical records need to contain relevant information in a format that can be identified and extracted easily by the personnel who regularly and actively review data sources (e.g. logbooks, medical discharge and deaths records) of participating institutions, to identify cases from all areas of the hospital where a potential neonate with a birth defect can be identified. This method of case determination tends to improve case detection and case reporting, and improves data quality because more extensive clinical details are collected.

Passive case determination

With passive case determination, hospital personnel who identifies a neonate with birth defect reports this information directly to the surveillance registry. The information that is reported to the surveillance registry is typically not verified by direct extraction of the medical record. Passive case determination is less expensive because fewer resources and personnel are required. The burden of reporting falls on the already busy hospitals or clinical staff. This could result in less optimal reporting rates, incomplete documentation or less timely reporting, or a combination of these. It also usually yields less complete detail on each case and underestimates the number of birth defects that occur. In addition, because reported information is not validated, it could overestimate certain birth defects.

Hybrid case determination

Hybrid case determination refers to a combination of passive case determination of most types of birth defects, with active case determination of specific birth defects, or for a percentage of all reported birth defects as a quality control tool. For example, a surveillance programme can conduct active determination of NTDs to gather more detailed case information in a timely manner, but carry out passive determination of all other birth defects under surveillance.

3.2.3 The national birth defect surveillance case determination.

The surveillance case determination will employ an active case determination model, where data extraction will involve both multiple teams of trained clinical staff in the various areas of the hospital, from where a potential neonate with a birth defect can be identified. A trained health information staff will verify and extract documented information and then upload case onto the surveillance electronic database.

All participating hospitals are to report only on the category of defects listed in Box 3.0 even as it is appreciated that hospitals may be interested in other defects. Such other defects of interest should be restricted to the hospital data and not reported on the National birth defect surveillance database.

The cases which meet the criteria for surveillance data collection will be documented in the hospital using the NBDS data abstraction form (Appendix I) following a conclusive diagnosis and consensus by the hospital surveillance team. The coding of the clinical condition would be done using the international classification of disease 11 (ICD-11). The ICD is developed and maintained by the World Health Organization (WHO) and is considered the international standard diagnostic classification system for all general epidemiological, health data management purposes as well as other clinical uses. Its use will facilitate partnership and collaboration with other programmes using the same coding system.

ICD-11 uses a hierarchical coding system to group conditions and provides more detailed descriptions for the various anomalies. In ICD-11, birth defects are found in Chapter 20 (Developmental anomalies- https://icd.who.int/browse/2025-01/mms/en#223744320).

3.3 National Birth Defect Surveillance Protocol for data collection

The National BDS protocol for data collection and management includes the following steps:

3.3.1 Case identification

The case is screened to ensure that criteria for inclusion is met using the protocol box (Box 3.3) below.

BOX 3.3: Case definition for NBDS programme

1. Neonate delivered in the participating hospital or outborn with at least one of the selected major birth defects in the NBDS programme
2. Affected live births or stillbirths
3. Birth defects identified at birth until the first 28 days of life (neonatal period)
4. Neonate delivered at 28 weeks gestation and above or a birth weight of 1000g and above where the gestational age is not ascertained

3.3.2 Data abstraction and initial uploading

The trained hospital personnel who encounters a neonate with birth defect in the identified units of the participating hospitals, will initiate the process of documentation based on established standardized procedures and trigger the subsequent steps.

For example:

S/N	Birth defect	Full description	ICD 11 Code	Confirmed(C)/ Preliminary (P)
1	Cleft lip and palate	Baby born with cleft hard palate and soft palate with bilateral cleft lip. Baby otherwise has no other anomaly.	LA4Y	C
				

3.3.3 Extraction and documentation of the case by trained staff in the unit

During the extraction and documentation of the data on the form, the trained staff uses a checklist to safeguard and guarantee high quality reporting. The checklist should be reviewed by the trained staff to confirm that complete data information is available and of high quality. For example;

Checklist for high quality data reporting;

Cleft Lip- documentation checklist

1. Describe in detail the cleft, including:
    - Laterality- right, left or bilateral
    - Lower lip- pits present or absent
    - Extension of the cleft lip-minimum, partial or total involvement of the gum extending at most through the alveolus to the incisive foramen (not beyond)
2. Describe procedures to assess further additional malformation, and if present describe these
3. Take and report photographs

4. Report specialty consultation and findings if done

3.3.4 Review, Coding and Classification

This entails confirmation of the case by the trained team in the unit where identification of the case was made through investigations, taking clinical photographs and arrival at a consensus diagnosis. The diagnosis made will be classified and coded using the ICD-11 coding system. The trained team in the unit where identification of case was made will review the described case including reviewing the patient and taking photograph within 48 hours of birth/ admission. Where investigations are required, the team will order and review the investigations for confirmation of the case. The case is confirmed through consensus with the aid of WHO birth defect Surveillance atlas of selected birth defects and the quick reference handbook for selected birth defects and infections. Where confirmatory investigations may delay case confirmation, a preliminary diagnosis, based on a greater portion of the available information, is made and ticked on the form while investigation continues.

With a diagnosis made following the NBDS protocol, the birth defect is then coded according to the ICD-11 coding system. For example:

S/N	Birth defect	Full description	ICD 11 Code	Confirmed(C)/ Preliminary (P)
1	Hydrocephalus	Baby born with large head, sunsetting eyes, prominent scalp veins and soft head on palpation.	LA04	C
2	Ambiguous genitalia	Asymmetrical labio-scrotal fold with prominent phallus and posteriorly placed urethral opening with presence of a ball	LD2A	P

3.3.5 Verification and Validation

The extracted information at the participating hospital will be verified by the trained Data clerk who assesses the completeness, accuracy and timeliness of data extracted. In situations where information appears incorrect or incomplete, the staff will collaborate with the hospital unit BDS team to review and update the data.

3.3.6 Final Uploading

The verified and validated complete, high quality de-identified data will be uploaded onto the password-protected national-level surveillance programme database by the data clerks. Only authorized personnel will have access to the database.

3.3.7 Data management:

Data Experts at the FMoHSW will review information sent from the participating hospitals and verify completeness of uploaded information. This data will be analysed, reviewed and used to make evidence-based recommendations for appropriate action.

3.4 Essential tasks

3.4.1 Filling the data abstraction form

When a baby with birth defect(s) is identified, the standard data abstraction form will be filled and attached to the case records of the baby by the unit team member assigned for the task. It is important to provide a complete physical description of the birth defects in the text box and photographs of birth defects should be taken as per the standard procedure. Complete and correct information must be ensured by using case records of mother and baby and taking further history from the mother as required. This is achieved by the review which should be conducted by the surveillance team to ascertain and generate all the necessary history required. All babies should be thoroughly examined for birth defects at the entry points of the hospital.

At the time of discharge or death of a baby or at the age of 28 days, all the fields in the abstraction form must be filled completely. The filled form will be retrieved and stored in the designated folder available with the hospital focal officer for BDS. It is important to keep these records for validation.

Details of any birth defect in each baby will also be recorded in the labour room, Obstetric Theatre (OT) and, neonatal unit admissions, discharge/ death registers maintained by the hospital.

3.4.2 Confirmation and coding of birth defects

Birth defects forms would be updated in the following situations:

- After any confirmatory tests (like X Ray, USG, MRI, CECT, karyotyping, etc.).
- A new or additional defect is detected during the baby's stay on the postnatal ward or neonatal unit.

For all the confirmed or diagnosed cases the most appropriate ICD-11code is selected from the ICD-11 list to describe all birth defects observed (based on the description and photograph included in the form). The online system provides the support for assigning the ICD codes for several birth defects through the drop-down menus. (Complete list of ICD codes for birth defects is available at the web link: https://icd.who.int/browse/2025-01/mms/en#223744320).

3.4.3 Uploading the data on the online NBDS system

The trained data clerk who is authorized will use his/ her log in detail to access the platform and upload the case within the first 14 days of the following month.

3.4.4 Management of birth defects

Upon identification of a birth defect, it is essential to provide appropriate comprehensive plan and services based on hospital protocols and or referral for collaboration with other sub-specialties and facilities.

3.4.5 Quality assurance of surveillance at the hospital level

The coordinator of the BDS Team in hospitals are responsible for quality assurance of data and information on each baby. This should cover three aspects:

- Completeness

- Accuracy
- Timeliness

3.5 Keys to effective Hospital-based Birth Defect Surveillance

1. Ensure that all babies delivered in the hospital (live-births and stillbirths) are clinically examined for detection of birth defects at the earliest opportunity after their delivery.
2. Ensure that the Scanned copies of filled out abstraction forms as well as photographs (that are appropriately labelled) are electronically stored in the computer that is password protected. form for each baby born with birth defect(s) is filled completely and accurately before discharge or death.
3. Ensure that the completed abstraction form is uploaded to the NBDS platform as soon as possible.
4. Each filled out abstraction form is checked for completeness and accuracy and taken out
5. of the baby's case record before it is dispatched to the hospital records section.
6. Ensure scanned copies of filled out abstraction forms as well as photographs (that are appropriately labelled) are electronically stored in the computer that is password protected.
7. Ensure all filled out abstraction forms are stored in the designated folder under lock and key in an office cabinet.

Quality assurance applies to the paper forms as well as the online data submitted from the

hospitals.

3.6 Analysis and interpretation

The FMoHSW will tabulate and analyse the data monthly, quarterly and yearly to generate National and sub-national disaggregated statistics and parameters. These will be disseminated to hospitals, state governments and other important stakeholders.

3.7 Assessment for quality of birth defects surveillance at a hospital

The BDS coordinator at the hospital is expected to do a periodic assessment of quality of the surveillance. This could preferably be done monthly for ongoing quality assurance. In addition, the FMoHSW shall also undertake quality assessment at the participating hospitals to support quality surveillance mentoring. This could be done quarterly.

A simple and short checklist is provided for hospital assessment (Appendix II). This can be used both for routine ongoing quality assurance as well as less frequent external assessment for improving the quality of the database.

Chapter 4

4.0 Programmatic Approach

4.1 Birth Defects of Interest for National Surveillance

The NBDS guideline for the purpose of generating and reporting birth defects across the 12 sentinel and other sites will collect data on the External and Internal anomalies listed in Box 3.1.

The anomalies for surveillance were selected on the basis of their burden as depicted by preliminary data from tertiary institutions across the six geopolitical zones, availability of interventions, probability of survival and the general consensus of the stakeholders.

4.2 Data management and protocols

Data management is essential to ensuring the integrity and confidentiality of surveillance data. The data management and protocol for this surveillance includes the following:

- Data collection methods and tools
- Data flow
- Reporting Timelines
- Data Quality
- Establishing Birth Defect Surveillance in participating hospitals

All responsible officers in the participating hospitals will be trained on protocol for data management. This will ensure the proper use of all tools and a standardized method for data management. Hospitals will use the national BDS abstraction form to collect data on cases including photographs. A team of trained personnel will review, agree and confirm the diagnosis. The case is then coded using the ICD 11. Finally, the confirmed and coded case is rechecked by trained data clerk for completeness before final upload of the de-identified data unto the national database using centre-specific codes. Figure 4.1 is the flow chart of how data collected at the hospital level progress through the National BDS programme.

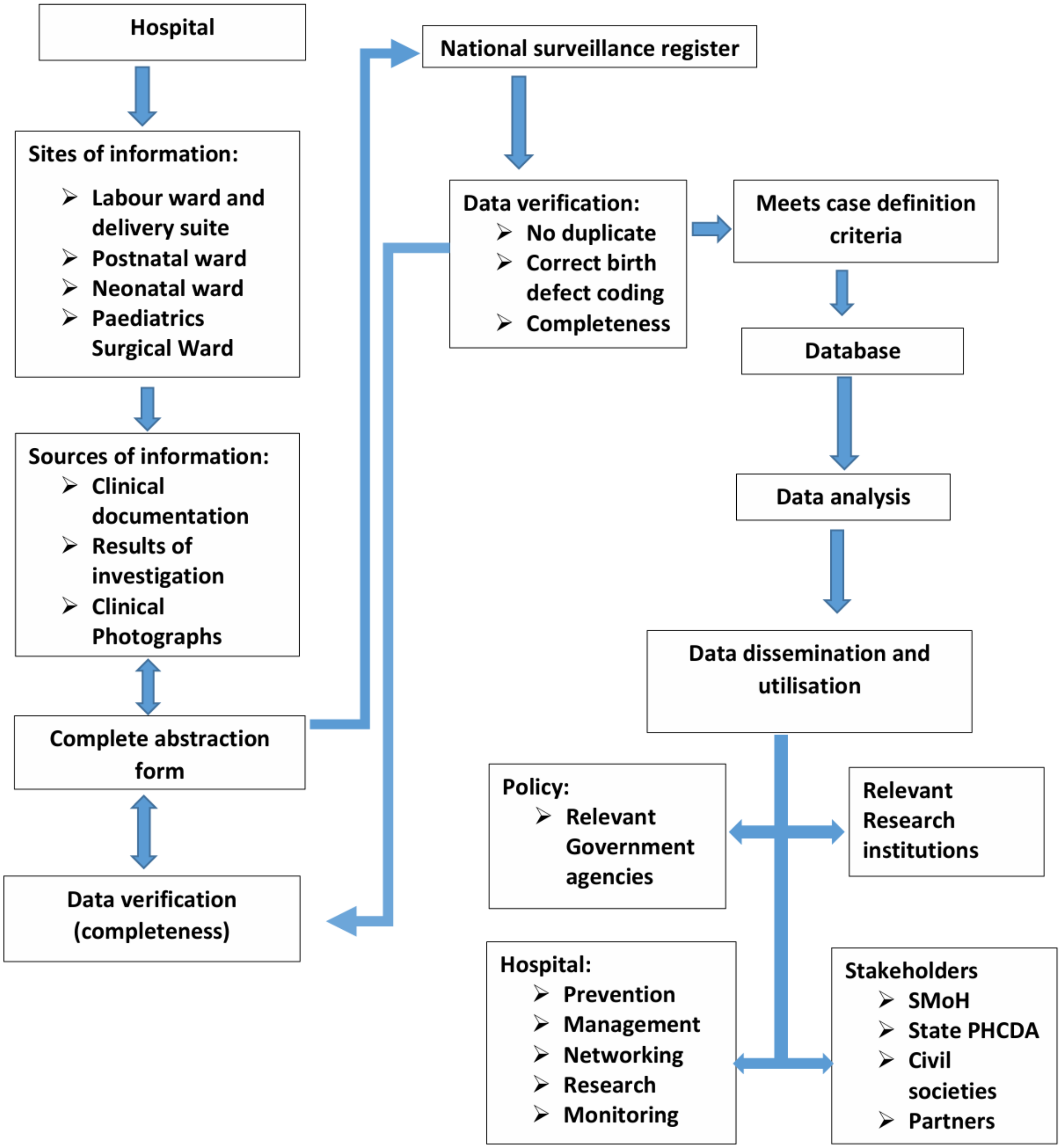

Fig 4.1: BDS data flow chart

4.2.1 Data collection methods and tools

The NBDS will collect data from participating hospitals using data abstraction form which will be both in paper and electronic format. This will then be uploaded to the

BDS electronic register. The electronic format of the abstraction form on the smartphones and tablets will provide options for data capture and transmission of pictures. Access to database of clinical information, including photographs will assist with differential diagnosis.

4.2.1.1 Paper-based data collection/Data Abstraction

Paper-based data are first collected on well-structured data abstraction form and then transcribed into an electronic format.

4.2.1.2 Electronic data collection and security

The electronic format to collect data for birth defect surveillance is a more efficient process that requires regular updating of a system's hardware and software to maintain a high level of security and data quality.

The electronic data collection tool allows data to be collected, transmitted securely to a data management centre for storage, analysis, and retrieval when necessary. Electronic devices to be used in the surveillance programme will all be programmed to encrypt all data in order to ensure confidentiality and security of information collected by the system.

4.2.2 Report Timeline

Extracted and confirmed diagnosis on the abstraction form will be uploaded unto the national database by 14th of the following month.

4.2.3 Data quality

Data collected for the National BDS using the abstraction form and electronic register should be complete, accurate and submitted in a timely manner.

Data collection procedures should be carried out properly and systematically. The National BDS has been designed to allow for uniformity in extraction of data and reporting.

4.3 Establishing Birth Defect Surveillance in Participating Hospitals

4.3.1 Hospitals birth defect surveillance team

The Chief Medical Directors/Medical Directors in the participating hospitals will establish the BDS team in the hospital domiciled under the Department of Paediatrics. The team will comprise:

1. The Neonatologist or Paediatrician in charge of the Neonatal unit as coordinator
2. Paediatric sub-specialists (Neurologists, Endocrinologists, Cardiologists, Gastro- enterologists, Nephrologists, Geneticists)
3. Obstetrician in charge of the labour ward/Head of Department, Obstetrics and Gynaecology.
4. Surgical department and all sub-specialists (Paediatric surgeons, Cardio-thoracic surgeons, Neurosurgeons, Plastic and reconstructive surgeons, Urologists, Orthopaedic surgeons, ENT surgeons, Ophthalmologists)
5. Maxillo-facial and Paediatric Dental surgeons
6. Pathologists
7. Radiologists
8. Physiotherapists
9. Child and Adolescent Health Specialists
10. Nurses (Labour ward, Postnatal ward, Neonatal and Paediatric ward)
11. Health management information officers
12. Medical Social Works Department
13. Any other relevant person(s) as co opted

The BDS team will identify a BDS secretary (a doctor who is already a member of the team) in the hospital. The coordinator, secretary and the data clerk will be trained on BDS and the trained members will step down the training to the BDS team at the hospital.

The coordinator of the BDS team would be the convener of all meetings. The team will:

- Identify personnel (doctor/ nurse) for data collection at the different sources of information.
- Share the SOPs for the management of the surveillance system in the hospital.
- Ensure that standardized coding is used in the filling of the abstraction form.
- Review and direct the entry of the collected data online to the NBDS Database by the data clerk.
- Make available adequate number of copies of birth defect abstraction forms as well as Manual and Atlas of birth defects surveillance and wall posters on birth defects in the units where birth defects are identified.
- Identify a BDS office which is equipped with a computer and accessories, tablets/ smartphones, printer, scanner, a broadband connection, back-up system, cabinet, tables, chairs and air conditioner.
- Analyse the data on birth defects in the hospital among intra-mural births every month, quarterly and annually, and discuss with the hospital team.
- Receive analysed data and report from the FMoHSW at quarterly/ annual intervals for dissemination and review in hospitals.
- Arrange for appropriate care, management and counselling in the hospital or by referral, as feasible.
- Network with other hospitals to provide appropriate and optimal care where needed.

Chapter 5

5.0 Roles and Responsibilities

Efficient coordination and the delineation of roles and responsibilities among stakeholders are critical for the successful execution of the NBDS guideline. The guideline acknowledges the multi-faceted nature of birth defect and recognizes the importance of multi-sectoral/ multi-disciplinary collaboration among all stakeholders. Promote child protection and safeguarding at all levels of care.

5.1 National Level

Federal Ministry of Health and Social Welfare:

The FMoHSW plays a pivotal role in plan formulation, development of guidelines and the overall oversight of the birth defect surveillance guideline. Its responsibilities include setting the national birth defect agenda, mobilizing resources, and establishing/ fostering partnerships with international organizations. The BDS Coordination Unit (Children with Special Needs Branch) is a branch of Child Health Division of Family Health Department of the FMoHSW, and serve as the central hub for the planning, implementation, and monitoring of the guideline. It is responsible for managing and overseeing all aspects of BDS, including resource mobilization, monitoring, evaluation, and communication.

Federal Ministry of Health and Social Welfare shall:

- Act as the principal coordinator of all the interventions aimed at achieving the goal and objectives of the guideline.
- Provide, operate, maintain and secure the NBDS database repository.
- Disseminate and monitor the operationalization of the guideline at all levels.
- Lead the monitoring and evaluation of all BDS activities including use of data for policy formulation and decision making.
- Provide technical support to State and Local Governments for advocacy, resource mobilization and orientation on BDS, in collaboration with relevant stakeholders.
- Promote inter-agency relationship on Children with special needs interventions.

- Develop training curricula and materials based on the guidelines.
- Coordinate nationwide training for healthcare providers on early detection, management, and prevention of birth defects.
- Coordinate nationwide training for BDS team on the use of the tools for data collection, documentation and uploading to the database.
- Ensure BDS training as a component of continuing professional development.
- Include children with birth defects among the beneficiaries of the poor and vulnerable component of the Basic Health Care Provision Fund.

5.2 State Level

The State Ministries of Health (SMoH) shall:

- Act as the principal coordinator of all the interventions aimed at achieving the goal and objectives of BDS by adapting the BDS based on state specific needs.
- Ensure adequate resource mobilization and allocation for implementation of the guideline.
- Ensure effective implementation of state specific BDS in collaboration with relevant Ministry Department and Agencies (MDA), professional associations, private sector, and development partners.
- Coordinate the implementation of BDS activities leveraging on existing coordination platforms including the joint review meeting.
- Facilitate the training and re-training of healthcare workers on relevant BDS training packages.
- Ensure that the BDS is reflected in the State Annual Operational Plan (AOP).
- Develop, print and disseminate the annual operational plan, guidelines, SOP and Social Behavioural Change Communication (SBCC) materials for standardized and quality services for BDS.
- Monitor and track progress of implementation and keep stakeholders updated as reflected in the workplan for accountability.
- Participate in the National annual review meeting on BDS.
- Collaborate with relevant State MDAs to strengthen service provision at secondary health facilities.
- Key into the NBDS.

- Include children with birth defects among the beneficiaries of the poor and vulnerable component of the State Health Insurance Scheme/ Contributory Health Care Management Scheme.

5.3 Local Government Level

Primary Health Care (PHC) Department shall:

- Oversee the implementation of BDS interventions at the LGA and community levels.
- Ensure the functionality of primary health care centres and engage with communities to promote BDS interventions.
- Provide budgetary allocation and ensure the timely release of funds for the implementation of BDS programmes.
- Establish/Strengthen Local Government Committees on Health to coordinate BDS interventions.
- Collaborate with private sectors on implementation of BDS.
- Build capacity of PHC workers on identification and referral of children with birth defects.
- Monitor, evaluate and supervise the implementation of the guideline at LGA and PHC facilities.
- Key into the NBDS.

5.4 Community Level

Community Leaders shall:

- Mobilize, advocate for BDS, and ensure that community members are aware of available services.
- Collaborate with PHCs through the Ward Development Committee (WDCs) to ensure that the community has access to functional health services.
- Create an enabling environment, support, and promote the guideline in their communities.
- Advocate for the inclusion of children with birth defects among the beneficiaries of the community-based health insurance scheme.
- Promote emergency transport services for referral.
- Support the implementation of the community health programmes.

- Institutionalise the community score cards for decision making in collaboration with health facilities.

5.5 Development Partners

The development Partners shall:

- Provide technical and financial support to the implementation of the BDS and AOP
- Support evidence generation for decision making and policy formulation
- Support resource mobilisation and partnership for BDS
- Act as advocate for BDS
- Key into the NBDS

5.6 Parents and Caregivers

- Serve as primary caregivers for the well-being of the child.
- Ensure prompt and appropriate care seeking behaviour for sick children.
- Advocate for the health and well-being of children with birth defects.
- Practice all components of key household and community practices.
- Ensure inclusion of these children with birth defects in social activities.
- Seek psychological support for themselves and the family

5.7 Institution

5.7.1 Hospital Management shall:

- Establish BDS team for the operationalization of the BDS.
- Provide secretariat and logistics for the team including office space, which should be equipped with a computer and accessories, printer, a broadband connection, cabinet, tables and chairs, air conditioner.
- Ensure implementation of BDS in accordance with the national guidelines.
- Compile data generation and ensure transmission to the National repository.
- Share the SOPs for the management of the surveillance system in the hospital.
- Make available adequate number of copies of birth defects abstraction forms as well as Manual and Atlas of birth defects surveillance and wall posters on birth defects in the units where birth defects are identified.
- Receive analyzed data and report from the FMoH&SW national at quarterly /annual intervals for dissemination and review in hospitals.

5.7.2 BDS Team

The BDS team shall:

- Ensure that standardized coding is used in the filling of the abstraction form.
- Review and direct the entry of the collected data online to the NBDS Database by the data clerk.
- Analyse the data on birth defects in the hospital among intra-mural births every month, quarterly and annually, and discuss with the hospital management.

- Arrange for appropriate care, management and counselling in the hospital or by referral, as feasible.
- Network with other hospitals to provide appropriate and optimal care where needed.
- Monitor and evaluate the BDS programme
- Ensure that babies (live; in or outborn or stillborn) are examined in the delivery rooms, operation theatres (for C-Section), postnatal ward and neonatal unit/ paediatric ward in the hospital.
- Conduct a comprehensive physical examination of all live born/stillborn babies.
- Fill the birth defects abstraction paper form, describe the defect(s) and take high-quality photographs of the birth defect(s).
- Ensure review of the data for accuracy, completeness and correct diagnosis of the case and coding.
- Ensure that birth defect(s) are recorded in the delivery, admission and discharge/ death register/ log books maintained in the hospital.
- Be responsible for reviewing the data for quality assurance.
- Ensure the accurate, complete entry and submission of data into the electronic database.
- Provide the total number of births (live births and stillbirths) that took place in the hospital– monthly, by the end of the 14th day of the next month.
- Provide ongoing support for skill-building and problem solving.

5.8 Private Sector

- Provide funding, technology, or other resources to strengthen surveillance activities.
- Support public–private partnerships to expand coverage and access.
- Ensure compliance with national health reporting requirements.
- Collaborate in awareness campaigns (media, pharmaceuticals, industry).
- Invest in research and innovation for prevention and management of birth defects.

5.9 Private/Faith-Based Health Facilities

- Detect and report suspected or confirmed cases of birth defects to surveillance authorities.
- Maintain accurate and timely records in line with FMoHSW guidelines.
- Provide counselling, referral, and follow-up care for affected families.
- Train staff on proper identification and reporting of birth defects.
- Collaborate with public health teams during monitoring, audits, and quality control.

5.10 Faith-Based Organisations

- Offer psychosocial support to families affected by birth defects.
- Facilitate referral to health facility
- Raise community awareness through faith networks to reduce stigma and improve acceptance.
- Partner with government and NGOs to provide outreach services, especially in underserved areas.

5.11 Civil Society Organizations (CSO)

- Advocate for improved policies, funding, and social support systems.
- Raise community awareness and stigma reduction; mobilize families for early detection, treatment and stigma reduction
- Provide training support for non-formal community-based health workers in case identification and referral.
- Monitor and demand accountability to ensure surveillance translate into policy actions, service delivery improvement and long-term system strengthening.
- Facilitate the strengthening of multi-sectoral coordination among government, academia, donors, and other relevant institutions on birth defect for harmonization of effort.
- Offer psychosocial and peer support for affected families.
- Promote child safeguarding and right based approaches for sustainable birth defects surveillance

5.12 Professional Associations

- Advocate for policy adoption and full implementation of Birth Defects Surveillance (BDS).
- Develop and disseminate professional guidelines on early detection, referral, and management of birth defects.
- Integrate BDS into continuous professional development (CPD) and training curricula.
- Mobilize members to actively participate in surveillance, research, and care.
- Support quality assurance through peer review and technical expertise.
- Collaborate with government and partners to improve health outcomes for affected children.

5.13 Allied Professions

- Physiotherapists, occupational therapists, speech therapists, and other allied professionals provide rehabilitative services to improve functional outcomes of children with birth defects.
- Social workers and psychologists support families with counselling, stigma reduction, and linkage to social services.
- Medical laboratory scientists and radiographers assist in diagnosis, confirmation, and follow-up of birth defects.
- Participate in training, advocacy, and community awareness programmes.
- Collaborate with healthcare providers and CSOs for comprehensive and multidisciplinary care.
- Document and share data relevant to their scope of work with BDS teams.

Efficient communication, collaboration, and information sharing among these stakeholders at various levels are essential for the seamless execution of BDS. Each stakeholder group has a unique role to play in the implementation of the guideline, and their collective efforts will lead to improved birth defect survival in Nigeria.

Chapter 6

6.0 Ethics and Legal Authority

At all data collection point, the BDS shall:

- Ensure compliance with ethical standards for data collection and reporting.
- Provide guidance on data privacy, consent, and use of identifiable information.
- Oversee regulations related to mandatory reporting, if applicable.

6.1 Data Ownership/Sharing

The data repository is the property of the FMoHSW. It shall not be shared or used by any party except with the explicit authorization.

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APPENDIX I

National Birth Defect Surveillance Abstraction Form

Case record ID (Site/Year/month/Serial no):

Date of report (dd/mm/yyyy):

Name of Hospital:

City:

State/LGA/Ward:

FOETUS/ NEONATE

1. Outcome at birth:
   [ ] live birth, [ ] stillbirth [ ] elective termination of pregnancy with foetal anomaly
2. Name, if available:
3. Place of birth: [ ] Inborn [ ] Out-born
4. Date of birth (dd/mm/yyyy):
5. Date of Presentation to Hospital: (dd/mm/yyyy)
6. Date of Final Diagnosis (dd/mm/yyyy):
7. Sex: [ ] Male [ ] Female [ ] Ambiguous
8. Gestational age: (Completed weeks)
9. Best estimation of GA:

PARENTS

19. Father's given name(s):
20. Father's surname(s):
21. Father's date of birth (dd/mm/yyyy):
22. Father's age:
    (complete years as at last Birthday)
23. Father's occupation:
24. Father's highest level of education:
25. Father's race/ ethnicity:
26. Father's phone number:
27. Father's NIN:

[ ] Ultrasound [ ] LMP [ ] Others

10. Weight: (grams)
11. Length: (cm)
12. Head circumference: (cm)
13. Multiple birth: [ ] Yes [ ] No if Yes, specify birth order
14. Photographs taken: [ ] Yes [ ] No
15. Outcome of hospitalization:
    [ ] Discharged [ ]Referred [ ] LAMA [ ] Died
16. If dead, specify date: (dd/mm/yyyy)
17. Cause of death:
18. Autopsy: [ ] Yes [ ] No, If yes, specify details at the back of this sheet:

28. Mother's given name(s):
29. Mother's surname(s):
30. Mother's maiden name):
31. Mother's date of birth (dd/mm/yyyy):
32. Mother's age:
    (completed years as at last Birthday)
33. Mother's occupation:
34. Mother's highest level of education:

35. Mother's race /ethnicity:
36. Primary address during 1st trimester of pregnancy:
    - State:
    - LGA:
    - Ward:
    - Street:
    - House number:
    - Major Landmark:
37. Current address if different from above):
    - State:
    - LGA:
    - Ward:
    - Street:
    - House number:
    - Major Landmark:
38. Mother's Telephone number:
39. Mother's NIN:
40. Total number of previous pregnancies:

a. Live births: b. Stillbirths: c. Abortions:

41.Are parents of foetus/neonate related? [ ] Yes [ ] No If yes, specify: [ ] First cousins [ ]Second cousins [ ]Aunt- nephew [ ] Uncle -niece [ ] Others(specify):	
Diagnostic tests performed [ ]Yes [ ] No Results: Notes and comments:	
Name of professional completing the form: Phone Number: [ ] Physician [ ] Nurse [ ] Others(specify)	

S/N	Birth defect	Full description	ICD 11 Code	Confirmed(C)/ Preliminary (P)

Data on birth defect which meets the criteria is collected, documented and described fully using the abstraction form with an attached high-quality photograph.

APPENDIX II

ASSESSMENT FORM FOR QUALITY CHECK OF HOSPITAL-BASED BIRTH DEFECT SURVEILLANCE

Date of Assessment:

Name and Designation of Assessor:

General information:

1. Name of Hospital:
2. State:
3. Hospital BD focal person:
4. Number of BD trained personnel in this facility:
5. Any new staff that needs to be trained: ☐ Yes ☐ No

   If Yes,

S/N	Name	Cadre/ unit	Training need

6. Places of delivery in the hospital included for capturing BD cases:
   - Mention the name(s) and cadre of staff at each site:

S/N	Name	Unit (Labour room, Operation theatre, Both)	Cadre

7. Other places in the hospital where birth defects are to be captured in in-born babies:
   - Mention the name(s) and cadre of staff at each site:

S/N	Name	Unit (Postnatal ward/ Neonatal Unit/ paediatric unit other areas)	Cadre

8. Are the pictures taken in all cases of birth defects: ☐ Yes ☐ No
    - If no, please specify why: ……………………………..
    - If Yes, are photographs being saved on laptop, smartphone, tablet in an orderly way (with proper identification case by case)?
      ☐ Yes ☐ No
9. Are the data captured directly on the online system (laptop, smartphone, tablet)?
   ☐ Yes ☐ No
10. Are the data first captured on the paper form (Birth defects abstraction form)?
    ☐ Yes ☐ No (If yes, sight it)
    - If Yes, are the filled out BD abstraction forms stored in a designated folder in the hospital? ☐ Yes ☐ No

Checklist:

S/ N	**Items**	**Response**	**Comments**
1.	Are blank birth defects abstraction forms available at all sites will be enough for data capturing for the next six months. (S (points 5-6 above) (Sight the quantity).	Yes ☐ No ☐	
2.	Is each baby delivered in the hospital examined clinically for detecting birth defects? (it will be good to observe this, as majority will answer "YES"	Yes ☐ No ☐	
3.	Are the babies also examined in the postnatal ward/ Paediatric	Yes ☐	

	unit/ Neonatal unit for detecting birth defects?	No ☐	
4.	Are birth defects recorded in the delivery room Register and Admission-Discharge Registers at all sites where BDs are captured? (Points 5-6 above).	Yes ☐ No ☐	If no, ask if there is a BD register documentation
5.	Proportion of mother/baby case records (10 randomly selected records) in which details of newborn clinical examination is recorded, including details of birth defects.		
6.	Is appropriate description of the birth defects written in the BD forms? Check 10 random forms and state the proportion with appropriate description.		
7.	If pictures of birth defects are taken, is the quality as per the guidelines? Check stored pictures in the laptop.	Yes ☐ No ☐	
8.	Are the birth defects correctly coded as per ICD-10? Check 10 random BD forms and state proportion with correct codes.		
9.	Time taken between identification of birth defect in a case and filling the paper BD abstraction form.	Same duty shift ☐ Same day ☐ Later ☐	

10.	Time taken between filling out the paper form and online entry.	Same duty shift ☐ Same day ☐ Later ☐	
11.	Proportion of BD forms verified by the hospital BD focal person.		There is need for the supervisor to note the number of BD cases, number duly documented from registers to the BD form and number verified by the BD focal person
12.	Proportion of verified forms that required changes/completion		
13.	Check the monthly denominator (total births, live births and stillbirths in the hospital in a month) from the hospital records	Correct ☐ Incorrect ☐	Note the number of BD cases too as a numerator for the month under review
14.	When was the last analysis of birth defects forms done? Mention the date		Sight the report/ findings of the analysis
15.	Was the analysis shared with the hospital team and state programme managers?	Yes ☐ No ☐	

Assessment of Challenging Factors:

<table>
<tr><th>Factors ⇩</th><th>Consequence ⇒</th><th>Missing BDs</th><th>Delay in filling forms</th><th>Delay in online reporting</th><th>Poor data quality</th><th>Others</th></tr>
<tr><td colspan="2">High load of deliveries</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="2">Early discharges</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="2">Baby being discharged without proper examination</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="2">Insufficient paper</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="2">Poor internet availability</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="2">Insufficient staff</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="2">Insufficient knowledge / training of staff</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="2">Insufficient supervision and support from Ministry of Health</td><td></td><td></td><td></td><td></td><td></td></tr>
</table>

Others (specify)

Summary of Assessment:

- **Main problems identified:** ……………………………………………………………………………………….
- **Debrief Hospital stake holders and work with them to:**
  - **Plan to improve the quality: (Include timelines)**
    i. ………………………………….
    ii. ………………………………….
    iii. ………………………………….
  - **Follow-up:**

    To confirm if each planned action for improvement has been completed for this cycle of quality check.

    i. ………………………………….
    ii. ………………………………….
    iii. ………………………………….

APPENDIX III

BDS Register

STATE *Plateau*

NAME OF FACILITY *Jos University Teaching Hospital (JUTH)*

			Consanguinity		DIAGNOSIS									Sex (tick)				Outcome at Birth		
Case Record ID	Date of Report (dd/mm/yyyy)	Mode of Entry (Inborn/Outborn)	Are Parents of fetus/neonate related? (Yes/No)	If yes, state type of relationship	Type of Congenital Anomalies Present	Full Description	Diagnostic tests done & notes	Possible Diagnosis	Confirmed Diagnosis	Associated Syndrome(s)	Name (If Available)	Date of Birth (dd/mm/yyyy)	Date of Diagnosis of Congenital Anomaly (dd/mm/yyyy)	Male	Female	Ambiguous	Unknown	Live birth	Stillbirth	of Pregnancy with Foetal Anomaly (ETOPFA)
UMTH/22/09/001	22/09/07	Inborn	No	No	Hypo	Glan dular Vent	None	Gland	No	None	Baby Fati H	07/09/2022	)7/09/202	Male				Live birth		

FEDERAL MINISTRY OF HEALTH, NIGERIA
NATIONAL BIRTH DEFECT SURVEILLANCE REGISTRY

FOETUS/NEONATE

GESTATIONAL AGE				Anthropometry at admission			Multiple Births		Photograph taken?		Neonatal Outcome (on the 28th day)							Any correctional interventions?		
GA (in completed weeks)	Best Estimation (LMP)	Best Estimation (Ultrasound)	Best Estimation (Others)	Weight (Grams)	Length(cm)	Head circumference (cm)	Yes/ No	If Yes, Specify Number	Yes/ No	If Yes, Consent Obtained? Y/N	If Dead, Date of Death (dd/mm/yyyy)	If Dead, Cause of Death?	If Dead, was Autopsy done? Yes/No	If Yes, Summarize autopsy finding	If Discharged, Date of Discharge (dd/mm/yyyy)	Against Medical Advise, Date of DAMA	Still on Admission	If yes, Date of first intervention (dd/mm/yyyy)	If yes, specify type	Final outcome (Discharged/Referred/Dead/LAMA)
38	LMP			3500	54	34	No		Yes	Yes					########		No	No		Discharge

PARENTS																					
											Primary Address During First Trimester					Obstetrics History					
Father's given name(s)	Father's Family name(s)	Father's Date of Birth	Father's Age (in Completed Years)	Race (Ethnicity)	Any Family History of Congenital Anomaly?	Mother's given name(s)	Mother's Family names (including maiden name)	Mother's Date of Birth	Mother's Age (in Completed Years)	Race (Ethnicity)	State	LGA	Town/City/Ward/ Street/No or Major Landmark	Current Address (If Different from 1st Trim. Address- (State, LGA, Town/City/Ward/ Street/No or Major Landmark)	Telephone Number	Total number of Previous Live births?	Total number of Previous Stillbirths?	Previous Spontanous	Previous Termination of	If Illness in first trimester	Fever & Rash (Y/N)
Hassan	Audu	No	45	Black/Fula	No	Fati	Usman	No	30	Black/Fula	Borno	Jere	Jere	Gwange	8.04E+09	6	NO	6	No	No	No

Risk Factors in Mother																Reporting officer
Other Substance use	Anticonvulsants	Anticancer	Syphilis	Herbicides	Herbal mixtures	HIV & AntiRetroviral	Antidepressants	Antipsychotics	Other Drugs used in 1st Trimester	Alcohol (Y/N)	Ionizing Radiation	Diabetic?	Hypertension	cong. Anomaly (Y/N)	Risk factors identified	
No	No	No	NO	No	No	No	No	No	No	No	No	No	No	No	No	Pius

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NATIONAL BIRTH DEFECT
SURVEILLANCE GUIDELINE 2025

World Health Organization
Gates Foundation
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HANDS
PLAN Health Advocacy and Development Foundation
The StraightChild Foundation
POSITIVE CARE AND DEVELOPMENT FOUNDATION
PCDF