Perinatal Surveillance and Prevention of Birth Defects: Progress Review

Meeting Report

18 to 20 July 2017
Denpasar, Bali, Indonesia
Perinatal surveillance and Prevention of birth defects: Progress review

Report of Regional Meeting

18 to 20 July 2017

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**Background**

Birth defects or congenital anomalies affect an estimated 1 in 33 infants, resulting in 3.2 million children with disabilities related to birth defects every year\(^1\). The South-East Asia Region (SEAR) has the second highest prevalence of birth defects in the world: 9% of under-five deaths and 12% of newborn deaths in SEAR were due to congenital anomalies in 2015\(^2\). As the under-five mortality decreases in the region\(^3\), the proportionate mortality from birth defects will increase. Birth defects are becoming increasingly important causes of morbidity and mortality, chronic illness and disability in childhood. In SEAR countries with low child mortality like Maldives, Sri Lanka and Thailand birth defects already cause more than 25% of newborn mortality\(^3\).

WHO-SEARO has supported Member States to promote primary prevention and improve the health of children with congenital anomalies. In 2014, WHO-SEARO in collaboration with CDC-USA created an online system to gather perinatal surveillance data via a web-based database (SEAR-NBBD). The surveillance network started with 44 hospitals from India, Bangladesh and Nepal. In the past three years, there has been a steady increase in the number of hospitals registered with the NBBD, reaching 221 by December 2016; expanding from 3 to 9 countries. With Indonesia and Sri Lanka joining the network offline in 2016 all except DPR Korea and Timor Leste of the 11 SEAR Member States are now a part of NBBD. Nine countries in the Region have national plans for prevention and control of birth defects.

**Objectives**

Regional meeting to review progress in perinatal surveillance and prevention of birth defects was held from 18\(^{th}\) to 20\(^{th}\) July in Bali, Indonesia to review progress in perinatal surveillance and prevention of birth defects. The objectives of the meeting were:

- To provide global and regional progress on perinatal and birth defects surveillance and prevention.
- To review implementation of national action plans for prevention and control of birth defects and share experience in integrated approaches for prevention and management of birth defects.
- To share successful experiences and challenges in hospital-based perinatal and birth defects surveillance.
- To identify key country actions to strengthen surveillance and prevention for the next two years.

The objectives of the meeting were achieved through various sessions and group work, for details on the programme (see Annex).

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3. WHO-SEAR, 2016- Remarkable progress, new horizons and renewed commitment: Ending preventable maternal, newborn and child deaths in South-East Asia Region
**Highlights**

The regional meeting was inaugurated by the Director of General Public Health, Ministry of Health (MoH), Republic of Indonesia. The meeting brought together NBBD programme managers, focal points from ministries of health, from 10 of the 11 SEAR Member States, along with WHO Country office staff and civil society organizations, UN and development partners (see Annex for full list of participants). He appreciated the support provided by WHO and that the regional meeting will provide the opportunity to share experiences among the countries of the region.

**Setting the stage:-**

Representatives from the National Center on Birth Defects and Developmental Disabilities, CDC Atlanta USA provided a global overview of birth defects, presented highlights of the collaborative initiative on birth defects with WHO-SEARO including the progress achieved in the few years since 2011.

Global Prevention of Neural Tube Defects and the Birth Defects COUNT (Countries and Organizations United for Neural Tube Defects Prevention) Initiative; specifically aimed to reduce death and lifelong disability due to neural tube defects, contributing to the achievement of Target 2 of SDG 3, while supporting the 63rd World Health Assembly resolution on birth defects, were highlighted as relevant global initiatives. BD COUNT is particularly focused on the South-East Asia and Africa through food fortification with Folic Acid.

March of Dimes Foundation representing civil society, advocated for a renewed focus of interventions on a life-course approach (expected to achieve better results, saving more lives), rather than focusing on the intra-partum period. The forum was introduced to the LINC concept (Lifestyle (women and girls), Infection (during/before pregnancy), Nutrition (improve nutritional status), Contraception (improving birth spacing and prevention of teenage pregnancy) with elaboration on the concept, including some supporting evidence from literature.

**Progress in National Birth Defects Surveillance, Prevention and Control in countries:-**

WHO-SEARO presented the regional overview and progress made in birth defects initiative with highlights of the progress in Perinatal Surveillance (SEAR-NBBD database) (see Annex for details). CDC-WHO collaboration on this birth defects initiative has been extremely effective in advocacy with ministries of health, partners and stakeholders leading to establishment of national plans for surveillance, prevention and management of birth defects in the South-East Asia Region.
• Online Birth defects surveillance has expanded to about 200 hospitals across seven countries in the Region (Indonesia and Sri Lanka submit data offline).
• Hospitals are being encouraged to add newborn and stillbirths data collection to have standardized perinatal data within NBBD base for public health actions.
• With global emergency of Zika virus infection the role of network hospitals in identification of microcephaly and other Zika related birth defects was deemed timely and important.

Bangladesh, Bhutan, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand, Timor Leste presented an update on the progress in hospital-based surveillance of birth defects and implementation of prevention and management interventions as included in their national birth defects plans (see Annex for details).

India presented an experience of community-based birth defects surveillance in a rural area. Trained health workers and volunteers are capable of capturing birth defects using pictures by their mobile phones. This cadre has been trained to identify babies with birth defects during first few years of life and for following up the affected babies for management of birth defects. The project has collected data of all the babies born in the area as well as their long term outcomes. Challenges of continuous monitoring and supportive supervision of the field staff (health workers) and referring babies with birth defects to the health facility for the treatment and care intervention for the affected babies were highlighted.

**Discussions**

**Expanding perinatal surveillance:-**

WHO Indonesia shared the experience and plan for surveillance of congenital rubella syndrome (CRS). They shared lessons from the national launch of rubella vaccination programme, the status of CRS surveillance in the country and the efficacy of leveraging the existing hospitals that are doing birth defects surveillance (including birth defects related to CRS) to introduce CRS surveillance. This made a strong case to combine CRS surveillance and birth defects surveillance in the common network of sentinel hospitals in the countries.

The critical role of NBBD to document Zika infection related microcephaly was highlighted. Appropriate method of measuring head circumference of babies at birth and the standards used for classifying microcephaly were disseminated. The head circumference module (HCM) created in the SEAR-NBBD database in response to announcement of global public health emergency of Zika virus infection in 2016 was elaborated upon. An analysis of head circumference data captured within the SEAR-NBBD database was presented. There is a need for correct head circumference measurement at birth for all babies delivered in the hospital to detect cases of microcephaly that could be further investigated for any possibility of relation with Zika infection. WHO guidelines for managing pregnancy and newborn affected by Zika infection were shared.
Integration of birth defects surveillance with national health information systems and scaling up:-

With standardized birth defects surveillance system when nothing existed in the countries and the progress attained over the last 3 years through NBBD good progress has been registered. It is important to move towards integration with national health information systems once capacity for handling standardized dataset has been developed. For the integration of NBBD data into national data systems, we need to:

1. Adhere to standards for facility-based and population-based perinatal surveillance data and link with HMIS. This will ensure scalability, sustainability, and data reliability
2. Focus on data consumption (not just data production) – to ensure that data is used in a timely manner for appropriate public health action
3. Learn from the success and failures and strategically reuse what works

WHO-SEARO provided information on WHO standards, guidance and support available for managing health information systems including CRVS (civil registration and vital statistics) and HMIS (Health Management Information System) for which DHIS2 platform is being used in the Region. Potential opportunities for integration of NBBD surveillance system with HIS were identified as:-

• promoting and adopting regional standard minimum NBBD data elements and unified forms,
• technology transfer of regional NBBD database, developing an API for data exchanges and developing a generic DHIS2 app for NBBD / perinatal surveillance
• SMART register for implementing community based health programs that could also include NBBD surveillance.

Selected country experiences on integrated approaches for birth defects surveillance:-

Bangladesh shared that BD variables from the NBBD data abstraction form have been included in the DHIS2 that collects data from all health facilities in the country. This has enabled reporting of common birth defects noticed at birth in babies delivered in public health facilities. ICD 10 system is used to code the birth defects. Challenge would be to build capacity of data abstractors’ at large scale to cover all birthing facilities, as well as to maintain quality of data that are the hallmarks of the current NBBD system.

India presented the plan to expand the NBBD system to about 75 hospitals to undertake the standardized birth defects surveillance and stillbirths’ surveillance. Initially the SEAR-NBBD database will be used and in due course a national data platform may be prepared. They have planned a network of national and regional resource centers under the leadership of MOH and ICMR, which will provide ongoing support for capacity building, monitoring, problem-solving and maintaining data quality. Resources will be provided by MoH for maintaining this network of sentinel hospitals.
Sri Lanka presented an example of the existing e-IMMR (electronic indoor morbidity and mortality records) that captures important data related to mothers admitted for deliveries and their newborns. They have included most of the variables from the birth defects and newborn forms of the SEAR-NBBD database. This will be able to provide ongoing data on birth defects. The challenges include building capacity to detect and correctly code the birth defects in all facilities as well as maintaining quality of data.

Improving performance of NBBD Birth defects surveillance:-

*Panel Discussion* was held on improving performance of hospital-based birth defects surveillance system with National Hospital Coordinators from Bangladesh, Bhutan, India, Indonesia, Myanmar, Nepal and Thailand. The panelists described their strengths and facilitating factors that have helped in success of the surveillance work.

Common factors that emerged include need for government mandate and interest from ministries of health, appropriate selection of committed people and hospitals, training and capacity building, and support from WHO and partners. Bhutan mentioned that clinicians in the hospitals are enthusiastic towards surveillance work. Thailand is capturing through birth registrations, insurance payments for treatment of birth defects and reporting from hospitals. They have a system of allotting a national unique identity number to all babies that prevents duplication of reporting and follow up of the cases.

The main challenges are related to work load, lack of coordination between ObGy and Pediatrics departments within the hospital, frequent change of staff necessitating repeated trainings. All countries shared their expansion plans. Indonesia would focus on the geographic areas where environmental pollution is high (mining activities). Bangladesh has included this in their next sector-wide plan and will have further support from the MoH. India proposes to expand the surveillance to 70 hospitals with establishment of national and regional resource centers.

Regional guidance on improving performance for birth defects surveillance among the hospitals and the role of having a complete, timely and accurate data was discussed. For future performance improvement concrete actions were identified:-

- National coordinators should identify the good performing hospitals and encourage them by appreciating them, helping them with presentation and publication opportunities.
- They should identify the centers which do not improve in spite of the continuous support and consider retiring them since poor quality data from even one site is not good for the network database.
- Monthly review of reporting performance of the hospitals by the national coordinator that will help in identifying delay and lack of completeness of reporting and help in problem solving.
- Data analysis should be done quarterly and annually at the hospital and national levels.
SEAR-NBBD database provides a standard method of analysis.
Analytic report should be shared within the network, with MoH and other stakeholders for appropriate interpretation and action for prevention and management of birth defects and address issues of newborn health and stillbirth prevention.

Importance of verifying data at hospitals and national coordinator’s level was stressed for improving data quality. WHO Collaborating Center at AIIMS explained the method of verification of forms for completeness and accuracy. There has been significant improvement in completeness and accuracy of data across the network over time because of progressive experience and monitoring by WHOCC and WHO-SEARO. Now the National coordinator hospitals should undertake the role of second level verification, analysis of data, preparing analytic reports and appropriate dissemination.

Prevention and management of birth defects:-
Standard protocols for prevention and management of selected birth defects were shared by the WHO collaborating Center. The selected birth defects included Thalassemia, Down syndrome, congenital hypothyroidism and congenital hearing defects. These protocols are based on the published evidence, evidence-based guidelines and best practices. These guidelines have been prepared in consultation with subject experts from countries in the South-East Asia region.

Indonesia shared their Cleft Repair Initiative at Birth Defects Integrated Center (BIDIC) in Harapan Kita Women and Children (HKWC) Hospital Jakarta, Indonesia. This center has become a premier institution in the country for management of birth defects. Experience of holistic management of cases of orofacial cleft was shared and importance of linking surveillance with treatment and care services highlighted.

India presented a brief profile of Rashtriya Bal Swasthya Karyakram (RBSK - National Child Health Programme). It is a national initiative to improve child survival & quality of life. Children of 0-18 years age are screened for selected birth defects and diseases and offered free of cost services and rehabilitation support. The programme has been successful in detection and treatment of a large number of cases afflicted with a range of conditions.

Sri Lanka presented a successful Pediatric cardiac surgery programme from the country. The cardiac surgery initiative at Lady Ridgway Hospital (LRH) of Ministry of Health, Sri Lanka with the championship role of an NGO has progressively expanded the surgery and management of congenital heart disease. This is extremely useful since the commonest birth defect in Sri Lanka have been congenital heart defects.

CDC Atlanta presented on Food Fortification for Prevention of Neural Tube Defects (NTDs). Up-to-date evidence on prevention of NTDs using flour fortification was highlighted. It was
stressed that mandatory fortification of flour and other major staple foods with folic acid and other micronutrients can have a great public health impact.

WHO-India presented the recently updated national standards for food fortification in India. WHO, with support from CDC, WFP and partners led an advocacy effort with the Food Safety and Standards Authority of India (FSSAI) and Ministry of Health to update the existing wheat flour fortification standards for India in line with the global evidence-based recommendations. The updates in national standards have been in response to the following issues:

1. Decide standards based on wheat consumption and not cereal consumption
2. Establish minimum concentration for fortification level for various nutrients
3. Increase folic acid levels to prevent neural tube defects in addition to address folate deficiency anemia
4. Increase vitamin B12 fortification levels to have a public health impact
5. Differentiate iron compounds for wheat flour and refined flour for better bioavailability.

World Food Programme, Bangkok made a presentation of rice fortification experience. A very high rice consumption (>400 gram per person per day) is observed in Bangladesh, Indonesia, Vietnam, Laos, Cambodia and Myanmar. High rice consumption (>200 gram per person per day) is found in China, India, Thailand, Philippines, Sri Lanka, Korea, Sierra Leone and Madagascar. Brazil falls into a third tier of countries with an average consumption of 100g/person/day, however rice is eaten throughout Brazil by all population groups. Experience of rice ice fortification with micronutrients in SEAR region was presented. Technology for rice fortification has evolved and is established now. The cost is higher than wheat flour fortification at present. More experience of large initiatives will further inform at scale implementation.

**Newborn Health**

India made a presentation on importance of collecting and using prospective data in a newborn unit in the hospital. Such newborn data is useful to understand demographic features, morbidity profile, mortality profile, case outcomes and follow up. It was highlighted that it is better to use prospective data through predesigned standard format and registers rather than analyze retrospective data. Data collection should be structured and standardized to ensure valid interpretation. Examples from the experience were shared to emphasize the importance of data to improve quality of care and patient outcomes, making evidence-informed decision for effective management of the newborn unit and for future planning.

Bangladesh shared experience of DHIS2 platform to collect the newborn data from hospitals. A real time health information dashboard was successfully launched in 2016 with the help of UNICEF along with other development partners. Standardized data management has paved the way for integrating Newborn indicators in National HMIS in Bangladesh using
the DHIS2 platform. Although there are several challenges, the way forward is to build capacity in diagnosis of birth defects, introduce GIS mapping of case tracking system, integrate photo ID for the registered cases, utilize the data more effectively for decision making and collect more information on mother’s condition related to newborn disease.

India presented prospective stillbirths’ surveillance from 20 hospitals in India, led by PGI, Chandigarh; who shared the analysis of possible causative factors and how to prevent stillbirths in future. They discussed the process followed for standardized data collection and analysis as well as the challenges. Based on this experience the Ministry of Health has prepared national guidelines for hospital-based surveillance of stillbirths to understand the burden across the country and possible preventable causes.

Regional model of quality improvement of maternal and newborn healthcare was presented. POCQI: Point of Care Continuous Quality Improvement for mothers and newborns in hospitals has been rolled out in the Region with the support of WHO and multiple partners. The simplified POCQI model of 4 steps approach to Quality Improvement at the level of health facilities:

1. Identifying problem
2. Analyzing and measuring quality of care
3. Developing and testing changes
4. Sustaining Improvement.

The differences between quality assurance and quality improvement which are both important and complementary towards efforts to improve patient outcomes were elaborated upon. Examples of successful application by healthcare teams in hospitals that have led to improvement in quality of care without the need of additional resources were shared. Hospitals in the SEAR-NBBD Network where teams of obstetricians and pediatricians are already working together closely should adopt the POCQI model to improve patient outcomes initially focusing on mothers and newborns.

**Country plans**

Country teams prepared an action plan for next two years for expanding and strengthening birth defects surveillance, adding newborn and stillbirths as well as for prevention and management interventions for birth defects (see Annex for details).

**Conclusions**

Conclusions and recommendations from the meeting were presented during the meeting. All delegates endorsed the recommendations.

- Member States reported significant progress in hospital-based birth defects surveillance, implementation of programmes for prevention of birth defects through
RMNCAH interventions, Immunization, food fortification; and scaling up of treatment programmes for specific birth defects like oro-facial clefts, and cardiac defects.

- Hospital-based birth defects surveillance is working well in about 150 hospitals in the Region and quality of data has also improved over time. However, performance of hospital nodal officers and national coordinators including verification function needs to be further strengthened, monitored and evaluated.
- Data analysis, interpretation, and dissemination need to be strengthened and use of data by policy and programme people ensured.
- Some of the network hospitals in countries are in a position for expanding integrated birth defects - newborn - stillbirth surveillance, and introduce WHO model for quality improvement of maternal and newborn care.
- Countries are introducing Congenital Rubella Syndrome (CRS) surveillance and head circumference monitoring (preparedness for Zika infection) in network hospitals and plan to extend to district level hospitals.
- DHIS-2 platform has been used to integrate NBBD database in Bangladesh and has high potential in the other countries.
- Country teams identified key actions for implementation of birth defects surveillance, prevention and management.

**Recommendations**

**Member countries:**

- Expand hospital-based birth defects surveillance, sustain the efforts to improve the quality of data, and consider initiating population-based surveillance where home deliveries are significant.
- Undertake monthly performance monitoring of the participating hospitals and provide supportive supervision including field visits to reporting hospitals, through the help of the National coordinator hospital.
- Promote data analysis at hospital and national level, as well as appropriate dissemination with all stakeholders and use it for taking actions.
- Provide government order to empower hospitals to collect, analyze and interpret data and share reports; and provide necessary financial, human and other resources to hospitals and coordination hospitals.
- Introduce monitoring of head circumference of babies at birth for Zika preparedness, newborn health surveillance, and Quality Improvement (POCQI) model for maternal and newborn care in the network hospitals.
- Build capacity in the hospitals for stillbirth surveillance, integrate within maternal-perinatal death surveillance and extend to community-based stillbirth surveillance as feasible.
- Ensure convergence of CRS surveillance and birth defects surveillance in the network hospitals as common sentinel sites.
• Initiate / strengthen integration of the birth defects-newborn-stillbirths database into the existing health management information system (e.g. DHIS 2).
• Strengthen life course approach for preventing birth defects and improving perinatal outcomes, with a particular focus on preconception care, and consider policy and strategy for food fortification with folic acid and other micronutrients.
• Expand the services for care, surgery and rehabilitation programmes for babies born with birth defects.

**WHO, CDC and Partners:**

• Support expansion of hospital-based and population-based birth defects surveillance, data analysis and use of data for action.
• Support management of the database until all countries are able to use the national health information systems for the integrated surveillance.
• Support convergence with CRS surveillance and microcephaly monitoring (Zika infection); and implementation pilots in countries to establish newborn health, stillbirth surveillance, MPDSR, quality improvement model for maternal and newborn care in the network hospitals.
• Create opportunities for Member States for reviewing progress, sharing of experience in the field of newborn health and birth defects and support publications of data analysis.
• Support Member States to implement plans for prevention and management of birth defects including strengthening of preconception care and food fortification with folic acid and other micronutrients.
## Annex

### Country Progress

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<th>National Birth defects prevention strategy</th>
<th>Year</th>
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**NBBD Denominator status**

**Performance Monitoring**

- Monitoring by National Coordinator Hospital or MoH: Yes, Yes, Yes, No, Yes, Yes, Yes, ... , Yes
- National coordinator/hospital sends data analysis of birth defects (occurrence & distribution) to MoH: Yes, Yes, Yes, No, Yes, ... , Yes
- Training of data abstractors: Yes, Yes, Yes, No, NO, Yes, No, ... , Yes
- Regular verification of forms: Yes, Yes, Yes, No, No, No, Yes, ... , Yes
- Regular analysis of forms: Yes, Yes, Yes, No, No, Yes, ... , Yes
- Use of checklist: Yes, No, Yes, No, No, No, Yes, ... , Yes
## Country Action Plans

<table>
<thead>
<tr>
<th>Bangladesh</th>
<th>Bhutan</th>
<th>India</th>
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<tbody>
<tr>
<td><strong>Integration of interventions for prevention and management of birth defects</strong></td>
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<tr>
<td><strong>Pre-conception care (Screening, RH education, Micronutrient – Folate supplementation)</strong></td>
<td>BSMMU: pre-conception care is going on, further scaling up in 13 public medical college hospitals. Folate supplementation is going on throughout the country</td>
<td>Package is under development. Guideline will be piloted and then scaled up.</td>
<td>Weekly iron-folic acid supplementation being scaled up.</td>
<td>“Nai pahal kit” - counseling for contraception, safe sex, child spacing, lifestyle</td>
<td>Extend folic acid fortification (pilot project in West Java). Dissemination TOT on thalassemia detection and referral system.</td>
<td>Folic acid supplementation. Awareness – IEC on nutrition, lifestyle diseases.</td>
<td>RH education (few universities). Develop Pre-conception care guidelines. Revision of BD incorporation with other programs where possible eg MPDSR. Supplementation of iron folic acid for adolescents to be scaled up.</td>
<td>Increase population coverage for pre-pregnancy screening, RH education &amp; Micronutrient supplementation and addition of Folate.</td>
<td>Will integrate RH education into primary health care and SISCA (Integrated Community health services). Provide advice to adolescent girls on healthy diet and healthy weight.</td>
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<tr>
<td><strong>Prenatal care and screening</strong></td>
<td>2018- to increase all 4 ANC from 31% to 40%. Further strengthening of prenatal screening in remaining public health facilities. Advocacy for screening of Thalassemia.</td>
<td>Introduction of Fetal Echographic Screening.</td>
<td>Anomaly scan -18 weeks</td>
<td>Improve prenatal screening for BD 2017: 1 Regional Prenatal and neonatal diagnostic centre: activity documentation 2018: Replicate at 3 hospitals.</td>
<td>Expand existing services: Thalassemia Down’s Syndrome Cardiac defects/ fetal ECHO</td>
<td>Diabetes (OGTT) Early USG scan for BD detection in CWH, and Yangon. Expansion of antenatal testing for syphilis and point-of-care treatment.</td>
<td>Quality improvement of ANC services: Strengthen HIV, VDRL, Blood glucose screening. Functionalize the national genetic lab Prenatal Anomaly screening &amp; termination for severe BD in the 16 NBBD hospitals.</td>
<td>Strengthen pregnancy screening – for obesity, diabetes. Thalassemia screening 90% couple screening 10% for Infection (HIV, Syphilis, HBV) and 90% Down syndrome pilot project.</td>
<td>Strengthen advice on avoiding alcohol and tobacco. Folic Acid 5 mg daily. USG screening to all pregnant women at national hospital.</td>
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<tr>
<td>Newborn screening</td>
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<tr>
<td>Visible birth defects screening to be established in all public medical college hospitals (31) Advocacy for thyroid function test</td>
<td>CHD – Ref Hosp (Pulse oximetry)</td>
<td>Pilot programs for congenital hypothyroid in selected states</td>
<td>Increase coverage of hypothyroidism screening from 6% to 15%</td>
<td>Metabolic screening</td>
<td>Newborn screening program for congenital hypothyroidism (2018)</td>
<td>Screening of BD in the SBA package and Newborn training package</td>
<td>Screening for CHD</td>
<td>Scale up NB screening for congenital hypothyroidism</td>
<td>TSH, PKU -&gt; 95% Inborn error metabolism 50,000 sample/year</td>
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<td></td>
<td>HC – all facilities</td>
<td>Introduce hearing screening</td>
<td>Introduce pulse oximetry screening at 19 teaching hospital</td>
<td>Newborn hearing screening</td>
<td>Screening for significant cardiac defects in peripheral hospitals</td>
<td>Strengthen the clinical screening of newborns at birth and discharge</td>
<td>Hearing screening</td>
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<td>Cong. Hypoth. – Ref Hospital</td>
<td>Introduce pulse oximetry screening at 19 teaching hospital</td>
<td>Introduce hearing screening</td>
<td>Microarray screening</td>
<td>Newborn hearing screening</td>
<td>Pilot ing of Congenital Hypothyroidism</td>
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<td>Hearing – Ref Hospital</td>
<td>CHD – Ref Hosp (Pulse oximetry)</td>
<td>Microarray screening</td>
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<td>Newborn hearing screening</td>
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<tr>
<td>Adolescence health (Micronutrient supplementation, screening, reproductive health education etc.)</td>
<td>Advocacy for Thalassemia screening</td>
<td>Strengthening of AFHS (Strategic Review)</td>
<td>Scale up the coverage of Fe and folic acid supplementation for adolescent girls from 15% to 30%</td>
<td>Awareness program/school based programs</td>
<td>Supplementation of iron folic acid for Adolescents - 8 districts</td>
<td>Micronutrient supplementation, screening, reproductive health education etc.) - maintain Thalassemia screening</td>
<td>AFHS HIV without parent counsel &amp; registration reproductive health in Adolescent HPV Vaccination</td>
<td>Will implement reproductive health education</td>
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<td>Strengthening the existing reproductive health education across the country</td>
<td>Family Planning Standard to be Updated, HW training</td>
<td>Scale up the coverage of Fe and folic acid supplementation for adolescent girls from 15% to 30%</td>
<td>Awareness program/school based programs</td>
<td>Supplementation of iron folic acid for Adolescents - 8 districts</td>
<td>AFHS HIV without parent counsel &amp; registration reproductive health in Adolescent HPV Vaccination</td>
<td>Will implement reproductive health education</td>
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<td>WIFS Saathiyan resource kits – for peer education (life style, life skill building, reproductive and sexual health)</td>
<td>WFS Saathiyan resource kits – for peer education (life style, life skill building, reproductive and sexual health)</td>
<td>Scale up the coverage of Fe and folic acid supplementation for adolescent girls from 15% to 30%</td>
<td>Awareness program/school based programs</td>
<td>Supplementation of iron folic acid for Adolescents - 8 districts</td>
<td>AFHS HIV without parent counsel &amp; registration reproductive health in Adolescent HPV Vaccination</td>
<td>Will implement reproductive health education</td>
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<tr>
<td>Rubella vaccination</td>
<td>National schedule</td>
<td>Measles &amp; Rubella vaccination from months 9-15 years: Started in 5 states Integrating CRS surveillance with NBBD</td>
<td>Starting MR immunization up to 15 years children 2017 in Java Island</td>
<td>National schedule</td>
<td>National schedule</td>
<td>Existing program with 95% coverage Integrating CRS surveillance with NBBD</td>
<td>All male and female under 15 years vaccinated in 2015 and 2 doses through routine immunization since 2016</td>
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<td><strong>Food fortification</strong></td>
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<tr>
<td>Advocacy to make folic acid fortification mandatory in larger flour and rice supplying companies</td>
<td>Roll-out of Fortified Foods in Boarding Schools, roll out to Higher Institutions. Exploring options for fortification of foods for general population.</td>
<td>Preparatory work for Flour fortification Iron and FA-Pilot project in one district</td>
<td>--</td>
<td>Baseline assessment on consumption patterns of rice/flour. Baseline study of red cell folate level</td>
<td>Rice fortification in selected area</td>
<td>Already initiated by Nutrition Program</td>
<td>Rice fortification research on feasibility and acceptability</td>
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</table>

| **Strengthen the care and management services for BDs in Newborn-Child Health and NCD programmes** | Planning to introduce in all public medical college hospitals and 50% of district hospitals. | Development of management protocols for top three BDs. | Under RBSK, activities of District Early Intervention Centres to be strengthened and scaled up | Collaboration among stakeholders and Working Group in MoH, professional organization | Rehabilitation expanded with IGMH | Assess and monitor | Revise the BD implementation package and expand | Strengthen Surgical facilities for Heart/Cleft lip-palate/deafness. Introduce BM transplant for Thalassemia and other hematological | Referral system for early treatment in regional health service area | Increase training of pediatricians in the country |


<p>| <strong>Strengthening capacity and facilities for prenatal screening</strong> | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- |</p>
<table>
<thead>
<tr>
<th>Country</th>
<th>Strengthening lab capacity for newborn screening / diagnosis</th>
<th>Strengthening capacity for care, surgery, rehabilitation of BDs</th>
<th>Strengthening capacity for genetics diagnosis and counselling</th>
<th>BD Prevention integration in the health promotion activities / IEC campaigns</th>
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<tbody>
<tr>
<td>Bangladesh</td>
<td>Thyroid screening in 19 public MCHs and Cong cardiac defect diagnosis in 8 MCHs</td>
<td>Expansion of care and surgery in 13 public MCHs Advocacy for rehabilitation of birth defects.</td>
<td>Identify interested person for capacity building for genetic diagnosis and counselling.</td>
<td>Advocacy for inclusion</td>
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<tr>
<td>Bhutan</td>
<td>Ensuring stock of reagent. Congenital hypothyroidism introduction.</td>
<td>Strengthened post-op. care for CHD. Expansion of pediatric physiotherapy services in referral hospitals.</td>
<td>Training of service providers on counseling/communication.</td>
<td>BD prevention in Diabetic Clinic. HLA Promote use of FA (pending general fortification) under MCH and general public.</td>
</tr>
<tr>
<td>India</td>
<td>Accreditation of labs</td>
<td>Public private partnership with DEIC (screening and referral)</td>
<td>Expand services to other genetic diseases (at present genetic testing and counseling for thalassemia)</td>
<td>Preparation of Pamphlets and audiovisuals</td>
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<td>Indonesia</td>
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<td>Conduct technical workshop on prevention, management and surveillance in hospitals</td>
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<td>Maldives</td>
<td>Start IEM screening at NDC</td>
<td>Expand rehab therapy Initiate specialty treatment</td>
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<td>Coordinate with NHEICC to incorporate BD Prevention activities / IEC campaigns; Celebration of BD – March 3rd Develop IEC materials of BD prevention</td>
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<td>Myanmar</td>
<td>Congenital hypothyroidism at least in two tertiary hospitals</td>
<td>Promote (walk for health program in limb defect (Mandalay Teaching Hospital), cleft lip &amp; palate repair</td>
<td></td>
<td>Coordinate with MN Communication Strategy implementation – include BD prevention and management IEC Messages related to DM, Obesity – BD specific messages are included</td>
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<tr>
<td>Nepal</td>
<td>strengthen the existing genetic lab</td>
<td>Advocate for free services for newborn with birth defect Develop referral system</td>
<td>Comprehensive newborn package</td>
<td>Folic acid, Fe, iodine supplement Campaign: Stop smoking and alcohol drinking, (New Legislation)</td>
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<tr>
<td>Sri Lanka</td>
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<td>Genetic laboratories scale up – public private partnership</td>
<td>IEC on Rubella Immunization, Healthy nutrition and Folic Acid Use</td>
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<tr>
<td>Thailand</td>
<td>Increase capacity building of tertiary care medical school etc</td>
<td>Expand Surgical facilities Introduce BM transplant for Thalassemia and others</td>
<td>Strengthen comprehensieve care in tertiary care hospital (MoPH+ medical school)</td>
<td>Strengthen services at National Hospital</td>
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<tr>
<td>Timor Leste</td>
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<tr>
<td>Birth defects prevention in non-communicable diseases programmes</td>
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<td>India</td>
<td>Indonesia</td>
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<tr>
<td>Regularly conducted through the MoH</td>
<td>Awareness on Alcohol in Pregnancy in high-burden communities.</td>
<td>Advocacy efforts to add the birth defect and adverse pregnancy outcome in the NCD</td>
<td>Advocacy to National Health Insurance for BD</td>
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### Surveillance

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<thead>
<tr>
<th>No. of Hospitals for Birth defects surveillance</th>
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<th>Myanmar</th>
<th>Nepal</th>
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<th>Timor Leste</th>
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<tbody>
<tr>
<td>20</td>
<td>7 hospitals till 2019</td>
<td>Expanded to 76 hospitals – will be functional from 2018</td>
<td>All medical college hospitals in 2019</td>
<td>Expanded to 34 hospitals</td>
<td>Expanded to 12 hospitals</td>
<td>Expand to 14 hospitals</td>
<td>Add 5 hospitals</td>
<td>Expand to 81 hospitals</td>
<td>Sustain in 929</td>
<td>Sustain 1 hospital</td>
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<table>
<thead>
<tr>
<th>No. of Hospitals for Newborn health and Head circumference reporting</th>
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<th>India</th>
<th>Indonesia</th>
<th>Maldives</th>
<th>Myanmar</th>
<th>Nepal</th>
<th>Sri Lanka</th>
<th>Thailand</th>
<th>Timor Leste</th>
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</thead>
<tbody>
<tr>
<td>Newborn health: 7 and Head circumference reporting: All 31 MCHs.</td>
<td>Expand to 3 hospitals by 2019</td>
<td>Expanded to 76 hospitals– functional from 2018</td>
<td>Expanded to 34 hospitals</td>
<td>Expanded to 12 hospitals</td>
<td>Expanded to 7 hospitals</td>
<td>In 450 hospitals</td>
<td>In all hospitals</td>
<td>In 5 hospitals</td>
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<table>
<thead>
<tr>
<th>No. of Hospitals for Stillbirths surveillance</th>
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<th>Myanmar</th>
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<th>Sri Lanka</th>
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<th>Timor Leste</th>
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<tbody>
<tr>
<td>Plan to implement in 2017; ensure more managerial involvement of OBGYNs moving forward- 5</td>
<td>7 till 2019</td>
<td>Expanded to 76– functional from 2018</td>
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<td>5</td>
<td>81</td>
<td>In process of development stillbirth registration</td>
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### Plan for sustainability at hospital level

<table>
<thead>
<tr>
<th>Integrate NBBD data abstraction forms in Hospital</th>
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<th>Bhutan</th>
<th>India</th>
<th>Indonesia</th>
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<th>Myanmar</th>
<th>Nepal</th>
<th>Sri Lanka</th>
<th>Thailand</th>
<th>Timor Leste</th>
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<tbody>
<tr>
<td>Integrated key indicators with 2017 in JDWNRH already done, Involvement of all stakeholders including WHO</td>
<td>2014-implemented -Policy from MoH, Already done Web-based HMS based</td>
<td>Already done: individualized hospitals</td>
<td>Plan by 2018</td>
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<table>
<thead>
<tr>
<th>Already done-NB (eIMMR), Separate BD and SB forms</th>
<th>Supported by MoH</th>
<th>Software developed and hardware</th>
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### Medical Record files

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</thead>
<tbody>
<tr>
<td>Still birth</td>
<td>the national HMIS</td>
<td>2018 in CRR Hospital, and ERR Hospital</td>
<td>needed to implement by 2018</td>
<td>support from hospital director - Financial support to extend BD workshop for TOT needed</td>
<td>on DHIS2 to be implemented; plan to link NBBD system by 2017</td>
<td>for indicated cases</td>
<td>installed at the National Hospital - Plan to extend to 5 referral hospital in 2018/2019</td>
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<td>Already included</td>
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### Plan for data analysis and dissemination

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### Resources needed for Quality of data

#### Hospital Level

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<thead>
<tr>
<th>Resource Required</th>
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<th>Bhutan</th>
<th>India</th>
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<th>Sri Lanka</th>
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<td>(Full time WHO/MoH)</td>
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<tr>
<td>Training for Clinicians of new Hospitals (WHO/MoH)</td>
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<tr>
<td>Additional Human Resources from MoH; DEO at each reporting centre may be needed based</td>
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<td>Additional Human Resources for data entry</td>
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<tr>
<td>Regular monitoring and evaluation from the BD hospital team</td>
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<tr>
<td>- Focal point and DEO</td>
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<tr>
<td>- Designated space/PC with internet connection</td>
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<tr>
<td>Dedicated person for BD; Additional budget for BD; Atlas of BD including picture, abstraction/ICD 10 needed</td>
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<tr>
<td>IT specialists, Data entry operators, Statisticians needed</td>
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<tr>
<td>Assessment of opportunities to integrate (eIMMR, BD surveillance, SB surveillance, Maternal and Neonatal near misses)</td>
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</table>

#### MoH/National coordinator Level

<table>
<thead>
<tr>
<th>Resource Required</th>
<th>Bangladesh</th>
<th>Bhutan</th>
<th>India</th>
<th>Indonesia</th>
<th>Maldives</th>
<th>Myanmar</th>
<th>Nepal</th>
<th>Sri Lanka</th>
<th>Thailand</th>
<th>Timor Leste</th>
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</thead>
<tbody>
<tr>
<td>Appoint dedicated personnel at national level</td>
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<tr>
<td>Additional Technical Resources from MoH / WHO / CDC for capacity development</td>
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<tr>
<td>Full-time MoH Focal Person for BD; Procurement of supplies (WHO/MoH)</td>
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<tr>
<td>Perform hospital evaluation for data collection and data entry</td>
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<tr>
<td>Provide feedback to hospital</td>
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<td>Provide &quot;Dashboard&quot; in <a href="http://www.ina-registry.org">www.ina-registry.org</a></td>
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<tr>
<td>Additional Technical Resources from MoH / WHO / CDC for training of personnel</td>
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<tr>
<td>- Regular meeting for analysis for report and feedback to implementing hospitals</td>
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<td>- Make database local for more use</td>
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<tr>
<td>Appoint a national focal point at the MoH</td>
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<tr>
<td>Human Resources from MoH - Ward clerks (for data entry and management), ICD 10 training for MROs, MOs and NOs, MO Public Health for all specialized hospitals</td>
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### Support Provided

<table>
<thead>
<tr>
<th>Support Provided</th>
<th>Bangladesh</th>
<th>Bhutan</th>
<th>India</th>
<th>Indonesia</th>
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<th>Myanmar</th>
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</thead>
<tbody>
<tr>
<td>Training of medical staff on case identification and reporting</td>
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<tr>
<td>Technical support for training</td>
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### Additional Information

- **MoH/National coordinator Level**
  - Appoint a national focal point at the MoH and National Hospital and 5 Referral Hospitals
### Additional resources needed for sustaining good quality national database

<table>
<thead>
<tr>
<th>Bangladesh</th>
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<th>India</th>
<th>Indonesia</th>
<th>Maldives</th>
<th>Myanmar</th>
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<th>Sri Lanka</th>
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</thead>
<tbody>
<tr>
<td>Poster for labor rooms; refresher trainings</td>
<td>Human/Financial/Technical Resources from MoH/WHO/CDC</td>
<td>All national resource centre and regional centre has been budgeted by MoH</td>
<td>Hospital coordinator dedicated only for BD surveillance</td>
<td>Additional resources needed: - technical consultant; hosting of website and related capacity</td>
<td>- Offline and web-based programme - Training for data analysis</td>
<td>- Need to incorporate the indicator into the DHIS - support from SEARO/CDC/UNICEF</td>
<td>Technical Resources from MoH/WHO/CDC – Assessment of opportunities to integrate Maternal, Neonatal data systems (eMMR, BD surveillance, SB surveillance, Maternal and Neonatal near misses)</td>
<td>--</td>
<td>NBBD yet to be implemented, May commenced in 2017 with full implementation of newly developed software</td>
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### Incorporation of Hospital based surveillance and database into national data systems by MOH

<table>
<thead>
<tr>
<th>What is being done</th>
<th>Inclusion of live and still births in national EmONC register and its reporting in national HMIS</th>
<th>NBBD database integration into national data systems by MOH</th>
<th>NBBD transitional plan in process – will be further discussed and finalized</th>
<th>Web-based HMIS based on DHIS2 to be implemented; plan to link NBBD system</th>
<th>---</th>
<th>Not yet initiated, DHIS 2 there; need to incorporate the indicator into it</th>
<th>Link NB (eMMR), BD and SB forms for indicated cases</th>
<th>---</th>
<th>Yet to be implemented</th>
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<tbody>
<tr>
<td>By when will it happen</td>
<td>Advocacy ongoing</td>
<td>2020 (Revision DHIS2)</td>
<td>2018</td>
<td>---</td>
<td>2017/2018</td>
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<td>2018</td>
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<tr>
<td>Additional resources needed</td>
<td>Consultative workshops</td>
<td>Technical Assistance</td>
<td>Resources needed</td>
<td>Technical consultant; hosting of website and related capacity</td>
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<td>Resources needed</td>
<td>Technical support</td>
<td>---</td>
<td>Full implementation of newly developed software</td>
</tr>
<tr>
<td>From where</td>
<td>WHO</td>
<td>WHO</td>
<td>MOHFW</td>
<td>WHO, Government (NCTI)</td>
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<td>SEARO/CDC/UNICEF</td>
<td>MoH, CDC, WHO</td>
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Incorporation of Hospital based surveillance and database into national data systems by MOH

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<td>MOHFW</td>
<td>WHO, Government (NCTI)</td>
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Page 23 of 32
Programme

• Inaugural Session
• Setting the stage
  – Overview and progress in Birth Defects Count
  – Global overview of birth defects, perinatal conditions
  – Regional progress in perinatal surveillance

• Progress in National Birth Defects Surveillance, Prevention and Control
• Expanding perinatal surveillance
  – CRS surveillance – convergence with Birth Defects surveillance
  – Microcephaly related to Zika Virus Infection

• NBBD surveillance - Integration into existing systems and scale-up
  – Opportunities for integration of NBBD data into national data systems
  – Country progress in Integration into national data systems - Web-based HMIS, eIMMR
  – Scaling up hospital-based surveillance

• Birth defects surveillance: Improving performance
  – Improving Hospital based surveillance: What has been achieved and what remains:
  – Regional guidance for performance monitoring
  – Revisiting Verification for improving quality of data
  – Community based BD surveillance: Case Study

• Prevention and management of birth defects
  – Standard protocols for prevention and management of selected birth defects
  – Country experiences in management of birth defects
    - Indonesia: Cleft repair initiative
    - India: Early intervention programme (RBSK)
    - Sri Lanka: Pediatric cardiac surgery programme

• Newborn health
  – Making sense of Newborn data in hospitals
  – Integrating Newborn indicators in national HMIS in Bangladesh
  – Stillbirths surveillance: Experience and scale-up plan
  – POCQI: Point of Care Continuous Quality Improvement for mothers and newborns in hospitals

• Country Plans of Action for Birth Defects Surveillance, prevention and management
• Conclusion and Recommendations
• Closing remarks
List of Participants

Country Participants

Bangladesh

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   Bangabandhu Sheikh Mujib Medical University  
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   Assistant Programme Officer

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   Pediatrician  
   Jigme Dorji Wangchuk National Referral Hospital  
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9. Dr Tshering Wangden  
   Gynaecologist  
   Jigme Dorji Wangchuk National Referral Hospital  
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    Nirman Bhawan  
    New Delhi, India

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15. Dr Nida Rohmawati  
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   Directorate of Family Health  
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   Ministry of Health  
   Jakarta, Indonesia

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   Hospital-Based Birth Defect Surveillance Coordinating Forum  
   Jakarta, Indonesia

18. Dr Johanes Edy Siswanto  
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   Yangon, Myanmar

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   Department of Health Services  
   Ministry of Health  
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   Chief  
   Child Health Division  
   Department of Health Services  
   Ministry of Nepal  
   Teku, Kathmandu, Nepal

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   Paropkar Maternity Hospital  
   Thapathali, Kathmandu, Nepal
30. Dr Kalpana Upadhyay Subedi  
   Chief Consultant Pediatrician  
   Paropkar Maternity Hospital  
   Thapathali, Kathmandu, Nepal  

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31. Dr Kapila Jayarathne  
   Consultant Community Physician  
   National Programme Manager-Maternal &  
   Child Morbidity & Mortality Surveillance  
   Family Health Bureau  
   Colombo, Sri Lanka  

32. Dr D.D.S. Rowel  
   Consultant Community Physician  
   National Programme Manager(Intranatal &  
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