

Hospital-based Birth Defects Surveillance

Facilitator guide



*Hospital-based
Birth Defects Surveillance
Facilitator guide*

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Facilitator's Notes

Introduction to training workshop

The objective of this training course on hospital-based birth defects surveillance (BDS) is to provide participants with the foundational skills needed to begin, implement and progressively improve hospital-based birth defects surveillance. Hospitals are expected to initially include externally visible and major birth defects in the surveillance plan. A set of such birth defects will be used as examples throughout this course. These defects are typically severe enough that they would probably be captured within the first few days after birth, have a significant public health impact and, for some of them, have the potential for primary prevention.

Overall learning objectives of the workshop

By the end of this workshop, participants will be able to:

- (1) Understand the public health importance of birth defects
- (2) Understand the basic concepts of birth defects surveillance
- (3) Understand approaches of birth defects surveillance
- (4) Understand how to code birth defects
- (5) Know about data collection, reporting and analysis at the hospital and methodology for maintaining data quality

Course materials

- Birth defects surveillance: A manual for programme managers. Geneva: World Health Organization; 2014. This manual provides reference material that will be useful to expand understanding. It will be provided to all participants so that they will not be required to take notes during the course.
- Birth defects surveillance: Atlas of selected congenital anomalies. Geneva: World Health Organization; 2014. This atlas can be used as a reference after the course; it will also be used for some of the coding activities during the training.
- Hospital-based birth defects surveillance - Standard operating procedures
- Exercise handouts
- Set of standard PowerPoint presentations

The Facilitator guide

The *Facilitator's guide* contains what you, as a facilitator, need in order to lead participants through the course. It contains detailed instructions on how to conduct each session. This is your most essential tool as a facilitator. It is recommended that you use it at all times and add notes to it as you work. These notes will help you in future courses.

Suggested Programme

Day 1		
Time	Topic	Presenter/Discussant
Inaugural session		
09.00-09.10	Welcome and objective of the workshop	
09.10-09.40	Remarks by invited dignitaries	
09.40-10.00	Inaugural Address	
10.00 – 10.30	Tea	
Session 1 10.30-11.15	Overview of Birth Defects	
Session 2 11.15-12.00	Overview of Birth Defects Surveillance	
Session 3 12.00-13.00	Surveillance approaches: a) Case ascertainment b) Case finding c) Case inclusion d) Exercises	
13.00 -14.00	Lunch	
Session 4 14.00-14.30	Data-collection methods and tools	
14.30-15.00	Exercise: Filling BD abstraction form*	
15.00-15.30	Tea	
Session 5 15.30-17.00	Introduction to SEAR-NBBD database	

* Be ready to provide a printed copy to each participant

Day 2		
Time	Topic	Presenter/discussant
Session 6 09:00-09.45	Coding principles: <i>Section 1:</i> How to code a birth defect	
09:45-10.30	Coding principles: <i>Section 2:</i> Coding of birth defects in SEAR-NBBD database	
10.30-11.00	Tea	
11.00-12:00	Coding principles: <i>Section 3:</i> Group exercise and individual exercises	
Session 7 12.00 -13.00	Data management <ul style="list-style-type: none"> • Quality of data • Data analysis 	
13:00 – 14.00	Lunch	
Session 8 14.00-14.30	Counseling and referral	
Session 9 14:30 – 15.15	Introduction to SOPs for establishing birth defects surveillance in the hospital	
15.15-15.45	Tea	
Session 10 15.45 – 16.45	Prepare personal plan of action for establishing birth defects surveillance at your hospital	
16.45– 17.30	Closing session	

Session 1: Overview of Birth defects

Time allocation – 45 min

[Slide 2] Objectives

By the end of this session, participants will be able -

- To learn the definition of birth defects
- To understand the public health importance of birth defects
- To know classification and clinical presentation of birth defects
- To know about etiology and common risk factors associated with birth defects
- To understand prevention interventions

[Slides 3-4] Congenital conditions

Explain that congenital conditions include a variety of conditions such as malformations, syndromes, metabolic disorders, prematurity, birth asphyxia, cerebral palsy, hemoglobinopathies, and so on.

Birth defects are one type of congenital conditions.

[Slides 5-6] Definition of birth defects and classification

Birth defects are structural or functional anomalies (for example, metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth or later in life.

Explain that different terms are often used

- *Congenital anomalies*
- *Congenital abnormalities*
- *Congenital malformations*: the use of this term to refer to birth defects in general is not appropriate because malformations are only one type of birth defect. However, this term is used in the ICD-10, Chapter XVII, to refer to malformations, deformations, disruptions and dysplasias.

In this guide and during the training, the term *Birth Defects* has been used.

[Slides 7-8] Public health importance birth defects

As per the March of Dimes Report (2006) every year an estimated 7.9 million children—6 percent of total births worldwide—are born with a serious birth defect of genetic or partially genetic origin. The burden of birth defects in the South-East Asia Region is second highest among the WHO Regions.

Birth defects are underestimated because of terminations of pregnancy for prenatally detected birth defects, and birth defects among spontaneous abortions and stillbirths are often missed out. The most common severe birth defects are heart defects, neural tube defects and Down syndrome.

Mortality: As per WHO estimates, 276 000 babies die within 4 weeks of birth every year, worldwide, from birth defects.

Morbidity: Birth defects can result in long-term morbidity and disability that requires long term management.

- **High economic cost:** Birth defects can result in long-term disability, which may have significant impact on individuals, families, health-care systems and societies. The costs related to chronic treatment, care and support are likely to increase as survival improves in developed countries.
- **High social cost:** Many birth defects are associated with social stigma and discrimination leading to social embarrassment and isolation.

[Slide 9]

Transition in child mortality

The graphic shows the shift in the burden of disease. As child mortality related to other conditions such as infectious diseases decreases, the proportional mortality caused by birth defects is expected to increase, for example, in Sri Lanka and Thailand.

[Slide 10]

Paucity of data on birth defects has been a challenge.

March of Dimes report (2006) provides estimates of birth defects in the countries based on a particular methodology of extrapolating available data. The estimates for SEAR countries range from 55–65 per 1000 births.

[Slide 11]

WHA Resolution

The 63rd World Health Assembly in 2010 adopted a resolution on birth defects to encourage countries to build in-country capacity related to the development of birth defects surveillance systems and the prevention of birth defects, and to raise awareness about their impact. The resolution calls on Member States to prevent birth defects wherever possible, implement screening programmes, and provide ongoing support and care to children with birth defects and their families. WHO is to support Member States in implementing these services and to strengthen research and data collection in this area.

WHO-SEARO has developed an electronic (web-based) integrated database for birth defects, and newborn health, the SEAR-NBBD in consultation with Member States.

[Slides 12-14]

Classification of birth defects

Birth defects can be classified based on location, health impact and clinical presentation.

Location of birth defects:

- **External birth defects:**
 - Easily recognizable at birth
 - Best choice when starting a surveillance programme
 - Example: spina bifida
- **Internal birth defects:**
 - Frequently delayed diagnosis
 - Requires imaging and/or other technology
 - Example: Tetralogy of Fallot

Structural birth defects can be classified as one of two types: major birth defects or minor birth defects. Major and minor birth defects may sometimes be present in one individual.

- **Major birth defects** are structural changes that have significant medical, surgical, social or cosmetic consequences for the affected individual, and typically require medical intervention. Examples include spina bifida, anencephaly, heart defects and orofacial clefts. Major birth defects account for most of the mortality, morbidity and disability related to birth defects.
- **Minor birth defects** are structural changes that pose little or no significant health problems and tend to have limited social or cosmetic consequences for the affected individual. Minor birth defects are more common than major birth defects and can be a useful tool for clinicians to identify syndromes. Examples of minor birth defects include single palmar crease and clinodactyly (mild curvature of a finger or toe).

Ask participants: What external birth defects are most often seen in their region? Ask participants to provide responses aloud.

[Slide 15]

List of major birth defects

Display the list of major birth defects considered in this manual. Tell participants that in this workshop, these major birth defects examples will be used.

[Slide 16]

Clinical presentation

Isolated defects have no other unrelated major anomaly present. They comprise about 75% of all major birth defects.

Sequences are also considered isolated defects. A sequence is a cascade of anomalies that are consequences of a SINGLE malformation. An example is hydrocephalus, spina bifida and talipes. The hydrocephalus and talipes are consequences of the primary malformation of spina bifida.

Multiple defects are two or more major defects that are unrelated. For example, the child could have a limb deformity and also have hypospadias. Under multiple defects are two other subcategories called associations and syndromes.

An association is a pattern of anomalies that occur with a higher frequency than would be expected from random occurrence. VACTERL stands for vertebral defects, anal atresia, cardiac defects, tracheo-esophageal fistula, renal anomalies and limb abnormalities.

Syndromes are pathogenically related multiple anomalies arising from a single cause, but not representing a sequence. For example, down syndrome or congenital rubella syndrome.

[Slide 17]

Causes of birth defects

Although birth defects may be genetic, infectious, nutritional or environmental in origin, most often it is difficult to identify the exact causes.

For more than 50% of birth defects, no cause can be found.

[Slides 18-20]

Risk factors associated with birth defects

- We are now going to discuss risk factors. In the case of birth defects, risk factors include genetic factors; maternal conditions, like diabetes mellitus and obesity; maternal age and behaviours and environmental exposures that may put a woman at risk for having a pregnancy affected by a birth defect.
- Display the slide and explain the list of common risk factors.
- Discuss the level of relative risks for some known risk factors.

Ask participants: Can any of the risk factors you mentioned be modified to help prevent birth defects?

Possible responses:

- *Have vaccinations up to date prior to pregnancy*
- *Maintain a healthy weight*
- *Consume adequate micronutrients, like folic acid, through fortified food products or vitamin supplements prior to and during pregnancy*
- *Control diabetes prior to pregnancy*
- *Use of iodine to prevent hypothyroidism (iodized salt)*
- *Abstain from alcohol abuse or smoking prior to, and during, pregnancy*
- *Speak with a health-care provider about any medication use*

[Slides 21-22]

Prevention of birth defects

Primary prevention of birth defects is effective in cases of birth defects in which definitive causes are known and preventable.

Secondary prevention of birth defects (early diagnosis and treatment) is important for all birth defects and is especially critical for some birth defects such as congenital hypothyroidism in which early treatment is essential for good outcomes.

Tertiary prevention (rehabilitation) and social integration is important for birth defects that are associated with long-term disability.

Example of neural tube defects emphasizes multiple causative factors that need different prevention approaches.

[Slide 23]

Take home messages

- (1) Birth defects are a specific group of congenital conditions
- (2) Burden of birth defects is high globally; proportionally higher in low- and middle-resource countries such as SEAR countries
- (3) WHO-SEARO has developed an electronic system for birth defects surveillance, SEAR-NBBD (Newborn-Birth Defects) database
- (4) Etiology of birth defects is unknown in more than 50% of BDs – increasing knowledge allows for new opportunities for prevention
- (5) Interventions for prevention, treatment and rehabilitation decrease the burden if implemented widely.
- (6) Therefore birth defects surveillance is needed to help establish the burden of birth defects and prepare health officials for implementation of identified needs and data driven prevention strategies.

Session 2: Overview of birth defects surveillance

Time allocation – 45 min

[Slide 2] Objectives

By the end of this session, participants will be able to:

- Describe the definition, purpose and importance of public health surveillance for birth defects
- Understand the objectives and importance of birth defects surveillance (BDS)
- Understand different types of birth defects surveillance
- Compare population-based surveillance versus hospital-based surveillance

Note: Let participants know that this part is discussed in detail in the *Birth defects surveillance: a manual for programme managers* by WHO/CDC/ICBDSR Chapter 1.

Public health surveillance – Definition

Ask participants: Can anyone give me a definition of public health surveillance?

After participants have provided their responses, project the slide

[Slide 3]

Public health surveillance is the

- ongoing*
- systematic collection*
- analysis and interpretation of health data, and*
- timely dissemination*
- for public health purposes.*

Purposes of birth defects surveillance:

What are some purposes for which surveillance data could be used? Ask participants to provide responses aloud.

[Slides 4-5]

The following are main objectives of a birth defects surveillance programme:

- (1) To define the magnitude and distribution of birth defects by time, person and place
- (2) To identify high-risk populations or identify clusters (aggregation of cases)
- (3) To refer affected infants to appropriate services in a timely manner

- (4) To monitor trends in the prevalence of different types of birth defects in a defined population

Additional objectives are:

- (5) To provide scientific data and information for priority setting, planning, implementing and evaluating birth defects programmes
- (6) To disseminate findings and interpretations to appropriate partner organizations and government agencies in a timely fashion
- (7) To provide a basis for epidemiologic research and prevention programmes
- (8) To inform public health and health-care policies and programmes
- (9) To plan for needed services among the affected population

Ultimately, the purpose of birth defects surveillance is to define and characterize the burden of birth defects; help design prevention strategies for birth defects and treatment and care for individuals living with a birth defect and to help identify resources.

[Slide 6]

Types of surveillance of birth defects

Birth defects surveillance is of two types:

- Population-based and
- Hospital-based.

[Slide 7]

Population-based programmes collect data from the entire population (all mothers giving birth to children either within or outside of a maternity facility, in a defined geographic area). The denominator would be the total number of births (live births and stillbirths).

[Slide 8]

Advantages and disadvantages of population-based surveillance

It includes ALL births regardless of place of delivery (especially useful for countries with many home deliveries), and it provides accurate prevalence estimates, less prone to referral bias. The findings are easy to generalize and hence also useful in evaluating the impact of an intervention.

However, population-based programmes are resource-intensive and take more time to establish.

[Slide 9]

Hospital-based birth defects surveillance programmes capture all pregnancy outcomes with birth defects that occur in selected hospitals in a defined geographic area (for example, a state, province, or county). Inclusion in a hospital-based programme depends on where the birth occurred rather than on the residence at birth. The denominator used to estimate prevalence in a hospital-based programme consists of births occurring in the participating hospitals. The numerator (cases) typically consists of affected live-births and stillbirths occurring in these same hospitals. Fetuses or newborns with birth defects who are delivered at home are not included, even if they are identified and captured in participating hospitals (because they are not part of the denominator).

[Slides 10–12]

Explain the features of hospital-based birth defects surveillance

- All fetuses or newborns with birth defects born to mothers in participating hospitals, regardless of maternal residency, are included in the programme. Fetuses or newborns with birth defects born to resident mothers *but born outside of a participating hospital or at home* are not included. Fetuses or newborns with birth defects born to *nonresident mothers* are included if born in a participating hospital.

So in a hospital-based programme, place of birth (participating hospital) is important and not the residence.

[Slide 13]

Advantages and disadvantages of hospital-based surveillance

Advantages

- Less resource intensive
- More efficient
- Can be started quickly
- Can generate high-quality data
- Can provide baseline data
- We need to identify **motivated champions** in these hospitals for ensuring good quality data.

Disadvantages

- Fetuses and neonates delivered at home would not be included, even if identified later in life in participating hospitals. Hence prevalence may be underestimated.
- May not be representative since hospital-based programmes are vulnerable to referral bias, since some hospital users may have particular characteristics.
 - Hospital births may only be common among families with higher socioeconomic status.
 - Hospital births may be more common among women who have been identified as being at high risk for a complicated birth.
- Cannot be used longitudinally for monitoring
- May be unreliable in evaluating the impact of an intervention

Nevertheless, in countries where nearly all births take place in the hospitals and all hospitals participate in the BD surveillance, hospital-based surveillance programmes can closely approximate true prevalence.

[Slide 14]

Summarize

- A country's selection between population-based and hospital-based surveillance programmes will depend on available resources and capacity.
- Countries with limited resources may choose to start with a hospital-based surveillance programme and expand it over time into a population-based programme. Population-based and hospital-based surveillance programmes are discussed in more detail in the Manual.

- Both population-based and hospital-based programmes may use a short period of time soon after birth to capture a birth defect in a neonate, since neonates are discharged within hours or days following birth. Internal birth defects and birth defects that are commonly identified after the neonatal period, such as congenital heart defects, are often missed unless the programmes have resources to conduct follow-up with children after discharge from the birth hospitals.

In SEAR countries, a hospital-based programme is being implemented in the initial phase.

[Slide 15]

Your hospital has been selected because of:

- High number of births
- Willingness to participate
- Experience of reporting other conditions to the ministry of health – such as number of births, complications, number of cases of paediatric infections (diarrhoea, pneumonia, hepatitis, dengue, and so on)
- Maintenance of delivery register/log book that may be used to include birth defects.

Session 3: Surveillance approaches

Time allocation - 60 min

In this session, three important topics will be discussed to make participants understand about the various surveillance steps: Case ascertainment, case finding and case inclusion.

3a: Case ascertainment – (Time: 15 min)

Case ascertainment actually means how to capture cases.

[Slide 2] Objectives

By the end of this session, participants will be able to:

- Describe the types of case ascertainment
- Describe the advantages and disadvantages of active and passive case ascertainment

[Slide 3] Methods of case ascertainment

- There are three methods for case ascertainment: **active**, **passive** and **hybrid** (a combination of active and passive)
- Each method has advantages and disadvantages

[Slide 4]

Active case ascertainment – Abstractors/surveillance personnel are hired and trained to abstract data from all participating hospitals.

- Abstractors regularly visit or have electronic access to participating hospitals
- Abstractors actively review multiple data sources such as log books, and medical, discharge and death records in the hospitals to identify cases.
- For those fetuses or neonates identified in the log books as having a birth defect, abstractors should use the maternal and infant medical records to record relevant information required to fill the reporting form.
- Medical records must be complete with relevant information in a format that can be readily identified and abstracted by the abstractors, who often have limited medical background. For example, the SEAR-NBBBD standard data abstraction form can be included in the medical records (case sheets).
- Advantages
 - This method usually improves case detection and case reporting, and improves data quality because more extensive clinical detail is collected.

- Disadvantages
 - This type of case ascertainment requires considerable surveillance programme resources and personnel.
 - The burden of work is placed on surveillance personnel.

[Slide 5]

Passive case ascertainment – Birth defects are reported by the hospital staff to the surveillance programme.

- The information that is reported to the surveillance system is not verified by surveillance personnel from the medical record.
- Advantages
 - This type of case ascertainment is less expensive because fewer surveillance programme resources and personnel are required.
- Disadvantages
 - The burden of reporting falls on hospitals, clinics or other sources that may require time and effort from already busy staff.
 - Case detection and case reporting can be compromised because of the following:
 - Not all cases are reported, leading to an underestimate of the number of cases – some cases may be missed as hospital staff do not actively look for birth defects in all babies born in the hospital
 - Stimulated/incentivized reporting may result in overestimation of certain birth defects
 - Incomplete documentation, resulting in less detail on each case
 - Personnel may have varying levels of training and commitment, leading to inaccurate information
 - Less timely reporting, leading to a delay in analyses and communication
 - Variation in reporting over time may generate spurious trends or hide real ones

[Slide 6]

Hybrid case ascertainment – uses a combination of passive and active reporting systems.

- This method may use active case ascertainment to gather more detailed case information for specific birth defects or to verify passive reporting for a percentage of all reported birth defects, as a quality control measure.

For example:

- A surveillance programme can use active ascertainment of neural tube defects to gather more detailed case information in a timely manner, while also using passive ascertainment of the other birth defects under surveillance.
- A programme can use passive reporting with active follow-up verification of the accuracy of data submitted.
- A programme can conduct active case ascertainment from some sources, such as birthing hospitals, and accept passive reporting from other sources, such as cytogenetic laboratories.

In your hospital, the nodal officer will be responsible for periodically verifying cases of birth defects to ensure completeness and accuracy.

[Slide 7]

Summarize the three systems – and provide clarifications.

3b: Case finding – (Time 15 min)

[Slide 2]

Objectives

By the end of this session, participants will be able to know:

- the differences between a single data source and multiple data sources
- there are several sites in the hospital to find cases of birth defects

[Slide 3]

Types of data sources

There are two types of data sources – Multiple and single source

Multiple source data means that you are procuring data from multiple sources within the hospital like the labour room, operation theatre (for caesarean deliveries), postnatal ward, newborn care unit, pediatric unit, pediatric surgery and orthopaedics units etc. Or, you are collecting data from hospitals such as prenatal services, maternity hospitals, as well as from treatment and rehabilitation centers, genetic labs, parent groups etc.

Advantage – It obviously provides more information and improves case ascertainment and data quality

Disadvantage – Time consuming

Single source data means that data are procured from a single source; for example, maternity hospitals.

It provides less information and results in under ascertainment and poor data quality.

In this programme, you will be capturing from multiple sites within your hospital.

[Slide 4]

Explain: In your hospital, birth defects would be captured in the following locations:

- Labour room
- Operation Theatre where Caesarean deliveries take place
- Postnatal ward where mother and baby are roomed-in for 24–48 hours before discharge
- Newborn unit/paediatric ward where sick babies are admitted soon after delivery or shifted from postnatal ward
- Others e.g. paediatric surgery ward

Using multiple sites to collect data, such as from units other than the delivery unit (as above) may improve data quality by increasing the number and amount of information for identifying cases of birth defects.

[Slide 5]

For example, a milder case of club foot, or a cleft in soft palate may be missed in labour room and detected only in postnatal ward or newborn unit.

3c: Case inclusion – (Time: 20 min)

[Slide 2] Objectives

By the end of this session, participants will be able to:

- Identify particular birth defects for inclusion in the surveillance
- Describe inclusion criteria used in the birth defects surveillance

[Slide 3]

The criteria for inclusion include the type of birth defects, the age up to which a case can be included, the pregnancy outcome and the gestational age or birth weight.

[Slide 4] Type of birth defect to be included

For case inclusion – one can debate to include all birth defects or include selected birth defects. It is basically tailored to the interests in the country and resources available

[Slide 5]

Selecting particular birth defects: Project the slide and explain the criteria of selecting birth defects for birth defects surveillance and prevention:

- (a) Public health burden for a particular birth defect
- (b) External major birth defects that are easy to diagnose without much investigations
- (c) Intervention for prevention is available
- (d) There is an urgency to treat

[Slide 6-9]

Based on these criteria, the birth defects that have been identified for SEAR countries in the initial phase are shown in the first column of the table.

Some countries may choose additional birth defects (as shown in the second column) based on the capacity to diagnose.

Externally visible major birth defects	Others
1. Neural tube defects	1. Down syndrome
2. Oro-facial clefts: Cleft lip/cleft palate	2. Congenital diaphragmatic hernia
3. Talipes equinovarus – Club foot	3. Congenital heart disease
4. Limb reduction defects	4. Tracheoesophageal fistula
5. Hypospadias	5. Exstrophy of bladder
6. Exomphalos / Omphalocele	6. Other defects
7. Gastroschisis	
8. Imperforate anus	

[Slides 10-12] Age of Inclusion

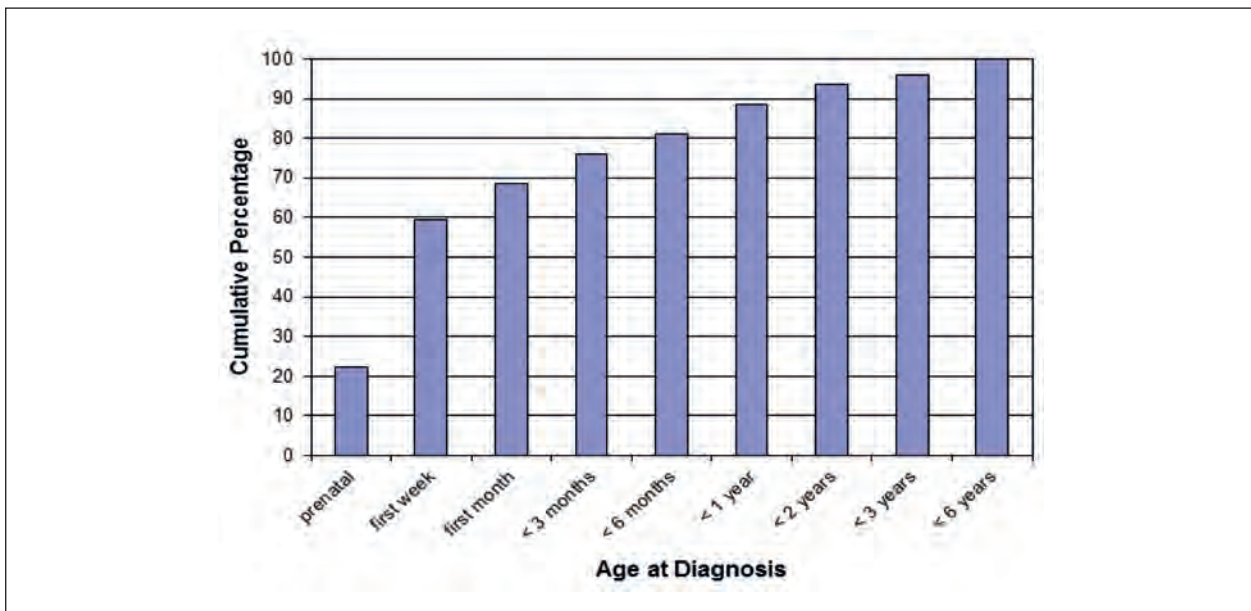
Now let us discuss Age of Inclusion. Age at diagnosis is a critical component of the case definition. Many countries may have different age inclusion criteria.

- The higher the age threshold, the greater the ability to identify additional birth defects. This is especially true for internal birth defects that might not be evident at birth, such as heart defects.
- The higher the age threshold, the greater a programme's expense because additional resources may be needed for follow-up.
- For SEAR-NBBD, the age of inclusion is limited to the first 7 days of life.

[Slide 13]

Explain to participants the graphic on the slide, which represents how researchers examined the age at diagnosis for all birth defects reported to the Western Australia Birth Defects Registry from 2000 to 2001.

Figure 1: Cumulative percentage of cases of major birth defects by age at first diagnosis



- As shown in Fig. 1, nearly 60% of all major birth defects reported to this registry programme are diagnosed during the first week; nearly 70% during the first month; nearly 90% during the first year; and nearly 100% by the sixth year of life.
- Prenatal diagnosis is not able to identify all birth defects.
- The birth defects that take longer to identify are probably not visible at birth.
- It is important to notice that most birth defects are captured during the first year of life.
- This graph is for all birth defects under surveillance and reported to the programme; if it only included external birth defects, the graph would probably look very different, since most such birth defects would be picked up soon after birth.

[Slides 14-15]

Selecting types of pregnancy outcomes:

Various pregnancy outcomes are

- Live births
- Stillbirths
- Spontaneous abortions/miscarriages
- Elective terminations of pregnancy with fetal anomalies, also known as ETOPFA
- Elective terminations for other reasons

Ask the following questions to generate discussion:

How are stillbirths defined?

- Possible responses: ≥ 28 weeks' gestation, ≥ 1000 g if gestational age unknown. However, some countries may define stillbirths as ≥ 22 weeks' gestation or ≥ 500 g if the gestational age is unknown.

[Slides 16-17]

If possible, surveillance programmes should aim to ascertain birth defects among all pregnancy outcomes, with the exception of early spontaneous abortions.

- Including as many types of pregnancy outcomes as possible ensures detection of maximum number of birth defects.
- Inclusion of live births alone is a significant limitation that can lead to unreliable rates and trends, particularly for conditions with a high rate of fetal loss. An example of such a condition is anencephaly.
- In your hospital, you will be required to include all live births and stillbirths to provide a more accurate estimate of the prevalence of birth defects.
- In some countries, it can be difficult to include stillbirths that occur before 28 weeks gestation and terminations of pregnancy for fetal anomalies.
- If a country has the capacity to ascertain stillbirths prior to 28 weeks, doing so can help provide a more accurate estimate of the prevalence of conditions such as anencephaly.

[Slide 18]

This graph shows that most of the pregnancies with anencephaly have been terminated or resulted in fetal death. Cuba –100% termination of anencephaly, Utah only 10% live births as anencephaly. So if we exclude termination and stillbirths, it will lead to underestimation of the anencephaly burden.

[Slide 19]

Similarly for spina bifida, the majority occur in live births in Utah, whereas in France, the majority as MTPs.

[Slide 20]

Your hospital would follow the inclusion criteria for the following criteria.

- *Baby born in the hospital with a birth defect*
- *Age at diagnosis: At birth and until 7th day*
- *Pregnancy outcome: live births and stillbirths*
- *Gestational age (≥ 22 weeks or ≥ 500 g)*

[Slide 21]

This flowchart tells you how you should go about filling the forms when you have a live birth or a stillbirth. If there are visible birth defects, you need to fill out the BD form.

[Slide 22]

Summarize the features of SEAR-NBBD

3d: Exercise – (Time 10 min)

[Slides 1-26]

Now the facilitator should conduct a quiz based on Session 3 using slides with questions and correct responses.

You may limit the number of questions depending on the availability of time.

If required, the slides can be used for providing clarifications during spare time.

Session 4: Data-collection methods and tools

Time allocation - 30 min

[Slide 2]

Objective

- To understand about data-collection methods and tools

[Slide 3]

Collecting data requires appropriate data-collection tools, such as an abstraction form for recording the standard information.

The two most commonly used collection methods are:

- Paper-based data recording
- Electronic data recording

[Slide 4]

Paper-based methods are still widely used for vital registration, surveillance and research purposes.

- Advantages:
 - May be cost-effective for low-resource settings
- Disadvantages:
 - Prone to human error, since transcribing is required
 - Requires more time to collect data and transfer to the data management centre

[Slide 5]

Electronic methods are improving as technology evolves. The ideal electronic collection tool should be able to collect data and provide data securely to a data management centre for storage and analysis.

- Advantages:
 - Improves record accuracy
 - Allows quick data transfer to a data management centre
 - Identifies missing data in a timely manner
 - Ability to take and transfer digital photographs
- Disadvantages:
 - More vulnerable to theft
 - Can compromise privacy/security if data are not encrypted
 - Requires training on how to use an electronic system

[Slides 6-7]

Project the SEAR-NBBD data abstraction form on the slide and ask participants to refer to the SOP document.

Mention that SEAR-NBBD is an electronic database for birth defects surveillance that uses a standard data abstraction form. It is a brief form that was developed in consultation with regional experts with focus on simplicity and feasibility. All participating hospitals in the countries are using this form. There will be an exercise on filling the form to get familiar with the fields. Emphasize that some fields are mandatory without which the form will not be accepted by the electronic system.

Exercise

Time allocation –30 min

Please distribute a paper copy of the birth defects abstraction form (blank) and the definitions form (defines all the fields on the BD form) to all.

[Slide 8-9]

Case details are provided in the slide. Ask each participant to use this information to fill the form. Give 10–15 minutes.

[Slide 10]

Ask participants to compare the form they have filled with the form on this slide.

Discuss if there are any issues or clarifications.

[Slide 11]

Explain that when they fill the information on the computer in the online system, this is how it will look like.

Session 5. Introduction to SEAR NBBD electronic database

Time allocation – 90 min

[Slide 2] Objectives

- (a) Introduction to the SEAR-NBBD electronic database
- (b) Steps on using the database

Section 5a: Introduction

[Slides 3-4]

Explain that WHO-SEARO has developed the SEAR-NBBD database, which is an electronic integrated database for newborns, stillbirths and birth defects for hospitals. It is a user-friendly secure web-based platform that has been used by countries in the Region.

The birth defects component of the database is used to study the at-birth prevalence of birth defects and their distribution for births taking place in participating hospitals. All live births and stillbirths are screened for presence of a birth defect, and the information is captured by using three standard data abstraction forms in the SEAR-NBBD database that will be described in this session.

[Slide 5]

The newborn component of the database is used to get prospective information on neonatal morbidity and mortality (including birth defects) as well as use of important clinical interventions such as use of oxygen, pattern of bacterial flora and the antibiotics resistance pattern. The software helps to print a standardized discharge summary (customized with hospital name) of the baby admitted in the newborn unit. The ongoing monitoring of these parameters is used to improve the quality of services being provided in the neonatal units in participating hospitals.

[Slide 6]

The stillbirth component of the database is used for studying the stillbirths that occur in hospitals, including type of stillbirth, maternal risk factors, care during antenatal period, antepartum complications, intrapartum complications, delivery care, fetal and placental risk factors, and cause of the stillbirth.

If birth defect/s is noticed in the live birth or stillbirth, the information is included in the newborn and stillbirth components through the standard BD form.

[Slide 7]

Salient features of SEAR-NBBD

The standardized system of data collection, management and analysis allows WHO-SEARO to study the regional situation as well as undertake comparison among countries.

Project the slides and explain that the SEAR-NBBD system offers the following features:

- (1) Web-based (Online) System: Easy-to-use software that provides the following advantages:
 - (a) Standardization of data capture, submission, analysis and feedback
 - (b) Efficiency of data management
 - (c) Alerts and reminders are sent for timely submission of data and for corrections that may be required.
- (2) Data Privacy and Security:
 - (a) There is no insistence to enter name of mother, father or the baby. However, this information will be useful if you are generating the discharge summary of the baby admitted in the newborn unit. Please note that names are hidden in the database in any case and are not visible to anyone beyond your hospital.
 - (b) Access to the system is provided only to authorized persons /institutions with password protection.
 - (c) Adequate firewall protection is provided in the system.
- (3) Capacity-building:
 - (a) Necessary training is offered to the staff in the participating hospital
 - (b) Technical know-how on standard coding of birth defects is provided
 - (c) Ongoing support for building capacity in data capture, submission and analysis is provided
- (4) Quality assurance: The database is supported by a dedicated team of professionals at SEARO and WHO Collaborating Centre, AIIMS, New Delhi, to ensure quality:
 - (a) Checking for completeness of data
 - (b) Checking for accuracy of numerator, denominator, description and coding of birth defects, and newborn conditions
 - (c) Ensuring timeliness of reporting and analysis
 - (d) Sending immediate feedback for information and ensuring corrections, if required
- (5) Problem-solving support: The dedicated NBBD database team provides solutions through email, calls and chats.

- (6) Compilation, analysis, interpretation and reporting back:
 - (a) For Regional, country and hospital levels
 - (b) Monthly, quarterly and annually
 - (c) Comparison among countries

- (7) Migration to country system: As the national capacity develops and data systems get ready, SEARO would be able to support migration of the database capacity into the national systems.

[Slides 8-9] Hierarchy of roles

Hierarchy of roles in a particular pattern is observed in the SEAR-NBBD system.

Indicate each role and its link with the next level:

- (1) **Data reporters (DRs) in the hospital: Doctor, nurse, data entry operator who have received training in BD surveillance**
 - Collects and reports data

- (2) **Hospital nodal officer: 1st verifier – paediatrician, neonatologist, gynaecologist**
 - Trains hospital staff (DRs)
 - Checks completeness, accuracy and timeliness of data at hospital level
 - Analyses data, prepares reports, provides feedback to hospital team

- (3) **Country Network Coordinator: 2nd verifier – The hospital designated by the MoH/SEAR-NBBD**
 - Coordinates with all participating hospitals in the country and builds their capacity
 - Checks for completeness, accuracy and timeliness of data from all participating hospitals (electronically)
 - Analyses data, prepares reports, provides feedback to hospitals

- (4) **WHO-SEARO NBBD Database Manager**
 - Monitors the overall function of the database
 - Assigns the roles and creates new network(s) hospitals in the system

Details will be provided in subsequent sessions and in hospital SOPs.

Section 5b: Steps for using the SEAR-NBBD database

[Slide 10]

Project slides and mention that the following steps will be covered in this section:

- (1) Registration with SEAR-NBBD
- (2) How to log in
- (3) Input data –
 1. Submitting the forms (BD forms)
 2. Monthly denominator (check point)
- (4) Other functions in the ribbon
 1. Dashboard
 2. Search records
 3. Reports on data monitoring
 4. Help and tips

[Slide 11]

Explains the procedure of registration

Step 1– Registration with SEAR NBBD database

Ask participants to open to page No. 26 in SOP document where they can go through the slides provided therein.

There are two ways of registering:

Option – 1: On request

Option – 2: Online

[Slide 12]

Option 1: On request through email addressed to secah@who.int

The hospital can send an email with the following information:

- (1) Name
- (2) Designation
- (3) Area of interest for which data will be collected: 1. All Newborns (delivered and admitted in the hospital); 2. Sick Newborns (admitted in the newborn unit); 3. Birth Defects in all births occurring in the hospital; and 4. Stillbirths
- (4) Annual delivery load in the hospital
- (5) Role required (DR/DEO or nodal officer)

- (6) Hospital name
- (7) Country
- (8) City
- (9) Email ID (Personal or create an Institutional ID); only Gmail or Yahoo are accepted. *If you have Hotmail, that can be registered by online only.*
- (10) Phone Number

WHO SEAR Office will send you a confirmatory email to inform you that your ID has been registered and log in details will be provided.

[Slides 13-16]

Option 2: Direct request through Online

Go to website link → <http://apps.searo.who.int/npn/>

You can use your personal Gmail, Facebook, Yahoo or Hotmail ID. *Or, you can create an institutional ID for your hospital/centre.*

Click on the Email icon depending upon your email ID.

When you first-time log in with your Email ID, the email provider asks for the authentication; please accept it.

After accepting, this will take you to the registration form. Fill the registration form.

After submitting the request for system access, the request will come to WHO-SEARO for approval.

Once it is approved, you will be informed by an email from WHO-SEARO with login details and site link.

You can log in to the system only after approval of your registration by WHO-SEARO.

[Slide 17]

How to log in and fill the BD form

Participants are requested to follow along with the presentation through the pages in the SOP document corresponding to the projected slides to understand the functions of the system.

After confirmation of your registration by WHO-SEARO, you can enter the database at the web link <http://apps.searo.who.int/npn/>

On the homepage, click on the approved email icon for which your registration was approved with the SEAR-NBBB system.

You can sign in with your email address and your personal password that you normally use to open your emails.

[Slide 18]

When you are logged in, you will notice a popup message window, where SEAR-NBBD posts regular communication messages. Once you have read the message, you can close the popup box; and behind that, you will see another message describing the status of the forms submission, verified OK, rejected, etc....

[Slide 19]

Now you will see the home screen of the SEAR- NBBD. On the home screen, you will notice on the top right-hand side: Your Name, Email ID, Location and Role

Welcome: WHO SEARO [searo.who@gmail.com] | Location: SEA \ IND \ TEST [Data Entry Operator]

[Slide 20]

How to input data

- (a) From the menu bar, you can choose newborn or birth defect or stillbirth form – based on the interest of your hospital/country.
- (b) However, in this training, we will be focusing on the birth defects form only. The SEAR-NBBD system is similar for both newborn and stillbirth.
- (c) Upon clicking the BD form, there will be two options – Inborn live birth and outborn live birth (babies delivered outside the hospital but brought to the hospital). All birth defects cases among inborn babies must be reported in the SEAR-NBBD. Birth defects in the outborn babies, if entered in the system, must be analysed separately.

[Slide 21]

Clicking on Inborn live birth or Outborn live birth will open a blank birth defect form.

The first section is for recording the **Basic information**. There you fill the baby and mother's hospital number. A unique NBBD number is generated automatically upon submission of the completed form.

Participants have already done an exercise on the BD form in session 4 and must be familiar with each field. If needed, ask them to open the definition form and explain once again the different fields on the BD form.

On the slide, go through the different callouts one by one.

Similarly, fill **Section 2** of the form: **History of Birth Defects**

Go through the fields one by one and discuss the options available in each of them.


[Slide 22]

Section 3. Type of Birth Defect(s)

- (1) Click 'Select' to open the dropdown menu of the type of BD.
- (2) Please select the appropriate BD type from the dropdown list. It will automatically provide you with the ICD Code for the selected birth defect.
- (3) For the birth defects not in the dropdown list, please select **others**. For such birth defects, you will have to manually enter the ICD coding based on the description, photographs and investigations available.

[Slide 23]

Use Photo Atlas

You may also choose the birth defects type and code from the **Photo Atlas provided**. To view the Photo Atlas, click the catalogue icon  that appears below the Select box.

Selection of the appropriate photograph and description will automatically provide you with the ICD Code for the selected birth defect.

[Slide 24]

Full description of the BD

Please provide full clinical (anatomical) description of the birth defect and not just the final diagnosis.

[Slide 25]

Assign the Code (ICD-10) to the BD

- (1) The ICD code can be obtained from the dropdown list, Photo Atlas catalogue as explained earlier.
- (2) If you select the type of birth defect as "others" you have to assign the ICD-10 code manually based on the description and picture of the birth defect. For the coding, you may use the reference document ICD-10 coding list – To view it, click the hyperlink to opens the pdf file of the coding list.
- (3) Select **Confirmed** (if the diagnosis of the BD is confirmed clinically) **or Possible** (when additional investigations or expert opinion are required before confirmation of the diagnosis of the birth defect).
- (4) Click **Save** – this will save the information entered in the birth defect row.
- (5) Click **Add New** to fill information on multiple birth defects or if a new or an additional birth defect is detected before discharge of the baby.

[Slide 26]

Upload photographs

- (1) Provide investigation reports and any findings to better characterize the birth defects.
- (2) Click **Yes** to upload clinical photographs of the birth defect.
- (3) Click **Save** to save the record in the system.
- (4) Click **Add New** to upload additional picture of the BD with different angle of view.

[Slide 27]

Monthly denominator (check point)

Upon logging in a set of fields appears on the 10th day of every month.

Asking for:

- Total births (including multiple births) in the hospital during the previous month
- Total live births
- Total stillbirths
- Total birth defects

Without filling these denominator details for the previous month you cannot move ahead to fill the new form, so please get these details from the hospital records during the first week of every month.

[Slide 28]

Alert

An Auto Email Alerts goes off on the first day of every month to DRs/DEO and Hospital/network administrators if there is no form uploaded during the last month.

For more details about the data management on SEAR system, one can refer to the SOPs for Hospital-based Birth Defects Surveillance.

[Slide 29]

Other functions on the ribbon

Dashboard

The dashboard screen displays daily and overall statistics of newborn and birth defects forms that have been uploaded at your hospital. If you are the national coordinator and have admin rights, you can see the status of forms uploaded from all hospitals.

Show how to get to the dashboard

The dashboard option is available on the ribbon of the home screen. With a click, the dashboard will open.

The dashboard gives you an overall view of the statistics of forms that have been uploaded. The information includes the type of forms (newborns, stillbirths and birth defects alone), status of verification and rejection of forms, and denominator. Some graphics are also provided including daily, weekly and monthly statistics. The geographical map is a useful graphic to understand the distribution of the reporting hospitals and the load of cases.

[Slide 30] Search function












Records can be searched based on the following criteria:

- (1) **Form Type** (Select the form type from the dropdown list)
- (2) **Search Text:** You can search records based on the **Baby hospital record number** or the **NBBD Number**, which is generated automatically when you submit the form; any other criteria should not be selected in this case.
- (3) **Forms filled on – to- :** Select the date range on which the forms were filled that you want to review.
- (4) **Status:** The status of the form could be: Incomplete, Complete, Verification Pending, Verified, or Rejected

Explain the use of the search function:

- Retrieve cases by the case number
- For time period
- Specifics category (NB/BD/SB)
- Get update on status of the cases (uploaded/pending submission/verified/rejected)

[Slide 31] Understand icons in Search

-  Import the search results in Excel for record keeping purpose
-  Newborn form
-  Birth Defects form
-  Discharge Summary
-  Incomplete Forms
-  Completed Form / Submitted
-  Verification Pending
-  Action Taken by DRs/DEO
-  Verified by 1st Verifier
-  Verified by 2nd Verifier
-  Rejected By Verifier

[Slide 32] Some examples of search based on the above criteria

To see all birth defect forms uploaded by your hospital:

Select **“Birth Defect (All BD)”** in the Form type

Keep “**Search Text**” and “**Form Filled On**” and “**to**” boxes blank

Select “**Status**” as “**All**”

When you press GO, it will give you the full list of all forms that have been uploaded.

[Slide 33]

Some examples of search

Similarly, if you select the “**status**” as **Incomplete**:

Then you will get the list of forms that are incomplete or not submitted for verification.

[Slide 34]

Some examples of search

To view the forms rejected by the verifier:

Select “**Status**” as “**Rejected by Verifier**”

Then you will get the list of forms that are rejected by the verifier due to some reasons. You can check the reason for the rejections from the comment box of each form one by one.

[Slides 35-37]

Report section

Reports are possible on data monitoring and data analysis.

This feature is used to get summary information of the data entered by your hospital from the system.

This could be used to monitor the data entry and improve the quality of data reporting.

The section on analysis is useful to obtain basic analysis of the data.

There are options to export the data from the system to Excel format so that it can be analysed according to the hospital’s requirements.

The report section will be described and demonstrated in detail in session 7.

[Slide 38-39]

Help

Click the ‘Help’ button to get this popup window.

This help section provides some useful information on the SEAR-NBBD system. It provides the soft copies of the user manuals and case abstraction forms with their definitions.

There are self-learning modules for the user to get familiar with their roles and functions in the SEAR-NBBD system.

Please take time to go through these materials to improve your competency.

[Slide 40] Tips

Explain tips on how to enhance the function of the NBBB system.

- **Use Internet Explorer** – all functions in the NBBB system are functional in the Internet Explorer – If any other browser is used, you might encounter limitations.
- **Enable Popups** – When the browser asks for enable Popups, enable it.

Logout – to log out properly, you need to log out from the database as well as from the shared account that you were using – Yahoo/Google, etc.

If you encounter any problem, report the problem in the following way by email:

Send full details with screen shots to the SEAR data manager:

- Provide the name of your institution and login ID used at that time
- Description of the error in details

Session 6: Coding principles

Section 1: How to code a birth defect

Time allocation – 45 min

[Slide 2] Objectives

By the end of this session, participants will be able to:

- Understand the importance and the principals of coding
- Know advantages and disadvantages of ICD-10 and ICD-10 RCPCH extension
- Identify critical issues for coding
- Understand the importance of good clinical description, photographs and drawings for accurate coding
- Provide full description of the birth defects
- Understand certainty of diagnosis.

*Note: Please inform and show that this part is discussed in detail in the *Birth defects surveillance: a manual for programme managers* by WHO/CDC/ICBDSR Chapters 4 and 5.*

[Slide 3] Coding

What is coding?

Coding is translating diagnoses of diseases and other health problems from words into a standard numeric/alphanumeric character.

Why do we need coding?

There are many diseases conditions, and coding helps to facilitate:

- Storage, retrieval, analysis and interpretation of data in a standard manner
- Compilation of data that is internationally consistent
- Allows valid comparison within and between populations.

[Slides 4-6]

Introduction to the International Classification of Diseases

We are now going to discuss how birth defects are coded utilizing the *International statistical classification of diseases and related health problems*, 10th edition, also known as the ICD-10.

- The ICD-10 is developed and maintained by WHO, and is considered the international standard diagnostic classification system. The most recent version of the ICD-10 is available on the WHO website <http://apps.who.int/classifications/icd10/browse/2010/en>
- It is useful in assisting with analysis and assessment of the health situation of population groups and for monitoring the incidence and prevalence of diseases and other health conditions.

[Slide 7]

ICD-10 codes are listed in alphanumeric order and are described in detail. Classification of structural birth defects is found in Chapter XVII: Congenital malformations, deformations and chromosomal abnormalities (Q00–Q99). Classification of haemolytic anaemias (thalassemia and sickle cell disorders) is found in Chapter III: Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50–D89). Inborn errors of metabolism (E70–E90).

- Congenital malformations, deformations and chromosomal abnormalities (Q00–Q99). Chapter XVII contains the 11 blocks of codes that are arranged to describe birth defects from head to toe (cranio-caudal order).

[Slides 8-9]

Introduce the parts of an ICD code

The first alpha character denotes the category of the disease/defect, and then the first two numeric characters denote the anatomic part or severity of the disease and finally with the last two characters, the decimal points denote the specificity of the disease or defects.

Slide 9 explains an example of the ICD code.

Q05.0 – Please note that before the zero after the decimal point, there is no space and no special characters used in the code.

When the condition is nonspecific, it is usually coded with a numeric nine after the decimal point – Qxx.9 or for example, “Q01.9 Encephalocele, unspecified”.

Sometimes you do not have a choice. However if possible, the use of codes for nonspecific diagnoses should be avoided.

[Slides 10-11]

Discuss the limitations of the ICD system and how to address them:

- Not as accurate as desired for birth defects surveillance
- No formal distinction between major and minor defects
- Not specific enough for some defects
 - Some cardiac defects, limb deficiencies

- Arbitrary classification of some genetic syndromes
 - Meckel-Gruber syndrome = Q61.9 Cystic kidney disease, unspecified
- Many syndromes are not included
- No specific codes for some rare defects
- At times, erroneous nomenclature

[Slide 12]

RCPHC extension

The ICD-10 codes lack specificity for uniquely coding some birth defects and most genetic syndromes. Therefore, some birth defects surveillance programmes use their own local modification of the ICD-10 that includes additional codes for some specific birth defects not found in the ICD-10, and add an extra digit to allow for more detailed coding of some birth defects and specificity of diagnoses.

- As a result of this lack of specificity of ICD-10 codes, the Royal College of Paediatrics and Child Health (RCPCH, UK) developed an adaptation of the ICD-10. Please refer to Chapter 5 of WHO/CDC/ICBDSR, *Birth defects surveillance: a manual for programme managers*, for an example of this adaptation of the ICD-10.
- This adaptation is most commonly used by programmes carrying out public health surveillance of birth defects.

The RCPCH classification – use of the **extension code** can provide more specific coding by providing a code at the second decimal point. Elaborate on this with the example – Q01.8 with RCPHC extensions 0-3 used for Encephalocele to further specify.

This is not used in SEAR-NBBD database at present.

[Slides 13-15]

Distortion of the information during coding

Explain that there is a risk in using a coding system. There is a possibility of losing information at each stage of the coding process. However, the likelihood of this distortion of information can be minimized by using:

- **Verbatim description of the birth defect**
- **Photographs**
- **Drawings / sketches**

[Slide 16]

Clinical (anatomical) description of the birth defect

It is important to provide adequate and accurate description of the birth defect/s for deciding the code. Poor descriptions will negatively affect data quality.

There are two methods for describing birth defects in data-collection tools: verbatim descriptions and checkboxes. Checkboxes alone might limit data quality.

Verbatim descriptions allow for more anatomical (clinical) detail, which may be necessary for accurate diagnosis.

[Slide 17] Detailed clinical description

Emphasize the importance of a good clinical description and demonstrate the key features required in recording a description of a birth defect. If these details are not addressed in the description, it will lack specificity and lead to wrong coding and classification of the defect.

Explain the examples:

GASTROSCHISIS and OMPHALOCELE – the location of insertion of the umbilical cord to the membrane/sac is important to distinguish the two. So, it is important to include these details in the description.

TALIPES EQUINOVARUS - the deformities at ankle, hind foot, forefoot are unique and need to be described. Also the position, alignment, flexibility need to be checked and reported to provide appropriate coding.

[Slide 18] Photographs of birth defect/s

Photographs of the external birth defects add information to the clinical description and help to ensure that the proper code is assigned. Although it is relatively easy to take photographs, it requires some training to obtain the best photographs.

Guidelines for taking pictures/photographs are provided in Annexure IV of the Hospital SOP document.

[Slide 19] Taking photographs

Describes advantages and challenges of taking photographs

[Slide 20]

provides examples of poor photographs. Discuss the limitations with bad photography:

- Unable to verify defects
- Might miss some associated defects
- Could be miss-classified and miss-coded if the full picture is not seen.

[Slide 21] What can be done if photographs are not taken or cannot be taken?

As an alternative, one can use standardized drawings or sketches to characterize the defect when there is no photography available or the photographs are of poor quality.

[Slide 22] Examples of drawings

Here are some examples of how to provide a drawing of a birth defect.

- Cleft Palate
- Limb Deficiencies

[Slides 23-24]

Coding of minor defects

Ideally, all birth defects should be coded regardless of their health impact, that is, minor birth defects should also be coded, if possible.

Discuss some advantages and disadvantages of identifying minor birth defects, implications of such a policy and alternative approaches if adequate resources are not available for capturing and coding all minor birth defects.

[Slide 25]

Certainty of diagnosis

We are now going to discuss the level of certainty of diagnosis.

- The certainty of diagnosis could vary for live births versus stillbirths and for prenatal versus postnatal assessments.
- In case of pregnancy terminations, the prenatal diagnosis may not get confirmed for many reasons, including the method of termination, the condition of the specimen, or lack of post-termination examination or autopsy of the abortus.
- Among fresh stillbirths and neonates who die shortly after birth, the diagnosis could also cause difficulties if certain examinations such as X-rays or an autopsy are not done.
- For purpose of analysis, it is important to consider '**possible**' diagnoses and '**confirmed**' diagnoses separately.
 - This is achieved by using a separate field on the birth defects abstraction form to include this information.

Ask participants: Give one example of a birth defect with a possible diagnosis.

Possible responses:

- *Live birth with open Spina bifida but neuroimaging could not be done to rule out hydrocephalus – for confirmed diagnosis we need at least a USG of head.*
- *Clinical diagnosis of holoprosencephaly without imaging studies or postmortem examination.*

[Slide 26]

Summary

Recap the session and summarize what had been learned up to now in this session.

- Standard coding system is useful for consistent interpretation and valid comparison of data.
- The ICD-10 is developed and maintained by WHO, and is considered the international standard diagnostic classification system
- We need detailed clinical information, pictures or drawings/sketches of the birth defect for correctly deciding the ICD code.
- In many cases of birth defects the diagnosis can be confirmed only after laboratory, radiological or genetic tests.

Section 2: Coding of birth defects in SEAR-NBBD – Interactive presentation

Time allocation: 45 Minutes

Use the interactive presentation to explain the method for coding the birth defect/s in SEAR-NBBD

[Slide 28]

Simple steps for coding the birth defect/s in SEAR-NBBD database

Explain the steps of coding the birth defect in SEAR-NBBD:

The four steps are:

- (1) Identify the type of birth defect/s: Major or minor, single or multiple
- (2) Fill in the detailed description of each birth defect
- (3) Assign ICD code and state “Possible” or “Confirmed”
- (4) Upload photos/ drawings

Explain the steps through the demonstration case of single birth defect.

[Slides 29-45]

Examples of how to code a single birth defect

Four examples of cases of birth defects are provided. Depending on the availability of time, explain the steps by interactive presentation in as many cases as possible.

[Slides 46-52]

How to code for multiple BDs

The method for coding multiple birth defects in SEAR-NBBD includes the following principles:

- Mention each defect in separate rows (10 rows have been provided in the BD abstraction form)
- Always list the defects in cranio-caudal order and from major BD to minor BD.
- Provide anatomical description of each defect
- Assign the appropriate ICD code for each defect
- Upload the photograph
- When coding syndromes, please provide the list of all associated defects in the above-mentioned manner.

Discuss the case scenario and demonstrate how to do the coding for multiple birth defects.

A baby is born with omphalocele and antenatal ultrasound had shown presence of ventricular septal defect(VSD).

Remember that *coding* is done in head-to-toe manner in the presence of multiple birth defects.

List the first birth defects and provide description.

When examining the baby from head to toe (cranio-caudal direction), the first abnormality encountered is congenital heart disease, that is, VSD.

Provide anatomical description of the defect.

Assign *ICD-10 code* and fill in this defect in the form as shown.

As it was detected on fetal ultrasound, we have to mention it as “Possible,” which means that it is to be confirmed later on ECHO and/or other specialized tests.

The ultrasound picture can be uploaded, if possible.

Then we proceed to the next abnormality – the abdominal wall defect.

Repeat the steps as described in the slides.

Section 3: Group Exercises on Coding of Birth Defects

Time allocation: 30 Minutes

Participants are divided into 4 small groups. There are four sets of pictures of birth defects. Each group will get one set of pictures that shows different types of birth defects.

*Note for Facilitator: all picture sets have different pictures, except for Group 1 and Group 2 picture sets, which share picture 9.

Activity Instructions:

- (1) Each of the 4 groups (consisting of 4–5 participants) will receive a set of 4 pictures labeled with numbers.
- (2) Participants in the group write the number of the picture on the answer sheet and write an anatomical description of the birth defect (shown in that picture). DO NOT put down the ICD-10 code.
- (3) Exchange answer sheets with the description of the BD (**but not pictures**) with another group.
- (4) Based on the description provided by the other group, the likely ICD-10 code is assigned.

Step-1: Give 10 minutes for each group to write detailed anatomical description of the birth defects shown in the pictures; and

Step-2: Give 5 minutes for assigning the ICD-10 code based on the description provided by participants of the other group.

After all have completed their group activity, start the discussion on each defect.

Since the time allocation is limited, select one/two pictures randomly from each group and project the Word file on the screen for everyone to see. First, ask the description from the group that was assigned this picture. Ask other groups to give additional points on description of the particular birth defect.

For example:

- Gastroschisis: fissure of the anterior abdominal wall *lateral* to the umbilicus, accompanied by herniation of the small intestine and part of the large intestine, and occasionally other abdominal organs (**Q79.3**)
- Talipes equinovarus: plantar flexed (talus pointing down), deviation of heel (calcaneus) and forefoot (inward), foot rests on outer side (upward rotation) (**Q66.0**)

Now move on to the diagnosis and coding.

Individual Exercise on Coding Birth defects

Time allocation: 30 Minutes

Case study

Project the case scenario slide and ask participants to fill in the paper form or online form if this facility is available at the training site.

Individual exercise

The data abstraction paper form or online form will be provided to each participant.

Everyone should be asked to complete the “birth defect details” section of the data abstraction form.

Give 10 minutes to complete this task.

Discuss with participants the difficulties in completing this section of the form and possible solutions and means of solving these issues at the hospital level.

Session 7: Data management

Time allocation: 60 Minutes

Quality of data

[Slide 2]

Objectives

- To learn about the importance of quality of data
- Mechanisms to ensure quality of data
- To learn analysis of data

[Slide 3]

Recap key points from previous sessions

- Cases with birth defects (live and stillbirths) can be identified at various places in participating hospitals.
- Relevant information of the baby with birth defect/s needs to be filled in the standard abstraction form.
- Birth defects are coded using the ICD-10 system based on adequate descriptive information of the birth defects, photographs and confirmatory reports as required.
- Information on birth defects is submitted online on the SEAR-NBBD system.
- Information on birth defects needs to be verified at participating hospitals and at national and regional levels.

[Slide 4]

Quality of data

- Quality of data collection, storage, management and analysis are critical for a birth defects surveillance programme.
- It is important that data collection and analysis are done in a systematic way by trained personnel and ensure accurate interpretation.
- Poor-quality data can lead to false conclusions about the occurrence of birth defects in a population, and weaken the credibility of the programme.
- Inaccurate interpretation could have an adverse impact on the decision-making process of public health authorities.

[Slides 5-6] Quality of data

- The important attributes of high-quality data are:
 - *Completeness*
 - *Accuracy*
 - *Timeliness*
- Completeness refers to the extent to which data are comprehensive. For example, all cases at a given source in a specific timeframe have been identified, and all required data have been abstracted. Hospital audits and linkage of cases to other sources of data, such as vital records or specialized diagnostic centres, can help evaluate the completeness of case ascertainment.
- Accuracy refers to the extent to which data are exact, correct and valid. Approaches to help ensure data accuracy include:
 - Re-abstraction of information
 - Validity audits, such as identification of missed diagnoses or coding issues
 - Clinical reviews, such as verification of diagnoses, codes assigned, tests and procedures (that is, two separate individuals input the same data and see if the database identified the duplicate)
 - Verification of data entry, such as customized programmes for range checks, automated fields, rejection of data that are known to be inaccurate, and routinely running data queries to identify duplicate entries and problems with variables
- Timeliness refers to the extent to which data are collected and analysed in a timely manner. It is measured by the time that elapses between the date of diagnosis and the date of abstraction; the date of abstraction and the date information is sent to the office; the date of arrival in the office to the date it is entered in the system; and the date of final product development and dissemination.
- **Explain the factors** that could affect data quality in each of the steps of the protocol:
 - *Missing values or empty data fields in the abstraction form*
 - *Duplication of cases*
 - *Errors in the description, diagnosis and/or coding of birth defects*
 - *Missing to report a case born with a birth defect*
 - *Incorrect denominator*

[Slide 7] Mechanisms to ensure quality of data

The nodal officer at each hospital is responsible for ensuring quality of data from each hospital. Following are the means by which the data quality is maintained.

- By doing forms verification
- Regular monitoring of data entry at hospital

[Slide 8] Data flowchart

It depicts an organized and smooth data flow system for an effective surveillance programme.

It shows the verification points for quality checks available in the system.

[Slide 9] Roles of first verifier – Hospital nodal officer

- Checks for completeness of the forms filled at the hospital – forms verification
- Compares the BD abstraction form with case records of the baby/stillbirth to confirm correctness of data filled by the DR/DEO
- Monitors the timely progress of data collection and data reporting (online entry) of the hospital data
- Compares and corrects the number of forms being filled up by the DRs/DEO and number of last month deliveries in the hospital.

How to do forms verification online

Explain the method of forms verification on the SEAR-NBBD database system

[Slide 10] Steps in verification

Go to Search Tab and identify the birth defect forms to be verified by selecting the **form type** as “Birth Defects (All BD)” and status as “Verification Pending” from the dropdown list and press the GO button to get the list of forms *to be verified*.

[Slide 11] Next, export the search results in the Excel file by clicking the first Excel icon

- Save this Excel sheet and use it as your Log file for record-keeping and future reference and follow-up.
- Select each case one by one from the search results by clicking the BD icon to open the form and verify the data entered.

[Slide 12] Verification of background information

- Once a case form is selected, check the basic information entered to find any extreme findings
- Check for logical conflicts in data
 - Ex: POA-39 weeks and baby’s weight 500gms
- Make a note of history of birth defect section if not completed.

[Slide 13] Verification types of birth defects

Special attention should be given to the birth defect section.

The verifier should check whether the type of birth defect is correctly identified, adequate description is provided, correct ICD-10 code assigned and level of certainty as “Confirmed” or “Possible” given.


Please note that in case of multiple defects, each defect has been filled in separate rows and coded separately.

Photographs and investigation findings should be uploaded whenever possible/ available.

[Slides 14-16]

If you find that the form is incomplete or some fields are missing or some information is not adequate, then provide your comments in the verifier comments box and reject the form for correction.

The colour icon of this form will turn red; ● these rejected forms can be picked up by the DEO, through search command.

If you find that the form is correct in all aspects, then click the checkbox I confirm; the form has been verified; the reject button will now turn to verify  ; click on the verify button.

Now the colour icon of these forms will turn to yellow. ●

The forms verified by the 1st verifier will be again verified by the coordinator of country network (2nd verifier) and if everything is ok, the form will be marked OK and the icon will turn **green**. (WHO-SEARO is providing this support at present until this role is taken up by the country level coordinator).

Data reporters / data entry reporters are required to correct the forms that are rejected. When the corrections are done, the colour icon of these edited forms by DEO will turn to blue.

[Slides 17-18] Data monitoring

Under the ‘Reports’ section on the screen, you can get the following reports for monitoring the performance of hospital/s.

- (1) Data Entry Statistics
- (2) Denominators Details
- (3) Day wise Data Entry Statistics
- (4) Reporting Status (Export)

[Slide 18] Data Entry Statistics

This option will provide the statistics of the newborn, stillbirth and birth defects; the total numbers of forms entered, data entry date range, exact range of date of birth of the babies reported to the system and details of data created (forms uploaded) within that period.

To get this report, click the “Data Entry Statistics” link and select the data range you wish – the name, list of hospital/s you want to view and the duration of data entry.

You have options to select the output by “data created on” or by “date of birth”.

[Slide 19]

Shows the output of this data report by “data created on”

Here you can view the output of the Data Entry Statistics: the number of complete, incomplete forms and how many forms have been uploaded of newborn and birth defects and total numbers of forms uploaded by the centre, and so on.

[Slide 20]

Denominator Details

The denominators for each month are collected on every 10th day of a month. A denominator-checkbox appears on the system to collect the total number of births, live births, stillbirths and birth defects detected. The DRs are expected to complete this and any missed entries in the previous months in order to proceed with the data entry.

These data could be used to crosscheck the total number of forms uploaded for a particular category – birth defects/stillbirths. If it is not tallying, one needs to investigate and identify the missing data entry.

[Slide 21]

Day-wise Data Entry Statistics

The day-wise data entry gives the details of forms entered into the system by days on a particular month. This will help to keep track of data entry and number of forms entered/pending uploads.

[Slide 22]

Reporting Status (Export)

Clicking on “reporting status” lets you save an Excel sheet with information on date of enrollment, date of submission, duration of data submission, and number and types of forms submitted.

If you have rights as an administrator (national coordinator), you can get the list of the centres (participating hospitals) enrolled with the NBBBD until now, as well as the date and duration of data entry activity; the surveillance; and status of all the enrolled centres.

Data analysis

[Slide 23]

Timely analysis and dissemination of data is an essential component of a birth defects surveillance system. An unusual increase in occurrence of a particular birth defect is important to capture in the data analysis and its timely reporting is critical for possible need of epidemiological investigation. The whole purpose of gathering data is to generate useful information for public health action.

Objectives:

- Understand the basic epidemiological concept used in disease surveillance
 - Incidence
 - Prevalence
- Understand how to compute these measures from the data entered.

The NBBD website provides you with some options to generate tables and graphs based on the data you have entered.

[Slides 24-25]

Incidence

Why do we need to measure occurrence?

Calculating occurrence of birth defects is useful:

- To study and compare birth defects occurrence in various populations.
- To compare birth defects occurrence over different time periods.

Incidence is a proportion of number of **new birth defects** (numerator) during a specified time period in specified population at risk (denominator).

Incidence proportion measure can be interpreted as a probability (risk) to develop a birth defect for a subject belonging to the same population in which the measure was computed.

In surveillance of birth defects, the word “incidence” is not commonly used to describe the occurrence of birth defects. This term refers to *all* new cases of birth defects. Because spontaneous abortions cannot be counted accurately, the suggested measure of occurrence of birth defects is “live birth prevalence”, “birth prevalence” or “total prevalence”.

[Slide 26]

The challenges faced in calculating incidence of birth defects:

- All birth defects are not identified at birth.
- Some birth defects result in stillbirths, abortion and elective termination of pregnancy for fetal anomalies (ETOPFA).
- Denominator needs to include all births – live births, stillbirths, abortion and all ETOPFA. This information is difficult to get in most situations.

[Slide 27]

Prevalence

A better measure to estimate incidence in a population is prevalence.

Number of all subjects (cases) with birth defects observed in a specified population during a specified time period limited to births in the same population during the same time.

Usually, the prevalence of birth defects is calculated and presented as prevalence per 10 000 live births. This prevalence can be calculated for all birth defects, for a specific individual birth defect (for example, spina bifida), or for groups of birth defects (neural tube defects).

The following expression is used to calculate the birth prevalence of birth defects, with the assumption that both live births and fetal deaths are being captured:

Birth prevalence = $a/b \times 10\,000$

- (a) Numerator: Number of live births and fetal deaths (stillbirths) with a specific birth defect (for example, spina bifida) counted among the source population in a given year.
- (b) Denominator: Number of live births and fetal deaths (stillbirths) (during the same year).

[Slide 28]

When measuring the prevalence of birth defects, it is important to note what is being counted in the numerator and in the denominator.

Numerator

- Number of birth defects
- Number of defects by type
- Defects among live birth and stillbirths

Denominator

- Number of births
- Number of stillbirths
- Number of live births

Note: it is important to remember that hospital-based prevalence estimates can be biased, in that they give the prevalence of a condition only for the participating hospitals. Prevalence estimates based on hospital data are not true estimates of the prevalence of a condition among a population.

[Slide 29]

Widely used prevalence measures and how they are calculated

- Live birth prevalence of BD
- Birth prevalence of BD
- Total prevalence of BD

[Slide 30]

Numerator and denominator in SEAR-NBBD

Explain how you can obtain the numerators and denominators in the SEAR-NBBD database for the BD prevalence and other calculations.

Go to the report section and select the data outputs to obtain the information on the numerator and denominator.

[Slide 31] Numerators

Under the report section and **Analysis** category, you can find the “**Birth Defect Data Analysis**” option.

When you click the text, you will get a dialup box requiring the parameters for the data requested. Carefully select the required health centre details, range of dates of data and the output by “data created on” or by “date of birth”.

[Slide 32]

The output table gives the summary details of birth defects entered during the requested duration. Here you can get the total number of all defects, major categories of defects and specific types of defects. These will be used as numerators for the calculation.

[Slide 33] Denominators

Under the report section and **Monitoring** category, you can find the “**Denominators Details**” option.

When you click the text, you will get a dialup box requiring the parameters for the data requested. Carefully select the required health centre details and the range of year.

[Slide 34]

The output table gives the summary details of birth defects entered during the requested duration. Here you can get the total number of all defects, major categories of defects and specific types of defects. These will be used as numerators for the calculation.

Other standard reports in the Report section – Analysis category

[Slide 35]

List the options of standard reports available for birth defects in the report section under Analysis category and demonstrate these options for newborn, stillbirth and birth defects data analysis reports.

Data Analysis

NBBD Report(s)

Monitoring

- (1) Data Entry Statistics
- (2) Denominators Details
- (3) Day wise Data Entry Statistics
- (4) Data Entry Statistics (Export)
- (5) Reporting Status (Export)
- (6) Data Reporting: Performance Monitoring by Hospital
- (7) Performance Monitoring of Verification Process and Verifier

Analysis

- (1) Birth Defect Data
- (2) New Born Data
- (3) New Born Health: Major Morbidities
- (4) Morbidity Pattern
- (5) BD Data (Export)
- (6) NB Data (Export)
- (7) SB Data (Export)
- (8) HCM Data (Export)
- (9) Data Analysis Report
- (10) Still Birth Analysis

These outputs are provided on a standard template. When you click the text of a particular option, you will get a dialup box requiring the parameters for the data requested. Carefully select the required health centre details, range of dates of data and the output by “data created on” or by “date of birth”.

[Slides 36-38]

Examples of outputs from these report links

[Slide 39]

There are options to download the newborn, stillbirths and birth defect raw data in an Excel sheet for customized analysis according to your needs. Here also you need to select the required health centre details, range of dates of data and the output by “data created on” or by “date of birth”.

Session 8: Services for birth defects – Counseling and Referral

Time allocation: 30 Minutes

[Slides 1-5]

Counseling is the art and science of working with clients to enable them to identify and understand a problem/issue and evolve solutions to address their own problem/issue.

When a birth defect is detected in a fetus or baby, doctors or nurses have to explain it to the mother and family and counsel them on possible options before birth, at birth or at diagnosis after birth.

They also need to be guided about appropriate services for treatment, care and management, including social integration.

Information should be provided on diagnosis, treatment and prognosis in a sensitive and caring, yet confident and straightforward manner, using understandable, non-medical terms, and language that is clear and concise. Informational resources can be provided, including contact information for local and national support groups, up-to-date printed information or fact sheets, and books. When appropriate, referrals to other specialists may also be helpful (for example, medical geneticists, genetic counsellors, cardiologists, neonatologists).

Families often want to know the possible causes and possibility of recurrence. Once we identify a birth defect, it is essential to provide information about the recurrence for that particular family and preventive measures to prevent the recurrence of these birth defects. Couples with isolated fetal birth defects are given a recurrence risk of about 5 % in the next pregnancy. The following table shows the recurrence risk for different birth defects.

Type of Birth defect	Recurrence risk after one affected child
Neural tube defect	3–5%
Cleft lip/palate	4–5%
Common cardiac defects	3–4%
Club foot	2–8%

(Adopted from SMITH's Recognizable Patterns of Human Malformation, Seventh Edition)

Session 9: Standard Operating Procedures (SOPs) for Hospital-based birth defects surveillance

Time allocation: 45 Minutes

WHO-SEARO has provided support for establishing Regional-National Networks of hospitals to maintain an integrated newborn-stillbirths-birth defects database that is hosted on the web-based platform SEAR-NBBD database. For this purpose and in consultation with ministries of health, the national network has identified hospitals for establishing a hospital-based surveillance mechanism. Hospitals have been selected based on certain parameters:

- Hospitals with maternity units (childbirth facilities) willing to at least begin birth defects surveillance in their hospitals.
- High delivery load (at least 5000 deliveries per year)
- Availability of a team of doctors (paediatricians, obstetricians, neonatologists) and nurses
- Availability of computers and internet connection
- Hospitals are located in various geographic areas.

One of the hospitals is made responsible for coordinating the national network of hospitals.

Team at hospital is provided with training on birth defects surveillance before they establish the surveillance system in their hospitals.

A brief manual of SOPs has been prepared for providing guidance to establish and maintain a birth defects surveillance system at hospitals.

In this session, an orientation on the SOPs document will be provided. A copy of the SOPs has been provided to participants. Ask them to browse through the document as you present the PowerPoint slides to briefly explain the main sections of the SOPs document, as follows.

Basic concepts of Birth Defects Surveillance:

- A. Birth Defects Surveillance:
- B. Inclusion Criteria:
- C. Case definitions:
 - Externally visible major birth defects (Essential)
 - Other birth defects (Optional)
- D. Case Ascertainment:

Establishing BD surveillance in the hospital:

Administrative arrangements in the hospital

Essential Tasks

- Filling the data abstraction form
- Confirmation and coding of birth defects
- Uploading the data on the online SEAR-NBBD system
- Management of birth defects
- Quality assurance of surveillance at the hospital level
- Analysis and interpretation
- Assessment for quality of birth defects surveillance at a hospital.

Role and responsibilities

- A. Data reporters (personnel assigned and responsible for data collection and uploading on online system)
- B. Hospital nodal person/s for birth defects surveillance (including role of verifier)

Annexures

Hospital SOPs document provides the following annexures

Annexure I: Wall Poster

This wall poster contains pictures of selected birth defects. The poster can be displayed in the labour room, OT, post-natal ward, paediatric ward and newborn unit to remind the doctors and nurses to get the birth defects form filled if a case of birth defects is observed in the hospital.

Annexure II: Birth Defects Abstraction Form

Annexure III: Definitions of the fields in the Birth Defects Form

Annexure IV: Taking Photograph of Birth defects

These guidelines provide instructions for taking good pictures of birth defects that need to be uploaded in the SEAR-NBBD database.

Annexure V: SOPs for Online Registration

Annexure VI: How to log in and fill the BD form

Annexure VII: Recurrence Risk of common birth defects

Annexure VIII: SOPs for Data Verification

The information provided in the Annexures V-VIII has been discussed in this training. The annexures provide ready-to-use instructions while working in the hospital.

Annexure IX: Quality assessment tool

This checklist is a simple tool to assess the quality of surveillance (completeness, accuracy and timeliness – already explained in the training). The tool can be used frequently by the hospital nodal person (once in a month or two) and also by an external supervisor (for example, programme manager or a designated expert) or national coordinator periodically (once a year). The findings must be discussed at the hospital level and actions for improvement implemented in a timely manner.

Session 10: Prepare personal plan of action for establishing birth defects registry at your hospital (in the standard template provided)

Time allocation: 60 Minutes

By this time, participants from the hospitals have understood the elements of hospital-based birth defects surveillance. They would have ideas on how to establish such a system in their own hospital and implement several activities.

In this session, they will prepare a personal plan of action to establish hospital-based birth defects surveillance upon returning to their duty station. Project the slide and explain the task that they need to:

- Identify activities: Examples
 - Briefing of the team members in hospital (paediatrics, neonatology, Ob-Gyn) and hospital superintendent/director
 - Administrative actions
 - Identify core team
 - Training/orientation of core team members
 - Data collection
 - Online submission
- Mention the reasons for undertaking these activities – what will it achieve (output)?
- Timelines by when these activities will be initiated and completed
- What resources do they have to undertake these activities?
- What new resources will they need and from where?

Provide participant from each hospital team a printout of the table in which they can fill in the details. Give 30 minutes to complete this exercise working as the hospital teams.

In the plenary feedback session (30 minutes), ask one hospital team to share the activities they have identified.

Provide opportunity to all participants to discuss and share additional or alternate activities as per their local contexts. If time permits, ask another hospital team to share their activities especially if they have identified some different and additional activities. In this way, all participants will be clear on what activities they will need to undertake upon returning to their hospitals.

Activities	Reason (Output)	Timeline	Resources available	Additional resources required; From Where

References

- (1) World Health Organization, Centre for Disease Control, International clearinghouse for birth defects surveillance and research. Birth defects surveillance: a manual for programme managers. Geneva: WHO, 2014.
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