Regional Network Meeting to Review Progress on Newborn Birth Defects Database

Report of the meeting
9 -11 August 2016, Jakarta, Indonesia
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# Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention, Atlanta, USA</td>
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<tr>
<td>CRS</td>
<td>Congenital rubella syndrome</td>
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<tr>
<td>ETOPFA</td>
<td>Elective termination of pregnancy for fetal anomaly</td>
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<tr>
<td>FFI</td>
<td>Food Fortification Initiative</td>
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<tr>
<td>ICD</td>
<td>International Statistical Classification of Diseases and Related Health Problems, Tenth Revision</td>
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<tr>
<td>MOH</td>
<td>Ministry/Ministries of Health</td>
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<tr>
<td>NBBD</td>
<td>Newborn and Birth Defects Database</td>
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<tr>
<td>NMR</td>
<td>Neonatal mortality rate</td>
</tr>
<tr>
<td>NTDs</td>
<td>Neural Tube Defects</td>
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<tr>
<td>RMNCAH</td>
<td>Reproductive, maternal, neonatal, child and adolescent health</td>
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<tr>
<td>SEARO</td>
<td>South-East Asian Regional Office</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Background

The WHO resolution on Birth defects WHA63.17, endorsed in May 2010 called for action on birth defect prevention and control among the Member States. This triggered a collaborative partnership between the WHO Regional Office for South-East Asia and the Centers for Disease Control and prevention, United States of America (CDC) to address the public health issue of birth defects in the Region. Regional strategic framework for prevention and control of BD was developed in 2013. WHO SEARO and country offices have assisted countries to develop national plans for prevention of birth defects and establish birth defects surveillance mechanisms. Networks of hospitals have been established in the countries in consultation with MoH for birth defects surveillance that are all connected within the Regional Network.

Generating information on birth defects that guides national action. The online integrated database (SEAR-NBBD) developed by WHO-SEARO provides a platform to collect data on newborns, stillbirths and birth defects from the participating hospitals across the countries in the Region. More than 170 hospitals from 7 countries have been enrolled over the past two years. A two-day training module for hospital based birth defects surveillance has also been developed to train the hospital staff and serve as a refresher when needed.

World Health Organization (WHO) has declared Zika virus disease a Public Health Emergency of International Concern on 1st of February 2016. Under these circumstances, WHO-SEARO, launched a module to record the Head Circumference (HC) measurements in all newborns born in the participating hospitals and to monitor the occurrence of microcephaly that is associated with congenital Zika infection, within the SEAR-NBBD database.

The Regional Network Meeting was organized on 09 - 11 August 2016, Jakarta, Indonesia to review progress on newborn-birth defects. Participants included country programme managers for newborn health and birth defects from Member states, network coordinators from Bangladesh, India, Indonesia, Maldives, Nepal, Sri Lanka and Thailand and representatives from UNICEF, WHO collaborating centers, CDC and staff from WHO Regional and country offices.
Objectives

1. To review the performance of national networks on newborn health and birth defects to identify strengths and challenges.

2. To focus on the quality of surveillance data and plan for improvement.

3. Introduce module on Microcephaly at birth in the database to prepare for surveillance Zika Virus infection.

4. To plan expansion/strengthening of national networks for newborn health and birth defects and the database and map the requirement of technical support.
Proceedings

Neena Raina, Coordinator, Health through the Life Course, Child and Adolescent Health, WHO-SEARO, welcomed the delegates to the regional meeting and shared the objectives of the meeting and encouraged the participants to contribute actively during the deliberation to have a successful meeting. The WHO Representative to Indonesia, Dr Jihane F Tawilah read out the inaugural address from the Regional Director WHO-SEARO.

The outstanding progress made by the region towards MDG goal was highlighted. The shift in the cause of infant mortality and the need for targeting birth defect prevention was emphasized in the RD’s address (see Annex 1). Anung Sugihantono, Director General of Nutrition and Maternal and Child Health, MoH – Indonesia delivered the keynote address. Rajesh Mehta, Medical Officer WHO-SEARO introduced the participants including representatives from the ministries of health, national network coordinators and hospital nodal persons from the countries; experts from WHO Collaborating Centers, representatives from partner agencies, CDC experts and WHO secretariat.

Setting the stage

Michael Canon, CDC, USA presented the global situation of Birth Defects (BDs) and the initiatives for prevention and control of birth defects. As per the March of Dimes estimates Birth defects are significantly prevalent in SEA countries. Talking about prevention of birth defects, Mr Canon mentioned that large number of these birth defects could be prevented by implementing evidence-based interventions, like supplementing Folic Acid (400 micro gram/day) before and after conception during early pregnancy to prevent Neural Tube defects (NTDs) and rubella vaccine to prevent congenital rubella syndrome.

Neena Raina, WHO-SEARO presented the progress and challenges in newborn health and birth defects in the region. Under-five mortality in SEAR has declined by 64% since 1990, this being higher than the global reduction in under-five mortality. Despite this reduction not all countries in the Region have been able to achieve the MDG 4 target. Newborn mortality reduction has been slower than the under-five mortality reduction and it is a major reason for not achieving MDG 4. The targets for reduction in maternal, newborn and child mortality are much lower in the Sustainable Development Goal 3 and the Global Strategy for Women’s, Children’s and Adolescents’ health. She said that in order to move forward towards the SDG targets we need to focus on improving skilled care for mothers and newborns around the time of delivery. This in turn contributes to reduction in maternal and neonatal mortality and reduction in stillbirths. WHO-SEARO has provided high priority to ending preventable maternal, newborn and child deaths by identifying
this as the Regional Flagship area and constitution of Regional Technical Advisory Group of global and regional experts.

She shared the progress in the SEAR-CDC joint initiative on birth defects under which Regional Strategic framework, National Strategic Plans and action plans for prevention and control of birth defects have been developed. The development and expansion of the regional newborn-birth defects surveillance (SEAR-NBBD) has been a success. This was further strengthened by preparation of the Regional training package that consists of a Facilitators guide, operation manual and a photo atlas. At present 174 hospitals are enrolled in SEAR-NBBD database and nearly 907666 births have been reported with about 10,000 defects. The proportion of defects contributed by NTDs among all births, stillbirths and pre- viable fetuses is 13%, 28.4% and 44.5% respectively. It means that a large number of neural tube defects would be missed when we count only the birth defects cases at or after birth.

**Progress in National BD Plans: Surveillance, Prevention and Control**

Rajesh Mehta presented on the remarkable progress in the BD surveillance under national action plans in SEAR, for prevention and control of birth defects. Countries presented the analysis on the surveillance data collected by them (see table below). It was observed that only a few hospitals are presently collecting data for newborn health or head circumference. There is a need to work towards improving and maintaining the quality of data. All the countries have been implementing preventive interventions in an integrated manner within the existing national programmes for RMNCAH, nutrition, immunization and non-communicable diseases.

<table>
<thead>
<tr>
<th>Country</th>
<th>Total BD Forms submitted</th>
<th>Total Babies with BD</th>
<th>Total Births reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>1352</td>
<td>824</td>
<td>80991</td>
</tr>
<tr>
<td>Bhutan</td>
<td>234</td>
<td>179</td>
<td>6743</td>
</tr>
<tr>
<td>India</td>
<td>7222</td>
<td>5170</td>
<td>578807</td>
</tr>
<tr>
<td>Maldives</td>
<td>103</td>
<td>54</td>
<td>2266</td>
</tr>
<tr>
<td>Myanmar</td>
<td>113</td>
<td>102</td>
<td>46139</td>
</tr>
<tr>
<td>Nepal</td>
<td>520</td>
<td>391</td>
<td>124418</td>
</tr>
<tr>
<td>Thailand</td>
<td>492</td>
<td>349</td>
<td>68302</td>
</tr>
<tr>
<td>Grand Total</td>
<td>10036</td>
<td>7069</td>
<td>907666</td>
</tr>
</tbody>
</table>
The progress in national newborn-birth defects prevention and control programme was presented by all nine member states that participated in the meeting (see Annex 3). Only a small proportion of the participating hospitals in the Regional Network are currently reporting newborn data; most of them from India.

**Bangladesh**

Mohammad Shahidullah from Bangladesh described the history of the birth defects prevention and control initiatives in Bangladesh since the inception from 2013. Fifteen hospitals currently enrolled in the network, conduct bi-weekly review on the data collected to ensure quality, identify gaps and provide feedback. Furthermore, the newborn care and birth defects are now getting integrated into the national DHIS2 platform that is being developed by the MoH that has will cover all births in the hospitals in the near future.

**India**

Pratima Mittal, Safdarjung Hospital New Delhi India, shared their experience of the birth defects registry of New Delhi hospital network. There are eight hospitals with heavy delivery load participating in this network. Challenges were related to quality of data; delay in submitting forms, inadequate description of the birth defects, wrong coding, poor quality of photographs, and completeness of the data. To address these issues Safdarjang Hospital has provided supportive supervision, reorientation of the relevant staff from the participating hospitals and retraining on ICD coding system.

**Indonesia**

Muhammad Karyana, National Institute of Health Research and Development, Ministry of Health presented the experience of database with 13 hospitals and key issues and challenges especially related to quality of data. Ten government and three private hospitals are reporting birth defects (MoH has prioritized 15 major birth defects) that started in 2014 after training in birth defects surveillance. The birth defects abstraction form has been adapted from the SEAR-NBBD and translated into local language. By now 40 thousand births have been screened and 283 birth defects reported in the network giving at birth prevalence of 6.93 / 1000 births with a range of 1.75/1000 to 19.8/1000 across the 13 hospitals. Top four common birth defects are Talipes, Oro-facial clefts, neural tube defects and abdominal wall defects in that order. Encouraged with the performance of hospitals and experience with the database the ministry has planned to include 6 new hospitals.
Nepal

R P Bichha, MoH Nepal presented that there are 10 hospitals in the network and the Paropakar Maternity and women’s Hospital is functioning as the national coordinating center. The main finding showed 0.41% of the births with visible birth defects and occurrence of birth defects was as high as 3.1% among the stillbirths. Retraining, maintaining regular monitoring and supportive supervision were mentioned as a solution to overcome the data quality issues.

Stillbirth surveillance, study of pre-viable birth defects and experience from hospitals in India

The latest research shows that half of stillborn deaths could have been prevented by providing basic care and better health monitoring both pre-labor and during childbirth. Stillbirth surveillance and maintaining a perinatal database is still new to NBBD, with surveillance in ten hospitals in India, supported by WHO. Neelam Aggarwal from PGIMER, Chandigarh India presented the pioneering experience of establishing stillbirth surveillance pilot. These hospitals use a definition for stillbirth as early stillbirths for gestational age from 20 to 27 weeks and late stillbirths for gestational age of 28 weeks onwards. She emphasized that more than half the stillbirths were fresh stillbirths pointing to occurrence during intranatal period and that many of such stillbirths are preventable by improving the quality of intranatal care. Occurrence of birth defects, especially neural tube defects was higher among stillbirths as compared to that among liveborn babies.

She also shared the experience from the pilot project for study of pre-viable births in India, also supported by WHO. She presented the data analysis from the pre-viable database. “This enables the doctors to council the mother regarding the condition and risk of recurrence”-she said. The use of standard operating procedures was stressed.

Stillbirth Surveillance Guidelines India

Shared by Ajay Khera, MoH India from the national stillbirth surveillance system based on the experience with hospital-based stillbirths’ surveillance piloted with the support of WHO. He shared the three main reasons why India has decided to scale up stillbirth surveillance- a) to classifying the stillbirth accurately; b) stillbirths should be counted is because these reflect the availability and quality of maternal and perinatal care; and c) to monitor the trends overtime. India has recently finalized the national guidelines for the hospital based still birth surveillance.
Strengthening quality of data

Madhulika Kabra, WHO Collaborating Center for Genetics at All India Institute of Medical Sciences (AIIMS), New Delhi presented main elements of Quality assurance and quality control of surveillance data. The quality indicators with acronym CAT were discussed and their relevance in the NBBD system was explained. The verifier functions at hospital level and network level were explained and the gaps in their performance were identified; lack of 1st verifier function in many hospitals leads to rejection of several forms. The quality checklist included in the WHO-SEARO Hospital based surveillance -guide was introduced and its usefulness in supervising the data collection was discussed. Quality related information in the NBBD data was presented. Nearly 50% of the data submitted were having lag period more than 14 days and 8% of the forms submitted were rejected requiring correction in the details entered. Only 3571 out of 5826 forms submitted were having photographs attached. However, she showed the progress in the quality of data over the two years and highlighted the improvement made. The success story by the India network was recalled and recommended to adopt similar approach to improve the quality of data.

Michael Cannon, CDC, USA, presented the mechanism and importance of quality assurance in public health surveillance programmes. He discussed the influence of the data quality in interpreting the finding in a database. The common data quality issues are missing values, duplicate cases, diagnosis errors and case description or coding errors. Following dimensions of quality of data were highlighted along with possible ways of improvement.

1. Completeness of information:
   - Hospital audits
   - Link cases to other data sources (i.e. vital records, records from specialized diagnostic centers)

2. Accuracy of information:
   - Clinical review—verify diagnosis, codes assigned, tests and procedures
   - Validity audits—identify missed diagnoses or coding issues
   - Data entry audit—run routine data queries to identify duplicate entries and problems with variables, reject inaccurate data

3. Timeliness of information:
   - Assess time between date of diagnosis → date of data abstraction → date of submission to central system → date of case review → date of product development/results dissemination

Rajesh Mehta elaborated the provisions for strengthening quality of data that are available in the SEAR-NBBD system. To affirm the need for quality assurance in any surveillance system he said that providing poor quality data can be as bad as not providing any data. He emphasized the importance of build in a mechanism at
every step to ensure the quality data flow. The role of the data reporter (DR) was described and following responsibility were highlighted; conducting a complete physical examination of all live born / stillborn babies to detect any birth defect/s, filling the birth defects abstraction form including complete description of the birth defect/s, taking standard photographs of the birth defect/s, assigning most appropriate ICD-10 code for all birth defects observed by using the Birth Defects atlas and entering the data from the paper form into the online system making sure that all the fields are filled accurately. He also clarified the role of the verifier (hospital nodal officer) and 2nd level verifier (national coordinator) that are responsible for measuring quality of data.

Regional Training Package

Dinesh Jeyakumaran, WHO-SEARO introduced the regional training package for birth defects surveillance under SEAR-NBBD system. The regional package has been adapted from the WHO-CDC global training package. The aim of this package is to lay down the key principals of hospital-based birth defects surveillance system, to ensure uniformity of data abstraction and transmission, to standardize and improve data quality. The Steps to establish birth defects surveillance at hospital are listed including the initial need for administrative clearance, training at the hospital staff and arrangements in the hospital. The hospital Guide provides description of the essential tasks like:

- Assuring screening of all babies, identify the birth defects,
- Filling the Data abstraction form
- Confirmation and coding of birth defects
- Uploading the data on the online SEAR-NBBD system
- Management of birth defects
- Analysis and interpretation
- Assessment for quality of birth defects surveillance at a hospital

Dinesh Jeyakumaran and Madhulika Kabra described in detail how to use the provisions of data verification for quality assurance in the SEAR-NBBD system. Data verification has to be done at the hospital level and national coordinator center levels. The steps of data verification were described live on the computer to build capacity of the hospital representatives present in the meeting. The session was kept as an interactive one and queries related to the functionality were addressed.

Zika Virus Infection and birth defects

Michael Cannon, CDC, USA presented the description of the Zika viral infection and explained the clinical disease course and its outcomes. Zika infection in pregnancy is a cause of microcephaly and other severe brain defects, eye defects, hearing loss, impaired growth, and fetal loss. He shared the updated interim pregnancy guidance published by CDC, USA that also includes clinical management. The
guidelines for the evaluation and testing of infants of mothers with a history of exposure to Zika infection during pregnancy are also included. He explained the etiology, types, case definition and measuring techniques for microcephaly and the ways to estimate different types of prevalence of microcephaly.

The newly launched Head circumference monitoring module in SEAR-NBBD database was introduced and the steps in entering selected variables were showed. An analysis of the data reported until now was shared. The definition of microcephaly and the standards used to identify babies with microcephaly was presented. The WHO standards provide separate tables for boys and girls. However it is only applicable for term babies – gestational age 37 weeks to 42 weeks. On the other hand the Intergrowth21 Standards are available for both boys and girls by gestational age ranging from 24 weeks to 42 weeks.

Anju Puri, WHO-India presented the experience of head circumference monitoring for Microcephaly from India. In order to prepare for possible outbreak in India, Ministry of health had organized a highest level review and taken decisions in managing the situation in India. A Joint Monitoring Group was activated and the States were informed and guidance provided. A 24X7 Control Room was set up for providing information on Zika Virus Disease. The surveillance activities were activated through the Integrated Disease Surveillance Programme (IDSP) network, Rapid Response teams on alert for fever and rash syndromes. The sentinel sites under NBBD were strengthened to detect microcephaly at birth. National protocols for augmenting surveillance for Zika virus have been strengthened- both for event based surveillance as well as birth defects surveillance. Challenges faced in these activities were listed. Establishing weekly reporting on babies born with head circumference less than 31cm is a demanding task. Hospitals were asked to send nil report if no case detected. Screening of all newborns delivered in the facility, head circumference measurement of the baby at least 24 hours after delivery (Period after 24-48 hours of age) and identifying accurate gestation age (diagnosis in preterm) were noted as practical challenges.

**Regional QI model: Improving care at the time of childbirth**

Rajesh Mehta, WHO-SEARO introduced the regional quality improvement model for improving care of women and newborns at the time of childbirth. He shared that the recently launched Global standards for maternal and newborn health care highlight the significance of the provision of care as well as the experience of care adherence to which will ensure quality of care. WHO-SEARO has developed a Regional framework for improving quality of care that recommends 7 step systematic processes.
The Assessment of quality of care has been undertaken with support of WHO that revealed existence of several quality gaps in a number of countries. Several of these quality gaps are correctable at level of health facility itself by modifying the process of care. Of course, there are some gaps like deficiency in human resource and physical infrastructure that need interventions from higher level of health system. The champions among healthcare professionals could be encouraged to start with the gaps that are correctable at facility level.

Furthermore, the need for improvement in both, content of care (clinical protocols and procedures) and process of care (how the care is organized to ensure that clinical guidelines and protocols are actually practiced) was highlighted. He briefly described the SEARO collaborative learning model using plan-do-study-act cycles. The Regional Package for MNH QI; Facilitators Guide, Participants Hand Out, Practice Guide and mentoring mechanism is being finalized. Delegates from ministries of health and hospitals from Member States were encouraged to include QI model in the present network hospitals that are participating in the SEAR-NBBD database.

**Population-based Surveillance for Birth Defects**

Michael Cannon showed a short video to present the principal of population based surveillance was presented. He described that after selecting a defined geographical area or population, the birth defects cases among elective termination of pregnancy in second trimester, among premature deliveries and all term deliveries should be included in the numerator. The data could be obtained from multiple sources like health facilities, vital registration, hospital admission database, home birth and any other source of birth details. The denominator should be the total pregnancies in the geographical area or population selected.

When considering for population-based surveillance it is important to keep in mind the appropriateness of the geographic area; the size of the population and location. The sample should be well representative of the population of both high prevalence and low prevalence area and both high burden hospitals and low delivery sites should be included. Since population based surveillance are resource-intensive it is recommended to always start small, with limited conditions to identify and scale up after the initial phase is successful.

**Expanding NBBD surveillance**

Plans on integration of NBBD surveillance in existing systems were discussed along with the current surveillance status (see Annex 4). Kapila Jayaratne, MOH described the progress of birth defects surveillance within the existing health information system in Sri Lanka. He highlighted the historic milestones of the birth defects program since the initiation from 2013. The priority defects selected in this
surveillance system are Neural tube defects (NTD), Congenital Heart Disease, Thalassemia, Cleft lip / cleft palate, Limb defects, Congenital rubella syndrome, Congenital hypothyroidism, Congenital syphilis, Chromosomal defects and Unspecified Severe deformities. He briefly described the Feto-infant Mortality Surveillance of Sri Lanka. This system uses the recently released ICD-PM coding system to characterize the cause of mortality. In Sri Lanka all stillbirths in hospitals are required to be registered with Registrar General’s Department before the dead body is disposed. Therefore this system will help to obtain information on stillbirth at national level.

Country teams were provided a template to prepare the plans for strengthening and expanding the surveillance programme over next two years (see Annex 5).
Conclusions

- There has been a good progress in hospital-based birth defects surveillance over the last 1-2 years and need to focus on improving quality of data.
- It will be important to sustain good quality of data while expanding the number of hospitals to cover most geographic areas in the respective countries.
- The role of data verifier at the level of the participating hospitals and the national coordination centers in the countries is crucial to ensure high quality of data.
- Country network hospitals would consider expanding the database to cover, in addition to birth defects, newborn health including head circumference monitoring (towards preparedness for Zika infection) and stillbirths with necessary support from ministries of health.
- Countries would like to move towards integrating the newborn-stillbirths-birth defects data in the national HMIS as and when possible.
- Countries will further strengthen care and treatment for birth defects within the existing health services and expand preventive interventions within the RMNCAH and related programmes with a focus on preconception care.
- Considering the urgent need for improving quality of care for maternal-newborn health the national network hospitals would be good sites to introduce the SEARO Quality Improvement model.
- In all instances data and information must be used for the identified purpose and improving the situation.
Recommendations

For Member Countries

• Focus on improving quality of data in the birth defects surveillance while expanding the database so that data and information can be used for public health actions with confidence.
• MoH to provide an official directive and necessary resources to the participating hospitals in order to integrate newborn-stillbirth component with birth defects surveillance as part of SEAR-NBBD database and build their capacity to verify and validate the data collection and reporting.
• Introduce head circumference monitoring for Zika preparedness and quality improvement for MNH in the network hospitals and provide necessary support.
• Provide resources for mentoring and monitoring national coordination centers and participating hospitals to sustain motivation and recognize good performance.
• Provide necessary resources to the national coordination centers and build their capacity to perform the role of verifier to ensure quality of data and to improve coordination with the participating hospitals, ministry of health and SEAR-NBBD system.
• Strengthen quality improvement for maternal-newborn care and maternal and perinatal death surveillance and response in the network hospitals.
• Work towards integrating the newborn-stillbirths-birth defects data into the existing health management information system.
• Review and strengthen national plans for birth defects prevention and control through integrated approaches and consider feasibility of food fortification with folic acid and vitamins for prevention of neural tube defects and strengthen implementation in countries where national mandate already exists.

For WHO, CDC and Partners

• Continue to support Member States for strengthening surveillance and prevention of birth defects and support integration of newborn (including head circumference monitoring), stillbirths and QI model for MNH in the network hospitals.
• Support further development of national capacities in the integrated newborn, stillbirths and birth defects surveillance and create a desktop application of the database.
• WHO-SEARO in collaboration with WHOCC for Genetics at AIIMS, New Delhi, to continue to manage the SEAR-NBBD database and share regional/national level summary of analyzed data on periodic basis.
• Provide support to build capacity of national coordinator centers in providing technical support to participating hospitals especially in appropriate coding of birth defects and improve overall quality of data.
• Create opportunities for Member States and national networks for reviewing progress, sharing of knowledge and experience in the field of birth defects and newborn health.
• Support pilots for population based surveillance for birth defects in countries.
• Support national plans for integration of birth defects prevention and control in the RMNCAH and related programmes and development of preconception care package.
Annexes
Regional Director’s Message

Message from Dr Poonam Khetrapal Singh Regional Director, WHO South-East Asia (Delivered by WR Indonesia)

I have the honour to present greetings from Dr Poonam Khetrapal Singh, Regional Director of the WHO South-East Asia, to the organizers of this meeting and to its distinguished participants. As the Regional Director is unable to be present, I have the privilege of delivering her address.

I QUOTE:

Distinguished participants, ladies and gentlemen,

There has been a significant decline in under-five mortality in most Member States of the South-East Asia Region during the MDG phase. It declined from 118/1000 live births in 1990 to 43/1000 live births in 2015 – a reduction of about 64%. Over the same period, neonatal mortality has declined less rapidly from 53/1000 live births to 24/1000 live births, or about 55%. Despite commendable progress, the Region as a whole narrowly missed the MDG 4 target in December 2015.

This decline in child mortality has initially been marked by a decline in mortality from infectious diseases that predominate in the early years of life. At the same time, however, the mortality from birth defects has remained constant. This has resulted in birth defects assuming a greater proportional cause of neonatal and infant mortality. In our Region, there are countries that have reduced child mortality to less than 15 per 1000 live births; and the mortality due to birth defects is as high as 30%.

An estimated 276 000 babies die within 4 weeks of birth every year, worldwide, from birth defects. It is also known that serious birth defects can be lethal for the fetus in-utero or soon after birth. Birth defects can also result in long-term disability, which may have significant impacts on individuals, families, healthcare systems and societies. In fact, an increasing number of infants with potentially disabling conditions, who would have previously died undiagnosed, now survive and require medical and supportive interventions, putting additional burden on health systems.

Considering these facts, prevention and control of birth defects would be a prerequisite to further reductions in newborn and child mortality and realize the new SDG 3 targets of reducing child mortality to as low as 25 per 1000 live births and reducing newborn mortality to at least 12 per 1000 live births.
Soon after World Health Assembly Resolution on birth defects in 2010, South-East Asia Regional Office of WHO initiated work in the area of surveillance and prevention of birth defects. Collaboration with Centers for Prevention and Disease Control (CDC), Atlanta, has been instrumental in this endeavor in our Region. WHO-SEARO developed the Regional Strategic Framework for prevention and control of birth defects in 2013 in consultation with Member States to guide countries to prepare national plans for prevention and control of birth defects. I understand that since then, nine Member States have developed national plans for prevention and control of birth defects. It is indeed appropriate that such plans have adopted an approach to integrate birth defects prevention interventions in the existing RMNCAH and related programmes such as nutrition and immunization programmes, as guided by the Regional Strategic Framework.

Ladies and gentlemen,

When we started to work on birth defects, we realized that adequate epidemiological data regarding birth defects were not available in the Region. There were no national level surveillance systems or registries to collect and analyze data on birth defects in the Member States. To address this situation, WHO-SEARO provided support to Member States to strengthen data and information on birth defects and establish birth defects surveillance mechanisms. In consultation with ministries of health, hospital-based surveillance system has been chosen as the proportion of hospital deliveries has increased in many Member States.

For this, WHO-SEARO in collaboration with CDC has established an online integrated birth defects, stillbirths and newborn health database, named South-East Asia Regional Newborn-Birth Defects Database (SEAR-NBBD). By now, we have a network of more than 160 hospitals in the Member States that have joined the surveillance system to collect and manage data related to birth defects in a standardized manner. We have supported countries to build capacity for undertaking birth defects surveillance in hospitals. WHO-SEARO along with the WHO Collaborating Centre at All India Institute of Medical Sciences, New Delhi, has been providing support to maintain the quality of data, their analysis, continuously strengthening the capacity of hospitals in surveillance, and providing feedback to participating countries.

It is important to note that this integrated neonatal-perinatal database would contribute to a wider understanding of neonatal morbidity and mortality overall with a focus on birth defects in countries. For example, in view of the present threat of Zika virus infection that has been associated with microcephaly and neurological birth defects in newborns, networks for the SEAR-NBBD database have provided an extremely useful platform to monitor the occurrence of microcephaly among newborns being delivered in the participating hospitals. The capacity built with the support of WHO-SEARO has been of great use, and a
dedicated module for microcephaly has already been introduced into the SEAR-NBBD database. This will be introduced to Member States during this meeting.

In line with the Regional Strategic Framework on prevention and control of birth defects, WHO-SEARO has supported Member States to implement strategies to prevent birth defects including, among others, supplementation and fortification with folic acid and vitamins for prevention of neural tube defects and rubella vaccination for prevention of congenital rubella syndrome, elimination of congenital syphilis.

This meeting provides an opportunity to review progress on newborn-birth defects database in the Region and take stock of performance of the Regional and National Networks as well as for mutual learning from country experiences. I am pleased to note that there will be a special focus on sustaining the quality of surveillance data during the deliberations. I am sure that you all will be able to collectively plan to further strengthen the activities of the regional and national networks and improve the performance of SEAR-NBBD database and overall national plan for prevention and control of birth defects.

I would like acknowledge the presence, in this meeting, of officials from ministries of health from Member States, experts from the fields of neonatology, pediatrics and obstetrics, development partners. We believe that prevention and surveillance of birth defects can be expanded and sustained over the long term in the countries only with leadership and support from the ministries of health. I strongly encourage ministries of health to continue to provide stewardship for strengthening national policies as well as capacities to implement plans for prevention and control of birth defects. WHO stands committed to support the efforts of Member States in this regard.

Ladies and gentlemen,

I gratefully thank the Ministry of Health, Indonesia, for hosting this important regional meeting and acknowledge the support of WHO Country Office, Indonesia, towards organization of the meeting. I extend my best wishes for the successful conduct of the meeting and comfortable stay for you all in Jakarta.

UNQUOTE.

I will, of course, apprise the Regional Director of the outcome and recommendations of this meeting. I too would like to take this opportunity to welcome you all, and to wish you fruitful interaction and a pleasant stay in Jakarta.

Thank You.
Annex 2

Agenda

• Update the global and regional status of birth defects prevention and control

• Review the progress in National birth defects Plans: Surveillance, Prevention and Control

• Introduce and discuss on the perinatal database; newborn, stillbirth and pre-viable databases

• Understand and address the issues related to the quality of data in the Birth defects surveillance system

• Training with live demonstration on the role of verifiers in the SEAR-NBBD system

• Provide technical updates on Zika virus outbreak and microcephaly monitoring system

• Introduce the Quality Improvement model to improve care at the time of childbirth

• Develop national plans to expand SER-NBBD surveillance in the Region
Annex 3

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Summary of the country progress in prevention and surveillance of birth defects

Bangladesh

National Birth Defects Plan

1. Goal in the national plan
   1.1. To improve the quality of life through surveillance, prevention and early management of correctable birth defects.

2. Targets in the national plan
   2.1. Birth defects addressed in the national strategic framework
   2.2. Reduction of the prevalence of folic acid dependent-preventable neural tube defects by 35%
   2.3. Reduction of the number of thalassemia births by 50%
   2.4. Reduce congenital rubella: MR Vaccine has been introduced since September 2012, and special blanket coverage given to adolescent girls (around 45 million) in 2012
   2.5. Eliminate congenital syphilis:

3. Status of achievement for each Target
   3.1. Reduce congenital rubella: MR Vaccine has been introduced since September 2012, and special blanket coverage given to adolescent girls (around 45 million) in 2012
   3.2. Eliminate congenital syphilis: programme is ongoing for reduction and screening started from ANC
   3.3. Cleft lip and cleft palate: Management facility available in both GOB & private Tertiary level health settings along with NGOs programme--Operation “Smile Train”
   3.4. Limb defect including clubfoot: Nationwide surveillance data collection ongoing and sustainable clubfoot care in Bangladesh: collaborative effort by GoB, NITOR, ICDDR,B, and Walk for Health and management for sustainable club foot.
   3.5. Congenital Hypothyroidism screening exist in National Newborn Health Strategy (NNHS) & guideline and Non-Communicable Disease related programmes
   3.6. Limited # of schools have the facility / curricula for down’s syndrome in children

Implementation of national BD Plan

1. Significant challenges or barriers impeding the progress on the national plan
   1.1. Not in priority list of other key MNCH partner like UNICEF, UNFPA, USAID, other DPs
   1.2. Shortage of skilled HR at different levels of facility and increased work-load
   1.3. 63% home delivery (challenges to collect household/ community data)
   1.4. Limited current data for strong policy advocacy with the government and other DPs/Stakeholders

2. Steps toward addressing the challenges or barriers
   2.1. Assign focal person at different GO and DPs level for smooth implementation
   2.2. Strong policy advocacy and sensitization with evidences and data for prioritization of BDs prevention intervention
   2.3. Allocation of adequate budget for BD prevention interventions in the OP
   2.4. Advocacy and sensitization with key MNCH partner like UNICEF, UNFPA, USAID, other DPs
   2.5. Orientation and training of HR at different levels of
   2.6. Strengthen community and facility HMIS to collect BD data
Progress in Strategic Direction 1: Establish or strengthen national policies and programmes for birth defects prevention

1. National focal point
   1.1. Program Manager- Maternal Neonatal Health, DGHS
2. National taskforce/workgroup members
   2.1. MoHFW, BSMMU, WHO, UNICEF, ICDDRB, Professional organizations
3. Status of national birth defects prevention plan and/or programme
   3.1. Approved, endorsed and disseminated by the government since 2014. NBBD has been included in the First Draft of the OP of 4th Health Sector Development Plan
4. Budget for national birth defects prevention plan and/or programme
   4.1. Budgetary provision will be in OP

Progress in Strategic Direction 2: Develop or strengthen birth defects surveillance, monitoring and evaluation capacity

Birth Defects Surveillance: Status of reporting hospitals

1. Status of national birth defects surveillance mechanism
   1.1. Hospital based : Yes
   1.2. Population based : No
2. Status of national birth defects information integrated in existing health information system(s)
   2.1. HMIS : Yes
   2.2. CRVS : Limited data
3. Number of Hospitals
   2.1. All newborns: 14 Centers
   2.2. Birth defects cases (live and stillbirths): 14 Centers
   2.3. Stillbirths: 14 Centers
   2.4. Sick newborns: 5 Centers

Progress in Strategic Direction 3: Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes

1. Birth defects prevention in RMNCAH
   1.1. To be included in upcoming AH Strategy
2. Immunization (Rubella Vaccination)
   2.1. Nationwide program
3. Food fortification and micronutrient supplementation programmes
   3.1. Iron- Folic acid supply for pregnant women (gob), Iodized salt and edible oil fortified with Vitamin A (Business men Pvt)
4. Birth defects prevention in non-communicable diseases programmes
   4.1. Included in OP
5. Strengthen the care and management services for BDs
   5.1. Hospital and Community based services available

Progress in Strategic Direction 4: Expand and strengthen national capacity for implementation of birth defects plan

1. Capacity building/trainings conducted
   1.1. From July, 2015 upto July, 2016--trainings and orientation programs conducted including ToT, annual review meeting, program review meeting, hands on training for doctors and data entry operators
**Progress in Strategic Direction 5:** Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

1. **National birth defects prevention partnerships and networks**
   1.1. Partnership of 14 Tertiary level hospitals on “Strengthening and expansion of Newborn Birth Defect Surveillance in Bangladesh” under the leadership of MOH, the network is being coordinated by BSMMU, supported by WHO.

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**Bhutan**

**National Birth Defects Plan**

1. **Goal in the national plan**
   1.2. Reduction of preventable birth defects in Bhutan

2. **Targets in the national plan**
   2.1. Institute birth defects surveillance system
   2.2. Reduce prevalence of folic acid-preventable neural tube defects (35%)
   2.3. Eliminate congenital rubella and congenital syphilis (next 5 years)

3. **Status of achievement for each Target**
   3.1. Need for reporting of all cases of congenital syphilis
   3.2. Separate the reporting system for GIT and Genitalia needed
   3.3. Higher prevalence of FAS - actively advocate for prevention of FAS with special focus to Eastern Bhutan
   3.4. Cleft lip and cleft palate is higher than reported worldwide - look into risk factors
   3.5. Mandatory measurement of head circumference at birth of all babies so as to pick up all babies with microcephaly

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**Implementation of national BD Plan**

1. **Significant challenges or barriers impeding the progress on the national plan**
   1.1. Low awareness on birth defect, therefore, low political and financial support from government
   1.2. Reporting problem due to shortage of manpower

2. **Steps toward addressing the challenges or barriers**
   2.1. Create awareness to politicians and decision makers for support

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**Progress in Strategic Direction 1:** Establish or strengthen national policies and programmes for birth defects prevention

1. **National focal point**
   1.2. Disability Prevention and Rehabilitation Program, DoPH, MoH

2. **National taskforce/workgroup members**
   2.1. Child Health Advisory Group (CHAG) assigned

3. **Status of national birth defects prevention plan and/or programme**
   3.1. Finalized but yet to be endorsed by High Level Committee

4. **Budget for national birth defects prevention plan and/or programme**
   4.1. NO

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**Progress in Strategic Direction 2:** Develop or strengthen birth defects surveillance, monitoring and evaluation capacity Birth Defects Surveillance: Status of reporting hospitals

1. **Status of national birth defects surveillance mechanism**
1.1. Hospital based: In three referral hospitals only
1.2. Population based: No population based birth defect

2. Status of national birth defects information integrated in existing health information system(s)
2.1. HMIS: Yes
2.2. CRVS: NO

3. Number of Hospitals
3.1. All newborns: 3 hospitals (only inborn, 2015 data)
3.2. Birth defects cases (in live and stillbirths): 136 babies
3.3. Stillbirths: 64
3.4. Sick newborns: NA

"Progress in Strategic Direction 3: Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes"

1. Birth defects prevention in RMNCAH
1.1. Plan to develop preconception care package and pilot it in national referral hospital

2. Immunization (Rubella Vaccination)
2.1. Rubella vaccination introduced into routine immunization since 2006 along with nationwide campaign

3. Food fortification and micronutrient supplementation programmes
3.1. Work ongoing to introduce food fortification in schools and educational institutes, plans to introduce micronutrient supplementation for under–five children

4. Birth defects prevention in non-communicable diseases programmes
4.1. Pilot study on GST for pregnant women conducted

5. Strengthen the care and management services for BDs
5.1. Clinical screening of visible defects available
5.2. Plan to introduce IEM screening

Progress in Strategic Direction 4: Expand and strengthen national capacity for implementation of birth defects plan

1. Capacity building/trainings conducted
1.1. Birth defect surveillance trainings conducted twice in three surveillance sites (Nurses from maternity, birthing center, NICU, CU pediatric, emergency department in two batches)

Progress in Strategic Direction 5: Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

1. National birth defects prevention partnerships and networks
   Partnership within and across public health programs and departments
   1.1. Nutrition, RH, DPR, HIV, Adolescent, school health, HPD, PHED and research/PPD
   1.2. Development and technical partners (WHO, UNICEF, UNFPA, SEARO, CDC)
India

National Birth Defects Plan

1. **Goal in the national plan**
   1.1. To establish Birth defect surveillance system in identified tertiary level institutions
   1.2. To screen children for birth defect for their management

2. **Targets in the national plan**
   2.1. To start BD surveillance in 50 identified institutions and further expand to 100 institutions by December 2016
   2.2. To ensure regularity of reporting using standard case definition as per BD surveillance guidelines.
   2.3. To establish a National center for continuous capacity building, quality reporting and regular feedback to reporting sites

3. **Status of achievement for each Target**

Implementation of national BD Plan

1. **Significant challenges or barriers impeding the progress on the national plan**
   1.1. Capacity to scale up is limited
   1.2. Quality of the data and no monitoring
   1.3. Feedback is limited and use of data for planning not done

2. **Steps toward addressing the challenges or barriers**
   2.1. Capacity building to be scaled up at regional level
   2.2. Mechanism of internal review and external validation to be built
   2.3. Increase geographic coverage
   2.4. Linkages with existing program – FBNC and RBSK to be strengthened

**Progress in Strategic Direction 1:** Establish or strengthen national policies and programmes for birth defects prevention

1. **National focal point**
   1.1. CH Division, MOHFW: Dr. Ajay Khera (DC), Dr. Arun Kumar (Advisor) Singh

2. **National taskforce/workgroup members**
   2.2. exists

3. **Status of national birth defects prevention plan and/or programme**
   3.1. The National guidelines for establishing BD surveillance has been developed

4. **Budget for national birth defects prevention plan and/or programme**
   4.2. Under consideration

**Progress in Strategic Direction 2:** Develop or strengthen birth defects surveillance, monitoring and evaluation capacity

**Birth Defects Surveillance: Status of reporting hospitals**

1. **Status of national birth defects surveillance mechanism**
   1.1. Hospital based: Present
   1.2. Population based: pilot population based birth defect surveillance initiated

2. **Status of national birth defects information integrated in existing health information system(s)**
   2.1. Not listed

3. **Number of Hospitals**
   3.1. All newborns: ~ 68
3.2. Birth defects cases (in live and stillbirths): 4883*
3.3. Stillbirths: 17012*
3.4. Sick newborns: na

Progress in Strategic Direction 3: Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes

1. Birth defects prevention in RMNCAH
   1.1. Pradhan Mantri Surakshit Matritva Abhiyan; Ultrasound is included as essential test
   1.2. Newborn Screening at birth part of RBSK
   1.3. MOHFW launched nationwide Weekly Iron and Folic Acid Supplementation (WIFS) programme in 2012 for Adolescents both boys and girls

2. Immunization (Rubella Vaccination)
   2.1. MMR vaccine is being administered in RI program in 5 selected states from their own state funds (Delhi, Puducherry, Sikkim, Goa and Kerala).

3. Food fortification and micronutrient supplementation programmes
   3.1. Revised guidelines for fortification of food are under consideration by regulatory authority to make public health impact on NTD

4. Birth defects prevention in non-communicable diseases programmes
   4.1. MoHFW has a National Programme for prevention and control of Cancer, Diabetes, CVDs and Stroke which aims at providing comprehensive care for NCDs through primary care approach

5. Strengthen the care and management services for BDs
   5.1. Rashtriya Bal Swasthya Karyakram (RBSK) has been rolled out in 31 states in India.
   5.2. More than 10,000 mobile teams in place and
   5.3. screened about 180 million children in the age group 0-18 years during FY 2015-16 and
   5.4. out of this 3.46 children identified with birth defects for their management.

Progress in Strategic Direction 4: Expand and strengthen national capacity for implementation of birth defects plan

1. Capacity building/trainings conducted
   1.1. Child Health Training – RBSK training for mobile teams, Screening at birth under RBSK
   1.2. Maternal Health – Diagnosis & management of gestational diabetes, screening of hypothyroidism during pregnancy, Training of MOs and ANMs, LHVts and SNs in pregnancy care
   1.3. Adolescent Health – WIFS Training
   1.4. BDS training: Three Dedicated training of 2 days conducted and trained 159 participants from reporting sites

Progress in Strategic Direction 5: Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

2. National birth defects prevention partnerships and networks
   Underway
Indonesia

National Birth Defects Plan

1. Goal in the national plan
   1.1. Reduce morbidity and mortality due to birth defect in order to improve the survival and quality of life of children

2. Targets in the national plan
   2.1. Folic acid supplementation for adolescents and all pregnant women.
   2.2. Improving career thalassemia screening as 50% for children who have a family history of thalassemia.
   2.3. Rubella immunization. It will be started in 2017
   2.4. Syphilis screening for all pregnant women, especially in endemic areas, and achieve 100% treatment rates for women (and their partners) who have test positive.
   2.5. Hypothyroid
   2.6. Increase corrective action for babies with cleft lip and/or palate at least 50%.
   2.7. Increase the corrective action for babies with Talipes at least 50%.

3. Status of achievement for each Target
   3.1. Implemented Hospitals + 6 New Sentinel Hospitals

Implementation of national BD Plan

1. Significant challenges or barriers impeding the progress on the national plan
   1.1. Birth defect program is not as priority program yet
   1.2. No availability of baseline data
   1.3. HMIS is not provide accurate diagnose of birth defect base on ICD-10
   1.4. Limited number of sentinel hospital involve
   1.5. Referral level regulation cause of the number of delivery in sentinel hospitals declined sharply. As a result, the number of in-born birth defect cases was much lower than out-born cases.

2. Steps toward addressing the challenges or barriers
   2.1. Establish minister of health decree on birth defect prevention and control programme
   2.2. Dissemination and advocacy
   2.3. Collaborate with Research and Development Board to report birth defect data online through ina-registry.org
   2.4. Expand hospital based birth defect surveillance to district hospital

Progress in Strategic Direction 1: Establish or strengthen national policies and programmes for birth defects prevention

1. National focal point
   1.2. Directorate of Family Health collaboration with Research and Development Board, Directorate of Nutrition, Directorate of Surveillance and Quarantine Health, and Directorate General of Medical Services

2. National taskforce/workgroup members
   2.1. Forum Coordination of Hospital-based Birth Defect Surveillance has been establish since 2013 that consist of related programme manager at MoH, Indonesia Obstetric and Gynecologic Association, Indonesia Pediatric Association, Indonesia Midwife Association, Indonesia Nurse Association, Indonesia Medical Record Association and Academics
3. **Status of national birth defects prevention plan and/or programme**
   3.1. Approved or endorsed by the government
   3.2. Published and disseminated from certain hospital and stakeholders

4. **Budget for national birth defects prevention plan and/or programme**
   4.1. Dedicated budget to support national plan:
   4.2. Directorate of Family Health
   4.3. Directorate of Nutrition (folic acid supplementation for 15% of adolescent and 100% pregnant women)
   4.4. Rubella Immunization programme
   4.5. Congenital Rubella Syndrome Surveillance at 10 Hospitals

**Progress in Strategic Direction 2:** Develop or strengthen birth defects surveillance, monitoring and evaluation capacity *Birth Defects Surveillance: Status of reporting hospitals*

1. **Status of national birth defects surveillance mechanism**
   1.1. Indonesia started with Hospital-based Birth Defect Surveillance at 13 sentinel Hospital since 2014 then it was expanded to 6 sentinel hospitals
   1.2. Population based : not yet
   1.3. Others : Congenital Rubella Syndrome Surveillance 10 hospitals
   1.4. Monitoring: Member of Birth Defect Coordination Forum visit 6 sentinel hospitals each years
   1.5. Evaluation : conducted evaluation meeting every year

2. **Status of national birth defects information integrated in existing health information system(s)**
   2.1. HMIS : number of delivery, stillbirth, life birth
   2.2. CRVS: no
   2.3. Any other : Data of babies who have birth defect were input by medical record staff at sentinel hospitals to online system ina-registry.org manage by Research and Development Board, MoH
   2.4. Survey: Basic Health Research every 3 years

3. **Number of Hospitals**
   Currently not included in NBBD

**Progress in Strategic Direction 3:** Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes

1. **Birth defects prevention in RMNCAH**
   1.1. Newborn screening in 31 provinces out of al 34 provinces implement Hypothyroidism screening (coverage 6% of LB Babies); Adolescent Friendly Services (reproductive health, sexual transmission disease prevention)

2. **Immunization (Rubella Vaccination)**
   2.1. Rubella Immunization will be introduce in 2017, total coverage in 2019state funds (Delhi, Puducherry, Sikkim, Goa and Kerala).

3. **Food fortification and micronutrient supplementation programmes**
   3.1. Folic Acid supplementation for adolescent and pregnant women

4. **Birth defects prevention in non-communicable diseases programmes**
   4.1. Smoking cessation and smoke free area campaign, promote physical activity, limited consumption of sugar, salt and fat

5. **Strengthen the care and management services for BDs**
   5.1. Disability program, therapy and correction of birth defect
Progress in Strategic Direction 4: Expand and strengthen national capacity for implementation of birth defects plan

**Capacity building/trainings conducted**
1st training in August 2014 (13 hospitals) and 2nd training in July 2016 (6 hospitals)

Progress in Strategic Direction 5: Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

**National birth defects prevention partnerships and networks**
Partnership between Indonesia Obstetric and Gynecologic Association; Indonesia Pediatric Association; Indonesia Midwife Association; Indonesia Nurse Association; Indonesia Medical Record Association; Hospital Association; Academics; Ministry of Trade; Logistic Board; Fe and Folic Acid Industry; Vaccine Industry; Ministry of Forest and Environment; Ministry of Agricultural

Maldives

National Birth Defects Plan

**Goal in the national plan**
Significant reduction of preventable birth defects in Maldives towards further reduction in newborn and child mortality and prevent long term morbidity and disability.

**Targets in the national plan**
- Reduce prevalence of folic acid-preventable neural tube defects by 14% in two years;
- Reduce the number of thalassemia births by 20% in two years;
- Eliminate congenital rubella
- Work towards eliminating congenital syphilis.

**Status of achievement for each Target**
Currently, a perinatal database is being maintained at IGMH, where all the information pertaining to all the live births and perinatal deaths are being entered. This project is planned to be scaled up to include Regional Hospital in the near future.

Implementation of national BD Plan

**Significant challenges or barriers impeding the progress on the national plan**
- Human Resources
- Political commitment

**Steps toward addressing the challenges or barriers**
- Training and capacity-building
- Coordination ongoing
- Integration into National RMNCH Programmes
- Adolescent health programme being established
- Micronutrient supplementation programmes: IFA
- Strong Immunization programmes
- NCD programmes: Diabetes, obesity, tobacco prevention, thalassemia prevention
- Health education and health promotion
**Progress in Strategic Direction 1:** Establish or strengthen national policies and programmes for birth defects prevention

**National focal point**
National RH program  HPA, MOH

**National taskforce/workgroup members**
MOH,HPA,IGMH,ADK hospital (private),NGO’s

**Status of national birth defects prevention plan and/or programme**
National birth defects prevention plan developed

**Budget for national birth defects prevention plan and/or programme**
National Programs conduct program runs programs directed towards areas which have direct affects towards reduction of birth defects,- eg: vaccination, folic acid supplementation

**Progress in Strategic Direction 2:** Develop or strengthen birth defects surveillance, monitoring and evaluation capacity

**Birth Defects Surveillance:**

**Status of reporting hospitals**

- **Status of national birth defects surveillance mechanism**
  - Hospital based: IGMH
  - Population based: na

- **Status of national birth defects information integrated in existing health information system(s)**
  - HMIS: na
  - CRVS: na

**Number of Hospitals**

- All newborns: 1 Center
- Birth defects cases (live and stillbirths): 1 Center
- Stillbirths: 1 Center
- Sick newborns:1 Center

**Progress in Strategic Direction 3:** Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes

**Birth defects prevention in RMNCAH**

Preconception awareness /education sessions for health care providers to selected atolls in 2016; Routine ultrasound screening in 2nd TM (12-13 weeks) for NTDs and aneuploidies and late 2nd TM(22-25 weeks) Termination of pregnancy within 120 days (approved by MOIA) selectively; Adolescent friendly health services established at 3 places

**Immunization (Rubella Vaccination)**
MR vaccine campaign 2006; Rubella Vaccination program for children under 18months
Food fortification and micronutrient supplementation programmes
Rely on imported food, to lobby for policy decision to import fortified food products through National food and nutrition council.

Birth defects prevention in non-communicable diseases programmes
Ultrasound screening for cardiac and other anomalies; Screening of mothers for Syphilis; Prenatal Diagnosis for Thalassemia Carriers, CVS;

Strengthen the care and management services for BDs
Immediate care and referral available at all health facilities, further care available at tertiary health facility

Progress in Strategic Direction 4: Expand and strengthen national capacity for implementation of birth defects plan
Capacity building/trainings conducted
Twice

Progress in Strategic Direction 5: Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

National birth defects prevention partnerships and networks
- IGM Hospital
- ADK Hospital
- REGIONAL HOSPITALS
- ATOLL HOSPITALS, 
- Maldives Blood Services
- SHE
- NGOS

Nepal

National Birth Defects Plan

Goal in the national plan
To significantly reduce preventable birth defects and reduce related mortality and morbidity in Nepal

Targets in the national plan
- Targets in the national plan:
- Establish a surveillance system
- Reduce the prevalence of folic acid-preventable neural tube defects
- Reduce the number of thalassemia & other genetic disorders
- Reduce the prevalence of congenital rubella
- Eliminate congenital syphilis
- Strengthen appropriate services for management of children with birth defects
Status of achievement for each Target
WHO is supporting for Birth Defect Surveillance as pilot in 16 Hospitals
GoN has also allocated budget for Neonatal & Perinatal Database Update in 16 pilot Hospitals

Implementation of national BD Plan

Significant challenges or barriers impeding the progress on the national plan
- Challenges in recording and reporting: Conventional way of record keeping (Paper based)
- Challenges in recruitment of staff: Permanent employee needed; Not electronic device friendly; Feel over burden; Delay in filling up the form (less enthusiasm)
- Challenges in HR: Old staff-Training & motivation and incentive needed; New recruitment needed

Steps toward addressing the challenges or barriers
Not Listed

Progress in Strategic Direction 1: Establish or strengthen national policies and programmes for birth defects prevention

National focal point
DoHS, Family Health Division

National taskforce/workgroup members
National Advisory Committee: Chair, Secretary, MOH
National taskforce/workgroup (TWG) members:
Chair DG, DoHS
Co-chair, Director, FHD
Member Secretary: Senior Demographer, DoHS, FHD
Member Representatives: FP/SM Section Chief of FHD, Public Health Expert from TUTH, Pediatric Surgion from Kanti Children Hospital, Neonatologist from Maternity Hospital, Representatives from WHO, UNICEF, UNFPA, Invitees as BD expert

Status of national birth defects prevention plan and/or programme
Approved or endorsed by the government
Published and disseminated to stakeholders

Budget for national birth defects prevention plan and/or programme
Dedicated budget through WHO matched by GoN

Progress in Strategic Direction 2: Develop or strengthen birth defects surveillance, monitoring and evaluation capacity Birth Defects Surveillance:

Status of reporting hospitals

Status of national birth defects surveillance mechanism
- Hospital based: 16 Hospitals
- Population based: na

Status of national birth defects information integrated in existing health information system(s)
- HMIS: Yes
- CRVS: na
Number of Hospitals
All newborns
– Birth defects cases (live and stillbirths): 16 Centers
– Stillbirths: 11 Centers
Sick newborns: 11 Centers

**Progress in Strategic Direction 3:** Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes

Birth defects prevention in RMNCAH
Clinical screening only
Adolescent health clinics opened all over the country

Immunization (Rubella Vaccination)
Programmatic in national schedule

Food fortification and micronutrient supplementation programmes
Iodized salt, Flour Fortification; Folic acid supplementation as per clinical practice

Birth defects prevention in non-communicable diseases programmes
Anti-tobacco program

Strengthen the care and management services for BDs
Free treatment to Newborn (<28 days); Free treatment of selected BDs (Cleft Lip & Palate)

**Progress in Strategic Direction 4:** Expand and strengthen national capacity for implementation of birth defects plan

Capacity building/trainings conducted
Three trainings done

**Progress in Strategic Direction 5:** Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

National birth defects prevention partnerships and networks
Karuna Foundation: Decrease No of BD & disabilities among children, working in 3 districts (Rasuwa, Ilam & Sunsari; Down Syndrome Society of Nepal; Down Syndrome Association of Nepal
Sri Lanka

National Birth Defects Plan

Goal in the national plan
To Improve the quality of life through prevention and early management of correctable birth defects in Sri Lanka to contribute to achievement of MDG 4 and beyond

Targets in the national plan
- To reduce prevalence of folic acid-preventable neural tube defects by 35% by 2018
- To reduce the number of thalassemia births by 50% by 2018
- To eliminate congenital rubella by 2018
- To eliminate congenital syphilis by 2015
- To reduce chromosomal defects (Trisomy 21) occurring in a subsequent pregnancy by 50% by 2018
- To detect 80% of correctable heart diseases and referred for care before 6 weeks of life by 2018
- To detect 80% of oro-facial defects and referred for care before 6 weeks of life by 2018
- To detect 80% of limb defects and referred for care before 6 weeks of life by 2018
- To detect 80% of congenital hypothyroidism and treated by 6 weeks of life by 2018
- To establish a national birth defect surveillance system by 2015

Status of achievement for each Target
MoH plans to establish a national birth defect surveillance system in SL by 2017 - Pilot test completed in 1 Province.
Coverage of pre-pregnancy folic acid supplementation – 50.7%
Hospital admissions for Thalassemia treatment are decreasing - Social marketing campaign and screening and counselling facilities in high prevalent areas
Eliminate congenital syphilis by 2015
On track - correctable heart diseases, oro-fascial and limb defects >50% coverage for Pulse oximetry screening before discharge
Multi Disciplinary Clinic/Team Management of Cleft Lip and Palate available

Implementation of national BD Plan

Significant challenges or barriers impeding the progress on the national plan
Na

Steps toward addressing the challenges or barriers
Na

Progress in Strategic Direction 1: Establish or strengthen national policies and programmes for birth defects prevention

National focal point
National focal point for birth defects prevention - DDG PHS II / Family Health Bureau of the Ministry of Health

National taskforce/workgroup members
Key stakeholders are supportive for birth defects prevention
Status of national birth defects prevention plan and/or programme

National birth defects prevention plan
Approved or endorsed by the government
Disseminated among the task force and stakeholders

Budget for national birth defects prevention plan and/or programme
BD prevention is integrated in to the routine system.

Progress in Strategic Direction 2: Develop or strengthen birth defects surveillance, monitoring and evaluation capacity Birth Defects Surveillance:

Status of reporting hospitals

Status of national birth defects surveillance mechanism
Not yet a part of NBBD

Status of national birth defects information integrated in existing health information system(s)
RH HMIS – present
eIMMR – Obstetric formats
Neonatal Examination Format – pilot in one district
Neo-NICS – In all THs, PGHs

Number of Hospitals
NA

Progress in Strategic Direction 3: Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes

Birth defects prevention in RMNCAH
Advocacy for integrate selected BD prevention and control strategies into the existing health and social services

Immunization (Rubella Vaccination)
Rubella Immunization present

Food fortification and micronutrient supplementation programmes
Present

Birth defects prevention in non-communicable diseases programmes
NA

Strengthen the care and management services for BDs
NA
Progress in Strategic Direction 4: Expand and strengthen national capacity for implementation of birth defects plan

Capacity building/trainings conducted
Pre-service training
- Doctors/Nurses/Midwives

In-service training
- Child Growth Monitoring and Promotion
- and Immunization
- School Health Inspection training package
- Adolescent and Youth Friendly Health service package
- Pre-pregnancy care package
- Maternal Care package
- Essential Newborn Care package

Postgraduate training - MSc (ComMed), MD (Paediatrics)

Special Workshops on birth defects as in-service training
- National Workshop
- Staff in the pilot institutions trained
- Training workshop for pathological postmortems
- Review workshop following completion of pilot test

Progress in Strategic Direction 5: Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

National birth defects prevention partnerships and networks
na

Thailand

National Birth Defects Plan

Goal in the national plan
The overall goal is to decrease the neonatal death rate to < 5 : 1000 live birth by 2016 and < 3 : 1000 live birth by 2020 by preventing preventable cases of BDs and treating the treatable and reduce disabilities.

Targets in the national plan
National targets BDs prevention and control is grouped into 6 plans covering 6 aspects related to BD prevention and each plan has the target at 2 years, and at 5 years

Status of achievement for each Target
- Birth Defect Surveillance
  Setting up of the national registry system was implemented in 41 provinces, as planned Initiative in setting access to care database
• **Newborn Screening**
  - Coverage of NB screening is more than 95% and reconfirmation is 95%
  - Center of monitoring and evaluation at QSNICH
  - National Networks for Prevention and Care
  - Selected prevention and care program was implemented in 22 provinces in provincial and district hospitals

**Implementation of national BD Plan**

**Significant challenges or barriers impeding the progress on the national plan**

- Extra Work
- Partnerships and networks:
  - Encourage harmonization among the networks
- Birth Defect, surveillance & prevention data base are integrated by using the main portal of data entry: the 13 digit ID
- The integrating of the registry system that links to the national maternal and children ID + neonatal registry provided by SEARO

**Steps toward addressing the challenges or barriers**

Being addressed

**Progress in Strategic Direction 1: Establish or strengthen national policies and programmes for birth defects prevention**

**National focal point**
- Department of Medical Service, MOPH
- Department of Medical Science, MOPH
- Department of Health, MOPH
- Department of Prevention and Control, MOPH
- Bureau of Policy and Strategy, MOPH

**National taskforce/workgroup members**
- Queen Sirikit National Institute of Child Health (QSNICH)
- Sirindhorn National Medical Rehabilitation Center
- Birth Defects Association of Thailand
- Faculty of Medicine, Siriraj Hospital
- Faculty of Medicine, Ramathibodee Hospital
- Faculty of Medicine, Chulalongkorn University
- Institute of Nutrition, Mahidol University
- Health Intervention and Technology Assessment Program (HITAP)
- International Health Program, Thailand (IHPP)

**Status of national birth defects prevention plan and/or programme**

- Approved or endorsed by the government
- Published and disseminated to stakeholders

**Budget for national birth defects prevention plan and/or programme**

Yes
**Progress in Strategic Direction 2:** Develop or strengthen birth defects surveillance, monitoring and evaluation capacity

**Birth Defects Surveillance:**

**Status of reporting hospitals**

**Status of national birth defects surveillance mechanism**

- Year-1 (2013) 20 hospital in 16 provinces (67,813 = 8.28% of total live births)
- Year-2 (2014) 27 hospital in 20 provinces (89,454 = 11.43% of total live births)
- Year-3 (2015) 49 hospital in 41 provinces (180,393 = 23.23% of total live births)

**Status of national birth defects information integrated in existing health information system(s)**

- HMIS: Yes
- CRVS: na

**Number of Hospitals**

13 Hospitals reporting on--

- All newborns: 49,119 cases
- Birth defects in live birth: 466 cases
- Stillbirths: 199 case (no data entry form)
- Sick newborns: 15,552 cases

**Progress in Strategic Direction 3:** Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes

**Birth defects prevention in RMNCAH**

- Pre-pregnancy clinic in every hospitals, Teenage pregnancy
- Quality ANC (screening HIV thalassemia, Early & education) Parental school
- Emphasis the existing program
- Early detection and quality M&E
- Health education (awareness & prevention)
- Coverage of NB screening is more than 95% and reconfirmation is 95%

**Immunization (Rubella Vaccination)**

- More than 95% coverage

**Food fortification and micronutrient supplementation programmes**

- Iodized salt advocacy
- Folate supplement advocacy

**Birth defects prevention in non-communicable diseases programmes**

- Thalassemia, Down, prevention program
**Strengthen the care and management services for BDs**
National Better Child Development Project
Birth Defects & Disabilities Care Project  Access to care program (Newborn service plan)

*Progress in Strategic Direction 4: Expand and strengthen national capacity for implementation of birth defects plan*

**Capacity building/trainings conducted**
Periodically conducted

*Progress in Strategic Direction 5: Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes*

**National birth defects prevention partnerships and networks**
Center for Monitoring and Evaluation with Queen Sirikit National Institute of Child Health, Department of Medical Science, National Health Security Office and Health System Research Institute

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**Timor-Leste**

**National Birth Defects Plan**

**Goal in the national plan**
Current National Strategy on RMNCAH, 2015 – 2019 was developed with emphasis on reduction of very high maternal, infant and under five mortality and reduction of unplanned pregnancies.

Surveillance and prevention of BD yet to be included into the RMNCAH strategic plan

**Targets in the national plan**

**Status of achievement for each Target**

**Implementation of national BD Plan**

**Significant challenges or barriers impeding the progress on the national plan**
TL is still a young / developing nation; the MOH has limited human and financial resources to manage multiple competing priorities
Existing HMIS has limits / inaccuracies which impact on its use for BD detection / reporting
Preconception care and adolescent programs targeting BD prevention are not yet established and neither are they yet included in the RMNCAH strategy.
High rates of home births, limited PNC and lack of a vital registration system limit health system contacts for data collection / reporting of BD.

**Steps toward addressing the challenges or barriers**
To begin TL will require technical and financial support to develop a national plan.
A first essential step that has been identified is the strengthening of recently established data collection systems at the national hospital (busiest birthing facility in the country ~ 5000 births / year).

**Progress in Strategic Direction 1:** Establish or strengthen national policies and programmes for birth defects prevention

**National focal point**
Not yet nominated

**National taskforce/workgroup members**
Yet to be established

**Status of national birth defects prevention plan and/or programme**
To be established

**Budget for national birth defects prevention plan and/or programme**
Not yet

**Progress in Strategic Direction 2:** Develop or strengthen birth defects surveillance, monitoring and evaluation capacity

**Birth Defects Surveillance:**

**Status of reporting hospitals**

**Status of national birth defects surveillance mechanism**

**Status of national birth defects information integrated in existing health information system(s)**

**Number of Hospitals**
no

**Progress in Strategic Direction 3:** Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes

**Birth defects prevention in RMNCAH**
Program not yet established (included in RMNCAH strategy)
CHCs in Dili have begun A/N syphilis testing.
Neonatal checks (clinical exam) – limited coverage and implementation. No blood testing.
HIV/STI/ illicit drugs /alcohol prevention education is included in RMNCAH strategy and National Youth Action Plan
A/N USS only at Referral Hospitals - ad hoc screen

**Immunization (Rubella Vaccination)**
MR vaccine catch up campaign in 2015 for children < 15yrs.
MR vaccine for all children at 9 and 18 months
Food fortification and micronutrient supplementation programmes
No fortification. Supplementary feeding for undernourished pregnant women.

Birth defects prevention in non-communicable diseases programmes
Strong anti-smoking drive including legislation.

Strengthen the care and management services for BDs
Case detection, referral and management as appropriate in the health system. Part of paediatric training

Progress in Strategic Direction 4: Expand and strengthen national capacity for implementation of birth defects plan

Capacity building/trainings conducted
TL took the opportunity of World Birth Defect Day 2016 to conduct it’s first advocacy / awareness raising event for BD. The event was sponsored by WHO SEARO. Neonatal unit data for 5 non-consecutive years were presented. Participants included multidisciplinary health and allied health staff from the National Hospital and a small number of external partners.
- No. of events : 1 full day
- No. of participants : approximately 50
The event included a session on Zika virus and a dedicated training on feeding of cleft lip / palate babies (a commonly encountered BD in Timor-Leste).

Progress in Strategic Direction 5: Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

National birth defects prevention partnerships and networks
No formal partnerships or networks yet established
WHO supported the National Hospital to conduct the advocacy day
WHO is committed to support the ongoing establishment of an effective database for improved case detection and reporting.
## Annex 5

### Summary of the proposed national action plans for strengthening surveillance

#### Bangladesh

<table>
<thead>
<tr>
<th>Plan for action</th>
<th>Short-term</th>
<th>Long-term</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bangladesh</strong> took initiative to integrate Birth Defect in the national system since 2014</td>
<td></td>
<td>Community detection of NBBD will start by September 2016 in all 13,000 community clinic of Bangladesh. NGOs working for NBBD (specially those are doing corrective surgery will be involved in case reporting-(Walk for Life, Sustainable Club Foot, )</td>
</tr>
<tr>
<td><strong>Existing web-based reporting system (DHIS-2)</strong> used for data collection from facility</td>
<td></td>
<td><strong>A guideline has been published for data collection with short list of birth defects</strong></td>
</tr>
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<td></td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current NBBD implementation</th>
<th>No. of Hospitals for Birth defects</th>
<th>14</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of Hospitals for Stillbirths</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>No. of Hospitals for Newborn health and head circumference</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expansion of hospital network</th>
<th>For Birth Defects</th>
<th>By 2017: - Add (8 Gov. + 2 AF + 5 Pvt.) MCH + 03 DH By 2018:- Add:16 Gov +4 AF + MCH + 15 DH</th>
</tr>
</thead>
<tbody>
<tr>
<td>For Still Births</td>
<td></td>
<td></td>
</tr>
<tr>
<td>For Newborn health and Head Circumference</td>
<td>By 2017:- Add: 09 Gov. MCH only NBBD hospitals By 2018:- Add: 20 MCH hospitals</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sustainability</th>
<th>Identify the Hospital Nodal Person (Level 1 verifier) and report to SEAR-NBBD:</th>
<th>By September, 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify the Hospital Nodal Person (Level 2 verifier) and report to SEAR-NBBD</td>
<td>In 05 NNPD-NBBD hospital by June, 2017</td>
<td></td>
</tr>
<tr>
<td>Plan for analysis of data and supervision</td>
<td>To be started from January, 2017</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Capacity building activities in the country</th>
<th>Number of trainings on Birth defects surveillance</th>
<th>Ongoing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality control training / Quality assurance for data</td>
<td>Ongoing</td>
<td></td>
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<tr>
<td>-----------------------------------------------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>Periodic Use of Checklist / Supportive Supervision</td>
<td>Ongoing</td>
<td></td>
</tr>
</tbody>
</table>

**Resources needed**

| Additional Human Resources from MoH | Needed |
| Additional Financial Resources from MoH | Needed |
| Additional Technical Resources from MoH / WHO/ CDC | Needed |

**Evaluation of the national database/surveillance system**

| National Plan | To improve the data quality UNICEF along with other partners developing easy guideline to selecting ICD-10 codes for facility staff Shortlist for NBBD is under process for community detection using pictorial description Data is used for monthly meeting at different level to improve the quality Continuous training, supported by WHO, ongoing on ICD 10 at national level |

**Timeline**

**Bhutan**

**Plan for action**

| Short-term | Plan to include data abstraction forms in the case files (BD form in Newborn case sheet; and Stillbirth form with Mother case sheet) by 2017 Essential steps for doing so -Conduct consensus meeting with obgyn, pediatrician, concerned nursing staffs/resident doctors of 3 referral hospitals on development/incorporation of still birth/BD form in the mother/newborn case sheet -Orient/sensitize on the obgyn, pediatrician, concerned nursing staffs/resident doctors, record officer of 3 referral hospitals |
| Long-term | Continue implementation and expansion of NBBD |

**Current NBBD implementation**

| No. of Hospitals for Birth defects | 1 |
| No. of Hospitals for Stillbirths | 2 or more |
| No. of Hospitals for Newborn health and head circumference | 2 or more |

**Expansion of hospital network**

| For Birth Defects | By 2016:- 1 By 2017:- 2 or more By 2018:- 2 or more |
| For Still Births | By 2016:- 0 By 2017:-3 By 2018:- 2 |
| For Newborn health and Head Circumference | By 2016:- 0 By 2017:-3 By 2018:- 2 |

**Sustainability**

<p>| Identify the Hospital Nodal Person (Level 1 verifier) and report to SEAR-NBBD: | Nursing Staff by 2017 |</p>
<table>
<thead>
<tr>
<th>Identify the Hospital Nodal Person (Level 2 verifier) and report to SEAR-NBBD</th>
<th>Obgyn &amp; pediatrician by 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan for analysis of data and supervision</td>
<td>6 monthly</td>
</tr>
</tbody>
</table>

**Capacity building activities in the country**

| Number of trainings on Birth defects surveillance | By 2016:- 1  
By 2017:- 1  
By 2018:- 1 |
<table>
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</thead>
<tbody>
<tr>
<td>Quality control training / Quality assurance for data</td>
<td>not done</td>
</tr>
</tbody>
</table>
| Periodic Use of Checklist / Supportive Supervision | By 2016:- 2  
By 2017:- 2  
By 2018:- 2 |

**Resources needed**

<table>
<thead>
<tr>
<th>Additional Human Resources from MoH</th>
<th>Nurses and data operator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional Financial Resources from MoH</td>
<td>Needed</td>
</tr>
<tr>
<td>Additional Technical Resources from MoH / WHO / CDC</td>
<td>Needed (supplies and funds)</td>
</tr>
</tbody>
</table>

**Evaluation of the national database/surveillance system**

| National Plan | With technical support from WHO and financial support from RGoB/who |

**Timeline**

| By 2018 |

**India**

**Plan for action**

| Short-term | Set up Sentinel Perinatal Registry (SPR)  
- Strengthen and Expand the current BD Sentinel Surveillance network to include newborn data, birth defect and still birth related data in identified tertiary level institutions in integrated manner by Dec 2016 |
|------------|---------------------------------------------------------------------|
| Long-term | Establish National Perinatal Registry Unit for oversight  
- A National level institution will be identified in technical collaboration with PGIMER, Chandigarh and Safdarjung hospital, New Delhi & MGIMS, Wardha for continuous oversight of Perinatal registry and funding will be provisioned under National Health Mission by Dec 2016 |

**Current NBBD implementation**

<table>
<thead>
<tr>
<th>No. of Hospitals for Birth defects</th>
<th>74</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of Hospitals for Stillbirths</td>
<td>15</td>
</tr>
<tr>
<td>No. of Hospitals for Newborn health and head circumference</td>
<td>13</td>
</tr>
</tbody>
</table>

**Expansion of hospital network**

| For Birth Defects | By 2016:- 55  
By 2017:- 55  
By 2018:- 55 |
|-------------------|------------------|
| For Still Births   | By 2016:- 100  
By 2017:- 100  
By 2018:- 100 |
### Sustainability

| Identify the Hospital Nodal Person (Level 1 verifier) and report to SEAR-NBBD | At the reporting site, a dedicated two member team consisting of project officer and data entry operator will be provided. Appointed nodal officer of the reporting site will act as Verifier 1 |
| Identify the Hospital Nodal Person (Level 2 verifier) and report to SEAR-NBBD | The National Perinatal registry unit will also be provided funding to support, mentor and supervise reporting sites under national health mission (Dec 2016). This unit will be the Verifier 2 |
| Plan for analysis of data and supervision | The supporting infrastructure will be provided under state national Health Mission. (December 2016) |

### Capacity building activities in the country

| Number of trainings on Birth defects surveillance | By 2016:- 2  
By 2017:- 3  
By 2018:- 5 |
| Quality control training / Quality assurance for data | Ongoing |
| Periodic Use of Checklist / Supportive Supervision | At least 1 visit in 6 months over the next two years |

### Resources needed

| Additional Human Resources from MoH | Needed |
| Additional Financial Resources from MoH | Needed |
| Additional Technical Resources from MoH / WHO/ CDC | Needed |

### Evaluation of the national database/surveillance system

| National Plan | The National perinatal registry unit will first conduct a gap analysis of all reporting sites and then conduct orientation of key officials, continuous monitoring, mentoring, analysis and feedback for ensuring completeness, accuracy and timeliness of perinatal data |

### Timeline

| By 2017 |

### Indonesia

#### Plan for action

**Short-term**

- Coordination inter-department (MoH), inter-professional (Obstetricians, Pediatricians, MR Officer, Board of Hospital Directors, Epidemiologist) to integrate, implement and sustain NBBD

**Long-term**

- Plan to include data abstraction forms in the case files (NB and BD form in Newborn case sheet; and Stillbirth form with Mother case sheet): By 2020

#### Current NBBD implementation

| No. of Hospitals for Birth defects | 13 |
| No. of Hospitals for Stillbirths | na |
| No. of Hospitals for Newborn health and head circumference | na |
| Expansion of hospital network | For Birth Defects | By 2016: 19  
By 2017: 25 (Riau, Balikpapan, Banjarmasin, Lombok, Jayapura)  
By 2018: 31 (Ternate, Sorong, Kupang, Palangkaraya, Aceh, Pontianak) |
|--------------------------------|------------------|---------------------------------------------------------------|
| For Still Births               | By 2016: 19      
By 2017: 25          
By 2018: 31          |
| For Newborn health and Head Circumference | By 2016: 19      
By 2017: 25          
By 2018: 31          |
| **Sustainability**             | Identify the Hospital Nodal Person (Level 1 verifier) and report to SEAR-NBBDD: To be discussed |
|                               | Identify the Hospital Nodal Person (Level 2 verifier) and report to SEAR-NBBDD: To be discussed |
|                               | Plan for analysis of data and supervision: Quarterly |
| **Capacity building activities in the country** | Number of trainings on Birth defects surveillance | By 2016: 1  
By 2017: 1          
By 2018: 1          |
|                               | Quality control training / Quality assurance for data | By 2016: 1  
By 2017: 1          
By 2018: 1          |
|                               | Periodic Use of Checklist / Supportive Supervision | By 2016: 1  
By 2017: 1          
By 2018: 1          |
| **Resources needed**           | Additional Human Resources from MoH | Dedicated person for BD  
Introduce the programme to Board of Hospital Directors – better service and referral system |
|                               | Additional Financial Resources from MoH | Additional budget for BD and linkage with HIMS and integration of surveillance form to medical record |
|                               | Additional Technical Resources from MoH / WHO / CDC | For CDC or WHO: Atlas of BD in terms for simulation including how to take picture, abstraction and putting in ICD-10  
For MoH: regular meeting for analysis for report and feedback to implementing hospitals; Supervision from Nodal and MoH to Hospitals. Development web-based programme, integrated the programme to HIS |
| **Evaluation of the national database/surveillance system** | National Plan | Make regional referral hospital for BD with Harapan Kita Hospital as a role model  
Budgeting for maintaining and increased capacity for server and additional dedicated persons for IT Regular meeting for analysis and report that can use for NBBDD and local user |
| **Timeline**                  | By 2020         |
## Maldives

<table>
<thead>
<tr>
<th>Plan for action</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Short-term</strong></td>
</tr>
<tr>
<td>Data abstraction forms in the case files (NB and BD form in Newborn case sheet; and Stillbirth form with Mother case sheet) included as part of ongoing surveillance</td>
</tr>
<tr>
<td><strong>Long-term</strong></td>
</tr>
<tr>
<td>Expand NBBD to cover all birth defects</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current NBBD implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No. of Hospitals for Birth defects</strong></td>
</tr>
<tr>
<td><strong>No. of Hospitals for Stillbirths</strong></td>
</tr>
<tr>
<td><strong>No. of Hospitals for Newborn health and head circumference</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expansion of hospital network</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>For Birth Defects</strong></td>
</tr>
<tr>
<td>By 2016: 10</td>
</tr>
<tr>
<td>By 2017: 10</td>
</tr>
<tr>
<td>By 2018: 15</td>
</tr>
<tr>
<td><strong>For Still Births</strong></td>
</tr>
<tr>
<td>By 2016: 1</td>
</tr>
<tr>
<td>By 2017: 10</td>
</tr>
<tr>
<td>By 2018: 15</td>
</tr>
<tr>
<td><strong>For Newborn health and Head Circumference</strong></td>
</tr>
<tr>
<td>By 2016: 1</td>
</tr>
<tr>
<td>By 2017: 10</td>
</tr>
<tr>
<td>By 2018: 15</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sustainability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify the Hospital Nodal Person (Level 1 verifier) and report to SEAR-NBBD:</td>
</tr>
<tr>
<td>Sep-16</td>
</tr>
<tr>
<td>Identify the Hospital Nodal Person (Level 2 verifier) and report to SEAR-NBBD</td>
</tr>
<tr>
<td>Sep-16</td>
</tr>
<tr>
<td>Plan for analysis of data and supervision</td>
</tr>
<tr>
<td>6 monthly from December 2016</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Capacity building activities in the country</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of trainings on Birth defects surveillance</strong></td>
</tr>
<tr>
<td>By 2016: 1</td>
</tr>
<tr>
<td>By 2017: 2</td>
</tr>
<tr>
<td>By 2018: 2</td>
</tr>
<tr>
<td><strong>Quality control training / Quality assurance for data</strong></td>
</tr>
<tr>
<td>By 2016: 1</td>
</tr>
<tr>
<td>By 2017: 1</td>
</tr>
<tr>
<td>By 2018: 1</td>
</tr>
<tr>
<td><strong>Periodic Use of Checklist / Supportive Supervision</strong></td>
</tr>
<tr>
<td>By 2016: 1</td>
</tr>
<tr>
<td>By 2017: 1</td>
</tr>
<tr>
<td>By 2018: 1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Resources needed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Additional Human Resources from MoH</strong></td>
</tr>
<tr>
<td>Data operators needed for IGMH</td>
</tr>
<tr>
<td><strong>Additional Financial Resources from MoH</strong></td>
</tr>
<tr>
<td>To support quarterly meeting and task force for NBBD</td>
</tr>
<tr>
<td><strong>Additional Technical Resources from MoH / WHO/ CDC</strong></td>
</tr>
<tr>
<td>Needed for development of SOPs, Training of DEO/Verifier and Additional Technical Resources from MoH / WHO/ CDC</td>
</tr>
<tr>
<td>Need to add functional BD (Thalassemia, G6PD etc)</td>
</tr>
<tr>
<td>Need for risk Factor asessement</td>
</tr>
<tr>
<td>Many defects are not included CHD , other specialties e.g. ophthalmology</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Evaluation of the national database/surveillance system</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>National Plan</strong></td>
</tr>
<tr>
<td>WHO/CDC and government support is key</td>
</tr>
<tr>
<td><strong>Timeline</strong></td>
</tr>
<tr>
<td>Feb-17</td>
</tr>
</tbody>
</table>
### Nepal

#### Plan for action

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short-term</td>
<td>To link existing software to NNBD software. To introduce software in those centers where only paper-based recording is in place. Orientation and re-orientation training.</td>
</tr>
<tr>
<td>Long-term</td>
<td>Capacity building training in NNBD surveillance for – Research – Genetic Lab establishment</td>
</tr>
</tbody>
</table>

#### Current NBBD implementation

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of Hospitals for Birth defects</td>
<td>16</td>
</tr>
<tr>
<td>No. of Hospitals for Stillbirths</td>
<td>5</td>
</tr>
<tr>
<td>No. of Hospitals for Newborn health and head circumference</td>
<td>10</td>
</tr>
</tbody>
</table>

#### Expansion of hospital network

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>For Birth Defects</td>
<td>By 2016: 16  By 2017: 16+5  By 2018: 21+5</td>
</tr>
<tr>
<td>For Still Births</td>
<td>By 2016: 5  By 2017: 10  By 2018: 15</td>
</tr>
<tr>
<td>For Newborn health and Head Circumference</td>
<td>By 2016: 10  By 2017: 10  By 2018: 10</td>
</tr>
</tbody>
</table>

#### Sustainability

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify the Hospital Nodal Person (Level 1 verifier) and report to SEAR-NBBD:</td>
<td>Sep-16</td>
</tr>
<tr>
<td>Identify the Hospital Nodal Person (Level 2 verifier) and report to SEAR-NBBD</td>
<td>Sep-16</td>
</tr>
<tr>
<td>Plan for analysis of data and supervision</td>
<td>Quarterly</td>
</tr>
</tbody>
</table>

#### Capacity building activities in the country

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of trainings on Birth defects surveillance</td>
<td>By 2016: 1  By 2017: 2  By 2018: 2</td>
</tr>
<tr>
<td>Quality control training / Quality assurance for data</td>
<td>Monthly</td>
</tr>
<tr>
<td>Periodic Use of Checklist / Supportive Supervision</td>
<td>Quarterly</td>
</tr>
</tbody>
</table>

#### Resources needed

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional Human Resources from MoH</td>
<td>To create a surveillance group</td>
</tr>
<tr>
<td>Additional Financial Resources from MoH</td>
<td>For capacity building of this group</td>
</tr>
<tr>
<td>Additional Technical Resources from MoH / WHO/ CDC</td>
<td>To link existing software to NNBD software  To introduce software in those centers where only paper-based recording is in place  Orientation and re-orientation training</td>
</tr>
</tbody>
</table>

#### Evaluation of the national database/surveillance system

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Plan</td>
<td>Monitor and evaluate NBBD surveillance with human resources and logistics</td>
</tr>
</tbody>
</table>

#### Timeline

<table>
<thead>
<tr>
<th>Description</th>
<th>2018</th>
</tr>
</thead>
</table>
## Sri Lanka

<table>
<thead>
<tr>
<th>Plan for action</th>
<th>Short-term</th>
<th>Aligning and integrating current system with NBBD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Long-term</td>
<td>Expansion of the surveillance to the field level – aiming a population-based registry</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Scaling up the system to cover the entire country by early 2016</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Linkage with routine HIMS &amp; eIMMR</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current NBBD implementation</th>
<th>No. of Hospitals for Birth defects</th>
<th>na</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. of Hospitals for Stillbirths</td>
<td>na</td>
</tr>
<tr>
<td></td>
<td>No. of Hospitals for Newborn health and head circumference</td>
<td>na</td>
</tr>
</tbody>
</table>

| Expansion of hospital network | For Birth Defects | By 2016: 21  
By 2017: 53  
By 2018: 61 |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>For Still Births</td>
<td>By 2016: 74</td>
</tr>
</tbody>
</table>
|                             | For Newborn health and Head Circumference | By 2016: 21  
By 2017: 53  
By 2018: 61 |

<table>
<thead>
<tr>
<th>Sustainability</th>
<th>Identify the Hospital Nodal Person (Level 1 verifier) and report to SEAR-NBBD:</th>
<th>Oct-16</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Identify the Hospital Nodal Person (Level 2 verifier) and report to SEAR-NBBD:</td>
<td>Oct-16</td>
</tr>
<tr>
<td></td>
<td>Plan for analysis of data and supervision</td>
<td>Dec-16</td>
</tr>
</tbody>
</table>

| Capacity building activities in the country | Number of trainings on Birth defects surveillance | By 2016: 6  
By 2017: 20  
By 2018: 25 |
|--------------------------------------------|--------------------------------------------------|---------|
|                                            | Quality control training / Quality assurance for data | By 2016: 6  
By 2017: 20  
By 2018: 25 |
|                                            | Periodic Use of Checklist / Supportive Supervision | By 2016: 2  
By 2017: 5  
By 2018: 10 |

<table>
<thead>
<tr>
<th>Resources needed</th>
<th>Additional Human Resources from MoH</th>
<th>MO – Public Health for all specialized hospitals and Geneticist / MO for MCMMS unit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Additional Financial Resources from MoH</td>
<td>For Expanding BD surveillance to 6 more provinces and National Capacity building</td>
</tr>
<tr>
<td></td>
<td>Additional Technical Resources from MoH / WHO / CDC</td>
<td>For Expanding BD surveillance to 6 more provinces and Trained personnel for data entering and Computer / Laptop / Internet facility at the grass root level</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Evaluation of the national database/surveillance system</th>
<th>National Plan</th>
<th>To be done with technical guidance from WHO / GoSL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timeline</td>
<td>2017</td>
<td></td>
</tr>
</tbody>
</table>
**Plan for action**

| Short-term | Plan to include data abstraction forms in the case files (NB and BD form in Newborn case sheet; and Stillbirth form with Mother case sheet) by Mar 2017. Essential steps - Internet connectivity, computer, printer, printer ink, paper all budgeted / supplied |
| Long-term | |

**Current NBBD implementation**

| No. of Hospitals for Birth defects | 1 |
| No. of Hospitals for Stillbirths | |
| No. of Hospitals for Newborn health and head circumference | |

**Expansion of hospital network**

| For Birth Defects | By 2016: 1  
|                   | By 2017: 3  
|                   | By 2018: 6  |
| For Still Births  | By 2016: 1  
|                   | By 2017: 3  
|                   | By 2018: 6  |
| For Newborn health and Head Circumference | By 2016: 1 (Contingent on having data operator / dedicated MOH personnel (currently no child health officer at MOH). |

**Sustainability**

| Identify the Hospital Nodal Person (Level 1 verifier) and report to SEAR-NBBD | Dec-16 |
| Identify the Hospital Nodal Person (Level 2 verifier) and report to SEAR-NBBD | Dec-16 |
| Plan for analysis of data and supervision | From Mar-17 |

**Capacity building activities in the country**

| Number of trainings on Birth defects surveillance | By 2016: 1  
|                                                    | By 2017: 2  
|                                                    | By 2018: 2  |
| Quality control training / Quality assurance for data | By 2016: 1  
|                                                    | By 2017: 2  
|                                                    | By 2018: 2  |
| Periodic Use of Checklist / Supportive Supervision | In 2017 & 2018: 4 |

**Resources needed**

| Additional Human Resources from MoH | Dedicated person – unlikely within current HR limitations (?possibly assign a recent graduate) |
| Additional Financial Resources from MoH | Additional Financial Resources from MoH for supplies |
| Additional Technical Resources from MoH / WHO/ CDC | Funding for data entry person; internet access; computer / printers; support for trainings |

**Evaluation of the national database/surveillance system**

| National Plan | Being incorporated |
| Timeline | By 2017 |