Birth defects (BDs) are progressively contributing to a greater proportion of infant and childhood mortality. However, the burden of BDs in the SEA Region remains unknown because of the lack of national-level surveillance mechanism for birth defects. In the SEA Region it is planned to develop a BDs surveillance manual along with tools based on the experience with the global package developed by WHO, International Clearinghouse on Birth Defects and Surveillance and the US CDC for the developing countries. This regional workshop was organized by WHO-SEARO in collaboration with the US CDC to help participants understand the principles of surveillance of BDs. National programme managers from countries, and technical officers from WHO, UNICEF and the US CDC attended the workshop. The report provides the summary of proceedings of the workshop. In addition to learning about the BD surveillance principles, the participants also developed recommendations on BDs surveillance activities for Member States, as well as for WHO and the partner agencies.
Capacity Building for Birth Defects Surveillance in South-East Asia

Report of the Regional Workshop on Birth Defects Surveillance
Colombo, Sri Lanka, 10–13 April 2012
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<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ARI</td>
<td>Acute respiratory infection</td>
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<tr>
<td>BDR</td>
<td>Birth Defect Registry</td>
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<tr>
<td>BDRI</td>
<td>Birth Defect Registry of India</td>
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<tr>
<td>BD</td>
<td>Birth defect/s</td>
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<tr>
<td>CAH</td>
<td>Child and Adolescent Health unit of WHO</td>
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<tr>
<td>FAS</td>
<td>Foetal alcohol syndrome</td>
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<tr>
<td>FASD</td>
<td>Foetal alcohol spectrum disorder</td>
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<tr>
<td>FFI</td>
<td>Flour Fortification Initiative</td>
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<tr>
<td>GAIN</td>
<td>Global Alliance for Improved Nutrition</td>
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<tr>
<td>ICBDSR</td>
<td>International Clearinghouse on Birth Defects Surveillance and Research</td>
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<tr>
<td>ICD-10</td>
<td>International Classification of Diseases-10</td>
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<tr>
<td>IEC</td>
<td>Information, education and communication</td>
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<tr>
<td>IFA</td>
<td>Iron and folic acid</td>
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<tr>
<td>IUGR</td>
<td>Intrauterine growth retardation</td>
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<tr>
<td>MDG</td>
<td>Millennium Development Goal</td>
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<tr>
<td>MI</td>
<td>Micronutrient Initiative</td>
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<tr>
<td>MNCAH</td>
<td>Maternal, newborn, child and adolescent health</td>
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<tr>
<td>MNCH</td>
<td>Mother–newborn–child health</td>
</tr>
<tr>
<td>MRH</td>
<td>Maternal and reproductive health unit of WHO</td>
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<tr>
<td>NFS</td>
<td>Nutrition and food safety unit of WHO</td>
</tr>
<tr>
<td>OMIM</td>
<td>Online Mandelian Inheritance in Man</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>RCPCH</td>
<td>Royal College of Paediatrics and Child Health</td>
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<tr>
<td>RMNCAH</td>
<td>Reproductive, maternal, newborn, child and adolescent health</td>
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<tr>
<td>SEA</td>
<td>South-East Asia</td>
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<tr>
<td>SEARO</td>
<td>Regional Office for South-East Asia</td>
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<tr>
<td>SMART</td>
<td>Specific, measurable, actionable, realistic and time-bound</td>
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<td>US CDC</td>
<td>US Centers for Disease Control and Prevention</td>
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Executive summary

Birth defects (BDs) are progressively contributing to a greater proportion of infant and childhood mortality since the infectious causes are decreasing due to the extensive and successful use of immunization, control of diarrhoeal disorders and respiratory tract infections and improvement in healthcare services. The World Health Assembly adopted a resolution in May 2010 to address the prevention of BDs. The Child and Adolescent Health (CAH) unit of the Regional Office for South-East Asia (SEARO) has been collaborating with the US Centers for Disease Control and Prevention (US CDC) to pursue activities in this important area.

The burden of BDs in the SEA Region remains unknown because none of the Member States has a national-level surveillance mechanism for BDs. Although small hospital-based studies have been conducted in some Member States, at this stage national-level estimates are available only from the global March of Dimes Report, 2006. At the Regional Expert Group Meeting (December 2011) on the prevention of BDs, national experts highlighted the need for capacity-building in BDs surveillance in the countries to define the magnitude of the problem, as well as monitor the progress of BD programmes. CAH-SEARO has been working with the US CDC team to meet this need. Efforts are being made to develop a manual and tools for BDs surveillance on the basis of the experience with the global training package developed by WHO, International Clearinghouse on Birth Defects and Surveillance and US CDC for developing countries. It is hoped that this would help strengthen surveillance mechanisms, which, in turn, would aid in the understanding of the epidemiology of BDs, as well as monitor the progress of prevention programmes in the countries.

This regional workshop was organized to help the participants understand the principles of the surveillance of BDs, premature births, and other adverse reproductive outcomes and risk factors; understand various types of surveillance methods; familiarize the participants with the global training package on BDs surveillance; and discuss issues related to national adaptation while developing BD surveillance mechanisms.
The workshop was attended by 42 participants, including national programme managers from the countries’ ministries of health, and technical officers from WHO, UNICEF and the US CDC. The workshop was inaugurated by the acting Secretary, Ministry of Health, Government of Sri Lanka and the WHO Representative. The technical sessions were conducted through technical presentations, group work and hands-on exercises on the computer. The draft manual for BDs surveillance was used to conduct the sessions. The participants were requested to review the chapters of the manual and provide feedback to strengthen it.

The participants agreed that there is a need for better data and information on BDs in the countries of the SEA Region. The existing health information systems (Vital Registration System, Demographic and Health Surveys, Health Management Information System, etc.) need to be improved to integrate information on foetal deaths (including stillbirths) and BDs. The countries must define the primary purpose of the BD surveillance and prioritize selected BDs on the basis of epidemiology, their public health importance, their amenability to prevention and the system’s capacity. There was a consensus that externally visible, major BDs that are easy to diagnose at birth should be considered in the initial phase. Such BDs are like neural tube defects, for which an evidence-based, cost-effective preventive intervention exists in the form of fortification and supplementation with folic acid.

The participants also developed recommendations on BDs surveillance activities for the Member States, as well WHO and the partner agencies.
Background

There has been a significant decline in the infant and childhood mortality rates in most countries in the past two decades. This can be attributed primarily to the extensive and successful use of immunization, control of diarrhoeal disorders and respiratory tract infections, and improvement in healthcare services. As a result of these factors, BDs account for a greater proportion of the causes of infant and childhood mortality. Taking cognizance of the situation, WHO included BDs as an agenda item in the 125th, 126th and 127th Executive Board sessions and made important recommendations to the World Health Assembly and subsequently Resolution WHA 63.17 was adopted in May 2010 to address the prevention of BDs.

The CAH unit of WHO-SEARO has been collaborating with the US CDC and is working closely with other technical units [Maternal and Reproductive Health (MRH) and Nutrition and Food Safety (NFS)] in WHO-SEARO to develop a comprehensive approach for activities to be pursued in the Region in the area of BDs prevention and control. SEARO is also developing a regional strategy for the prevention and control of BDs to provide guidance to the Member States.

A situational analysis report is being developed on BDs in the Region. It has been observed that at present, there are no national-level BD surveillance mechanisms, such as BD registries, in any of the Member States. Therefore, the burden of BDs is largely unknown and one has to depend on the estimates developed by global experts, such as in the March of Dimes Report, 2006.
WHO and US CDC organized an Expert Group Meeting on the prevention and control of BDs in New Delhi, India from 13 to 15 December 2011. The national experts endorsed the need to develop strategies for the prevention and control of BDs. In addition, they highlighted the need for capacity-building in BDs surveillance in the countries to help define the magnitude of the problem and monitor the progress of BD programmes once implemented. This need was emphasized also at the Regional Programme Managers’ Meeting on the Prevention and Control of Birth Defects, convened in Bangkok, Thailand from 20 to 22 March 2012 by WHO-SEARO and CDC.

The Regional Workshop on Birth Defects Surveillance was organized to develop capacity for BDs surveillance in the SEA Region. WHO, International Clearinghouse on Birth Defects Surveillance and Research (ICBDSR) and CDC are collaborating on the development of a surveillance manual for low- and middle-resource countries. A training package consisting of the manual and training tools can help build capacity for surveillance globally. The draft manual was piloted in the workshop, and the participants reviewed it and provided feedback. On the basis of the participants’ feedback, the draft manual and training tools are being further revised, with the goal of having a final training package that can be adapted to the individual situations of the countries in the Region. The experience in the workshop and the training package on BDs surveillance would help develop surveillance mechanisms in the countries so that they can obtain accurate estimates of the prevalence of BDs, utilize this data to develop and implement prevention activities, and monitor the progress of these prevention activities.

Participants

The participants attending the workshop were drawn from the following categories:

- National nodal persons from the ministries of health
- Technical officers from WHO
- Technical officers from partner agencies such as US CDC, ICBDSR and UNICEF
- Experts from WHO Collaborating Centres and national institutions from Member States.
Objectives of the workshop

The specific objectives of the workshop were:

- To understand the principles of surveillance of BDs, premature births, and other adverse reproductive outcomes and risk factors;
- To understand various types of surveillance methods;
- To familiarize the participants with the global training package on BDs surveillance; and
- To discuss issues related to national adaptation while developing BD surveillance mechanisms.

The following tasks were also accomplished during the workshop.

- The participants gained an understanding of various types of surveillance methods.
- The participants were familiarized with the manual on BDs surveillance being developed by WHO, ICBDSR and US CDC in collaboration.
- There was discussion on issues related to national adaptation while developing BD surveillance mechanisms.
- The purpose and importance of public health surveillance of BDs were outlined.
- The participants identified select initial diagnoses of BDs eligible for monitoring.
They described common modifiable risk factors for BDs, together with selected primary prevention strategies.

The tools needed to ascertain and code identified BD cases were identified.

The processes for managing and analysing data were described.

The participants gained an understanding of how to calculate the prevalence of BDs.

The use of logic models for the planning and evaluation of a surveillance system was described.

The participants discussed how to present data to policy-makers.

The participants gained a better understanding of how to use data for the development of prevention campaigns and for policy/programme evaluation.

The task of identifying partnerships that can help build and sustain a surveillance system was discussed.
Summary of the proceedings

Day 1: 10 April 2012

Regional overview of birth defects
(Neena Raina, Regional Adviser, Child and Adolescent Health, WHO-SEARO)

Globally, 6% (8.1 million) of neonates are born with a BD of genetic or partially genetic origin. In addition, there are BDs of non-genetic origin, which may be caused by exposure to alcohol, smoking, rubella infection and other teratogenic agents. Globally, each year, 3.3 million babies die before the age of five years and 3.2 million are disabled because of BDs. According to the global report of March of Dimes on Birth Defects, the prevalence of BDs in South-East Asia ranges from 54.1 to 64.3 per 1000 live births.

In its resolution on BDs, the 63rd World Health Assembly expressed concern about the high number of stillbirths and neonatal deaths occurring worldwide, and the large contribution of neonatal mortality to under-five mortality. The resolution emphasized the importance of the prevention of BDs to achieve a reduction in stillbirth and neonatal mortality rates. The attainment of the Millennium
Development Goal 4, which refers to a reduction in child mortality, will require accelerated progress in reducing neonatal mortality, and the prevention and control of BDs is necessary for this.

The resolution urges the Member States to raise awareness among all the relevant stakeholders, including government officials, health professionals, civil society and the public, regarding the importance of BDs as a cause of child morbidity and mortality. Further, it calls upon them to set priorities, commit resources, and develop plans and activities for the integration of effective interventions (including comprehensive guidance, dissemination of information and generation of awareness to prevent BDs, and care for children with BDs into the existing maternal, reproductive and child health services and social welfare programmes. The resolution also urges Member States to record surveillance data on BDs as part of the national health information system, and to develop expertise on and build capacity in the prevention of BDs and care of children with BDs. It calls for the strengthening of research and studies on the aetiology, diagnosis and prevention of major BDs, as well as for the promotion of international cooperation in combating them. In addition, the resolution urges the Member States to promote the collection of data on the global burden of mortality and morbidity due to BDs, and to consider broadening the groups of congenital anomalies included in the revision of the International Statistical Classification of Diseases and Related Health Problems (tenth revision). It calls for support to the Member States in developing national plans for the implementation of effective interventions to prevent and control BDs within their national maternal, newborn and child health plan; in strengthening health systems and primary care, including improvement in the coverage of vaccinations, such as for measles and rubella, and food fortification strategies, for the prevention of BDs; and in promoting equitable access to such services. It recommends that the Member States should receive support for the development of the ethical and legal guidelines relevant to BDs.

Under-five and infant mortality in the SEA Region is gradually declining. The decline in post-neonatal mortality has been relatively faster because of programmes for the control of acute respiratory infection (ARI) and diarrhoea and due to a decrease in the incidence of vaccine-preventable diseases.
the SEA Region, neonatal mortality now accounts for about 52% of under-five mortality. Seven of the 11 countries in the SEA Region have either met the MDG 4 (the Maldives and Timor-Leste) or are on track for achieving it. India, DPR Korea, Myanmar and Sri Lanka are making slower progress. As child mortality declines, congenital anomalies account for a greater proportion of neonatal deaths, with the proportion caused by BDs already increasing or likely to increase. Hospital-based data from the SEA Region show that 22% of neonatal deaths were caused by congenital anomalies (Regional Neonatal-Perinatal Database).

The Member States of the SEA Region are already implementing useful programmes and initiatives that can contribute to the prevention of BDs. These include strong mother-newborn-child health (MNCH) programmes, established adolescent health programmes, family planning services, congenital syphilis elimination activities, iron/folic acid (IFA) supplementation programmes, iodine deficiency prevention programmes, strong Immunization programmes (rubella vaccination) and programmes for the prevention of noncommunicable diseases. Currently, the continuum of maternal, newborn, child and adolescent health (MNCAH) services aimed at achieving a reduction in neonatal and child mortality has very little to offer during the preconception phase. This can be changed by the integration of specific preconception package including interventions such as folic acid supplementation during adolescence and the periconceptional period, immunization against rubella, the prevention of noncommunicable diseases through healthy lifestyles, and counselling to make people aware of the risks of consanguinous marriages and pregnancy at an advanced maternal age. The interventions that can be reinforced and improved while offering antenatal care services relate to the prevention of the use of medications during the first trimester, syphilis screening, prevention of exposure to tobacco and alcohol, prevention and management of diabetes and obesity during pregnancy, and antenatal screening and prenatal tests for BDs. Recent initiatives in this direction include the introduction of the MMR or Rubella vaccines in several countries, development of information, education and communication (IEC) material on the prevention of BDs in Bhutan and Myanmar, and a weekly IFA supplementation programme for adolescents.
in India. However, there is lack of availability of a suitable formulation (2800 mcg) of folic acid for weekly supplementation for adolescents as recommended by WHO guidelines.

The Regional Office plans to advocate for BD surveillance and preventive strategies in the Region, mobilize resources, strengthen partnerships, develop a network of experts and institutions, develop a Regional Strategic Framework for the prevention and control of BDs, and develop capacity in the Member States. Progress has been made in this direction through the development of a Regional Situation Assessment on Birth Defects. A Regional Expert Group Meeting was held in New Delhi in December 2011 and a Regional Programme Managers’ meeting was convened in Bangkok in March 2012 to advocate for and discuss possible strategies for the prevention and control of BDs. The Regional Office is collaborating with US CDC and is developing partnerships with the countries’ ministries of health, and international partners such as ICBDSR, PHG Foundation, Global Alliance for Improved Nutrition (GAIN), Micronutrient Initiative (MI), Flour Fortification Initiative (FFI) and UNICEF. The proposed Regional Strategic Framework would include the following strategic directions:

1. Establish or strengthen national policies and programmes for the prevention and control of BDs
2. Develop and strengthen national BDs surveillance and evaluation mechanisms
3. Integrate BDs prevention strategies into the public health, nutrition and other relevant programmes
4. Expand and strengthen the national capacity for the formulation of policies, programmes, surveillance, and laboratory support for the prevention and control of BDs
5. Develop and expand national, regional and international multisectoral partnerships and networks to support programmes for the prevention and control of BDs.

The Regional Strategic Framework would promote the following key principles:

The prevention of BDs would contribute to the attainment of MDG 4 (and beyond), which is recognized in the Region as a public health priority, as there is a high number of preventable foetal, neonatal and infant deaths.
Data and information on BDs in the Region needs to be strengthened, given that insufficient surveillance and evaluation in this area impede effective and equitable actions.

Sustained advocacy is necessary to identify the resources required, as well as the partnerships and networks that are needed for supporting the prevention and control of BDs in the Region.

Emphasis should be placed on the implementation of cost-effective interventions for the prevention of selected high-priority BDs across relevant sectors.

The interventions would be integrated into the continuum of care currently being implemented by the Member States to improve reproductive, maternal, newborn, child and adolescent health (RMNCAH), as well as into other related programmes, such as those related to nutrition, immunization, noncommunicable diseases, tobacco and alcohol control.

The rapid implementation of an evidence-based strategy for food fortification and supplementation with folic acid should be ensured to prevent many neural tube defects.

The Regional Strategic Framework proposes to achieve a significant reduction of BDs to contribute to the attainment of MDG 4 and beyond, as well as to achieve a reduction of folic acid-preventable neural tube defects, the specific target being a reduction in the prevalence of folic acid-preventable neural tube defects by 50% in selected countries in five years.

**Introduction to draft Birth Defects Surveillance Manual (Csaba Siffel, US CDC)**

Recognizing the importance of monitoring and evaluation of programmes for the prevention of BDs, WHO, CDC and ICBDSR are developing a BDs surveillance manual for low- and middle-resource countries. BDs would eventually become the main cause of up to one-third of infant deaths, and would add to morbidity and the cost of health care. The manual emphasizes that one of the first steps in developing a BDs surveillance system is to define the BDs that will be included in the national surveillance system, and the need for differentiating between structural and functional defects,
and identifying the pattern (isolated, multiple, of known or unknown pattern or syndromes) of their occurrence. Dr Siffel said that about half of all BDs-associated infant deaths are due to neural tube defects and heart defects.* The risk factors for BDs can be identified through multiple lines of evidence. The frequency of exposure and population-attributable risk can be calculated by surveys. Targeting reduction in one malformation through decreased exposure to a modifiable risk factor can also have the collateral benefit of reducing other defects.

The manual is divided into six chapters. Each chapter deals with important issues related to surveillance of BDs. The issues covered are the science of surveillance, case ascertainment and the codification of BDs, preconception health, modifiable risk factors, data entry and analysis, and the communication of the findings of surveillance to different audiences and in different formats. The manual provides the structure for conducting training of the relevant staff in BDs surveillance in the countries.

Feedback on the Birth Defects Surveillance Manual

Over the four days of the workshop, the country participants reviewed each chapter of the draft manual and gave their feedback chapter by chapter. The suggestions ranged from better organization of the contents of a particular chapter to rationalization of the emphasis on selected BDs (e.g. congenital heart defects) which are unlikely to be included in the initial BDs surveillance programme. The feedback is being used to strengthen the manual for subsequent training.

Birth defects: Overview and modifiable risk factors
(Csaba Siffel, US CDC; presentation prepared by Lorenzo Botto, ICBDSR)

The term ‘birth defect’ is defined as an abnormality in structure or function, present at birth, which has medical, social or cosmetic consequences for the affected person. The term connotes a wide range of conditions, which might include structural malformations, inborn errors of metabolism (e.g. phenylketonuria), single-gene disorders (thalassaemia), developmental

disabilities, intrauterine growth retardation (IUGR) and prematurity. The focus of the workshop was on major and structural BDs.

Three birth conditions, namely BDs, pre-term birth/IUGR and birth asphyxia, account for 25%-55% of under-five mortality in South-East Asia, and share many risk factors. As under-five mortality decreases, the fraction of mortality due to BDs would increase. Eventually, in every country in South-East Asia, BDs will account for more than 30% of infant deaths, become the leading cause of paediatric hospitalizations, and become the leading contributor to high healthcare costs (chronic care). As survival of persons with BDs improves owing to availability of required services, their contribution to long-term disability would proportionately increase. There is a real potential for primary prevention of select BDs - about half of all infant deaths due to neural tube and heart defects are preventable.

For a BDs surveillance programme, the definition of BDs must be explicit and operational. Surveillance and prevention programmes usually prioritize major structural anomalies which present at birth, and which have significant medical, social or cosmetic consequences that require medical intervention. Most structural BDs are malformations. They occur early in gestation and, therefore, have key implications for prevention. Minor BDs do not have serious medical and/or social consequences and usually do not require treatment. They may be useful clinically as clues for the diagnosis of syndromes and could be helpful in surveillance in combination with major anomalies. However, there is a variability and inconsistency of reporting of major and minor BDs as in the case of pre-auricular tags, certain types of polydactyly and ankyloglossia. Therefore, it is essential to define minor defects operationally before listing them for surveillance.

Birth defects may be isolated or multiple, and the pattern or syndrome may be unknown or recognized. An isolated BD may be one major defect, such as spina bifida, or a sequence of multiple BDs resulting from a single primary malformation, such as spina bifida and clubfeet. For a surveillance programme, the classification of
BDs into single BDs, multiple BDs or BDs that are part of a syndrome depends on the availability of detailed clinical information, as well as expert review. Therefore, it is crucial to get high-quality detailed primary data at the time of capturing a particular case of BD so that a review can be made at a later date, if required.

The identification of modifiable risk factors related to BDs is important for a surveillance programme. Risk factors may be associated with many significant outcomes. The prevention of BDs requires the mitigation of risk factors (e.g. diabetes, infections, smoking, alcohol intake) and the promotion of protective factors (e.g. healthy eating, folic acid fortification, physical activity).

Prevention activities are based on gathering evidence from multiple sources. The risk factors to be targeted are chosen on the basis of the magnitude of the risk, severity of the associated BDs, frequency of exposure, range of outcomes and effectiveness of interventions. The important interventions include rubella vaccination, control of diabetes and obesity, and cessation of smoking. Population-wide strategies (e.g. fortification) can have a rapid and sustained impact that touches the entire population.

The participants discussed the increasing prevalence of obesity and diabetes in the countries of South-East Asia. It was also felt that undernutrition remains more common among pregnant women in this part of the world than other parts and, along with deficiency of micronutrients such as folic acid, may contribute to an increased prevalence of BDs.

**Purpose and objectives of birth defects surveillance**

*(Diana Valencia, Consultant; presentation prepared by Lorenzo Botto, ICBDSR)*

Public health surveillance is an ongoing and systematic collection, analysis and interpretation of health data for the planning, implementation and evaluation of public health practices. Other data systems like monitoring (assessing
progress and bottlenecks), tracking (staying informed), registry (collection and storage of data) and health surveys (usually a one-time or infrequent event) have some things in common with public health surveillance, but do not have all the elements. Among the actions outlined by the Member States in the World Health Assembly Resolutions are the development and strengthening of surveillance systems for BDs. A surveillance programme is the key to the implementation of other programme activities, like raising public and policy awareness, increasing the coverage of effective prevention interventions, strengthening research on the aetiology, diagnosis and prevention of major BDs, and promoting international cooperation.

In the short term, BDs surveillance aids in the detection of sudden outbreaks (e.g. thalidomide tragedy, environmental disasters) and provides a safety net. In the long term it gives an estimate of the chronic burden of disease (e.g. neural tube defects and their relationship with folic acid; oro-facial clefts and their relationship with smoking) and provides information for evaluation of prevention programmes on their success or failure.

When planning for a surveillance programme, one has to start by defining clear objectives and priorities. The sustainability of the programme can be improved by identifying stakeholders, ensuring the availability of resources and making detailed plans for implementation. The quality and value of surveillance can be improved by ensuring that the information collected is reliable, up to date and relevant.

The purpose of BD surveillance is multifold and includes monitoring the trends, clustering and spatial variations; linking individual cases to health services; serving as a case registry for case–control studies of possible risk or protective factors; serving as a case registry for studies of outcomes (e.g. survival, development); evaluating the impact of prevention interventions (i.e. primary and secondary); and designing activities for education, advocacy and health promotion.
Ms Valencia emphasized that surveillance and prevention programmes offer useful opportunities for addressing unacceptable occurrences of preventable disease, disability, and death, ensuring ‘what we know’ actually works and avoiding funding interventions with minimal or no value added for patient or population.

The first step in a surveillance programme for BDs is to identify goals focusing on public health problems and to frame specific, measurable, actionable, realistic and time-bound (SMART) objectives. The subsequent steps include identifying the source area and population, defining information needs and developing the process of obtaining accurate data on a timely and ongoing basis. Sampling of a target population can be through hospital- or population-based programmes. Information about the population can be obtained through active, passive or hybrid surveillance.

Population-based surveillance programmes have the advantage of including all resident births, regardless of whether they are in hospitals or not. This is especially useful in countries with many home births. Such programmes allow for the inclusion of conditions diagnosed beyond the neonatal period and make it possible to generate accurate estimates of prevalence. As such, when surveillance covers the whole population, it is easier to generalize the findings. Such surveillance is useful for documenting the presence of a problem and evaluating the impact of an intervention on a population. However, it is resource-intensive, takes more time to establish and requires more extensive protocols. As limited resources may need to be spread over a larger area with a greater workload, it may be challenging to maintain high-quality data consistently.

Hospital-based surveillance programmes include cases and births from select hospitals in a defined area. They are less resource-intensive and more efficient, especially if most of the births are occurring in hospitals. However, the prevalence is under-reported as some BDs are detected late, after the neonatal period. One must also beware of referral patterns and the resultant bias, and the lack of representativeness of the findings. As a hospital-based surveillance programme requires fewer resources, it can be started quickly.
It can generate high-quality data, typically from highly motivated clinicians and hospitals. It is also useful when trying to establish (approximate) baseline data for the documentation of the fact that a problem exists, and for alerting health and government officials to the need for investing further in surveillance. Hospital-based surveillance is more useful when most births occur in hospitals. The estimates of prevalence are limited to the population born in hospitals. Besides, the participation of hospitals can change over time, making the interpretation of the findings and trends difficult. The estimates of prevalence may also be unreliable because the referral pattern in the area may be variable and difficult to estimate. In addition, selection bias can make extrapolation to the entire population uncertain. The data may be unreliable for evaluating the impact of an intervention on the underlying, wider population.

The participants discussed various options for designing a BDs surveillance programme in their respective countries. It was felt that in most of the countries in South-East Asia, a hospital-based programme using passive case ascertainment is the way forward in the initial phase. Initially, hospitals or centres with champions (leaders) in the field of the prevention, diagnosis and control of BDs should be enrolled.

**Approaches to surveillance**  
(Diana Valencia, Consultant)

Further details of surveillance options were discussed in this session. The availability of potential partners and the identification of their roles, as well as supportive policy for BDs surveillance, are extremely helpful. Putting the required legislation for surveillance in place, whether mandatory or voluntary, is also useful.

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**Methodological Approaches for Birth Defects Surveillance**

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<tr>
<th>Coverage</th>
<th>Case Ascertainment</th>
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<td>Population-based</td>
<td>Active</td>
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<tr>
<td>Hospital-based</td>
<td>Passive</td>
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</table>
In the active case ascertainment method, trained data abstractors review multiple data sources for case-finding, abstract information from various records and enhance case ascertainment. Active case ascertainment, though resource-intensive, improves the rate of case detection. In passive case ascertainment, personnel submit case reports from data source locations. Passive case detection requires fewer resources and is dependent on voluntary reporting by hospital personnel. No follow-up visits are made to verify the information obtained from hospitals. Due to the nature of data collection in the passive method, there are chances of missing cases and non-verification.

One may go about case-finding by using a single source of data or multiple sources; using different pregnancy outcomes: live births only or including stillbirths and pregnancy terminations; and using different age groups (at birth only, at discharge or up to 1 year of age). Using a single-data source is less time-consuming since there is less data. Using multiple data sources, although time-consuming, ensures improved case ascertainment and better quality of data.

Case inclusion in a surveillance programme may include all types of BDs or only selected (pre-defined) ones. Those BDs that are selected initially may include externally visible defects, such as neural tube defects, orofacial clefts, limb deficiencies, talipes equinovarus and gastroschisis, or may target pre-specified malformations of public health or clinical importance. The description of BDs could be obtained by recording verbal information or by using standard checklists (checkboxes). Data once collected needs to be coded according to the standard ICD classification or locally developed classification systems. Depending on their capacity, countries in the SEA Region must identify a surveillance method suitable to their individual requirements. No one system will be perfect for all situations.

**Country examples of birth defects surveillance**

*(Country participants)*

India and Thailand shared their early experience with the development of BDs registries.
India

The Foetal Care Research Foundation instituted the Birth Defect Registry of India (BDRI) in 2001 to document the incidence of congenital anomalies among the Indian population. At present, the BDRI covers more than 650 hospitals across 27 states and has collected data from more than 0.9 million births over the past 10 years. This hospital-based voluntary registry collects data from live births, stillbirths and medical terminations of pregnancy. It uses the passive surveillance methodology for the detection of only structural malformations from the antenatal period to 1 year of age, and the malformations are classified according to the ICD-10 coding system.

A group of hospitals willing to report data from a region—a village, town, city or zones of a city—may collaboratively form a registry under a nodal hospital and furnish data to the BDRI. According to the data collected by the BDRI over the past 10 years, the prevalence of BDs ranges from 84.2 to 137.3 per 10000 births. CNS defects have been found to be the most common (32%) and of these, 80% are neural tube defects. There are some inherent limitations in the BDRI. Data collection from different centers is not uniform, with the reporting rate of some centers being much higher. The data also indicate that major BDs are over-represented, with minor BDs not being given adequate importance. There is a need to adopt a hybrid case ascertainment method, which would require additional resources. Among the other measures that would help are online submission of data, the participation of government hospitals, and the use of mobile phone technology for on-the-spot reporting and uniformity of approach. The interest of the participating units must also be sustained.

Thailand

The working group for the Thailand Birth Defect Registry (BDR) was constituted in 2008. The first National Forum on Birth Defects and Disabilities was organized in July 2009 and was attended by 200 participants. A proposal for a Thai BDR was placed before the national Thai Health Fund, which
suggested formulating a national plan for the prevention and care of BDs in Thailand.

As a result, a strategic roadmap with a master plan was drawn up and the Birth Defects Registry of Thailand was launched to detect five main disorders: trisomy 21, neural tube defects, cleft lip and palate, limb anomalies and Duchenne muscular dystrophy. A map has been prepared for the prevention, detection and control of these BDs at the primary, secondary and medical college levels. Thailand now plans to establish a national BD registry by 2014 for the early diagnosis, prevention and treatment of BDs, and to provide appropriate and accessible holistic health care. Birth defects will be identified by linking the online birth registration system with insurance data collected by the National Health Security Organization. Coding would be as per ICD 10. The process has been led by the Queen Sirikit National Institute of Child Health on behalf of the Department of Medical Services, Ministry of Public Health, in collaboration with the Birth Defects Association (Thailand) and university hospitals.

**Group work activity**

Group work activity on case ascertainment was conducted by facilitators. The participants learned the methodology described in the BDs manual.

**Day 2**

**Selection of birth defects for surveillance**

*(Cynthia Moore, NCBDD, US CDC)*

Birth defects are most commonly defined as an abnormal change in structure (such as cleft lip, spina bifida) that develops before birth and is present at the time of birth. Established surveillance systems for BDs usually collect information on chromosomal or other genetic disorders (such as Down syndrome). Functional and developmental disorders (such as hearing loss, sickle cell disease and cerebral palsy) may also be classified as BDs.
Major BDs are structural changes that have significant medical, social or cosmetic consequences for the affected individual (such as microtia or small, malformed ear). Minor BDs are structural changes which pose no significant health problem and tend to have limited social or cosmetic consequences for the affected individual (such as ear tags).

External BDs can be readily identified as anomalies without extensive training and can be reported in a variety of ways (such as specific diagnosis, description, code and photograph). The diagnosis of internal BDs requires expertise in clinical examination and diagnostic studies. In the absence of prenatal imaging or an autopsy/pathology examination, BDs in stillbirths and terminated pregnancies may be under-reported.

The criteria for the selection of BDs for inclusion in a surveillance programme include ease of identification and public health impact. A BD may be considered as of public health importance if its prevalence is high or increasing, the prevalence of its risk factors is high or increasing, it is severe, its management entails a high cost, a low-cost prevention intervention is available or the risk factors are modifiable. Birth defects which may initially be selected for surveillance include neural tube defects, oro-facial clefts, club feet, limb deficiencies, and gastroschisis and selected congenital heart defects (hypoplastic left heart syndrome, transposition of great arteries and tetralogy of Fallot). However, congenital heart defects are much harder to detect if trained personnel and medical technology are not available on site.

Neural tube defects are among the most common BDs, affecting approximately 300 000 births per year worldwide. These are severe abnormalities of the brain and spinal cord, resulting from failure of closure of the neural tube, which normally closes by the 28th day of gestation. The most common types of neural tube defects are anencephaly, spina bifida and encephalocele. Rarer types of neural tube defects (craniorachisdis, encephalophy) seem to be more common in areas with a higher prevalence of BDs. Folic acid significantly reduces the risk of neural tube defects. The risk factors include obesity, diabetes and certain medications. Anencephaly is characterized by either total or partial absence of the brain, together with total or partial absence of the cranial vault and the covering skin. Most cases
are stillborn, although some infants survive for a few hours or even days. Spina bifida is a general term used to describe a congenital defect of the spine caused by a failure of closure of the posterior elements of the vertebrae, resulting in exposure of the meninges with or without associated spinal cord herniation. Hydrocephalus is a common complication, especially among children with meningomyelocele. Meningocele is herniation of the meninges due to a spine defect, resulting in the formation of a cyst filled with cerebrospinal fluid. The cyst does not contain spinal cord, but may have some nerve elements.

Meningomyelocele is the most common type of spina bifida. It is characterized by the protrusion of the meninges and the spinal cord through a posterior opening in the vertebral column, and is most frequently located in the lumbosacral area. Myelocoele or myeloschisis (rachischisis) refers to an open spinal cord, covered by a thin membrane, which protrudes through a defect in the vertebral column. Spina bifida is characterized by anatomic level of lesion, whether open or closed, and the presence of hydrocephalus. These characteristics also have an impact on the extent of neurological deficit. Level of lesion is classified as per the highest level of the defect in the vertebral column. It may extend beyond the visible defect. Spina bifida is classified as closed or open depending on the presence or absence of normal skin covering. Lesions with membrane covering are considered open. Hydrocephalus is seen in most children with open spina bifida.

Craniorachischisis is characterized by the presence of anencephaly with a contiguous spine defect and with the meninges not covering the neural tissue (rachischisis). It may be limited to the cervical region or affect the entire spine and may be accompanied by spinal retroflexion. It should be coded as one defect—not anencephaly and spina bifida. Encephalocele is a pedunculated or sessile cystic lesion protruding through a defect in the skull. It may contain herniated meninges and brain tissue (encephalocele or meningoencephalocele) or only meninges. It is most frequently located in the occipital area. Among children in South-East Asia, the most common location is the anterior region (frontal or nasofrontal). Iniencephaly is a rare and complex neural tube defect involving the occiput, resulting in extreme
retroflexion of the head, variably combined with occipital encephalocele or rachischisis of the cervical and thoracic spine. Closed cranium helps differentiate iniencephaly from craniorachischisis with spinal retroflexion. Multiple neural tube defects are multiple noncontiguous neural tube defects. While reporting such defects, all the lesions should be coded separately and defects in each neural tube defect category should be counted. Infant is counted only once even if there are more than one NTDs in that baby.

Cleft lip with or without cleft palate and cleft palate are collectively referred to as oro-facial clefts. Most clefts can be successfully closed with surgery; however, there is a potential risk in terms of cognitive and psychomotor development. Clefts are about 1.5 times more prevalent in Asian populations. There is evidence that tobacco use during early pregnancy increases the risk, particularly of cleft lip and palate. Periconceptional folic acid may decrease the risk of cleft palate. Cleft palate is characterized by an incomplete fusion of the palatal shelves (secondary palate) and may affect the hard and/or the soft palate. It is more likely to be underascertained than cleft lip and palate. Cleft lip with or without cleft palate is characterized by partial or complete upper lip clefting. Such cases account for 70%-80% of all oro-facial clefts. Cleft lip with or without cleft palate is more commonly unilateral than bilateral. Cleft lip with cleft of the primary palate (anterior to the incisive foramen) is coded as cleft lip alone.

Clubfoot is a term used by many to describe several kinds of ankle or foot anomalies present at birth. It is often used as a synonym for talipes equinovarus, the most common true type of congenital clubfoot, occurring in 95% of all cases of clubfoot. It affects approximately 1 in 1000 live births and is bilateral in approximately 50% of cases. It often accompanies neural tube defects, especially spina bifida. Smoking is associated with an increased risk of clubfoot, for which nonsurgical treatment is available.

Gastroschisis is a BD of the anterior abdominal wall, lateral to the umbilicus. It is characterized by herniation of the small and part of the large intestines, and occasionally other abdominal organs, into the amniotic cavity. Herniated organs lack a protective membrane. It usually occurs to the right of the umbilicus, sometimes with a small bridge of skin separating the defect from the umbilicus. The prevalence of gastroschisis at birth is increasing worldwide. The severity varies greatly. Most such defects can be closed successfully with surgery. Gastroschisis is associated with an increased risk of intrauterine growth restriction, foetal death and pre-term birth. A low
maternal BMI increases the risk of gastroschisis, which also has a strong link to young maternal age. Ruptured omphalocoeles are often mistaken for gastroschisis. However, the two defects have very different clinical and epidemiological characteristics.

Limb deficiencies are defects of limb development that are characterized by total or partial absence or different degrees of hypoplasia of the skeletal structures of the limbs. Limb deficiencies are classified into three large groups: longitudinal, transverse and intercalary. Limb deficiencies have been associated with maternal exposure to thalidomide (intercalary), chorionic villus sampling (transverse), misoprostol (transverse) and valproic acid (longitudinal), and are also linked to obesity (combined), among other things. The use of multivitamins is protective. A longitudinal limb deficiency is the partial absence of a limb along the long axis of the limb. These deficiencies typically involve specific components of the limbs and can be pre-axial (first ray: thumb/radius in the arm(s), or first toe/tibia in the leg[s]), post-axial (fifth ray: fifth finger/ulna in the arm(s), fifth toe/fibula in the leg[s]), or involving central components (typically, third/fourth rays in hands/feet, also called split hand/split foot). A transverse limb deficiency is the complete or partial absence of the distal structures of a limb in a transverse plane at the point where the deficiency begins, with the proximal structures being essentially intact. These deficiencies are also known as congenital amputations. An intercalary limb deficiency is the complete or partial absence of the proximal or middle segment(s) of a limb, with all or part of the distal segment present. These deficiencies are also known as phocomelia. Amniotic band sequence refers to BDs caused by the entrapment of foetal parts (usually a limb or digits) in fibrous amniotic bands while in the uterus. These are also called congenital constriction bands and the resultant limb deficiency may be difficult to distinguish from transverse limb deficiencies.

Hypoplastic left heart is a rare congenital heart defect, in which the left side of the heart is severely underdeveloped and consequently, the left-sided heart structures (i.e. the left ventricle, mitral and aortic valves, and ascending and descending portions of the aorta) are either not formed or are underdeveloped and small. In the transposition of the great vessels, the origin of the aorta and the pulmonary artery (“great arteries”) is switched (“transposed”)—the aorta arises from the right ventricle and the pulmonary artery from the left ventricle. Tetralogy of Fallot is the most common cyanotic heart defect, which includes the simultaneous occurrence of ventricular septal defect, stenosis of the pulmonary valve or just beneath it (infundibular
stenosis), or pulmonary atresia, hypertrophy of the right ventricle and
dextraposition of the aorta.

Photographs/videotapes may serve as a field atlas to aid the identification
and reporting of external BDs. The field atlas may contain a written
description of the BD, photographs showing preferred views, instructions
for reporting features (such as measurements) and other information.

Prenatal screening and diagnosis is a powerful tool for the identification
and control of BDs. However, BDs identified prenatally need to be confirmed
after birth. Birth defect surveillance programmes can use prenatal information
to improve care for affected newborns right at birth if required or later
during childhood.

The participants extensively discussed the types of BDs to be
incorporated in the programme. It was initially felt that congenital heart
defects should be included in surveillance since these are common and
some of them are easily treatable. However, it was later considered that
since a large number of congenital heart defects do not manifest by the time
the baby is discharged from the hospital, it would not be feasible to include
them in a hospital-based surveillance programme.

Some BDs can be of importance in specific regions of the countries,
e.g. thalassaemia in north India, sickle cell anaemia in central India and
hypothyroidism in the sub-Himalayan belt. However, since these are
functional defects and their manifestations are not apparent at birth, their
inclusion in BD surveillance at this stage would be difficult. Moreover, the
infrastructure required for diagnosing functional BDs such as thalassaemia
is altogether different and a different approach is needed for surveillance,
screening, testing and management. The participants also felt that
omphalocele is more common than gastrochisis in South-East Asia and,
therefore, should be considered for surveillance.

**Classification and coding of birth defects**
(Csaba Siffel, NCBDD, US CDC)

The classification of BDs is important to (i) facilitate recording in a
standardized and efficient way, (ii) aid treatment and prognosis, (iii) identify
the magnitude and trend of the problem, and (iv) understand the pathology
and underlying cause(s). Birth defects can be classified into major and minor.
Minor BDs have limited social or cosmetic consequences, and may or may
not require medical intervention. They may be objective (e.g. ear tag) or subjective (e.g. low-set ears).

At the start of a surveillance programme, information may not be collected about minor BDs. Birth defects may also be classified as external (visible on body surface) or internal (requiring imaging or specialized procedures). A detailed description of BDs helps to specify their characteristics and allows the reviewer to verify and classify. Taking photographs or making a video recording is relatively easy, not very expensive and supplements the clinical description. However, training is required to obtain the correct view and the information captured may be incomplete. Besides, confidentiality issues may be involved. The collection and coding of cases in a standardized manner helps in efficient data management. Coding allows for accurate and consistent classification. The classification system used by a BD surveillance system should correspond with the focus of the system and the resources available. The classification should ideally include both the code and a description, and should mention the certainty of diagnosis and the completeness of work-up. The ICD-10, developed by WHO, is an alphanumeric coding system. It is available in 42 languages: six official languages of WHO (Arabic, Chinese, English, French, Russian, Spanish) and 36 other languages. The ICD-10 interactive self-learning tool is available for training purposes. The ICD serves as an international standard diagnostic coding system for all general epidemiological and health data management purposes, as well as for clinical use.

It is useful in the analysis and assessment of the health situation of population groups, and in monitoring the incidence and prevalence of diseases and other health problems. It has been used to code diseases in health records and vital records for the compilation of national mortality and morbidity statistics by WHO Member States. The ICD-10 classification includes a

<table>
<thead>
<tr>
<th>Why is Classification Important?</th>
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<tbody>
<tr>
<td>Allows a surveillance program to collect and classify cases with birth defects in a standardized way</td>
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<tr>
<td>Helps clinicians to address treatment and prognosis</td>
</tr>
<tr>
<td>Helps public health officials to understand the scope of the problem and trends for specific birth defects</td>
</tr>
<tr>
<td>Helps researchers to better understand the etiology, pathogenesis, and other aspects of birth defects</td>
</tr>
</tbody>
</table>

**International Classification of Diseases**

Tenth edition (ICD-10): widely used by many countries as a classification system for diseases
Developed and maintained by WHO

http://apps.who.int/classifications/icd10/browse/2010/en

Available in 42 languages
6 official languages of WHO (Arabic, Chinese, English, French, Russian, Spanish)
36 other languages
ICD-10 interactive self-learning tool is available for training purposes (WHO website)
section (chapter XVII) on BDs. Each defect should be coded separately. The classification of syndromes may be facilitated by the use of the Royal College of Paediatrics and Child Health (RCPCH) modification of ICD-10 or the Online Mandelian Inheritance in Man (OMIM) system in addition to the ICD-10 codes.

The participants discussed the need for on-site tools, such as mobile phone programmes, which can help in rapid identification for ICD classification at the time of filling the reporting forms.

**Group work activity**

The facilitators conducted group work activity to practise ICD coding of selected BDs on the basis of case scenarios. They sought clarifications on the use of the ICD codes, and became aware of the intricacies of and need for accurate coding.

**Data collection/management procedures**

(Diana Valencia, Consultant)

Laws and regulations provide mandates for establishing BD surveillance systems, and ensure that information on BDs is captured, analysed and disseminated on a regular and timely basis. When participation in surveillance is mandatory, the participating sites are required to keep a log and report babies identified with BDs. Hospitals are usually required to report information in a standard format. In voluntary surveillance systems, the participating sites can only be encouraged (since there is no legal requirement) to keep a log and report all babies identified with BDs. The surveillance system may request reports of cases in a uniform manner, but each participating site decides whether to participate, as well as how and when it will report. The existence of state legislation helps in timely, uniform collection of data and facilitates collection in a structured manner. It also eases access to data.

Inclusion criteria need to be defined before laying down the procedures for data collection:

<table>
<thead>
<tr>
<th>Why Having Legislation for Birth Defects Surveillance is Important</th>
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</table>
| **Voluntary**  
Participating sites are encouraged to keep a log and report all babies identified with birth defects. The Surveillance System may request report of cases in a uniform manner, but each participating site can decide whether, how and when they will report. |
| **Mandatory**  
Participating sites are required to keep a log and report babies identified with birth defects. Usually requires hospitals to report information in a standard format. |
e.g. live births or stillbirths after 28 weeks of gestation or babies weighing more than 1000 g at birth with the specified BDs and diagnosed at specific periods (antenatal confirmed at birth, at birth or up to a pre-specified age). They should specify the hospital where data are collected, the registration pattern followed by the hospital, the services available and the relation of the hospital with the smaller hospitals surrounding it. Exclusion criteria include newborns who do not have one of the selected major BDs, newborns born after less than 28 weeks of gestation (or weighing less than 1000 g at birth when the gestational age is not available), and all live births and cases of foetal death with BDs identified at nonparticipating hospital(s). Sample protocols help in standardizing data collection. The use of uniform coding and classification and uniform abstraction forms helps in standardization. Before beginning data collection, it may be useful to look at various hospital documents, such as log books and vital records, or to make a quick survey of routine data collection. Data collection tools have a series of maternal, paternal and infant variables in demographic and clinical domains.

Data collection forms may be paper-based, electronic or mobile phone-based. Each participating hospital should follow guidelines for data collection and reporting so that there are no duplicate cases, forms are completed and there is a detailed description of BDs. Photographs/videos are helpful when an experienced healthcare provider is not available. They also allow for later verification of diagnosis. Guidelines for photography/videos should be included in a pre-established protocol. Parental consent is often necessary. The verification of data at the regional/national level should ensure that there are no duplicate cases and no missing data, and that a unique identifier is assigned to each case and the data are entered into the system. The system ensures that the data are analysed systematically and in a timely manner, and that they are reliable and valid. Data management consists of developing procedures to protect information as well as designing and documenting office and field procedures. Abstraction forms should be kept in a safe place. Paper files should be kept in a locked cabinet. Electronic files should be password-protected. Access to forms and the database should be restricted to authorized personnel. Identifying information should be separated when
sharing data unless it is necessary for referrals. Data dissemination is the dissemination of useful information in a timely manner to those who need to know (i.e. end-users). It helps others to recognize the value of public health surveillance of BDs.

**Preconception health and health care**
*(Cynthia Moore, US CDC)*

Preconception health aims to promote the health of women of reproductive age before conception and thereby improve pregnancy-related outcomes. Early prenatal care is not enough for the prevention of BDs and in many cases, it is too late. The mean time at which women enter the perinatal care system is after the most susceptible time for the development of major malformations. The aim of promoting preconception health is to decrease BDs through primary prevention. The interventions available in the preconception period include giving protection (folic acid supplementation or rubella vaccination), managing health conditions (achieving good glycaemic control for diabetics, monitoring thyroid function and the use of medication for hypothyroidism, decreasing obesity), and avoiding teratogens (alcohol, smoking and the use of medication).

Folic acid supplementation significantly reduces the occurrence of neural tube defects. The US Public Health Service recommends the consumption of 400 micrograms of synthetic folic acid every day for the prevention of neural tube defects. More research is necessary to investigate the possible links between folic acid and the reduction of the risk of cleft lip/palate and heart defects. Rubella immunization provides protective sero-positivity to prevent the occurrence of congenital rubella syndrome. The MMR vaccine should be offered to all women who are of child-bearing age and do not have acceptable evidence of rubella immunity.

A threefold increase in BDs has been observed among infants of women who have type 1 or type 2 diabetes and who are not on treatment or among whom the disease is poorly controlled. Good glycaemic control should be achieved prior to pregnancy through nutrition management and medication.
Women who optimize glycaemic control prior to conception can lower the risk of having babies with BDs to close to the risk faced by the general population. Hypothyroidism increases the risk of intellectual disabilities in children. Women being treated for hypothyroidism should consult their doctor on the adjustments usually required in medication during pregnancy. All women should use iodized salt.

Obesity is associated with adverse outcomes such as neural tube defects, pre-term birth, Caesarian section, hypertension and thromboembolic disease. Optimal weight should be achieved before pregnancy.

Drinking alcohol during pregnancy can cause miscarriage and stillbirth, and also cause the child to suffer from a range of lifelong disorders, known as foetal alcohol spectrum disorders (FASDs). Therefore, the consumption of alcohol should be avoided during pregnancy. There is no known safe amount of alcohol, no safe time to drink, and no safe kind of alcohol to drink during pregnancy. Foetal alcohol syndrome (FAS) and other alcohol-related BDs can be prevented.

Some medications (such as thalidomide, anti-epileptics, retinoic acid and anti-coagulants) are known teratogens; alternate medications may be available. Women should talk to their doctor about their prescription medications before pregnancy so that any modifications can be planned in advance. Smoking is associated with adverse outcomes such as pre-term birth, low birth weight and some BDs, including cleft lip/palate and clubfoot. It is recommended that the pregnant woman avoids smoking or exposure to environmental tobacco smoke for her own health and that of the baby.

The discussion among the participants centred on the opportunities in their current health system to target women in the preconception period. The difficulty in the implementation of folic acid supplementation programmes aimed at adolescents, arising from the absence of a suitable formulation of folic acid, was discussed. Concern was also expressed about the difficulty in the fortification of food with folic acid as most cereals are purchased loose rather than as pre-packaged preparations which can be fortified like iodized salt. However, it was felt that snacks that are widely consumed, for example, biscuits, can be fortified with folic acid. Another idea was to ask girls to take folic acid as an ‘engagement pill’ once they are ready to marry. It was also recommended that religious leaders who conduct marriage ceremonies be involved in advising newly-wed couples to take preventive measures.
Opportunities in SEARO for preconception care
(Rajesh Mehta, WHO-SEARO)

The provision of reproductive, maternal, newborn and child health services over the life-cycle can ensure that all women and babies are healthy. However, there are gaps in the continuum of care for adolescent girls and women before and between pregnancies.

Preconception care is any preventive, promotive or curative healthcare intervention provided to women of child-bearing age in the period before pregnancy and between consecutive pregnancies, to improve health-related outcomes for women (regardless of their pregnancy status), newborns and children up to five years of age. The period before pregnancy has been divided into a proximal period and a distal period. The former is the period immediately preceding pregnancy (up to two years before conception), while the latter refers to adolescence or in general a longer time before pregnancy. Preconception health care plays an important role in preventing BDs. The target group for preconception care includes adolescent girls, women, couples who wish to have a child, adolescent boys and men. The latter also display behaviours and have health problems and risk factors that contribute to maternal and child morbidity and mortality. Engaging them will increase the well-being of women and children.

Periconception care is any preventive, promotive or curative healthcare intervention provided to women of child-bearing age preceding, during and immediately following conception to improve health-related outcomes for women, newborns and children up to five years of age. Such care is given from three months before pregnancy to up to the first trimester.
According to the Systematic Review by the Aga Khan University, interventions can be divided, depending on the level of evidence available, into those which are ready to be implemented (e.g. birth spacing, prevention of adolescent pregnancy, diabetes screening and control, folic acid supplementation), those which need more evidence (prevention of alcohol consumption and smoking) and those which are not backed by evidence.

Many of these interventions can be provided in packages. The intervention packages can be delivered at health facilities as outreach activities and as simple family communication. Some of these health intervention packages may have the collateral benefit of reducing the rate of low birth weight and prematurity. Other means of delivering elements of preconception packages include youth development programmes, adolescent health programmes, workplace programmes and food fortification programmes. Support groups for individuals with a particular risk and for high-risk couples and women, including those who have experienced a poor outcome previously, may also offer an opportunity to deliver such packages. Most countries in South-East Asia have developed adolescent health programmes that provide an opportunity to provide pre-conception care package.

Day 3

Data analysis (Jorge Rosenthal, US CDC)

It is necessary to analyse the data collected during surveillance to know the birth prevalence of specific BDs, description of data with respect to time, place and person, and to identify patterns or trends and their association with risk factors. Before data analysis is started, one needs to assess the quality of the data by considering the quality control processes, as well as the accuracy and completeness of the data. The quality control process includes reviewing sources of information for case ascertainment, clinical reviews, checking multiple sources of data, validity audits, reviewing medical records and identifying coding issues. The validity of data is checked by looking out for missing values, logical errors, duplication of cases, errors in diagnosis and biases related to the lack of representation. The last arises if the data only pertain to, for example, very severe cases, urban cases or private sector sources.
Birth prevalence of BDs is a measure of the total number of the existing cases of BDs at a given point in time or during a period or in a given population. The preferred indicator is population-based birth prevalence. Incidence is a measure of all new cases of BDs in a given population and within a given time-frame. It is impossible to measure as one would need to ascertain all new cases (live births, and embryonic and foetal deaths).

The recommended measure of the occurrence of BDs is prevalence measured as:

\[
\frac{\text{Number of live births and foetal deaths (stillbirths) with a BD in a particular catchment area in a given year}}{\text{Number of live births in the catchment area during the same year}} \times 1000
\]

Measuring the birth prevalence helps to ascertain the occurrence with respect to person, place and time. During the presentation, examples were provided to show differences in the occurrence of BDs by person, place and time. In addition, an example was provided of how the enumeration of cases alone does not help to explain differences in the occurrence of and how birth prevalence facilitates an appropriate comparison of such differences by person, place or time.

Data analysis is a prerequisite for the dissemination of data in a timely and manner.

**Group work activity**

The participants practised entering data in Epi-Info and then analysed it to estimate the prevalence of BDs and the association with risk factors. The facilitators provided the participants with guidance in a step-by-step manner. The participants were able to familiarize themselves with the Epi-info package.

**Logic model for planning and evaluation**

(Diana Valencia)

A logic model is a graphic representation of how a programme works and is helpful in the construction of a roadmap for a surveillance programme.
Logic models provide an overview of the activities required, the order of activities, and how outcomes are achieved. They are used throughout the stages of planning, implementing and evaluating the project. A logic model can be simple, complex or intermediate and in linear, round or columnar shape. It takes into account the resources/input, activities, output, outcomes and impact. Defining a logic model has several benefits. It helps in the early identification of problems/gaps in planning and implementation, enables reaching a consensus on planned activities, and in achieving clarity on smaller implementation components and in ensuring that goals are defined/revised.

### Logic Model

<table>
<thead>
<tr>
<th>Resources</th>
<th>Activities</th>
<th>Outputs</th>
<th>Short-Term and Long-Term Outcomes</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need the following resources in order to accomplish activities:</td>
<td>Need to accomplish the following activities in order to address the problem:</td>
<td>Once activities are accomplished expect to have the following product(s) or services:</td>
<td>If activities are accomplished they will lead to the following changes in 1-3 years:</td>
<td>If activities are accomplished, they will lead to the following changes in 4-6 years:</td>
</tr>
</tbody>
</table>

### Group work activity

The participants worked on developing logic models. On the basis of the situation in their countries, they developed a specific logic model for their country’s proposed surveillance programmes and presented them at the workshop.
Role of surveillance in monitoring and evaluation
(Jorge Rosenthal)

A programme is a systematic, objective and organized response to address a specific problem. Programme evaluation is a systematic method for collecting, analysing and using information to measure the impact, relevance and cost-effectiveness of the programme, to improve it and to plan for future programmes. Monitoring is an ongoing process of collecting and analysing data to compare the implementation of a programme/project against the expected results (impact and cost-effectiveness). Once a programme is under way, ongoing monitoring and evaluation are necessary to systematically collect, analyse and disseminate information on its impact and cost-effectiveness. These are important in the formulation of strategies to improve the programme and for future planning. Monitoring and evaluation use input, process and output indicators to compare the implementation of the programme against the expected results. Surveillance is a component of monitoring activities and its results are shared among stakeholders, for example, hospitals involved in BD surveillance, district health officials and public health officials. The sharing of information among the stakeholders helps to determine whether the condition requires preventive intervention. Several countries have evaluated the effects of folic acid supplementation programmes. Programme evaluation guides activities, identifies what needs to be done, aids decision-making, provides information on the programme’s impact and cost-effectiveness, and facilitates comparison between different regions or countries.

Day 4

Communication and dissemination for surveillance
(Diana Valencia)

The information collected by a surveillance programme needs to be communicated to the target groups in a timely and comprehensive manner, and in a way that is easy to understand to guide specific actions. Information outputs may be in the form of data, publications, reports or guidelines. Birth defects surveillance data are used to identify infants/children with BDs, to plan, implement and evaluate prevention programmes, to inform policymakers and government officials, to inform clinical/public health practitioners and the public, and to identify and refer children with special needs.
Examples of Uses of Data

**Birth defects surveillance data are used to:**
- Identify infants/children with birth defects
- Plan, implement and evaluate prevention programmes
- Inform policy makers and government officials
- Inform clinical/public health practitioners and the public
- Identify and refer children with special needs

The development of communication and dissemination plans for a surveillance programme involves the identification of intended programme outputs (data, publications, reports, guidelines), the intended audience and their information needs, and the objectives of the programme (change behaviours, create policies, increase referral to services). The mode of communication can be written, electronic (website, social media or list serve) or verbal. Forms of written information include news releases, letters, educational brochures, reports and scientific articles. Verbal dissemination can be used in the case of healthcare providers or community health workers. Healthcare providers can influence the decisions made by their patients. Community health workers often do not have formal training, but are looked upon as being knowledgeable about health by the community. They live in the community they serve and can be used to reach sub-populations. It is important to evaluate dissemination strategies. Evaluation can help to set reasonable goals and objectives, determine whether strategies achieved the intended effect, guide future activities and provide information on how best to use funding for education. The effectiveness of dissemination can be judged by surveying the target groups.

**Group work activity**

In this group activity, the participants practised formulating communication strategies for different types of scenarios and target groups.

On the final day of the meeting, representatives from each participating country presented a framework of the BD surveillance and prevention programme they planned to develop. Each country agreed upon a time-frame within which to make a detailed proposal and present it to the stakeholders in their respective countries.
Conclusions and recommendations

Conclusions

(1) Data and information on birth defects in the countries in the SEA Region need to be strengthened. The existing national health information systems (Vital Registration System, Demographic and Health Surveys, Health Management Information System, etc.) should be improved to integrate information on foetal deaths (including stillbirths) and BDs.

(2) The countries must define the primary purpose of BD surveillance and accordingly decide on the surveillance mechanism to be used, adopting standardized approaches and ensuring cultural and ethical acceptance.

(3) The countries need to prioritize selected BDs on the basis of epidemiology, the public health importance of the BDs, their amenability to prevention and the capacity of the system in the country. Externally visible major BDs that are easy to diagnose at birth could be considered in the initial phase. One example of such BDs is neural tube defects, for which an evidence-based, cost-effective preventive intervention exists (folic acid fortification and supplementation).
There are multiple risk factors associated with BDs. These risk factors tend to cluster and are also associated with other adverse reproductive health outcomes. Addressing these risk factors would improve the overall health of women, mothers and children. Such risk factors may be included in the BD surveillance system.

The participants acknowledged the need for advocacy and social mobilization to support BD programmes, including the establishment of a surveillance system and the dissemination of results. A national communication strategy needs to be developed for this.

Birth defect prevention programmes include population- and individual-based strategies (rubella vaccination and food fortification/supplementation with micronutrients, counselling for lifestyle changes and screening).

Preparing a package of interventions for the prevention of BDs, including preconception care, would facilitate effective advocacy, strengthen the continuum of care over the reproductive years and improve the synergy between the existing public health programmes.

In addition to primary prevention, services for the early detection of BDs and the care of babies with BDs should be strengthened to prevent secondary disability.

There is a need to identify a nodal unit in the Ministry of Health that would steer the BD surveillance and prevention activities in close collaboration with other departments, partner agencies and other stakeholders, including professional associations. The countries would need assistance for advocacy, the mobilization of resources and capacity-building for BD surveillance.

To support BD surveillance and prevention, the countries need to develop partnerships, networks and working groups at the regional and country levels.

The participants commended the SEARO initiative to take forward the World Health Assembly resolution on the prevention of BDs in collaboration with the National Center on Birth Defects and Developmental Disabilities, CDC.
Recommendations

For Member States

1) Develop and pursue a national policy and provide a legislative mandate for BD surveillance, as well as prevention interventions.

2) Identify a national nodal person and unit in the Ministry of Health to steer and coordinate BD surveillance and prevention activities in collaboration with other ministries.

3) Decide the primary purpose of BD surveillance and identify specific BDs to be included in the surveillance programme on the basis of feasibility and the situation in the country. The eminent choices would be externally visible and preventable defects, such as neural tube defects, and others like congenital rubella syndrome and congenital syphilis, depending on the local epidemiology.

4) Develop and implement a communication strategy for advocacy and social mobilization for the prevention of BDs, as well as a dissemination strategy for the use of surveillance information to promote effective advocacy with all the relevant stakeholders.

5) Strengthen the existing vital registration systems (by focusing on foetal losses/stillbirths, among other things) and other health information systems in line with the recommendations of the Commission of Information and Accountability for UN Strategy for Women’s and Children’s Health.

6) Develop and implement a package of evidence-based preventive strategies for BDs to ensure synergy and maximize resources. The preconception package could include locally relevant interventions that will not only contribute to the prevention of a number of BDs, but also improve the overall health of women, foetuses and children.

7) Develop country-level partnerships and networks to support and guide surveillance and prevention of BDs, and mobilize resources.

8) Strengthen the national capacity for BDs surveillance, monitoring and evaluation, diagnostics and services for the primary and secondary prevention of BDs, and for the care of babies born with BDs.
For WHO and partners

(1) Support high-level advocacy and resource mobilization in the Member States for surveillance and prevention of BDs.

(2) Support the development of regional and national partnerships and networks for the promotion of BD surveillance and prevention.

(3) Support capacity-building and establish generic guidelines and tools for the development and implementation of BD surveillance in the Member States.

(4) Support national-level efforts, such as operationalizing BD surveillance, putting in place prevention programmes, including preconception care and fortification and supplementation of food with folic acid, and developing a communication strategy, among others.

(5) Mobilize support for the implementation of pilot projects and demonstration models, create opportunities for the sharing of knowledge and experience, and support research to guide the implementation of BD surveillance and prevention.
Annex 1

Country-proposed actions

1. Identify nodal unit in MoH/related ministry

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<thead>
<tr>
<th>Country</th>
<th>Recommended Actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
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<tbody>
<tr>
<td>Bangladesh</td>
<td>Consultation among Director PHC and Line Director MNCAH, Director MIS, Director MCH and Line Director MRCAH</td>
<td>Programme Manager IMCI and MNH</td>
<td>May-June 2012</td>
</tr>
<tr>
<td>Bhutan</td>
<td>Identification of appropriate unit Possible - Reproductive Health, Department of Public Health</td>
<td>Ministry of Health</td>
<td>June 2012</td>
</tr>
<tr>
<td>DPR Korea</td>
<td>Official joint letter to MoPH and NCC to identify nodal unit and establish working group on establishment of surveillance system on BDs</td>
<td>WHO &amp; UNICEF Country Offices</td>
<td>Within two months</td>
</tr>
<tr>
<td>India</td>
<td>1. Identification of region/state-wise nodal centres 2. Advocate with centre and state health ministry/department: Develop advocacy note &amp; situation analysis report for the Health Minister</td>
<td>Dr IC Verma Workshop participants Other colleagues WHO experts</td>
<td>Two months</td>
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<tr>
<td>Indonesia</td>
<td>Workshop: National participants who attended WHO meetings on BDs in New Delhi, Bangkok and Sri Lanka, NIHRD, Professional Associations (Paediatrics and obstetric), WHO, other agencies</td>
<td>Ministry of Health</td>
<td>May 2012</td>
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<tr>
<td>Country</td>
<td>Recommended Actions</td>
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</table>
| Maldives         | 1. Child and Adolescent Health Programme (Population Health Division, CCHDC)  
2. Endorsement by policy level                                                                                                                                  | Programme Manager, Department Head    | Next one month|
| Myanmar          | To prepare a trip report to MoH which will include National Nutrition Centre of the Department of Health as a focal point                                                                                   | National Nutrition Centre, HMIS, Focal Neonatologist | April 2012    |
| Nepal            | Identification of appropriate unit within Ministry of Health and Population (MoHP): Family Health Division (FHD), Department of Health Services (DoHS)                                                 | Ministry of Health and Population     | May 2012      |
| Sri Lanka        | 1. Establish Multisectoral Working Committee (MWC) on Prevention and Control of Birth Defects  
2. DDG (PHS) identified as the focal point for entire Birth Defects programme  
3. Maternal & Child Morbidity & Mortality Surveillance Unit of FHB recognized as the nodal unit                     | Ministry of Health                   | Already completed|
| Thailand         | Draft Policy Communicate to stakeholders  
Implement policy  
Financial support  
Database linkage  
2. **Develop a national mandate (policy/legal) for BDs surveillance**

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<tr>
<th>Country</th>
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<th>Responsibility</th>
<th>Timeframe</th>
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<tbody>
<tr>
<td>Bangladesh</td>
<td>Include in either existing National Neonatal Health Strategy (NNHS) or newly developed child health strategy or in Maternal Health Strategy</td>
<td>Programme Manager IMCI and MNH, Support by: WHO, UNICEF, ICDDR,B</td>
<td>May-Dec 2012</td>
</tr>
</tbody>
</table>
| Bhutan       | 1. Initiate development of Birth Defects Surveillance System policy  
               2. Draft legal document within RH policy document | Ministry of Health                    | September 2012     |
| DPR Korea    | 1. Orientation workshop with main stakeholders on National Action Plan  
               2. National Action Plan development and adaptation  
               3. TOR for technical working groups and focus groups | Department of Prevention and Treatment  
Department of International and Foreign Affairs  
National Coordination Committee | Within six months |
| India        | 1. National & Regional Consultation  
               2. Creation of Task Force - BDRN  
               3. Identify goals of programme and project proposal and identify research areas | WHO  
ICMR | Three months |
| Indonesia    | National multi-sectoral working group | Directorate of Child Health, MoH | June - Dec         |
| Maldives     | 1. Situation assessment of birth defects (use available data)  
               2. Advocate for policy - Informing/convincing the Minister of Health  
               3. Revision/Inclusion in the programme mandate/maternal/RH and child health strategy  
               4. Incorporation in the newly drafted Public Health Act | Programme Manager, Department Head Policy division, MoHF | Three-six months |
<p>| Myanmar      | Need preparation and submission of project proposal/action plan for surveillance and prevention of birth defects to Minister | Programme Manager (Nutrition), HMIS, Focal Neonatologist | May 2012          |</p>
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<tr>
<th>Country</th>
<th>Recommended Actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
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<tbody>
<tr>
<td>Nepal</td>
<td>Development of a draft policy document to include birth defects as a part of</td>
<td>Family Health Division</td>
<td>July 2012</td>
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<td></td>
<td>Reproductive Health (RH) protocol followed by national endorsement</td>
<td>MoHP</td>
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<td></td>
<td>surveillance as one component</td>
<td>Committee</td>
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<td></td>
<td>2. Incorporation of relevant strategies in sectoral plans</td>
<td>Relevant NPM</td>
<td>Oct 2012</td>
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<tr>
<td>Thailand</td>
<td>National BD surveillance reporting system being established</td>
<td>MoPH, NHSO</td>
<td>Three years</td>
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3. **Engaging partners for BDs surveillance**

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<tr>
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<th>Recommended Actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
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<tbody>
<tr>
<td>Bangladesh</td>
<td>Involve IMCI national working team, professional bodies and development partners</td>
<td>Programme Manager IMCI</td>
<td>May –Dec 2012</td>
</tr>
<tr>
<td>Bhutan</td>
<td>1. Organization of one-day workshop on birth defects for raising awareness</td>
<td>MoH</td>
<td>Aug 2012</td>
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<tr>
<td></td>
<td>2. Draft a plan of action on implementation of birth defects surveillance</td>
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<tr>
<td>DPR Korea</td>
<td>1. Advocacy, fund raising and resource mobilization</td>
<td>MoPH WHO UNICEF</td>
<td>Within six months</td>
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<td>2. National consultation/workshop with key experts to select methodology and</td>
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<td>Within 12 months</td>
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<td></td>
<td>surveillance mechanism</td>
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<td>3. Training on Epi Info or any other software</td>
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<td>4. Training for HHD (Household doctors) and other clinicians on BDs</td>
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<td>5. Printing of reporting forms</td>
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<tr>
<td>India</td>
<td>1. Engaging UNICEF, CDC, professional associations: NNF (neonatal)/IAP (Paediatrics)/</td>
<td>Through WHO &amp; ICMR Task Force</td>
<td>One year</td>
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<td>FOCSI (Ob-Gy)</td>
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<td></td>
<td>2. Identify target institutions and nodal persons</td>
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<td>3. Consultation with NNPD/BDRI centres</td>
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<tr>
<td>Indonesia</td>
<td>National workshop with identified partners</td>
<td>Directorate of Child Health, MoH</td>
<td>Dec 2012</td>
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<td>Country</td>
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<tr>
<td>Maldives</td>
<td>1. Identification of stakeholders/supporting agencies/support groups</td>
<td>MCH Programme</td>
<td>Six-nine months</td>
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<td></td>
<td>2. Invitation and identification of participating hospitals (gov &amp; private)</td>
<td>Department Head</td>
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<td></td>
<td>3. Formulation of working group/steering committee</td>
<td>Policy division, MoHF</td>
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<tr>
<td>Myanmar</td>
<td>Conduct a coordination meeting to organize PSC &amp; TWG (related sectors especially agriculture, paediatricians &amp; ObGys, private sector)</td>
<td>NNC, HMIS, Focal Pediatrician, ObGys</td>
<td>June 2012</td>
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<tr>
<td>Nepal</td>
<td>Organize a consensus meeting among the partners</td>
<td>FHD-MOH</td>
<td>August 2012</td>
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<tr>
<td>Sri Lanka</td>
<td>1. Identification of stakeholders (SLCP/PSSL/SLCOG/CCPSL/CFPSL/SLCOS/Geneticists etc + provincial healthcare administrators/hospital Heads)</td>
<td>NPM - MCMMS</td>
<td>Feb 2013</td>
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<tr>
<td></td>
<td>2. Development of surveillance mechanism:</td>
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<td></td>
<td>a. Single system for the country</td>
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<td>b. Selection of cases</td>
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<td>c. Time period for case ascertainment</td>
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<td>d. Formats/tools</td>
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<td></td>
<td>e. Methodology/process</td>
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<td>f. National data base/NBDR</td>
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<td></td>
<td>g. Guidelines</td>
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<tr>
<td>Thailand</td>
<td>1. Integration with birth registry</td>
<td>UNICEF/MOI/Local government</td>
<td>1 Year</td>
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<td></td>
<td>2. Data entry</td>
<td>Surveillance Hospitals</td>
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<td>3. Data linkage and transfer</td>
<td>NHSO</td>
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<td>4. Financial support</td>
<td>Thai Health Fund Academia</td>
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<td>5. Technical support</td>
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### 4. Communication and social mobilization

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<th>Country</th>
<th>Recommended Actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
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<tbody>
<tr>
<td>Bangladesh</td>
<td>Revise the C-IMCI C4D strategy to include strategy for birth defects</td>
<td>Programme Manager IMCI</td>
<td>June 2013</td>
</tr>
<tr>
<td>Bhutan</td>
<td>1. BBS on importance of birth defects system</td>
<td>MoH</td>
<td>July 2012</td>
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<tr>
<td></td>
<td>2. Disseminate the information on the website</td>
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<td>3. Develop IEC materials on birth defects</td>
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<tr>
<td>DPR Korea</td>
<td>1. Development of IEC materials for population and healthcare providers</td>
<td>MoPH WHO UNICEF</td>
<td>Within 12 months</td>
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<td></td>
<td>2. Establishment of focus groups in all 10 provinces</td>
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<td></td>
<td>3. Training for HHD on social mobilization</td>
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<tr>
<td>India</td>
<td>1. Establish website and list serve for communications between networking institutions</td>
<td>Through participating institutions/ICMR</td>
<td>One year</td>
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<td>2. Training workshops for healthcare workers involved in collection of data</td>
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<tr>
<td>Indonesia</td>
<td>Intersectoral workshop to develop the communication strategy</td>
<td>MoH</td>
<td>July</td>
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<tr>
<td>Maldives</td>
<td>1. Awareness campaign/education materials</td>
<td>MCH programme</td>
<td>12-18 months</td>
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<tr>
<td></td>
<td>2. Prepare community health workers/education and orientation</td>
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<tr>
<td>Myanmar</td>
<td>Advocacy meeting for higher authority</td>
<td>NNC, HMIS, Focal paediatrician, ObGys</td>
<td>July 2012</td>
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<tr>
<td>Nepal</td>
<td>Develop IEC and disseminate materials for social mobilization</td>
<td>FHD</td>
<td>Sept 2012</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>Incorporate communication &amp; social mobilization in RH communication strategy</td>
<td>NPM - MCMMS</td>
<td>Mar 2013</td>
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<tr>
<td>Thailand</td>
<td>1. Create registry network</td>
<td>Timely report every trimester</td>
<td>One Year</td>
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<td>2. Annual meeting on “sharing lessons learned and knowledge management”</td>
<td>Provide feedback on accuracy of case identification</td>
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5. Develop consensus on specific surveillance mechanism for BDs in the country

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<th>Timeframe</th>
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<tbody>
<tr>
<td>Bangladesh</td>
<td>Workshop with GoB officials, professional bodies and development partners to establish hospital-based surveillance system</td>
<td>IMCI section, WHO, UNICEF, ICDDR,B, professional bodies</td>
<td>June-Dec 2012</td>
</tr>
<tr>
<td>Bhutan</td>
<td>Organize a meeting on births defects surveillance: finalization the type of surveillance for initial phase</td>
<td>MoH</td>
<td>Oct 2012</td>
</tr>
<tr>
<td>DPR Korea</td>
<td>Development of consensus framework: who does what, when, how and why</td>
<td>National focus group</td>
<td>Dec 12</td>
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<tr>
<td>India</td>
<td>1. Discussion on existing BDRI workplan</td>
<td>AIIMS</td>
<td>One year</td>
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<td>2. Surveillance programme proposal writing workshop (BDRN)</td>
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<td>3. Workshop for finalization of SOP</td>
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<tr>
<td>Indonesia</td>
<td>Working group for BD surveillance to decide the type of surveillance</td>
<td>Directorate of Child Health, MoH</td>
<td>Dec</td>
</tr>
<tr>
<td>Maldives</td>
<td>1. Consultative meetings with hospitals: pediatricians; gynecologists; reproductive health unit; medical records</td>
<td>Programme manager, Department head Policy division, MoHF</td>
<td>Six-nine months</td>
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<td></td>
<td>2. Awareness sessions &amp; FGDs with NGOs, community members, parent groups for feedback and support</td>
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<tr>
<td>Nepal</td>
<td>1. Organize consensus meeting among stakeholders</td>
<td>FHD, DoHS</td>
<td>December 2012</td>
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<td>2. Formation of task force for finalization of manual on birth defects surveillance</td>
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<td>3. Development/amendment of recording and reporting tools &amp; training manuals for birth defects</td>
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<td>4. Development of M&amp;E framework/guidelines</td>
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### 6. Piloting BDs surveillance: design, implementation and evaluation

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<th>Country</th>
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<th>Timeframe</th>
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</table>
| Bangladesh    | 1. Introduce and implement hospital-based surveillance in 10 tertiary level hospitals and region-wise  
2. Develop population-based surveillance in research setting | IMCI section, WHO, UNICEF, ICDDR,B, BSMMU | June 2012 - Dec 2013 |
| Bhutan        | Include for BD surveillance:  
1. One regional hospital and four district hospitals  
2. 10 Basic Health Units at the community level | MoH                                     | Jan 2013           |
| DPR Korea     | 1. Pilot testing  
2. Data collection  
3. Data analysis  
4. First report | National and provincial focus groups                                                 | Jan 2013  
                          | Day 13  
                          | Oct 13  
                          | Dec 13 |
| India         | 1. Run pilot programme in two-three institutions (hospital-based)  
2. Evaluate input, process and outcome indicators | Ongoing BDRI BDRN                       | Parallel two years  |
| Indonesia     | Establish a BD surveillance system at some chosen provinces (population-based surveillance):  
- Insert questions on birth defects in mother and infant cohort study  
- Establish a surveillance birth defects cohort study in community  
- Insert questions on birth defects in National Basic Health Survey | Directorate of Child Health, MoH         | 2013  
                          | 2012  
                          | 2012 – 2017  
<pre><code>                      | 2013 (every three years) |
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<th>Country</th>
<th>Recommended Actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maldives</td>
<td>1. Selection/identification of BDs for surveillance</td>
<td>Programme manager, working group; Hospitals: medical record unit</td>
<td>10-12 months</td>
</tr>
<tr>
<td></td>
<td>2. Design and pretest of data collection forms</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Pilot in one main hospital (for six months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myanmar</td>
<td>TWG meeting to plan in detail</td>
<td>HMIS, Pediatrics concerned NNC</td>
<td>Nov 2012 Dec 2012</td>
</tr>
<tr>
<td></td>
<td>Hospital-based intramural</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Define data flow mechanism (monthly report)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Training including data entry &amp; management-paediatricians, &amp; statisticians</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nepal</td>
<td>1. Preparation of baseline datasets from maternity and children’s hospitals,</td>
<td>HMIS, DoHS</td>
<td>February 2013</td>
</tr>
<tr>
<td></td>
<td>2. Implement birth defects surveillance in six districts on pilot basis,</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Monitoring &amp; Evaluation of birth defects surveillance programme</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. To pilot BD surveillance system in representative district/s</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. To modify based on lessons learnt</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. To mainstream in a phased manner to other districts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thailand</td>
<td>1. Hospital-based in 20 provinces, cross-sectional, descriptive</td>
<td>Ensure uniform implementation</td>
<td>One Year</td>
</tr>
<tr>
<td></td>
<td>2. Develop online software</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Training how to identify cases, enter, and verify data</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Challenges expected for BDs surveillance at the country level

- Sensitization of policy makers and opinion leaders on birth defect issues
- Getting political commitment: Advocacy needed in each participating state, support from intersectoral programme, may not be a priority in states with high IMR
- Integration of BD surveillance with the existing system
- Mobilization of funds for BD surveillance activities
- Human resources: Lack of skilled professionals/experts, current cadre reportedly overburdened
- Adaptation of ICD 10 code by clinicians
- Data collection and reporting challenges: Quality of data, modification of HMIS/HSIS for data entry and analysis, review of birth-defects datasets regularly
- Geographic challenge (difficult and rough terrain)

Challenges for BDs prevention programme

- Health-care seeking behaviour
- Adequate supply of iron folic acid tabs for adolescents/peri-conception period/pregnant women, feasibility of rice fortification as long-term strategy.

Support needed at country level

- Support for advocacy with health ministries
- Technical support: Developing Birth Defects Surveillance System, Fortification of rice, engaging potential partner
- Funding support
- Capacity building of human resources (training of personnel)
- Logistic support (IT equipment, medical equipment)
- Identification of medium-term and long-term goals.
Annex 2

Agenda

- Presentation of regional overview of birth defects
- Share an overview of birth defects and modifiable risk factors and evidence on preventive strategy
- Discuss purpose and objectives of birth defects surveillance
- Share examples of birth defects surveillance activities from selected Member States
- Discuss various approaches for birth defects surveillance
- Discuss method for selection of birth defects for surveillance, their classification and coding
- Share principles of data analysis
- Present and discuss logic model for planning and evaluation of birth defect surveillance
- Discuss role of surveillance in monitoring and evaluation of birth defects prevention programmes
- Discuss communication and dissemination of surveillance reports and findings
- Review the proposed manual for birth defects surveillance in developing countries.
Annex 3

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Birth defects (BDs) are progressively contributing to a greater proportion of infant and childhood mortality. However, the burden of BDs in the SEA Region remains unknown because of the lack of national-level surveillance mechanism for birth defects. In the SEA Region it is planned to develop a BDs surveillance manual along with tools based on the experience with the global package developed by WHO, International Clearinghouse on Birth Defects and Surveillance and the US CDC for the developing countries. This regional workshop was organized by WHO-SEARO in collaboration with the US CDC to help participants understand the principles of surveillance of BDs. National programme managers from countries, and technical officers from WHO, UNICEF and the US CDC attended the workshop. The report provides the summary of proceedings of the workshop. In addition to learning about the BD surveillance principles, the participants also developed recommendations on BDs surveillance activities for Member States, as well as for WHO and the partner agencies.