

Prevention and surveillance of birth defects



Report of a meeting of regional programme managers
14–16 April 2015, New Delhi, India



**World Health
Organization**

Regional Office for South-East Asia

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Acronyms

AIIMS	All India Institute of Medical Sciences, New Delhi, India
ANC	antenatal care
BD	birth defect(s)
CDC	Centers for Disease Control and Prevention, USA
COIA	Commission on Information and Accountability
CRS	congenital rubella syndrome
HMIS	health management information system
ICD10	International Classification of Diseases and Related Health Problems, Tenth Revision
ICDDR,B	International Centre for Diarrhoeal Disease Research, Bangladesh
IT	information technology
MDG	Millennium Development Goal
MMR	maternal mortality rate
MMR	measles, mumps and rubella (vaccine)
MoH	ministry/ministries of health
MR	measles and rubella (vaccine)
NBBD	newborn health and birth defects
NICU	neonatal intensive-care unit
NMR	neonatal mortality rate
NNPD	neonatal–perinatal database
NTD	neural tube defects
RBSK	Rashtriya Bal Swasthya Karyakram (India)
RCH	reproductive and child health
RMNCH+A	reproductive, maternal, neonatal, child and adolescent health
SAARC	South Asian Association for Regional Cooperation



SBR	stillborn rate
SEAR	WHO South-East Asia Region
SNCU	special newborn care unit
STP	standard treatment protocol
TOT	Training of trainers
TT	tetanus toxoid (vaccine)
UNICEF	United Nations Children's Fund
WHO	World Health Organization
YLD	Years without a disability



1. Executive summary

The WHO Regional Office for South-East Asia developed and disseminated the Regional strategic framework on prevention and control of birth defects (BD) in collaboration with the Centers for Disease Control and Prevention (CDC), Atlanta, USA. Following this, ministries of health in nine countries developed national plans for prevention of BD.

The WHO Regional Office has established a regional network on surveillance on BD and newborn morbidity, and mortality. There has been a steady rise in the number of hospitals in Member States that have enrolled with this surveillance network.

A meeting of regional programme managers on prevention and surveillance of BD was organized by the WHO Regional Office for South-East Asia, on 14–16 April 2015, in New Delhi, India to review the status of implementation of national action plans for prevention of BD, share experiences and challenges in BD surveillance, share progress on implementation of integrated approaches and plan the follow-up steps.

Participants included national programme managers for newborn health and birth defects (NBBDD) from Bangladesh, Bhutan, India, Maldives, Myanmar, Nepal, Sri Lanka and Thailand, network coordinators and representatives from UNICEF, WHO collaborating centres, CDC and WHO Regional and country offices.

The experience from the national BD surveillance programme had enriched the understanding and relevance of BD prevention in the Region. A regional communication strategy for the prevention and control of BD was launched during the meeting. Country teams developed implementation plans to scale up BD surveillance and prevention activities with the communication strategy.



2. Background

It has been recognized that BD are emerging as a cause of under-five morbidity and mortality. Globally, BD cause the deaths of at least 3.3 million children under five years of age each year, and an estimated 3.2 million of those who survive might have lifelong mental, physical, auditory or visual disability. Many of these conditions are preventable with a high coverage of available interventions. Resolution WHA63.17 on BD endorsed in May 2010 triggered the collaborative efforts of the WHO Regional Office for South-East Asia and the Centers for Disease Control, United States of America (CDC) to address the regional need on neonatal–perinatal health and BD. Despite these calls to action, many countries are not geared to face the reality and launch large-scale interventions for prevention and control of BD.

An expert group consultation was organized in 2011 to formulate recommendations on BD control and prevention in the Region. As a result of the deliberations at that consultation, a regional strategic framework for prevention and control of BD was developed in 2013. The WHO Collaborating Centre at the All India Institute of Medical Sciences (AIIMS), New Delhi, India, had spearheaded the initiative of a regional NBBD network with cooperation from nodal institutes in the Member States. With continued support from the WHO Regional Office and CDC, regular regional forums were organized to strengthen national and regional networks for NBBD and share national experiences and challenges.

BD surveillance had been the key strategy to direct and strengthen BD control and prevention activities. In this regard, a NBBD surveillance system was introduced by the WHO Collaborating Centre at AIIMS, with support from the WHO Regional Office and CDC. This was subsequently revamped to form a South-East Asia Regional Network for Surveillance on Newborn Morbidity, Mortality and BD (SEAR-NBBD). Facilitative tools like a BD surveillance manual for programme managers and a photo atlas were developed and distributed to strengthen surveillance activities among Member States. Since then, there has been a steady rise in the number of hospitals and Member States enrolled with this surveillance network.



Given this background, a meeting of regional programme managers on prevention and surveillance of BD was organized on 14–16 April 2015 in New Delhi, India. Participants included country programme managers for NBBB from Bangladesh, Bhutan, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka and Thailand, country network coordinators and representatives from UNICEF, WHO collaborating centres, CDC and WHO Regional and country offices. (See Annex 1 for List of participants.)



3. Opening session

Welcoming the participants, Dr Neena Raina, WHO Regional Adviser, Child and Adolescent Health, highlighted the significant progress in BD surveillance activities achieved in the recent past and encouraged the programme managers to strengthen and expand regional actions. She commended the 'champions' from Member States to actively participate in the sessions to make the meeting a success.

Dr Roderico Ofrin, Acting Regional Director and Acting Director, Health Security and Emergency Response, WHO Regional Office for South-East Asia, read out the message from Dr Poonam Khetrpal Singh, Regional Director, WHO South-East Asia. In her message, the Regional Director underlined the rising proportion of mortality related to BD among newborns and called for regional action in scaling up known and ongoing interventions. She emphasized the successes recorded among developed countries in preventing 70% of BD and encouraged every Member State to consider investing in similar interventions. She concluded by acknowledging progress made over the past three years, lauding BD surveillance activities and commemoration of the first ever BD day in the Region. (See Annex 2 for the text of RD's address.)

In his opening remarks, Dr Rakesh Kumar, Joint Secretary, Ministry of Health & Family Welfare, Government of India, pointed out the achievements made in India in the recent past through the *Rashtriya Bal Swasthya Karyakram* (RBSK) programme to address the 4D's: **D**efects at birth, **D**iseases of childhood, **D**eficiency and **D**evelopmental delays including disabilities. He said that within a short period of time, BD had become a major focus area for such initiatives and significant progress had already been achieved. He concluded by emphasizing the critical need for a national communication strategy to move forward with clear directive on communication needs.

In his presentation, Dr Michael Cannon, Acting Team Lead, National Center on Birth Defects and Developmental Disabilities, CDC, appreciated the successful partnership and progress made over the past years and reiterated the need for networking for better programmatic outcomes.



Dr Genevieve Begkoyian, Chief, Health and Nutrition, UNICEF, commented on the remarkable developments attained by the BD prevention and control initiatives in the Region and assured full support from UNICEF in future.

The Regional communication strategy for prevention and control of BD was released by Dr Roderico Ofrin, Ag. Regional Director, WHO South-East Asia.



4. Objectives

The objectives of the meeting were to:

- ◆ review the implementation of national action plan for prevention and control of BD;
- ◆ share experiences and challenges in BD surveillance;
- ◆ share progress on implementation of integrated approaches for prevention of BD; and
- ◆ discuss follow-up steps and develop national implementation plans for the next two years.

(See Annex 3 for agenda.)

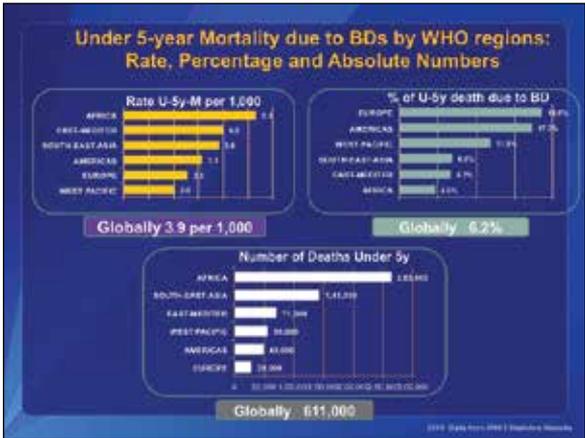


5. Proceedings

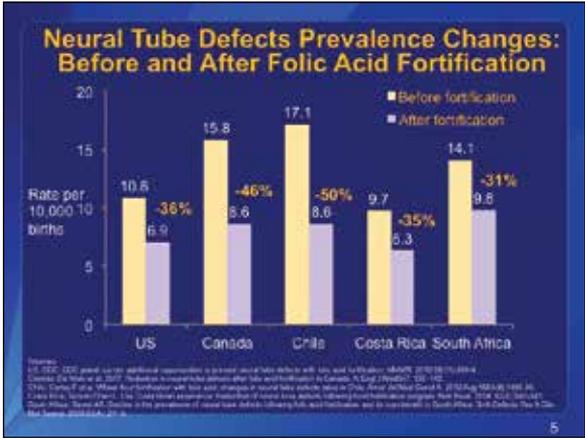
5.1 Overview of birth defects

5.1.1 Global situation

Dr Michael Cannon said that the global burden of BD was estimated as one in every 33 newborns and the morbidity attributed to BD was one in 260 births. Even these figures underestimated the true picture due to the poor reporting of spontaneous abortions, stillbirths and elective terminations of pregnancy for fetal anomaly, which went uncounted and unnoticed.



The South-East Asia Region had the second highest prevalence of BD in the world, with a case-load of 1.13 million annually. In fact, the efforts taken to address infant mortality during the past had not adequately taken into account the issues of BD control and prevention. When there was a reduction in infant mortality, the proportion of infant mortality due to BD got highlighted. Further reduction in infant mortality required that adequate attention be paid to BD control and prevention.



Describing the global burden and etiological factors related to NTD, it was reiterated that folic acid proves efficient in preventing such BD. A brief description of CDC’s Birth Defects COUNT initiative to address NTD was presented. Fortification of food with folic acid was stressed as a simple and cost-effective preventive initiative, which gives a return of US\$ 12–150 for each dollar spent on food fortification. He summarized the progress made in the Region over the past three years and encouraged each Member State to scale up ongoing initiatives.

5.1.2 Regional situation

Dr Neena Raina underlined the agony and difficulties faced by each parent giving birth to a baby with BD. The reality of BD transcended

Under 5 Mortality				
Major causes – Hospital Deaths: Sri Lanka				
Causes	2006	2007	2008	2009
IUGR, Prematurity and LBW	743	759	636	609
Birth asphyxia / Intrauterine hypoxia	371	444	405	443
Other Perinatal causes	377	321	351	406
Congenital malformations	439	501	531	564
Septicaemia / Meningitis/Encephalitis	277	231	225	306
Diarrhoea and Gastroenteritis	9	16	12	6
Pneumonia	148	107	204	189
Other respiratory disease	87	65	168	72
Malignancies	50	39	40	46
Other	441	441	464	616
Total	2942	2924	3036	3257

Sources: Medical Statistics Unit

national borders and boundaries and affects various populations. Moreover, mortality trends among newborn and children due to BD were on the rise. As the management of the two major causes of neonatal deaths – infection and asphyxia – improved, BD assumed greater

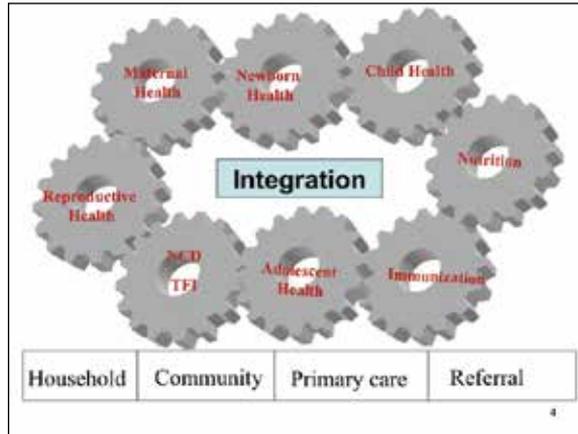
importance as causes of neonatal mortality. In countries like Sri Lanka with lower levels of child mortality, high rates of BD had been reported as the second major cause of under-5 mortality. Therefore, to further progress towards Sustainable Development Goals beyond 2015, BD prevention was vital.

Risk factors for BD were often common ones associated with other outcomes like preterm birth and intrauterine growth restriction (IUGR). Therefore, linking BD prevention initiatives to the existing newborn health programmes would create synergies and facilitate implementation.

The progress achieved by the Region through collaborative action by the WHO Regional Office and CDC demonstrated that considerable



headway had been made by Member States. The goals, targets and regional strategic framework for BD prevention and control were recapitulated and supportive tools developed to strengthen the BD surveillance activities



enumerated. Dr Raina appreciated the level of commitment in many Member States in taking forward the surveillance network to a wider range of hospitals. Pointing out significant new developments in the area of pre-visible surveillance, she urged the ‘champions’ to take forward initiatives to uncover hidden information related to BD control and prevention activities.

It was stressed that diverse opportunities existed among national health programmes to integrate preventive interventions. The potential of the regional strategy for communication to support BD programmes was emphasized and Member States were encouraged to adapt it to their national communication policies and strategies.

Efforts towards scaling up BD surveillance with quality and completeness, integrating prevention services with packaging and providing improved access to referral and rehabilitation services were some of the major challenges identified as roadblocks to successful implementation of BD prevention and control in the Region.

5.1.3 Country situation

Seven countries (Bangladesh, Bhutan, India, Myanmar, Nepal, Sri Lanka and Thailand) had developed national plans for prevention and control of BD and reported progress in the implementation of action plans as summarized below. (See Annex 4 for detailed information.)

- ◆ Goals and targets for BD had been defined in their national plans.

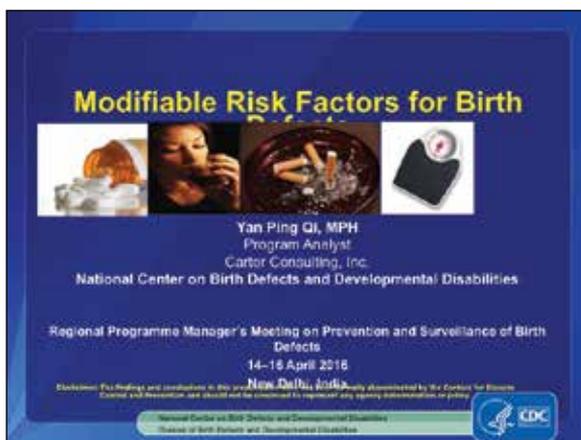


- ◆ Seven National focal points for BD prevention and control had been identified in the ministries of health and some countries had also established national taskforces or workgroups.
- ◆ Hospital-based BD surveillance mechanisms had been initiated and integration of the BD information system into the existing national health information system was being considered.
- ◆ Actions taken to integrate prevention and management of BD in the existing national programmes on maternal health, adolescent health, newborn and child health, immunization, and micronutrient fortification were enumerated.
- ◆ Progress in capacity-building for BD surveillance and plans for development of guidelines for prevention and management of BD was reported.
- ◆ Development of partnerships for BD prevention and control had been initiated in some countries.

5.2 Evidence-based birth defects preventive strategies

5.2.1 Modifiable risk factors for birth defects

Ms Yan Ping Qi, Program Analyst, CDC highlighted global and national progress towards achievement of MDG 4 and 5. She pointed out that



despite tremendous improvements in the under-5 mortality; many Member States still fell short of achieving MDG targets. A total of 4.4% under-5 mortality and 10% neonatal mortality were related to BD. Therefore, further reduction necessitated

adequate attention for prevention and control of BD. Furthermore, as survival rates of newborns with BD increased due to advancements



in science and technology, the cost related to long-term care and management of these babies escalated. Therefore, prevention of BD increases benefited both individuals and nations in terms of saving costs related to treatment and care.

Presenting the causative factors of BD and its relationship to maternal risk factors, she stated that although many causes of BD were unknown, preventive activities should be implemented to prevent the known causes. Prevention activities were summarized and discussed under three key approaches, namely:

'Provide protection', 'Manage conditions' and 'Avoid harmful exposure'. Folic acid supplementation or fortification, vitamin B12 supplementation and rubella vaccination were listed as the known approaches to provide protection during pregnancy.



The benefits of early management of maternal syphilis and obesity were discussed as the most effective management approaches for risk conditions. Avoiding harmful medication, smoking and alcohol during pregnancy were stressed as risk-reduction strategies for BD.

5.2.2 Food fortification

Cereal grain fortification

Dr Subrata Dutta, India Coordinator, Flour Fortification Initiative (FFI), said that the burden of NTD was reported as 320 000 annually across the globe. State- and national-level data (from India) were highlighted to depict the severity of this problem in the states. It was pointed out that 75% of these BD were preventable with the simple intervention of providing 400 mcg folic acid/day for women capable of becoming pregnant.

However, there were practical challenges to providing the required amount of folic acid through regular diets. Food fortification presented





a viable solution to such difficulties. Currently, there was a surge of scientific evidence supporting food fortification and rapid expansion of commitments from government including legislation to make food fortification mandatory by many nations across the globe.

The types and levels of staple food used among the Member States of WHO South-East Asia Region were mentioned and the feasibility of wheat, rice and maize fortification among different settings was discussed. In conclusion, food fortification was cost-effective and evidence demonstrated that fortification promised a larger return on investment.

Staple food fortification

Ms Deepthi Gulati, Senior Associate, Global Alliance for Improved Nutrition (GAIN), said that the composition of meals consumed by children



in India and their micronutrient value revealed a low intake in micronutrient-rich food items in their daily diets. High prevalence of anaemia levels (up to 83%) among married women and children indicated the significance of micronutrient deficiency in India.

A similar situation may be found among others Member States in the Region. Most common approaches employed to address these



micronutrient deficiencies were supplementation, diet diversification and food fortification. Of these, food fortification was the most efficient, on account of comparatively lower implementation costs and ability to yield significant results within a short period of time. Moreover, it was stated that food fortification was comparable to no other technology available today which offered as large an opportunity to rapidly improve lives and accelerate development in a cost-effective manner.

Case studies of successful development of large-scale food fortification projects in Madhya Pradesh and Rajasthan were shared. Involvement of stakeholders from multiple sectors, motivation among large mill-owners and village-level 'chakki' owners (millers) and leadership role by the ministries of health in keeping the momentum, complemented by high-pitched social marketing campaigns were highlighted as key factors in developing and sustaining food fortification initiatives.



A list of regulations and supportive initiatives by the Government of India that created an enabling environment for food fortification were outlined. Challenges identified in expanding food fortification programmes at state, national and regional levels included insufficient prioritization, lack of effective consensus and coordination between sectors at national level; and insufficient motivation and capacities at national and decentralized levels to design, implement and monitor food fortification.

Wheat flour fortification

Dr Sucharita Dutta, Country Director, Micronutrient Initiative (MI), shared the experience gained from the flour fortification programmes in India, Nepal and Pakistan. A flour fortification project was launched by the Flour



Mills Association of Nepal in 2008 which began with voluntary fortification of wheat with technical support provided by MI. A key milestone was achieved in 2011 with the Government of Nepal making fortification mandatory for iron, folic acid and vitamin A. An evaluation of this project indicated a reduction in the prevalence of anaemia among women of child-bearing age from 33% in February 2009 to 18% in April 2011 with coverage levels going up to 80% in households using fortified flour. A similar experience was noted in a wheat flour fortification programme in Pakistan which began in 2003 for a period of five years.

The state government in Gujarat, India, launched a wheat flour fortification programme during 2006–2011 to fortify flour with iron, folic acid and vitamin A. The end-line survey showed reduction in anaemia and



vitamin A deficiency among adolescent girls, schoolgoing children and pregnant and lactating women as well as among pre-school children. Later, this intervention was scaled up across all districts of the state, reaching approximately 11 million beneficiaries.

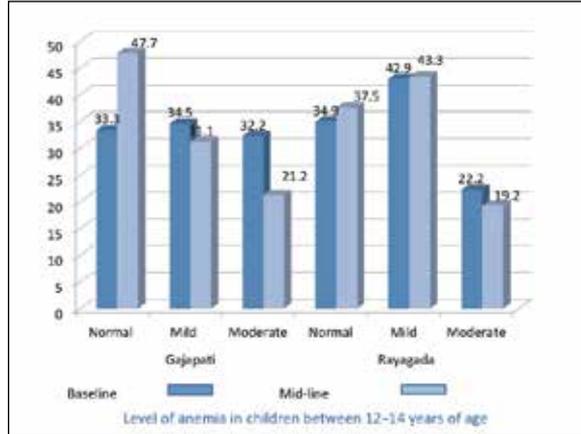
Requirement of legislation and standards and establishing and sustaining quality control and quality assurance systems incorporating strong enforcement mechanisms and high quality fortificants and equipment were highlighted as the challenges faced by such fortification programmes.

Rice fortification

Dr Shariqua Yunus, Programme Officer, Health and Nutrition, World Food Programme, shared the experience from a food fortification initiative in a mid-day meal programme in the Gajapati district of Odisha State, India for schoolchildren between 6–14 years implemented for 24 months. The food given in the mid-day meal programme was replaced with fortified rice-based meals. The chain of activities included in this project were — setting up of food fortification points; establishing supply chain manage-



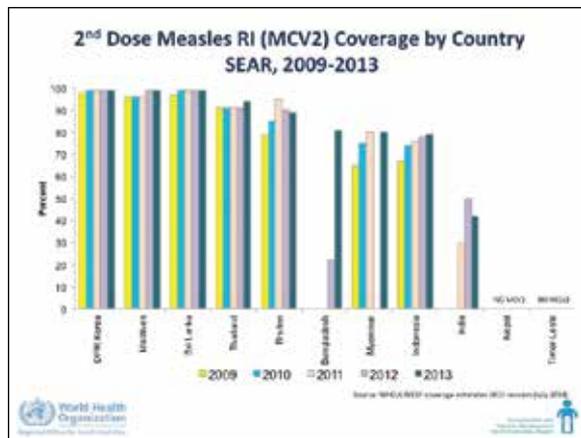
ment; building capacity of teachers and school management committee members; implementing information, education and communication activities; sustaining quality assurance; quality control; and regular monitoring.



An intervention-control approach was adopted by assigning schools in Gajapati district implementing the food fortification initiative to intervention groups and schools in Rayagada to the control group. Analysis showed that iron-fortified rice meals had a significant positive impact in reducing the prevalence of anaemia (10%).

5.2.3 Congenital rubella syndrome surveillance and prevention

Dr Jeffrey McFarland, WHO Regional Adviser, Vaccine Preventable Diseases, referred to resolution SEA/RC66/R5 on Measles elimination and rubella/ congenital rubella syndrome (CRS) control adopted at the Sixty-sixth Session of the Regional Committee for South-East Asia in September 2013 in New Delhi. The regional progress in reducing disease and deaths due to measles during the past has been remarkable. Most health ministries of the Member States had already started immunization with measles vaccine in their routine national immunization programme. However, India and Indonesia, despite relatively high levels of virus transmission, were yet to conduct a nationwide measles (MR) campaign.



Immunization, surveillance, laboratory facilities, support and linkages were identified as key strategies to achieve the regional target by 2020. The target for immunization was to achieve and maintain at least 95% population coverage with two doses of vaccination against measles and rubella (MR) within each district of each country in the Region through routine and/or supplementary immunization.

The second equally significant target was to develop and sustain a sensitive and timely case-based measles, rubella and congenital rubella syndrome (CRS) surveillance system in each country in the Region. All Member States already had a national surveillance system with some form of case-based surveillance which needed strengthening. Rubella surveillance was a by-product of measles surveillance initiatives. Currently, six countries had sentinel site surveillance for CRS and two more were in the process of initiating such sites.

Early detection and early interventions to treat CRS symptoms and break through the rubella transmission from mothers to newborns were highlighted as the most important objectives of rubella and CRS surveillance systems. Developing and maintaining an accredited regional measles and rubella laboratory network to support case-based surveillance and special studies were underscored as key strategies to help improve the surveillance system. The significance of support and linkages with partners were highlighted.

The key challenges identified were — expanding the routine immunization coverage to reach 95% coverage. The reality of this challenge was enormous for countries with larger populations such as India and Indonesia. In addition, ensuring adequate vaccine supply, sufficient funding, adequate trained staff and public awareness were listed as matters of concern in achieving the stated goals.

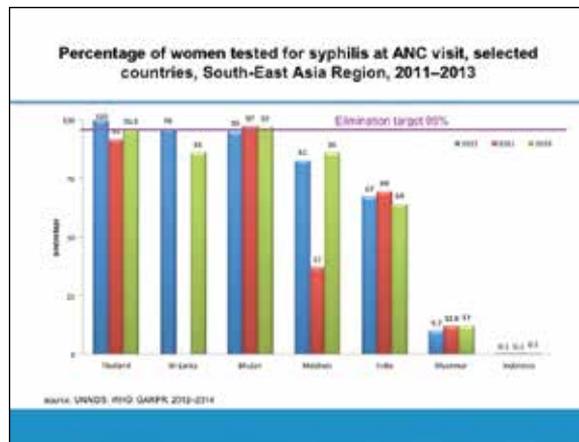
5.2.4 Elimination of congenital syphilis and HIV

Dr Razia Pendse, WHO Regional Adviser, HIV/AIDS and STI, highlighted the magnitude of the effects of syphilis on newborn outcomes. When a pregnant woman with syphilis was left untreated, her foetus had more than 50% probability of getting affected; nearly 30% of such cases resulted in still-birth, foetal loss and neonatal deaths. The timing of treatment and



outcome of syphilis were closely linked. The earlier the treatment, the higher the ability it had to prevent these adverse outcomes. Nearly all foetal outcomes could be prevented if treated in the first trimester of pregnancy. However, the reality was that the burden and failure to implement these preventive actions were high in the South-East Asia Region.

She emphasized the fact that cost-saving or the cost-effectiveness of syphilis testing and treatment at antenatal care (ANC) points in various settings was high. She presented the current statistics on syphilis care among Member States. Except for Bhutan and Thailand, all other countries fell short of achieving the elimination target of 95% coverage of testing for syphilis at antenatal visit. The common points where programme failure in providing adequate coverage occurs were: coverage of ANC, early syphilis testing, report-tracing and prompt management of maternal syphilis during early pregnancy.



The following five preventive strategies were discussed as priority activities for syphilis elimination:

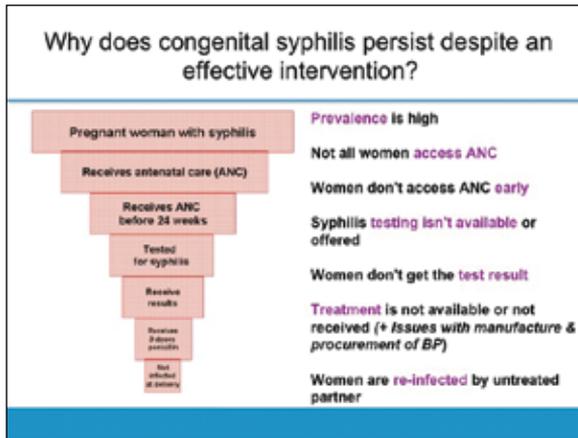
- (1) Know your epidemic
- (2) Strive for early, quality ANC for all pregnant women
- (3) Ensure same day testing and treatment
- (4) Increase support for dual elimination of mother-to-child transmission of HIV and syphilis
- (5) Celebrate success stories through validation of elimination.

The process, impact and additional indicators were listed as useful tools for national monitoring and identifying the level of epidemic.



Additional tools for getting relevant data were listed, such as the website on World Health Observatory and the WHO website: <http://www.who.int/reproductivehealth/topics/rtis/syphilis/pregnancy/en/index.html>.

The rapid diagnostic tests available for diagnosis of syphilis and HIV infections were discussed and the cost-effectiveness, sensitivity and specificity



of the dual rapid HIV and syphilis test highlighted. Community outreach to increase early ANC; training of health workers in rapid diagnostic test use; procurement of diagnostics (and penicillin); laboratory quality assurance systems; improved programme monitoring; and operational research on integration were noted as measures to strengthen the national programme for prevention of syphilis.

operational research on integration were noted as measures to strengthen the national programme for prevention of syphilis.

5.2.5 Prevention of preterm births and birth defects

Dr Christopher Howson, Vice-President - Global Programmes, March of Dimes Foundation, New York, USA gave a succinct overview of the global toll of BD including shared risk factors with preterm births. He reiterated that the Foundation focused on both BD and preterm births. The global toll of birth conditions was high – 23 million born with serious BD of genetic origin (8 million) and 15 million preterm births. The Foundation had published two reports. The one titled 'Born too soon' documented the first-ever country level outcomes of preterm births. It highlights that an estimated 4.4 million children die from BD globally. Preterm birth was the leading cause of under-five mortality globally; geographic distribution of BD and preterm births was the highest (in numbers) in sub-Saharan Africa and South Asia.

Maternal risk factors were common for both BD and preterm births. They included: underweight and overweight, chronic diseases,



micronutrient deficiencies, anaemia, mental health, infectious diseases, tobacco use, hypertension, stress, teenage pregnancies, older maternal age, and exposure to toxins among others.

The benefits of addressing BD and preterm births together in developing surveillance and prevention activities were enumerated as follows:

- ◆ similar systems for surveillance
- ◆ similar risk factors
- ◆ similar target populations
- ◆ similar interventions before and during pregnancy
- ◆ similar stakeholders (government, funders, health-care providers, professional organizations, NGOs, civil society).

These linkages strengthened synergies in BD prevention and control programmes. However, there were still relatively few studies on evaluation of preconception care and ANC for preterm birth outcomes and for adverse birth outcomes. Still births were seldom linked to lack of proper ANC and preconception care. There was a need to find partners for BD interventions and programmes. Surveillance was an important component requiring large-scale stakeholder involvement and implementation of evidence-based interventions.

The March of Dimes Foundation was initiating a public–private partnership programme in India, Nigeria and Pakistan. The goal of this initiative was to halve preterm birth rates in five years in high-burden populations, especially since these countries had the burden of 50% of all preterm births worldwide. There was evidence to support that high prevalence of risk factors in all three countries was exacerbated by diabetes, newborn deaths due to syphilis, anaemia and teenage pregnancy. Identifying factors that impinged on BD, he presented the acronym LINC i.e. **L**ifestyle, **I**nfection, **N**utrition, and **C**ontraception. Combined in a model – these factors empowered women and communities to reduce the risk factors of preterm births.

Three areas for partnership and a set of three core activities outlined were as follows:



- ◆ Preterm birth blueprints: needs assessment, population specific roadmaps outlining five-year strategies, prevalence of LINC factors, coverage of prenatal care coordination and prenatal interventions;
- ◆ Preterm report cards: rating of prenatal care coordination and prenatal performance, LINC factors to be shared with media and public circulation; and
- ◆ Preterm communication campaigns: incorporating BD prevention and control messages and promoting ownership.

Providing a succinct view of project conceptualization, he said that local multi-stakeholder teams would be formed with governments, civil society and business/corporate sector partners. Research would be conducted in all three countries to build a healthy global ecosystem for prevention of preterm births.

5.3 Birth defects surveillance

5.3.1 Principles of birth defects surveillance and surveillance toolkit overview

An overview of the main elements of BD surveillance including the tools, public health framework for prevention and health promotion was provided. It was explained how surveillance was linked to health promotion; epidemiological studies and preventive health policies. The definition of health surveillance was reiterated and the essential components of surveillance mechanism highlighted.

Essential elements of surveillance included: defining needs and purposes, collecting prevalence data, assessing data quality and using data effectively. Two types of systems (active and passive) were described and their mechanisms of getting data discussed. The importance of participating in data collection for the surveillance system was stressed. The use of uniform definitions for each BD and the criteria were discussed. The following issues were highlighted:

- ◆ list of BD (NTD, external defects or all defects) to be included in the surveillance;
- ◆ capacity to identify internal defects;



- ◆ upper age limit for screening BD in the system;
- ◆ capacity to do follow-up;
- ◆ timing of collection of data (after delivery and before discharge);
- ◆ pregnancy outcomes (live births, stillbirths, terminations of pregnancy); whether terminations of pregnancy were legal in the country and all stillbirths were to be examined for BD; and if so, whether there was in-country capacity for this;
- ◆ whether gestational age at delivery or birth weight was to be included and the country has capacity to evaluate births less than 28 weeks gestation;
- ◆ maternal residency - very important if surveillance was population-based.

Further to that, case ascertainment approaches and plurality of data sources were discussed. Improved levels of case detection and enhancement of case ascertainment were the benefits of active surveillance, while need for fewer financial and human resources that of passive surveillance. Similarly, using a single source was obviously less time-consuming, but there was a chance of getting less data. By using multiple sources, data quantity and quality improved, as did case ascertainment, resulting in more complete data of higher quality.

Data from the Puerto Rico BD surveillance system from 1989–2004 was used to demonstrate vital records versus a BD surveillance system. It was pointed out that use of multiple data sources resulted in much more complete data.

This could also serve as an example of passive vs. active systems – passive systems often used only vital records as a source, resulting in surveillance missing all the other cases. It was reiterated that data should be **Complete**, **Accurate** and **Timely** (CAT)!



Completeness and accuracy were critical in effective surveillance systems. Completeness was the extent to which data are all-inclusive and comprehensive and accuracy the extent to which data were exact, correct, and valid.

Data analysis and dissemination was the final step in surveillance. It was useful to meet the information needs of the health system and its stakeholders. The audience was encouraged to give importance to the quality of data at early stages of surveillance programmes. The steps needed to establish the surveillance system were highlighted and some toolkits available for wider use listed. The surveillance toolkit consisted of a surveillance manual, a facilitator guide and an atlas of BD. More tools would be added, as they are developed. The BD surveillance manual, developed jointly with CDC, WHO and International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) was available online and in several languages. The facilitator guide for ToT was piloted in Thailand in 2013. The following additional tools were available:

- ◆ toolkit that will link to a data collection and management template developed by ICBDSR;
- ◆ Epi Info 7;
- ◆ standardized variables allow for cross-country comparisons;
- ◆ A BD abstraction application for use with Android devices will be included in the toolkit.

5.3.2 Regional progress in newborn health and birth defects surveillance

Dr Jeyakumaran recapped the development of BD networks in the Region. BD surveillance activities in nine countries from the Region: Bangladesh, Bhutan, India, Maldives, Indonesia, Myanmar, Nepal, Sri Lanka and Thailand were summarized. The evolution of SEAR–NBBBD regional surveillance system and its coverage and performance were highlighted. The objectives of the SEAR–NBBBD database surveillance system were listed and its usefulness to achieve them emphasized.

The attractive features of the SEAR–NBBBD database and the hierarchical links with institutions connected to this surveillance network were highlighted. The role of the verifier in ensuring quality of data



was stressed and champions (national network coordinator) from the Member States were urged to scale up the network. The capacity of the current database to include newborn health, BD and still births and the expandability of existing networks was discussed.

SEAR–NBBD database has included selected major externally visible BD in the initial phase. However, all types of BD can be entered into the system according to the requirement of the hospitals in the countries. It is a hospital-based surveillance system with International Classification of Diseases and Related Health Problems, Tenth Revision (ICD10) coding system to categorize the defects.

The number of hospitals reporting to this surveillance system has increased to 53 hospitals from five countries over the past nine months. Nearly 130 000 births have been covered and a total of 1051 babies with BD reported. Among these cases, the number of reported BD was 1615. A higher number of BD were reported among preterm births; less than 37 weeks of gestation. A total of



180 NTD were reported and the breakdown of each type was listed. It was highlighted that nearly 20% of them died before discharge and screening at birth could improve detection.

Recent findings from the surveillance system of BD in pre-viable and stillbirths from a network of hospitals India were shared and the significance of NTD in these cases was highlighted.

The common challenges observed in SEAR–NBBD surveillance system and the opportunities to improve this surveillance network in the Region were discussed. There were significant opportunities in the form of high commitment among the Member States and the increasing number of



institutional deliveries which allowed coverage of increasing number of births in the hospital-based surveillance in the country. Member States were urged to scale up surveillance on BD to improve understanding and for informed preventive action.

5.3.3 Country progress in birth defects surveillance and database

Bangladesh

Professor Mohammad Shahidullah, Chairman, Department of Neonatology, Bangabandhu Sheikh Mujib Medical University, Dhaka, (BSSMU) outlined the progress made in BD surveillance activities in Bangladesh. He pointed out that preterm birth complications intrapartum-related events and sepsis/meningitis were the three main killers of newborns (accounting for 88% of all newborn deaths). Congenital anomalies contributed to 8% of neonatal mortality.

He discussed the progress made in the National Strategic Plan for Prevention of Birth Defects, Prevention of Rubella Programme and BD surveillance and establishment of a database. The Department of Neonatology, BSMMU was the nodal centre acting in concert with the Ministry of Health and Family Welfare, Government of Bangladesh to conduct consultative meetings, training and database maintenance, including monitoring and review activities. He highlighted some events and training and supervision activities conducted by the centre.

Regarding the progress of the surveillance and database, he named eight hospitals involved in this network including their reporting status. All staff, except nurses, were currently involved in the reporting, but there were plans to involve nurses as well. Six training programmes for hospital staff were conducted to date.

Among the BD detected by the surveillance system – 26% were NTD and orofacial clefts and 16% children with BD died during the early reporting period. He also discussed the findings from data on newborn health.

Monitoring and quality check

Monitoring approaches: daily monitoring of data entry was done by nodal centres. Supervision and monitoring of participating centres was conducted



on a regular basis (every three months) and quality checks by faculty and trained doctors conducted frequently.

Lessons learned

- ◆ Under-reporting should be minimized to get the accurate estimation.
- ◆ Hands-on training should be provided for all staff involved in data collection and reporting.
- ◆ Regular checking and feedback was mandatory to ensure quality of data.
- ◆ Involvement of obstetrics and gynaecology department was essential to record the number of deliveries and stillbirths.

Challenges

- ◆ monitoring
- ◆ sustainability
- ◆ quality
- ◆ server problem
- ◆ shortage of trained human resources or personnel.

Way forward

- ◆ establishing networka in other medical colleges and institutes;
- ◆ acaling up the network in district and *upazila* (sub-district) level hospitals;
- ◆ establishing surveillance programme for BD;
- ◆ incorporating newborn screening programme in the health-care facilities; and
- ◆ formulating strategies to prevent common newborn illnesses.

Bhutan

Ms Khina Maya Mohora, Senior Programme Health, Ministry of Health, Thimphu, presented the progress made in BD surveillance activities in Bhutan. A total of 399 births were reported with four stillbirths and five



cases of BD, including cases of congenital heart disease, fetal alcohol syndrome, NTD and muscular skeletal deformities. Newborn morbidity was also reported; cases of sepsis and jaundice are common. Pen-and-paper formats were used for reporting. BD thus recorded, were confirmed and signed by a paediatrician.

Capacity-building

One TOT was organized in December 2014 to sensitize hospital staff on BD surveillance. As measures of monitoring and quality checks, each case would be confirmed by the paediatrician.

The following challenges were discussed together with the way forward in this scenario:

Challenges

- ◆ need to improve the recording system for easy access of data;
- ◆ need for an online database;
- ◆ difficulty convincing and encouraging parents to participate in the study;
- ◆ inaccurate information regarding social habits; and
- ◆ parent's refusal to agree to referrals.

Way forward

- ◆ documentation and maintaining confidentiality;
- ◆ holding review and coordination meetings at local level;
- ◆ establishing an online reporting system;
- ◆ developing capacities of doctors and nurses;
- ◆ supplies to facilitate surveillance; and
- ◆ M&E at the national level.

India

India shared experience from two networks of hospitals.

Dr Lakhbir Dhaliwal, Professor and Head, Department of Obstetrics and Gynaecology, Post Graduate Institute of Medical Education and Research,



Chandigarh, India, presented the progress made in BD surveillance activities in 10 hospitals from different states of India. Consultants for Ob-gyn and paediatricians had been in-charge for surveillance activity in each hospital.

Two one-day trainers' programmes for hospital nodal persons were conducted in February and October 2014, with 40 participants. During January 2014 to April 2015, 48 000 births were reported. All forms were submitted online into NBBD database. Over this period, 704 BD (570 BD among live births and 134 among stillbirths) were reported.

Detailed analysis on BD data was presented. Initiatives among still birth surveillance and pre-viable surveillance were also highlighted.

The following challenges were discussed together with the way forward in this scenario:

Challenges

- ◆ scaling up with stillbirth data, which was not being submitted online earlier;
- ◆ inability to get the types of BD on the online drop-down list;
- ◆ lack of availability of pages for pre-viable BD data; and
- ◆ discrepancy among newborn data analysis retrieved.

Way forward

- ◆ expedite the process of online submission of new born data;
- ◆ enter all the still births recorded so far on the recently provided; and
- ◆ start online entries of pre-viable BD project.

Dr Pratima Mittal and Dr Shobna Gupta, Senior Consultants, shared the progress made in BD surveillance activities among eight Delhi hospitals coordinated by Safdarjang Hospital, New Delhi.

Data on live births and stillbirths collected over a period of three months (since January 2015), from the participating hospitals of Delhi were shared. The steps taken in submitting BD forms were described and information on BD from data collected was presented.



Maldives

Dr Ahmed Faisal, Paediatric Consultant, Indira Gandhi Memorial Hospital, Malé, presented the progress made in the BD surveillance activities in Maldives. There were two tertiary referral hospitals in Maldives (one public and one private) and 50% of the deliveries were conducted at the public hospitals. All babies were examined by a paediatrician at birth.

Some key findings were presented from the BD report published recently on the basis of eight years' data from the hospital. These data were manually entered into the BD register and included maternal variables, infant data and outcomes.

Among the BD reported, circulatory system involvement was found in 27% babies and central nervous system involvement in 14% babies. A large majority of the BD had single system defects and 77% of all BD were among babies with low birth weight. An association with maternal age (particularly age 40 and above) was demonstrated in the cases reported.

Approval from MoH to use the WHO Regional Office database was awaited. A plan had been developed to establish a national BD register, coordinated by MoH as a focal point with three hospitals (with the addition of two existing hospitals, this will cover 75% of the births in the Maldives).

Myanmar

Dr Aye Aye Thein, Professor of Neonatology, University of Medicine 1 and Central Women's Hospital presented the progress made in BD surveillance activities in Myanmar. Although the initiative on newborn health surveillance dated back to 2002, in 2014 the format was changed to Regional Office database. However, due to lack of online connectivity, the database had been maintained offline.

Currently, surveillance activities covered four main maternity hospitals. In 2014, 385 BD had been reported from the four hospitals. Common BD included: chromosomal defects, muscular-skeletal, central nervous system, circulatory system defects and orofacial clefts. The pattern of newborn mortality and morbidity from the four hospitals was also presented.



Nepal

Dr Laxman Shreshtha, President, Nepal Paediatric Society, Kathmandu, presented the progress made in BD surveillance activities in Nepal. Ten hospitals had joined the surveillance programme. Reporting covered sick newborns, sick newborns with BD, and BD only categories. Paediatricians, obstetricians and gynaecologists, medical officers and medical recorders were involved in this process.

Results from the surveillance data analysis revealed that 84 BD were reported from among 26 343 births (prevalence rate of 0.31 %). Among the BD, 15.4% were NTD and 15.4 % were orofacial clefts.

Monitoring and quality checks were planned as follows:

- ◆ one person from each networking hospital has been identified for quality checks;
- ◆ coordinator to visit each hospital at least once every three months;
- ◆ internal review meeting to be held in each hospital every two months;
- ◆ review meeting of hospitals inside valley every two months;
- ◆ coordinator to hold telephone conversations with hospitals at least every week; and
- ◆ the national coordinator and Family Health Division staff to visit the networking hospitals.

Sri Lanka

Dr Dhammica Rowel, Programme Officer, Family Health Bureau, Sri Lanka, highlighted the progress made in the pilot project on BD surveillance in the country and presented the results of data analysis from the database. The features of the surveillance system included all the important variables of BD. It was an online system and a designated medical officer from each institute maintained the database. At this stage, the quality of data was poor and needed improvement. Paediatricians/neonatologists, obstetricians, nurses and midwives, medical recorders and pathologists were involved in the system.



In addition to surveillance, screening for congenital hypothyroidism had been initiated, which would be incorporated with BD surveillance later. A pilot deafness screening would be started in Kandy in April 2015, which would also be incorporated in BD surveillance at a later date. Pulse oxymetry screening for serious congenital heart diseases was also planned to be started in 2015 in 48 government hospitals, which will be linked to the BD database. The Ministry of Health would be providing free Wi-Fi system to all hospitals and this would aid online reporting.

Thailand

Dr Suthipong Pangkanon, Deputy Director, Queen Sirikit National Institute of Child Health described the progress made in BD surveillance activities in Thailand and the national plan on scaling up the BD surveillance system. In 2013, 20 hospitals in 16 provinces were involved. In 2014, 27 hospitals in 20 provinces were included and in 2015, surveillance would include 52 hospitals in 64 provinces. Currently, 27 hospitals were reporting BD. The involvement of paediatricians, obstetricians, nurses, midwives was high in this project.

Training programme was conducted twice a year – last time in February 2015. Overall, 92 people were trained using SOP, manual, atlas and other tools and BD annual report. Eighteen BD were prioritized for surveillance. Only live births were included and BD up to one year of age were reported. In 2013, 2669 BD were reported in 89 454 live births (a prevalence of 2.989). Congenital heart defects were the commonest (47.58%) followed by limb defects (19.447%).

5.4 Standard protocols for prevention and management of selected birth defects

Dr Madhulika Kabra, Professor, Division of Genetics, All India Institute of Medical Sciences, New Delhi, India, acknowledged the support provided by the WHO Regional Office to convene regional expert groups to develop standard protocols for newborn screening, prevention and management of Down syndrome, thalassaemia, hearing defects and clinical examination of newborn. The protocols would be adapted by the countries for use in the local context.



5.4.1 Protocols for management of thalassemia

Professor Dr M Mahapatra, Department of Hematology, All India Institute of Medical Sciences, New Delhi emphasized that thalassemia management required a team of experts. The initial management included close monitoring to determine the likely course of the condition. Detailed information of the condition and its management should be given to both parents.

It was recommended that blood transfusion therapy should be started before complications like anaemia and bone marrow expansion occurred. However, unnecessary transfusions should be avoided. Dr Mahapatra discussed the criteria for deciding on transfusion and listed the baseline laboratory tests needed before transfusion. The facility for blood transfusion and the type of blood product needed was described.

Iron overload assessment and chelation therapy was presented. The approach with splenectomy was discussed and pre-and postoperative care were specified. The place of haematopoietic stem cell transplantation in thalassemia was mentioned and concerns regarding graft rejection and factors responsible for it were pointed out. A list of risk factors to be assessed before transplant was provided and the survival benefit was argued.

5.4.2 Thalassemia prevention

Dr Neeraja Gupta, Scientist, Department of Genetics, All India Institute of Medical Sciences, New Delhi, India, described the importance and severity of haemoglobinopathies in SEAR. Except Thailand and Sri Lanka, other Member States of the Region did not have national thalassemia prevention and control programmes. The thematic expert group met in August 2014 to develop standard protocol for prevention of thalassemia in the Region. It consisted of three components – screening methods for thalassemia, screening timing and prenatal diagnosis strategy.

The strategy for screening during premarital, preconception and antenatal care was presented. The screening timing and strategy was dependent on factors like – family history, ethnicity, consanguinity, haematological parameters and gestation of pregnancy. The importance of counselling in prenatal diagnosis was highlighted. Several risks – such as



the chances of the fetus being affected, diagnosis techniques, limitations of the test, its complications and follow-up requirements after birth were discussed. In conclusion, the best practice guidelines for antenatal diagnosis of thalassemia were explained.

5.4.3 Newborn screening

Dr Madhulika Kabra said that only a few ongoing national programmes on newborn screening existed in the Region and provided information about such screening programmes and pilot studies from countries. The rate of incidence of clinically significant conditions was provided to stress the public health importance of screening programmes. The need for national-level advocacy for scaling up these programmes was emphasized.

The programme should respond to felt needs such as careful selection of disorders and objective of screening should be defined at the outset of the programme. She highlighted the recommendations on the list of newborn conditions by the regional expert group which included screening for congenital hypothyroidism, hearing screening and the G6PD deficiency. Standard protocols for these conditions were under preparation.

5.4.4 Protocols on hearing screening guidelines

Dr Suchita Gupta, Assistant Professor of Pediatrics described the global burden of disabling hearing impairment in adults as 360 million and in those below 15 years of age, it was 32 million. Deafness cost US\$ 154–186 billion on rehabilitation, special education and employment for the people with disabling hearing impairment. However, there was still no consistent approach to newborn hearing screening in most countries of the Region. Only India and Thailand had newborn hearing screening.

The algorithms for both well baby (without risk factors) and high-risk baby (infant with risk factors) were described. The need for follow-up through regular surveillance, standardized screening of global development – especially if the infant did not pass speech language development – was described. The two-step hearing screening (by 1.5 months) and comprehensive audiological evaluation (by three months) were described.



5.5 Communication strategies

5.5.1 Regional communication strategy for prevention and control of birth defects

Dr Rajesh Mehta, Medical Officer, Child and Adolescent Health, WHO Regional Office for South-East Asia, presented the regional communication strategy which was consonant with resolution WHA63.17 on Birth defects calling for raising awareness among all relevant stakeholders. The regional strategic framework for the prevention and control of BD recommended implementation of strategic communication to generate awareness; advocate for policy change; support healthy behaviours; increase demand and support for health services and behaviour change for providers and clients. Large-scale impact at the national level required political will and policy support; financial and technical resources; shared understanding of BD and their prevention and management.



In order to have broader ramifications, however, communication should be collaboratively designed and implemented, recognize sociocultural factors, a multi-channel environment and include multimedia. All communication initiatives should be monitored and evaluated.

The objectives of the communication strategy were as follows:

- ◆ orient programme managers to the importance of communication for prevention and control of BD;
- ◆ provide guidance for developing country-specific communication plans;
- ◆ build understanding and capacity of programme managers on the use of communication tools and techniques for advocacy, behaviour change and community mobilization; and
- ◆ provide guidance to implement, sustain, monitor and evaluate the communication activities for prevention and control of BD in the countries.



The following steps were recommended for national adaptation of regional communication strategy (RCS):

- (1) landscape analysis: review of health communication plans
- (2) communication needs analysis
- (3) orientation of implementation plans
- (4) development of national communication plans
- (5) implementation of national communication plans
- (6) monitoring and evaluation of communication plans.

The communication strategy was designed to support national plans for prevention and control of BD in order to achieve the overall goal of preventing BD, improving newborn survival and ensuring quality of life and dignity.

5.5.2 Communication toolkit

Mr Burke Fishburn, Consultant, Centers for Disease Control (CDC), Atlanta, USA, said that the communication toolkit available on the WHO Regional Office website was developed by CDC communication experts in collaboration with WHO and complemented RCS insofar that the tools can be used for advocacy and awareness generation.

The purpose of the toolkit was to provide information on BD and inform national action plans. The target audiences were the public, policy-makers, stakeholders, and funders. Its mechanism was the print and electronic media.

The toolkit consisted of a series of customizable, quick-use templates. Its contents covered information about BD, causes and types and the most common BD, globally. It also summarized the reasons why BD were a public health concern and provided information on the prevalence of BD. It contained comprehensive information to support communication and advocacy activities in Member countries including:

- ◆ FAQs, information on public health impacts on BD, causes and risk factors, prevention, detection, treatment and care;
- ◆ templates for letters and emails, targeted at policy-makers, potential funders and partners;



- ◆ country profile fact sheet: where countries can contextualize information content;
- ◆ templates for key message development, letters/email templates;
- ◆ press release formats;
- ◆ web and social media content (design and development of a landing page for a website, for example, for audiences searching for information on BD); and
- ◆ executive summary of the SEA regional framework.



The strategy and toolkits were meant for use by programme managers and could be adapted to the country context and target audiences.

The presentations on communication strategy and toolkit invoked significant interest. It was suggested that it would be useful to provide an open platform on the website where people could share their stories and experiences of communication activities from all countries of the Region. The use of the visuals on BD could be appropriate in some settings, but perhaps not for the general public. It was important to target both policy matters and the general public for advocacy on BD. Participants were informed that Indonesia uses the MCH handbook to disseminate messages on BD and Thailand has planned to focus on one BD every year to commemorate International BD Day.

5.6 Preparing national implementation plans

Dr Rajesh Mehta briefed the participants on preparing implementation plans for BD prevention for the next two years using the template provided for this purpose. Countries developed implementation plans based on their national action plans. A summary of the implementation plans developed is provided in Annex 4.



Annex 1

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Annex 2

Message from Dr Poonam Khetrupal Singh, Regional Director, WHO South-East Asia Region

I welcome you all to this regional programme managers' meeting where we will review progress in country plans for prevention and control of birth defects in the WHO South-East Asia (SEA) Region as well as deliberate on the way forward.

You are aware that birth defects cause a higher proportion of neonatal and child mortality in the Region, in spite of our countries having achieved a progressive decline in overall child mortality over last two decades. For example, birth defects cause 24% of neonatal mortality in Thailand and 27% in Sri Lanka. In addition, we must not forget that birth defects are responsible for significant long-term morbidity and disability that lead to a huge economic and social burden for individuals, families and health systems.

Although there is insufficient information in our countries, it must be admitted that there is a large burden of birth defects in the SEA Region. Every year, an estimated one in thirty three infants – about 1 million in a year – are born with birth defects in the Region. A large majority of birth defects is attributed to the poor health status of women during the pre-pregnancy and pre-conception periods. Many of the maternal risk factors for birth defects, pre-term births and intrauterine growth retardation are common.

Experience from high-income countries has shown that up to 70% birth defects could be prevented by evidence-based interventions. For example, sufficient intake of folic acid by women before and after conception prevents occurrence of NTD. Rubella vaccination of women before they get pregnant prevents congenital rubella syndrome in their babies associated with heart defects, hearing and visual impairment. Improvement in the maternal status linked to iron, folic acid and iodine intake, and "awareness"



of the impact of exposure to teratogens during the antenatal period could significantly reduce the number of babies with birth defects.

In response to this situation and in pursuance of the resolutions of the WHO Governing Bodies, the WHO Regional Office for South-East Asia has developed a regional strategic framework for prevention and control of birth defects for 2013–2017 in collaboration with Member States. I would like to place on record our collaboration with the Centers for Disease Control (CDC) Atlanta, United States of America for this important regional initiative on prevention and control of birth defects.

Over the last three years, we have supported countries in developing national plans and strengthening capacity for birth defects surveillance to prevent and manage birth defects. Nine Member States in the Region have developed national plans for prevention and control of birth defects including birth defects surveillance. All of them have followed the approach of integrating interventions for prevention and management of birth defects in their existing public health and related programmes in line with the regional strategic framework. Now it is important for the countries to develop implementation plans with increased investments for prevention and control of birth defects. WHO in partnership with other agencies, will continue to provide support to the countries.

Simultaneously, the Regional Office has been supporting capacity development to establish birth defects surveillance mechanisms in countries to help strengthen the information on birth defects. WHO and CDC have jointly developed a training manual and a photo-atlas on birth defects surveillance. Regional and national capacity-building workshops have been conducted in Bangladesh, India, Indonesia, Sri Lanka, and Thailand. WHO has supported regional and national networks on newborn health and birth defects to strengthen hospital-based surveillance in Member States.

Considering that prevention and control of birth defects require multidisciplinary, multisectoral and multiple programme efforts, programmes such as child and adolescent health; maternal and reproductive health; nutrition; immunization; HIV; and noncommunicable diseases in our Regional Office have worked together in a coordinated manner. Similarly, in countries, we are promoting multidisciplinary and multisectoral involvement of all concerned stakeholders in the development



and implementation of national plans for prevention and control of birth defects.

The first ever World Birth Defects Day was recently observed this year on 3 March. For this event, the Regional Office collaborated with global partners to raise awareness about the occurrence of birth defects, advocate for developing and implementing primary prevention programmes; and expand referral and care services for all persons with birth defects. We are pleased that WHO's advocacy initiatives on birth defects were widely reported by the media in several countries of the Region and beyond. There was an extensive following on the social media as well. We believe that such awareness-building and policy advocacy would contribute to reducing the public health burden of birth defects in our countries and prompting policy-makers as well as individuals to take appropriate measures.

I appreciate that progress related to national plans on birth defects will be reviewed by national programme managers in this meeting. This will help us learn from the past and plan for the future. I am sure that experience-sharing among Member States will be useful for strengthening country capacity. This regional meeting should also be an effective platform for promotion of intercountry cooperation in this complex area of birth defects prevention and control.

I sincerely thank all country participants; representatives from CDC, United States and partner agencies; experts from centres of expertise in the Region; and all other participants for having spared their valuable time to participate in this meeting. We need to work together to prevent birth defects to provide timely care to children born with birth defects, and minimize their sufferings and save their lives.



Annex 3 Agenda

1. Global and regional overview of birth defects
2. Status of national plans for birth defects prevention
3. Evidence-based birth defects preventive strategies – addressing modifiable risk factors for birth defects
 - (a) Food fortification
 - (b) CRS surveillance and prevention
 - (c) Elimination of Congenital syphilis and HIV
 - (d) Addressing common risk factors – Prevention of preterm births and birth defects
4. Principles and progress in birth defects surveillance
 - (a) Principles and best practices
 - (b) Regional and national progress birth defects surveillance
5. Regional protocols on thematic areas of birth defects prevention
 - (a) Thalassemia prevention and management
 - (b) Newborn screening
6. Communication for birth defects
 - (a) Discussion on Regional communication strategy for birth defects and steps for national plan and communication tool kit
7. Draft national implementation plans



Annex 4

Status of national plans for birth defects prevention – country presentation

	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
National goal	To improve the quality of life through surveillance, prevention and early management of correctable BDs	The significant reduction of preventable BDs to contribute to achievement of MDG4 and beyond	<ul style="list-style-type: none"> • Early health screening and management of all children from birth to 18 years on BDs, diseases, deficiencies and development delays 	The significant reduction of preventable BDs to contribute to achievement of MDG 4 and beyond.	To significantly reduce preventable BDs and related mortality and morbidity	To improve the quality of life through prevention and early management of correctable BDs and to treat to achievement of MDG 4 and beyond	To reduce the neonatal death rate < 8: 1000 live birth by preventing the preventable new cases of BDs and to treat the treatable conditions to reduce disability.
National targets	<p>BDs identified for the national strategic framework – SEAR set targets and beyond:</p> <ul style="list-style-type: none"> • Reduce the prevalence of folic acid-preventable NTD by 35% by 2018 	<ol style="list-style-type: none"> 1. Reduce prevalence of folic acid-preventable NTD by 35% in five years; 2. Reduce the number of thalassaemia births by 50% in five years; 	<ul style="list-style-type: none"> • Estimated 27 crore children from birth to 18 years to be screened in a phased manner <p>30 health conditions to be screened and managed</p>	<ol style="list-style-type: none"> 1. Reduce prevalence of folic acid-preventable NTD by 10 per cent in five years in selected townships 2. Reduce congenital rubella in five years 	Framed for (2015–2019) <ol style="list-style-type: none"> 1. Establish a surveillance system 	<ol style="list-style-type: none"> 1. To reduce prevalence of folic acid-preventable NTD by 35% by 2018 2. To reduce the number of thalassaemia births by 50% by 2018 3. To eliminate congenital rubella by 2018 	<p>Targets in 6 action areas</p> <p>BD surveillance</p> <p>NB screening</p> <p>Folic acid supplementation</p> <p>Thalassaemia</p> <p>National networks</p> <p>Communication strategy</p> <p>Each area has its own plan and focal point</p>



	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
	<ul style="list-style-type: none"> Reduce the number of Thalassaemia births by 50% Reduce congenital rubella Eliminate congenital syphilis Cleft lip and cleft palate Limb defect including clubfoot Congenital Hypothyroidism Down's syndrome 	<ol style="list-style-type: none"> Reduce congenital rubella in five years; Eliminate congenital syphilis in five years. 		<ol style="list-style-type: none"> Eliminate congenital syphilis in five years in implemented townships Establish and institutionalize BD surveillance system in 3 Regional Hospitals To establish the baseline data for seven identified BD 	<ul style="list-style-type: none"> BDs related information collection is started through health management information system (HMIS) recording tools and reporting started from the health facilities with birthing facilities. Need further capacity building for information management and analysis The neonatal perinatal database network is established, but needs to be strengthened. It is part of the national surveillance system Reduce the prevalence of folic acid-preventable NTD 	<ol style="list-style-type: none"> 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 	



	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
					<p>3. Reduce the number of thalassemia births</p> <p>4. Reduce the prevalence of congenital rubella</p> <p>5. Eliminate congenital syphilis. Baseline data needs to be collected before progress can be measured</p> <p>6. Strengthen appropriate services for management of children with BD</p> <p>Services are currently being provided both by government, private actors and NGOs, however these need to be coordinated, strengthened and expanded</p>	<p>9. To detect 80% of congenital hypothyroidism and treated by 6 weeks of life by 2018</p> <p>10. To establish a national BD surveillance system in SL by 2015</p>	





	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
National focal point for BD prevention	Programme Manager-MNH, DGHS	DPR Programme, NCDD, DoPH		Dr May Khin Than, Deputy Director/ Programme Manager (Nutrition), Department of Public Health	<ul style="list-style-type: none"> Family Health Division, Ministry of Health and Population 	<ul style="list-style-type: none"> DDG PHS II / Family Health Bureau of the Ministry of Health 	Each area has its own plan and focal point
Status of national BD prevention plan	Plan of action has been developed and endorsed			<ul style="list-style-type: none"> Planning workshop – Feb 2014 5 y plan approved by the MOH Dissemination workshop – Sep 2014 Plan for TOT on BD surveillance 	<ul style="list-style-type: none"> Approved by Ministry of Health and Population (March 2015) 	<ul style="list-style-type: none"> Approved or endorsed by the government Disseminated among the task force and stakeholders 	Approved
National taskforce/workgroup members	Available	Available		Available	Available	Available	Available

	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
Status of national BDs information integrated in existing health information system(s)	<p>Process is ongoing to integrate indicators of BDs in national HMIS (DHIS 2)</p> <p>BSMMU being the nodal centre is doing surveillance, monitoring and evaluation of 8 centres</p>		<p>Under RBSK, Screening for BDs at 4 levels for 12 BDs</p> <p>Sentinel sites with the help of WHO. Focus is on external & structural major BDs</p>	<p>BD information will be integrated in existing health information systems; HMIS</p> <ul style="list-style-type: none"> Registries to BD-some hospitals Established national Network for Newborn health since 2013 	<ul style="list-style-type: none"> HMIS initiated providing information on visible malformations at the time of delivery in birthing sites. But non visible malformations are not captured A micronutrient survey is initiated Integration of information from HMIS, neonatal and perinatal database network, survey and studies, population census and Nutrition Information System in a central database is planned 	<ul style="list-style-type: none"> RH HMIS – Rubella Immunization Screening for VDRL Folic Acid supplementation Screening and Management of DM Screening BMI eIMMR – Obstetric formats Neonatal Examination Format – pilot in one district (insert picture) Neo-NICS – In all THs, PGHs 	<p>Already having national online birth registry</p> <p>Recently established BD registry</p> <p>Hypothyroid screening database</p> <p>Thalassaemia database are developed</p>





	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
					<ul style="list-style-type: none"> • Maternal and perinatal death review (MPDR) data is used to monitor lethal CM • HMIS provides total figure on the BD. Details can be observed in the neonatal perinatal database • The plan is to strengthen and expand the network • ICD coding in network database, but not in the HMIS (not by type, can be used as denominator) 		

Integration of BD into other relevant programmes	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
<p>Partially incorporated in the new maternal health SOP</p> <p>STD/STI screening incorporated in SOP of MHS</p> <p>incorporation of newborn screening is in process;</p> <p>Existing guidelines include 400 microgm folic acid supplementation for adolescent girl & pregnant mother at prenatal stage (different doses)</p> <p>Started the fortification programme (MOHFW, UNICEF, MI but preliminary stage)</p> <p>Yet to be initiated by NCDC</p>	<ul style="list-style-type: none"> Pre-conception care services: <ul style="list-style-type: none"> Preventing pregnancy at advanced maternal age Folate supplementation: during adolescence and peri-conception period Immunization: Rubella vaccine NCD (diabetes and obesity) prevention through healthy lifestyles promotion, screening and treatment Preventing consanguineous marriages 	<p>Interventions</p> <ol style="list-style-type: none"> Folic acid supplements during perinatal period Iodine supplementation in mothers diet Rubella immunization Avoid alcohol, smoking or drugs at any time Gestational diabetes screening and management Avoid infection by washing hands, food well cooked Avoid stress or working near furnace 	<ul style="list-style-type: none"> Maternal health programme: Quality ANC incl. Nut education & counselling, iron folate supplement-tation, cong. syphilis Child health programme: BDs information will be integrated with neonatal networking, Neonatal screening and management Immunization programme: M-R vaccination in 1st Measles this year, 5-9 years old children, till 15 years old Introduction of rice fortification (1st pvt will be in 3rd qr 2015) Micronutrient sprinkles (U3 in n. situation, U5 in disaster condition, some tsps) 	<ul style="list-style-type: none"> Maternal health programme: ANC: It is planned to improve nutrition counselling and laboratory testing during ANC. Review the Adolescent Sexual and Reproductive Health strategy in regard to nutrition counselling is planned. Also preconception iron and folic acid supplementation is prioritized Child health programme: Newborn screening and management at birthing sites, CB-IMINCI 	<ul style="list-style-type: none"> Already integrated – life cycle approach – system of service delivery 		





	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
	<ul style="list-style-type: none"> • Reinforcing and improving ANC services: <ul style="list-style-type: none"> – No medications during first trimester – Syphilis screening – Prevention of exposure to tobacco and alcohol – Prevention and management of diabetes and obesity during pregnancy – Antenatal screening and prenatal tests for BD • Improved perinatal care: <ul style="list-style-type: none"> – Asphyxia prevention and management – Neonatal screening for BD 			<ul style="list-style-type: none"> • Iron folate supplementation (Nationwide) • Folic acid supplementation – not started/not planned yet • Newborn screening (kit for hypothy, G6PD etc. in Parami private Hospital, umbilical cord G6PD in Ygn CWH & some private hospital) • NCD programme: • Tobacco law enacted in May, 2006 • National Diabetes/ Cancer/heart diseases control programme • NCD section in new organization set up of DoPH 	<ul style="list-style-type: none"> • Immunization programme: Measles and Rubella vaccination for children, 88% of the target under one year infants is achieved in 2013/2014 • NCD Screening and management of diabetes mellitus in referral hospitals. 		

	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
<p>National guidelines</p>		<p>Develop Guidelines, SOP and surveillance forms</p>	<p>Tools for screening for BD along with developmental delay and disability</p>	<p>There is no peri-conception folic acid supplementation policy, however, planned for the future.</p> <p>Pre conception Folic Acid supplementation is planned, currently piloting in 2 districts out of 75.</p> <p>Very few (10) roller mills fortifies iron, folic acid and vitamin A.</p>	<ul style="list-style-type: none"> Food fortification and supplementation programmes: <ul style="list-style-type: none"> No national guidelines on food fortification and supplementation. Food fortification criteria for national level as well as sub national level considering geographic and cultural diversity is stated in the IP. BDs prevention interventions in pre-conception, prenatal and newborn screening, child health, adolescent health and other programmes 	<ul style="list-style-type: none"> Food fortification and supplementation programmes <ul style="list-style-type: none"> Salt iodination guidelines, Thripasha supplementation, Micronutrients supplementation during pregnancy and lactation BDs prevention interventions in pre-conception, prenatal and newborn screening, child health, adolescent health and other programmes – included in MCH Policy, guidelines available BDs prevention in noncommunicable disease programmes <ul style="list-style-type: none"> Focus has to improve 	<ul style="list-style-type: none"> National guidelines on : <ul style="list-style-type: none"> Food fortification / supplementation <ul style="list-style-type: none"> Prevention interventions in pre-conception, prenatal, newborn screening, child health, adolescent health etc. BDs prevention in noncommunicable disease programmes





	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
Capacity building/trainings for BDs prevention	Training of the statisticians and service providers from selected facilities	<ul style="list-style-type: none"> Conduct ToT for resources, focal persons from Surveillance sites Training and sensitization of Hospital staff Training on recognition of BD, ICD 10 Coding & reporting needs to be completed by December 2014 Training of staff on Data entry at Hospitals level and national level 	ToT for hospitals from 19 Member States under RBSK	<ul style="list-style-type: none"> Not conducted yet Planned for TOT training for BD Surveillance 	<ul style="list-style-type: none"> Training has been provided for focal persons from hospitals participating in the neonatal, perinatal database network 	Pre-service training Doctors/Nurses/Midwives In-service training	<ul style="list-style-type: none"> List of capacity-building/trainings that have been conducted for BDs prevention List of planned conduct capacity-building/trainings for BDs prevention

	Bangladesh	Bhutan	India	Myanmar	Nepal	Sri Lanka	Thailand
List of planned conduct capacity-building/trainings for BDs prevention	Not yet initiated by MoHFW	<ul style="list-style-type: none"> • Training of IT personnel for data base software National level • Social mobilization and advocacy has to be carried out for creation of awareness • Resource mobilization, financial and human resource. Implement surveillance, January 2015 • Monitoring and evaluation has to be conducted before final evaluation of the surveillance 			<ul style="list-style-type: none"> • Additional training will take place as refresher for already reporting hospitals in the neonatal, perinatal database network, and the additional zonal hospitals to be included • BD screening and management module is planned to incorporate in the SBA training • Other trainings to be planned according to IP 	<ul style="list-style-type: none"> • Child Growth Monitoring and Promotion and Immunization • School Health Inspection training package • Pre-pregnancy care package • Maternal Care package • Essential Newborn Care package <p>Introduced through out the country – now continue as in-service training</p> <p>PG training</p> <p>National Workshop</p> <p>Staff in the pilot institutions trained</p> <p>Training workshop for pathological postmortem</p> <p>Review workshop following completion of pilot test</p>	





Implementation plan for BD prevention for 2015 prepared during regional network meeting April 2015

Strategic direction 1.5 – Develop and implement national communication strategy

	Bangladesh	Bhutan	India	Maldives	Myanmar	Nepal	Sri Lanka	Thailand
<p>Landscape analysis:</p> <ul style="list-style-type: none"> • Review of RMNCAH communication plans and activities • Resources available • Partners 	<p>Will start</p> <p>Will explore and dialogue with DPs/Donors/HQ/RO</p>	<ul style="list-style-type: none"> • Already have RMNCH communication strategy • Complete analysis 	<p>Review in Sep 15</p>	<p>Review the existing programmes and identify the strengths and weakness</p>	<ul style="list-style-type: none"> • To be reviewed by TWG & communication committee 	<ul style="list-style-type: none"> • Conduct a landscape analysis to make recommendations for a BD communications strategy (through NHEICC) • Develop National BD Communication Strategy and an implementation plan for the strategy 	<p>National maternal and newborn health communication strategy already available -</p> <ul style="list-style-type: none"> • Include BD prevention and detection communication strategies into the same – HEB, FHB, and other relevant colleges 	<p>Review of each action plan by each stakeholder once a year (6 action areas)</p> <ul style="list-style-type: none"> • BDR • Newborn screening • Folic acid • Thalassaemia
<p>Communication needs analysis under the national plan for prevention and control of BDs</p>			<p>Analysis-Communication need by Dec 15 with focus on different stakeholders CH, AH, MH</p>		<p>To be reviewed by TWG & communication committee</p>	<p>Conduct a communication needs analysis (NHEICC and FHD)</p>	<p>Some aspects already available eg, Pre pregnancy, maternal</p> <p>Needs assessment on undressed areas</p>	<p>Communicate to</p> <ul style="list-style-type: none"> • health service system • network • Thai society

	Bangladesh	Bhutan	India	Maldives	Myanmar	Nepal	Sri Lanka	Thailand
<p>Orientation and advocacy of implementation partners from health, nutrition and other related programmes</p>	<p>Will start (Policy dialogue with Policy makers/ programme planners/ GO & NGO- Implementing Institution & agencies</p>		<p>Orientation with different stakeholders (MoSJE, WCD, MoHRD, MoHFW) at national and state officials</p>	<p>To expand communication strategies to other ministries such as Min. Youth and sport, Islamic affairs, Min Environment</p>	<ul style="list-style-type: none"> Dissemination workshop has been done in 2014 To present in CBFN mtg 	<ul style="list-style-type: none"> Orientation and discussion with partners and policy makers in a national 1 day workshop Policy briefs to be developed and communicated 		<ul style="list-style-type: none"> Orientate to health supervisors Orientate to programme network Implement to the existing health system





Strategic direction 2 – Develop and strengthen national BDs surveillance, monitoring and evaluation mechanisms

	Bangladesh	Bhutan	India	Maldives	Myanmar	Nepal	Sri Lanka	Thailand
<p>2.1 Establish and strengthen national BDs surveillance mechanisms:</p> <p>E.g.</p> <ul style="list-style-type: none"> • Hospital-based • Include in MIS • Include in DHS/MICS/Special surveys 	<ul style="list-style-type: none"> • Exist/ will be expanded • Integrated HMIS (DHIS 2) • Will start discussion 	<p>Draft surveillance plan (September 2014)</p>	<p>Expanding the existing hospital-based surveillance in the existing sites (Delhi, Chandigarh, Punjab, Jammu, Himachal, Haryana, Wardha)</p> <p>Inclusion in MIS simultaneously if available</p> <p>Integrating community based</p>	<p>Include 3 more hospitals ADK, HDh RH, S RH</p>	<ul style="list-style-type: none"> • Already planned for TOT on BDS tentatively in July • Hospital based • Included in HMIS 	<ul style="list-style-type: none"> • Strengthen monitoring of the NNPD of the existing hospitals (monitoring visits, review meetings) • Include Bheri, Janakpur, Seti, Lumbini Zonal hospitals in the Network • MPDR integration for BD surveillance 	<p>Scale up the hospital based BD surveillance into Western Province</p>	<ul style="list-style-type: none"> • Hospital-based
<p>2.2 Monitor, evaluate and report on the performance of surveillance mechanisms</p>	<p>M&E – in progress</p>	<p>Form national level CHAG with defined roles and responsibilities (December 2014)</p>	<p>Timely reporting, quality assurance, timely feedback.</p> <p>Try to form monitoring team</p>	<p>Case-by-case evaluation by paediatrician in charge</p>		<p>Periodic review meetings</p>	<p>Pilot Southern Province one year complete by end Oct 2015. Review and report</p>	<p>M&E Annual report</p>

	Bangladesh	Bhutan	India	Maldives	Myanmar	Nepal	Sri Lanka	Thailand
2.3 Monitor, evaluate and report on the effectiveness of BD prevention activities		TWG with focal points from surveillance, HOD JD Lead develop SOP, guidelines and reporting form (December 2014)	Annual evaluation of data generated from the existing sites To build specific preventive strategy	Active data collection in IGMH Get permission of MOH to use WHO SEARO database for BD			Identify and develop and impact and outcome indicators for evaluation	DH prevention programme <ul style="list-style-type: none"> • Down syndrome • Thalassemia • Hypothyroid • Maternal DM&teen-age pregnancy • Vaccination

Strategic direction 3.2 – Integration of food fortification and supplementation in the national nutrition programmes for micronutrients

	Bangladesh	Bhutan	India	Maldives	Myanmar	Nepal	Sri Lanka	Thailand
Situation analysis of anaemia and BDs	Will review	<ul style="list-style-type: none"> • Strengthen iodine fortification • Conduct advocacy for folic acid and iron fortification • Strengthen folic acid and iron supplementation for adolescents 	End of august 2015	Survey UNICEF	<ul style="list-style-type: none"> • USI nation wide • Home fortification in some tsp • Prep. for introduction of rice fortification 	Evidence analysis Programme reviews	No fortification available except salt	Existing (multi cluster survey)





	Bangladesh	Bhutan	India	Maldives	Myanmar	Nepal	Sri Lanka	Thailand
Advocacy	Exist (coordinated with NNS)		Ongoing	Meeting with minister and DGHS	Done	Policy advocacy and fact sharing		Yes, by DH
National consultation			End of august 2015	Assess the quality of fortified food types imported and available in the country- MFDA and trade- To include in Food Act	Regular mtg on TWG & focal team for RF	Stakeholder meeting	National consultation and decide on policy	Yes, by DH
Develop guidelines / standards	Exist				Already developed	Review existing guidelines	Would be decided following policy decision	Yes, by DH
Develop strategy and plan	Exist				Done	Discuss	-	Yes, by DH
Implement and monitor	Exist				Since last qtr		-	Yes, by DH
Evaluation	Exist						-	Yes, by DH

Strategic direction 4 – Expand and strengthen national capacity for implementation of BDs prevention and control programmes

	Bangladesh	Bhutan	India	Maldives	Myanmar	Nepal	Sri Lanka	Thailand
4.1 Improve national capacity for BD surveillance, monitoring, evaluation	Will plan	Training on surveillance	Ongoing and regular consultation. Plan to identify National and Regional Resource centre	Participate in training the trainers workshop. Train a doctor, nurse and tech staff from each 3 hospitals IGMH to have separate office with staff for data handling	TOT & multiplier training on BD Surv. in 19 hospitals	TOT, Refresher training, On-site coaching for NNPD HIMIS strengthening meetings and workshop Online resource centre	Train regional teams	Integrate to the existing national health database
4.2 Improve capacity for management of BDs	Will plan	Develop a monitoring mechanism	Mapping of the services both at National and regional centre under RBSK	Strengthen physiotherapy		Orientation for referral hospitals on the national plan on BDs	Train regional teams and include in PG curriculum	Set up center for management of BDs Personal training
4.3 Improve national capacity for diagnostics / laboratories	Will plan	Paediatricians/ OBGYN training	Strengthening and developing lab in DEIC	IGMH lab for screening CH, G6PD Include private hospital - ADK		Consultation with Curative Division, National Public Health Lab: focus on thalassaemia screening and genetic analysis Situation analysis of labs in Nepal		Set up centre for diagnostics/ laboratories of BDs DMSC





Strategic direction 5 – Develop and expand national, regional and international multisectoral partnerships and networks to support BDs prevention and control programmes

	Bangladesh	Bhutan	India	Maldives	Myanmar	Nepal	Sri Lanka	Thailand
5.1 Increase the number of partners	Will plan + Explore + Start liaison	Development and technical partners (WHO, UNICEF, UNFPA, CDC)	Identify all academic centres both at National and regional levels	National and international (beautiful eyes, MTS, family court,)/(WHO, UNICEF, Food Fortification Initiative)	MNTN SUN Network Rice fortification WG	National stakeholders meeting. Partners and functions mapping	Regional professional organizations from the newly recruited areas to be added on	+ HITAP
5.2 Establish and expand networks of institutions	Exist + Explore for further expansion	National stakeholders (MOAF, GNHC, MOE, MOF, NSB, NGOs)	Ongoing	More hospitals	SUN Network Myanmar Nut. Technical Network	Meeting with partners and professional org.	Will be established regionally as per plan	Medical schools

Birth Defects (BD) have been recognized as an emerging cause of under-five morbidity and mortality. The World Health Assembly resolution WHA63.17 in May 2010 has prompted the collaborative efforts of WHO Regional Office for South-East Asia and CDC-USA to address Regional priorities on neonatal-perinatal health and BD.

Under the WHO-SEARO and CDC collaboration in the area of prevention of BD several landmarks have been achieved, including development of a regional strategic framework for prevention and control of BD and national plans on BD among nine countries from the Region. Rapid expansion of the South-East Asia regional network on surveillance for newborn morbidity, mortality and BD among the Member States is another product of this effort.

This Regional Programme Managers' Meeting on Prevention and Surveillance of BD was organized on 14–16 April 2015, in New Delhi, India, by the WHO South-East Asia Regional Office to review implementation of national action plans, share experiences and challenges in BD surveillance, share progress on implementation of integrated approaches and discuss the follow-up steps. This report presents the proceedings of this regional network meeting. The report would be useful for national governments and other stakeholders to take forward the agenda of prevention and control of birth defects in the South-East Asia Region.



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