

Newborn Birth Defect (NBBD) Surveillance in Nepal

Factsheet No. 3 (January – December 2023)

As reported in SEAR-NBBD Website

Birth Defects (BD), also known as congenital disorders are defined as structural or functional anomalies (for example, metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth, or sometimes may only be detected later in infancy, such as hearing defects.

- WHO 2016 and 2020

Birth defects not only cause mortality but also contribute to lifelong morbidity in the form of mental, physical, auditory or visual disability. This results in loss of productivity and impaired quality of life, accounting to huge economic burden to family, community and the health system.

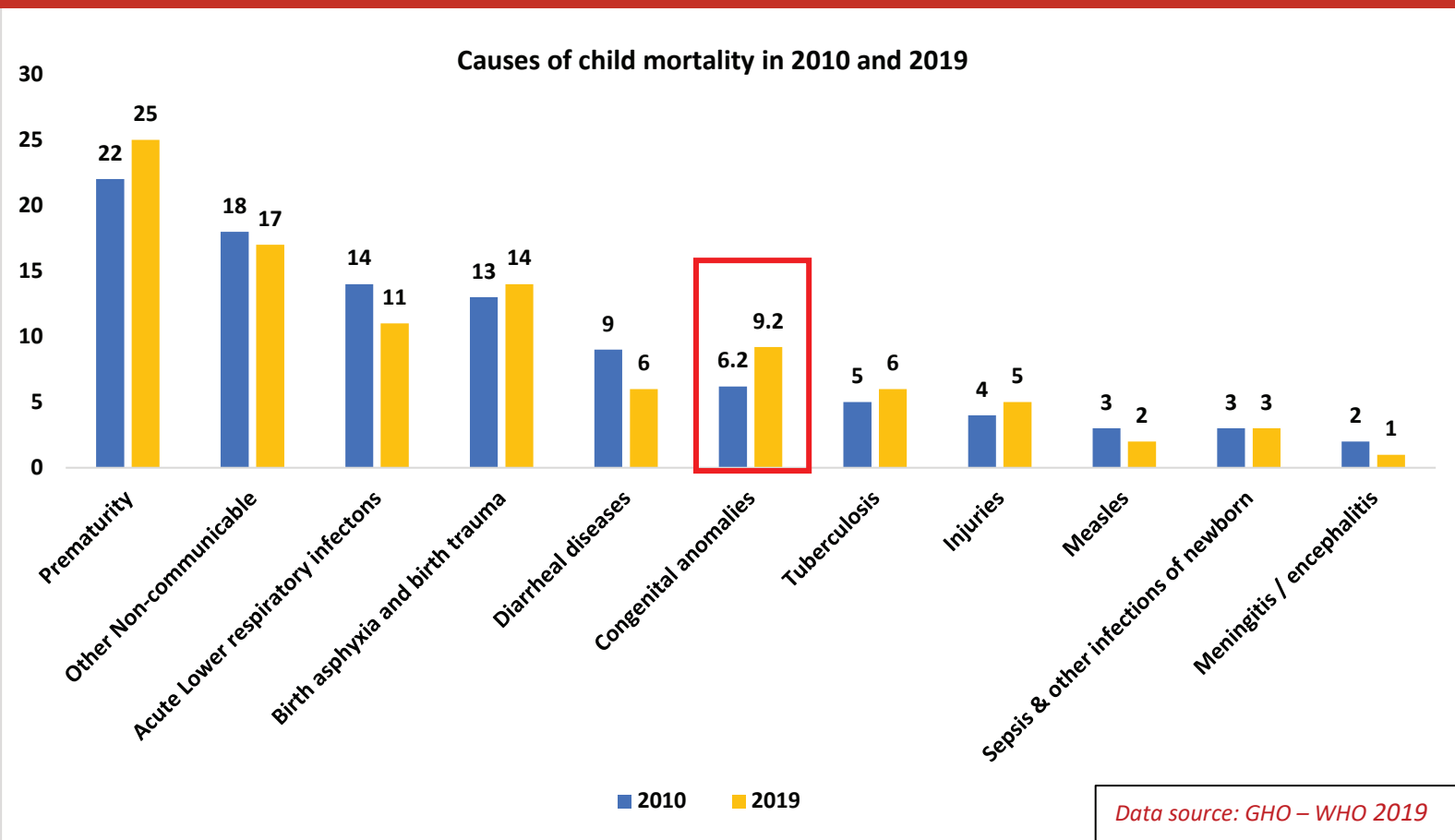
Preventing congenital conditions by mitigating risk factors and early detection and management could help to reduce the burden of birth defects.



Birth Defects Scenario:

- 27 hospitals are implementing the Newborn Birth Defect Surveillance in Nepal.
- Nepal has updated the Birth Defect Surveillance, Prevention and Management – National implementation Plan 2025 - 2030.

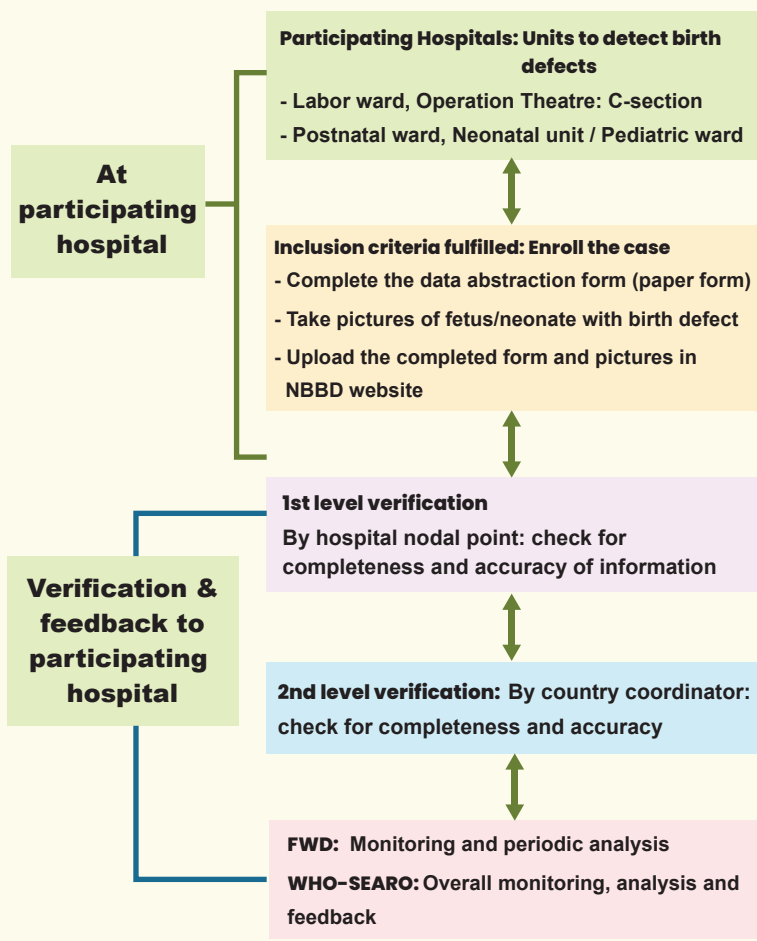
Contribution of BDs to child mortality has increased between 2010 and 2019 South East Asia Region: From 6.2% to 9.2%



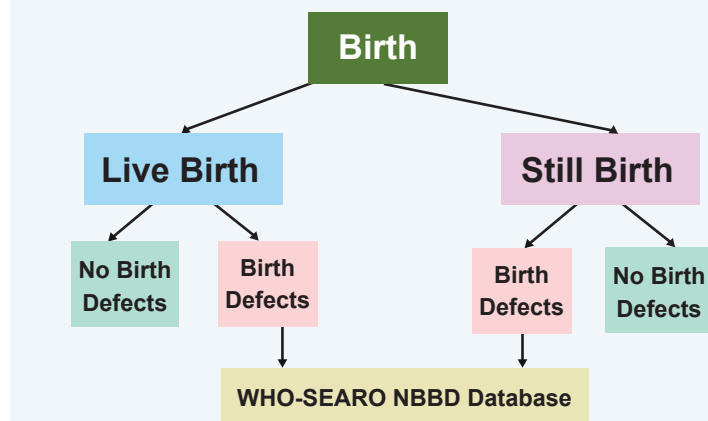
Criteria for Birth Defects Surveillance

- Online Hospital based at birth surveillance
- Passive reporting system: passive reporting of cases from hospitals
- Gestational age: All births from ≥ 28 weeks of gestation (if gestational age not known: birth weight ≥ 1000 gms)
- Pregnancy outcome: Live births and Still births
- Age at Diagnosis: At birth and until 7 days of age
- Inborn cases: only babies born in the BD Surveillance implementing hospital
- Mandatory to report: eight major externally visible birth defects
 - Neural tube defects,
 - Oro-facial clefts,
 - Talipes equinovarus,
 - Limb reduction defects,
 - Hypospadias
 - Exomphalos / Omphalocele
 - Gastroschisis
 - Imperforate anus
- All external / internal birth defects based on the ability to detect

Birth Defects verification System:



Birth Defects Reporting Mechanism in Nepal:

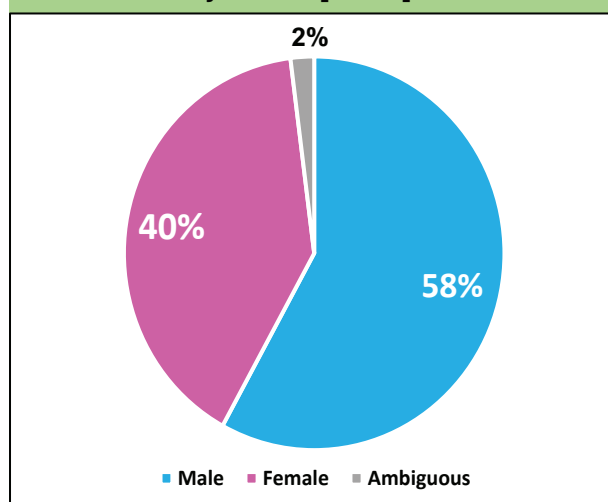


Implementation and Reporting Status (Jan-Dec. 2023):

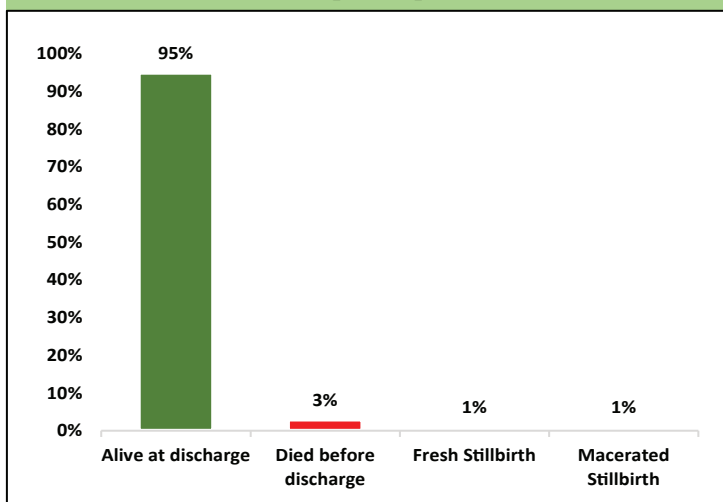
Newborn Birth Defects Surveillance Implementing Hospitals:	27
Hospitals reporting Birth Defects cases:	22
Total Births:	86,741
Total Live births:	85,627
Total Stillbirths:	1,113
Total babies with birth defects:	481

One baby can have MORE THAN ONE birth defect !!

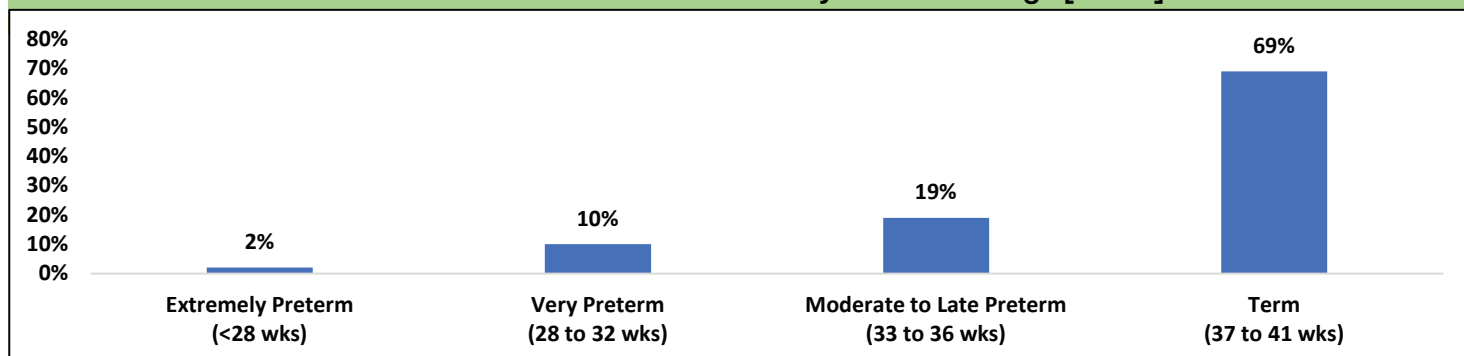
Distribution of Babies with Birth Defects by Gender [N=481]



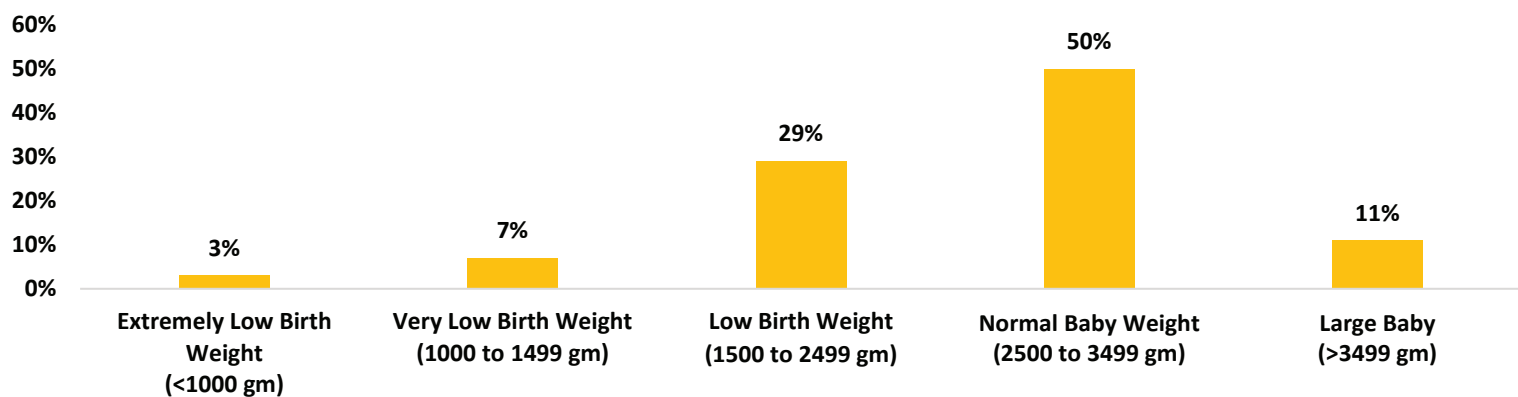
Distribution of Birth Outcomes of Babies with Birth Defects [N=481]



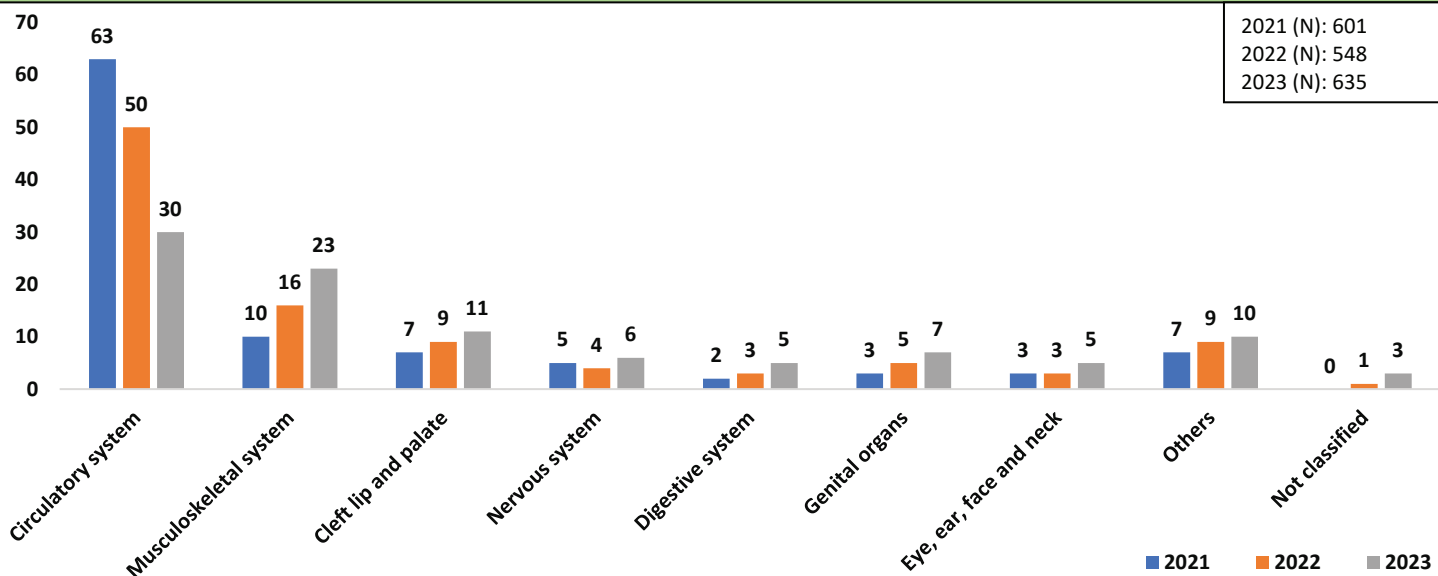
Distribution of Babies with Birth defects by Gestational Age [N=481]



Distribution of Babies with Birth defects by Birth Weight [N=481]



Three-Years Trend in Percentage Distribution of Birth Defects by System Affected



Issues and Challenges:

- Gap in recording, reporting and timeliness and completeness of data from implementing sites.
- Gap in utilization of allocated budget due to lack of knowledge on budget availability/division and utilization.
- Frequent change of focal person at implementing hospitals leading to issue in ownership and delay in recording and reporting.
- Medical recorders not actively involved in BD recording and reporting due to work overload/lack of training.
- Challenge in second level verification of BD cases.

Way Forward:

- Strengthen the NBBD program in implementing hospitals / medical colleges through regular review, monitoring, follow-up and orientation under the leadership and guidance of Family Welfare Division (FWD).
- Sensitize the service providers involved in Newborn Birth Defect recording and reporting in hospitals.
- Support to establish atleast one hospital in each province as the MPDSR and Birth Defect Nodal site.
- Province to take the lead in successful implementation on BD Surveillance in hospitals.
- NBBD data reporting to be done through FWD website (data entry application to be included in FWD website).
- FWD to identify and train experts as 2nd level verifiers to verify the completeness, quality and validity of the BD cases reported in the web-based system.