Birth defects surveillance in South-East Asia

*Report of the regional workshop*
*Bangkok, Thailand, 15–18 July 2013*
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Acknowledgement

The collaboration and support provided by the National Center on Birth Defects and Developmental Disabilities, CDC, Atlanta, United States of America, is gratefully acknowledged.
Executive summary

The *Prevention and Control of Birth Defects in the South-East Asia Region: Strategic Framework (2013–2017)* was developed by WHO Regional Office for South-East Asia in collaboration with Centers for Disease Control and Prevention (CDC), Atlanta, United States of America. The framework underlines the importance of developing birth defects surveillance mechanisms to determine the burden and evaluate the preventive programmes as they are implemented in countries. This is in response to the Sixty-third World Health Assembly resolution WHA63.17 addressing the prevention and management of birth defects. Resolution WHA63.17 emphasizes the need to develop expertise and build capacity on the prevention of birth defects and care of children with birth defects, including developing and strengthening registration and surveillance systems.

In this context, a regional workshop on birth defects surveillance was organized by the Queen Sirikit National Institute of Child Health (QSNICH) Thailand with the support of WHO Regional Office for South-East Asia. The objectives were: (i) to understand the principles and practice of surveillance; (ii) to understand the health impact and effective prevention strategies for common modifiable factors; and (iii) to practise specific skills including how to develop a logic model, code and classify cases, enter and analyse data, and communicate effectively with professionals, the public and policy-makers about the importance of surveillance to support prevention efforts. National nodal persons for birth defects in the ministries of health, national programme managers responsible for surveillance from Member States (except the Democratic People’s Republic of Korea and Timor-Leste), representatives of the Regional Network for Newborn Health and Birth Defects, the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) and CDC Atlanta, and staff from WHO country offices in Bangladesh and Indonesia, and staff from the WHO Regional Office for South-East Asia, attended the workshop. The draft surveillance package was used
to conduct the workshop. Participants reviewed the package and provided feedback. The principles of surveillance were discussed and specific skills related to birth defects surveillance were practised. Tentative country action plans for birth defects surveillance over the next few years were developed by participating country teams.
1. Introduction

A significant decline in infant and childhood mortality rates has been documented over the past two decades. This is due primarily to the decline in mortality from infectious diseases and vaccine-preventable diseases, as well as the improvement in health care services. However, the newborn mortality rate remains high and, at the same time, mortality due to birth defects remains unimproved. As a result, birth defects are accounting for a greater proportion of the causes of infant and childhood mortality. Every year, it is estimated that 6% of babies worldwide are born with serious birth defects due to genetic and/or environmental causes.

In response, the WHO Executive Board discussed prevention of birth defects in its 125th, 126th and 127th sessions. Consequently, the World Health Assembly adopted resolution WHA63.17 to address birth defects by developing expertise and building capacity on the prevention of birth defects and care of children with birth defects, including developing and strengthening registration and surveillance systems. The WHO Regional Office for South-East Asia, in collaboration with CDC, Atlanta, has taken initiatives to support and develop programmes on birth defects prevention and control. A series of meetings have been organized including an expert group meeting in December 2011, a regional workshop on capacity-building for birth defects surveillance in April 2012, a programme managers’ meeting in March 2012, and a regional network meeting on strengthening newborn health and prevention of birth defects in April 2013. In these meetings, regional experts and national programme managers have deliberated and developed a broad consensus, that birth defects deserve to be a public health priority and addressing them will contribute to a reduction in neonatal mortality rate. A strategic framework for prevention and control of birth defects in the South-East Asia Region has been developed to provide guidance for Member States in developing and planning for birth defects prevention using a public health approach. The framework underlines the importance of developing birth defects surveillance mechanisms to determine the burden and evaluate the preventive programmes.
In this context, a regional workshop on birth defects surveillance was organized by the Queen Sirikit National Institute of Child Health (QSNICH), Bangkok, Thailand with the support of WHO Regional Office for South-East Asia and CDC Atlanta. The workshop aimed to achieve understanding of the principles and practice of surveillance, the health impact and effective prevention strategies for common modifiable factors, and to provide an opportunity to practise specific skills including how to develop a logic model, code and classify cases, enter and analyse data, and communicate effectively with professionals, the public, and policy-makers about the importance of surveillance to support prevention efforts.

The workshop was attended by national nodal persons on birth defects, national programme managers responsible for surveillance from the ministries of health in Member States (except Democratic People’s Republic of Korea and Timor-Leste), representatives of the Regional Network for Newborn Health and Birth Defects, staff from WHO country offices (Bangladesh and Indonesia) and WHO Regional Office for South-East Asia. The workshop was facilitated by experts from the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) and CDC Atlanta.
2. Objectives

The objectives of the workshop were:

(1) to understand principles and practice of surveillance, including planning, implementation and evaluation;

(2) to understand the health impact and effective prevention strategies for common modifiable risk factors;

(3) to practise specific skills, including how to develop a logic model, code and classify cases, enter and analyse data, and communicate effectively with professionals, the public and policy-makers on the importance of surveillance to support prevention efforts.
3. Summary of the proceedings

Inaugural session

The workshop was inaugurated by Dr Prapon Tangsrikertikul, representative of the Director-General, Ministry of Public Health, Thailand. He delivered the key note address on behalf of the Director-General, Ministry of Public Health, highlighting the importance of building country capacity and developing national plans for effective interventions to prevent and manage birth defects, including birth defects surveillance.

Dr Joe Sniezek, CDC Atlanta, affirmed the collaboration between CDC and the Regional Office for South-East Asia over the past 2 years and noted the rapid advances made, including the development of the regional strategic framework for prevention and control of birth defects. He mentioned the four goals of the framework, which are: to reduce the prevalence of folic acid-preventable neural tube defects by 35%; to reduce the number of thalassaemia births by 50%; to reduce congenital rubella; and, to eliminate congenital syphilis within 5 years. To achieve these goals, it is important to build capacity in birth defects surveillance, for which CDC provides support including training materials. Dr Sniezek further highlighted that the CDC global initiative, the Birth Defects COUNT, focuses on the elimination of folic acid-preventable neural tube defects.

Dr Yonas Tegegn, WHO Representative for Thailand, noted the importance of prevention of birth defects for accelerating progress towards Millennium Development Goal 4, and beyond 2015. He emphasized the need for capacity-building in birth defects surveillance in the countries and the need to standardize surveillance, in order to define the magnitude of the problem as well as to monitor the progress of birth defect prevention programmes. Dr Tegegn noted that WHO, CDC and ICBDR have developed a birth defects surveillance training package and that countries were encouraged to move forward to develop a more comprehensive national plan, using the regional strategic framework for prevention and control of birth defects.
Dr Neena Raina, Regional Adviser, Child and Adolescent Health, WHO Regional Office for South-East Asia, stated that the Regional Office in collaboration with CDC had organized a series of meetings on prevention and control of birth defects, and developed the regional strategic framework for prevention of birth defects. The framework provides guidance for developing a more comprehensive plan for the prevention and control of birth defects. Dr Raina introduced the participants and welcomed them to the workshop.

Dr Suthipong Pangkanon, Medical Officer, QSNICH, Thailand proposed a vote of thanks to all speakers and WHO, CDC, and ICBDR for making this important workshop possible.

**Overview of the workshop**

*(Dr Neena Raina, Regional Adviser, Child and Adolescent Health, WHO Regional Office for South-East Asia)*

During the workshop, a pool of resource persons would be trained to facilitate subsequent country-level trainings on birth defects surveillance. Participants would practise and learn how to conduct or strengthen birth defects surveillance, risk factors for birth defects, logic models for planning surveillance, legislation related to birth defects, approaches to surveillance, data collection, coding birth defects, analysis and management.
Pre-course material was shared with the participants prior to the workshop. A draft of the birth defects surveillance manual was used for the workshop. Participants were requested to review and provide feedback for the improvement of the surveillance manual and facilitators’ guide. The package would be finalized based on the feedback received during the workshop.

**Overview of the surveillance toolkit**

_(Dr Joe Sniezek, CDC Atlanta)_

A birth defects surveillance manual for low- and middle-income countries is being developed by CDC, WHO and ICBDSR to address the need in countries wanting to develop or strengthen birth defects surveillance.

The surveillance toolkit consists of a surveillance manual, a facilitators’ guide and a photo atlas on birth defects. The surveillance manual was drafted in October 2011 and pilot-tested in Sri Lanka in April 2012. Workshop participants would review and provide feedback on the manual. The surveillance manual would then be finalized, posted to the website and translated into the six WHO languages.

The manual consists of five chapters covering the purpose and methodological approaches of birth defects surveillance, the use of the logic model, coding, confidentiality, and managing and analysing data. Birth defects listed in the manual
include those that are observable; severe enough to be captured within the first few days after birth; have significant public health impact; and, have potential for primary prevention. This includes neural tube defects, orofacial clefts, hypospadias, talipes (clubfoot), limb defects, omphalocele and gastroschisis. Photos, drawings and ICD-10 codes for these birth defects are also included in the manual. There is a standardized database template to allow country comparisons. The database uses Epi Info 7 and links with the ICBDSR website. The Android-based apps forms are being finalized.
Global overview

(Dr Pierpaolo Mastroiacovo, Director, ICBDSR)

Congenital conditions are present at the time of birth and can be categorized as birth defects and others, such as intrauterine growth retardation and preterm birth. By definition, birth defects are abnormalities of body structure or function, present at birth, which are of prenatal origin. “Present at birth” does not mean always evident and diagnosed at birth, as some of these defects become manifest later in life, such as congenital heart disease.
Prenatal origin or genetic does not necessarily mean “hereditary” or “transmitted”, but can also be a genetic mutation. Various types of birth defects can be prioritized on account of their importance in terms of severity, frequency, disease burden and primary prevention opportunities. Congenital malformation is included in ICD-10 Chapter XVII (Q00-Q99).

Congenital malformations can be classified in multiple ways, based on their presentation (external/internal), health impact (major/minor), pathogenesis (malformation/dysplasia) and clinical diagnosis (isolated/multiple/syndrome). External defects are visible and easy to recognize, malformations are more frequent than dysplasia, and major defects have significant impact on appearance as well as function. When initiating birth defects surveillance programmes, external and major defects make a good starting point.

In the past, birth defects were misinterpreted as genetic in origin – that is, hereditary and unpreventable. Enormous evidence now shows the etiology is also non-genetic and includes maternal lifestyle, nutrition and illness as well as environmental chemicals. Additionally, many birth defects are caused by multiple factors, known as etiologic heterogeneity. Spina bifida, for example, occurs due to folic acid deficiency, vitamin B12 deficiency, maternal diabetes and obesity, zinc deficiency and environmental toxicants. Knowledge of such etiologic heterogeneity is useful for advocacy, as well as for correctly informing parents that folic acid supplementation can prevent only 75% of neural tube defects because other factors can also be a cause. There are certain modifiable risk
factors that can cause birth defects. It is important to qualify outcomes associated with each risk factor, to quantify the risk magnitude for each outcome, to quantify the risk prevalence in the population of each factor, and to quantify the attributable fraction of each of several risk factors that may be present concurrently.

The burden of birth defects is huge everywhere in the world, but it is disproportionately high in low- and middle-income countries. Globally, it is estimated that 1 in 24 births, or 5.4 million babies, are born with congenital malformations each year, of which 1.6 million are born in the South-East Asia Region. When elective termination of pregnancy for fetal anomalies, stillbirths, spontaneous abortions, comorbidity and long-term disability are considered, the burden of congenital anomalies is even higher.

There are five sets of interventions that can be offered to address the burden of birth defects: diagnosis, counselling, treatment, social integration and prevention. Diagnosis must be very precise and can be made prenatally or postnatally. Counselling needs to be offered before birth, after birth, or at any other time. Treatment can be surgical, medical or a combination of both, as well as supportive. Social integration helps persons with birth defects to remain part of society and includes community mainstreaming in schools and workplaces. Prevention can mean primary prevention, by promoting reproductive and preconception care, or secondary prevention such as newborn screening.
Public health surveillance is a necessary and powerful tool. It includes collecting, analysing and disseminating data for public health actions. There is integration between intervention, surveillance and evaluation. Without surveillance, it is difficult to evaluate and improve public health programmes.

Discussion

- There is no one standard approach for surveillance. It is decided on the basis of a country’s need and capacity, including the availability of diagnostic facilities.
- It is recommended to start surveillance at selected sites with good quality data, and then to expand.
- Before prevention programmes are started, it is important to have evidence on birth defects including the burden of risk factors. The regional strategic framework has four targets, which can be used when there is not enough evidence available in a country.

Regional overview of birth defects

(Dr Neena Raina, Regional Adviser, Child and Adolescent Health, WHO Regional Office for South-East Asia)

Infant and childhood mortality rates are declining in the Region, however neonatal mortality remains high. As a result, it is unlikely that the Region as a whole will achieve the Millennium Development Goal 4 target, although some countries have already achieved it. In countries such as Sri Lanka where infant and childhood mortality is low, neonatal deaths contribute to more than 67% of under-five deaths, while in other countries newborn mortality if responsible for around 50% of under-five mortality. At the regional level, congenital anomalies are responsible for 4% of newborn mortality; however, in countries with low infant mortality rates, the proportionate mortality due to congenital anomalies is much higher. Three major congenital conditions – birth defects, preterm births and birth asphyxia – contribute to 35–55% of newborn deaths in countries of the Region. Thus, it is important to link newborn health and prevention of birth defects.

The WHO publication *Birth defects in South-East Asia: a public health challenge* presents a situation analysis of the burden of birth defects in the Region based on
published literature, preventive interventions and surveillance efforts that exist in countries. However, nationally representative information on the burden of birth defects is not available.

Countries will not have to start from scratch to initiate birth defects prevention programmes. Preventive interventions for several birth defects can be integrated into existing programmes including: reproductive, maternal, newborn, child and adolescent health; nutrition (e.g. folic acid supplementation and fortification); sexually-transmitted infections; and, immunization programmes (e.g. introduction of rubella vaccination). In most countries, iron-folic acid supplementation programmes for children, pregnant and lactating women, and weekly iron-folic acid supplementation programmes for adolescents are already being implemented. In the South-East Asia Region, wheat flour fortification with folic acid may prove to be more effective, since compliance to folic acid supplementation has been inadequate. Indonesia and Nepal, for example, have legislation for mandatory wheat flour fortification. In addition, the evolving noncommunicable disease programmes in Member States offer a good opportunity to focus on obesity, diabetes and smoking among adolescents and women of reproductive age. Health education and promotion programmes also exist in countries of the Region.

It is important to focus on the continuum of care across the life-course. One window of opportunity is the preconception period – either before pregnancy or during the interpregnancy interval. A regional meeting would be held in August 2013 on preconception care programmes that would be made available to adolescents as
a healthy transitions package and to couples as a preconception care package before pregnancy and during the interpregnancy period.

The *Prevention and Control of Birth Defects in the South-East Asia Region: Strategic Framework (2013–2017)* gives four targets to be achieved within a 5-year period, and five strategic directions to guide Member States in developing prevention and control programmes for birth defects. One strategic direction relates to developing and strengthening national birth defects surveillance, monitoring and evaluation mechanisms. Countries are encouraged to develop a national strategy and plan for prevention of birth defects based on the strategic framework.

There has been some progress at the country level. A national planning meeting was organized in Sri Lanka, Thailand would conduct a planning meeting after the workshop, and some other countries would hold meetings by the end of 2013. National focal points on birth defects have been identified in nine Member States. A Regional Network for Newborn Health and Birth Defects has been established. A national network of institutions has also been launched in some countries to establish the database on neonatal–perinatal health and birth defects. A facility-based database of the regional neonatal–perinatal database is being developed and finalized. Bangladesh is piloting community-based surveillance for talipes and will integrate other visible birth defects and extend the surveillance to selected hospitals. Stillbirth surveillance that includes birth defects has been field-tested in India in five sites and is planned in Nepal and Sri Lanka. India has recently launched a national screening programme for children aged up to 18 years, which focuses on the “4Ds”: deficiencies, diseases, developmental delays.
(including disabilities) and defects at birth (including nine defects). A birth defects registry has been established in Chennai, India. Thailand has a national birth defects registry focusing on five common genetic disorders. A regional communication framework and toolkit for birth defects is being developed. Despite the progress, however, some challenges remain including: the need to sustain advocacy at all levels; how to identify birth defects in the hospital or community, and link to referral; how to provide support for treatment and care; and, how to develop and implement preventive programmes.

**Birth defects: prevention, prioritization and modifiable risk factors**

*(Dr Joe Sniezek, CDC, Atlanta)*

Globally there were 3.1 million neonatal deaths in 2011, of which congenital anomalies were responsible for 500,000 deaths. As under-5 mortality decreases, the fraction due to birth defects will increase and they will contribute a larger proportion of infant mortality. In response, the Sixty-third World Health Assembly adopted resolution WHA63.17 recommending that Member States develop programmes for the prevention of birth defects.

In the South-East Asia Region, birth defects are estimated to account for over 30% of infant deaths. As the survival rate among babies with birth defects improves, more long-term care will be required and consequently this will have a significant financial
impact. Many birth defects, however, have great potential to benefit from primary prevention programmes.

Initially, countries prioritize only the major birth defects for surveillance. Major birth defects have significant medical and financial consequences. Minor birth defects are more frequent, but have a less significant impact. There are certain maternal risk factors that are associated with birth defects, such as behaviours and environmental exposures. Fortunately, there are several interventions that can be delivered to address these maternal risk factors.
Discussion

- There is an issue regarding when to start and when to end folic acid supplementation. In the Netherlands, for example, folic acid is given until 14–15 weeks after conception. In the USA, it is given before and during the entire pregnancy. In Thailand, preconception folic acid is given 2 months before pregnancy until 3 months after pregnancy. The WHO recommendation is to give folic acid 3 months before until 3 months after the conception, 400 µg daily. If a woman has had previous experience delivering a baby with birth defects, 4 mg folic acid is recommended; however, there is no 4 mg dosage formulation available. For weekly iron-folic acid supplementation programmes, 2800 µg folic acid and 100 mg elementary iron is recommended for adolescents.

- Periconceptional supplementation with folic acid is proven to prevent certain neural tube defects, but many pregnancies are unplanned and the effective opportunity for folic acid supplementation cannot be utilized. In developing countries, the majority of patients see doctors when they realize that they are already pregnant. Therefore, the best recommendation could be that made by CDC – that all women capable of pregnancy should consume 400 µg folic to prevent neural tube defects.

Birth defects surveillance

(Dr Diana Valencia, CDC, Atlanta)

Dr Valencia explained the purpose and importance of public health surveillance for birth defects. According to CDC, public health is defined as the science of protecting and improving the health of families and communities through education, policies, services and research.

Public health surveillance is the ongoing and systematic collection, analysis and interpretation of health data essential to the planning, implementation and evaluation of public health practice. Public health surveillance has several purposes, an important one of which is how to disseminate and interpret data. Dr Valencia further explained the elements and uses of public health surveillance.

- Assess the prevalence of certain conditions in own country
- Look at places where rates are high or low
- Try to identify epidemics or clusters
Dissemination of public health information for assessment and public health response

Planning, implementation and evaluation of health strategies

- For example, surveillance data are critical to help determine whether a program is having an impact, to evaluate if new strategies are necessary, and to identify problem areas and target populations that require more intensive intervention and follow-up
• Integration of data with the decision-making process for the prevention or care of adverse health conditions
• Document burden to develop public health priorities
• Develop political and social will
• Document burden to plan for services

Discussion

• One important component of surveillance is how to ensure and monitor the quality of data.
• ICD-10 uses the term “congenital malformations” (not birth defects), which includes metabolic defects. In the South-East Asia Region the term birth defects continues to be used, including in surveillance activities, as the WHO Resolution also uses this term.

Logic models

(Dr Diana Valencia, CDC, Atlanta)

A logic model is a visual/graphic representation of the roadmap of a programme, and depicts how a programme works. It includes the planning, implementation and evaluation stages and takes into account the resources required, activities that need to be accomplished, results, and the short- and long-term impacts of the programme.
By using logic models, the goals and objectives of a programme can be well defined, any problems/gaps can be identified earlier, consensus about the programme activities and intended “effects” can be established, and connections between activities and results can be ensured. Participants discussed and developed the logic model for birth defects surveillance programmes.

**Discussion**

- Prevention activities should not wait until surveillance has been established.
- It is encouraged to use the logic model at the national meeting.
- In planning, the first step is to identify the objectives to be achieved and then to identify what activities are needed to achieve those objectives: the timeframe, who will implement the activities, to whom the activities are directed, how and at what level activities will be carried out.

**Legislation, privacy and confidentiality**

*(Dr Arvind Mathur, WHO Regional Office for South-East Asia)*

Legislation is an important issue for birth defects surveillance. It provides a legal mechanism or framework for access to data and information, including its collection, sharing and reporting. There are two types of reporting: mandatory and voluntary. When staff is legally required to document and report all cases of live births and
stillbirths with birth defects, within a specified timeframe in a specified format, it is called mandatory reporting. The advantages of mandatory reporting include receiving the data regularly, uniformity, sustainability and the possibility to analyse prevalence and trends. The challenges of mandatory reporting are related to ensuring the quality of data, and the increased workload for staff.

Voluntary reporting can be a good starting point, leading to mandatory reporting with time. The drawback of voluntary reporting is that it is likely to result in poorer data quality, and there is potential for skewed prevalence and trends due to under- or over-reporting. Voluntary reporting has been initiated in some Member States of the Region. It is necessary to adopt a reporting type according to local context and situation, and voluntary reporting is a good way to start.

Issues of privacy and confidentiality related to birth defects are applicable both at the individual and system level. At the individual level, privacy is one’s right to control the collection, use and disclosure of one’s identifiable health information. At the system level, it relates to the protection of private information by assigning each case a unique identifier, such as a numeric code, and keeping parents’ information separate from birth defects data.

At the individual level, confidentiality is one’s right to have one’s identifiable health information kept secure. Thus, data must be accessible only to health-care providers and those directly involved in the surveillance programme. At the system
Privacy

- Issues related to privacy can be at both the individual and systems level.
- At the individual level, privacy is one’s right to control the collection, use and disclosure of one’s identifiable health information.
- At the systems level, can protect the privacy of information by:
  - Assigning each case a unique identifier such as a numeric code.
  - Keeping parents’ information separate from birth defect data.

Photographs in the context of privacy, confidentiality and security

- Photographs of the birth defect can:
  - Increase the quality of information transmitted to a surveillance program.
  - Help clinicians give the parents a more precise diagnosis.
- HOWEVER
  - Photographs should never be used in non-scientific settings, for example newspapers or magazines.
  - They should be transmitted in encrypted files, and should be stored securely.
- When photographs of birth defects are taken for educational or publication purposes, countries might require that parents sign authorization forms.

level, confidentiality can be ensured by removing all identifiers, locking or securing files, providing passwords to protect files, and requiring signed confidentiality agreements for surveillance workers.

The security of patient data and information can also be applicable both at individual and system levels. All individuals have the right to have their health data secured. At the system level, it is necessary to have safeguards and practices in place to protect data systems against unwarranted disclosure, modification or destruction.
Photographs of birth defects are needed to increase the precision of clinical diagnoses, and to help field workers (as a field atlas) to identify birth defects in the community. Photographs should not be used in non-scientific settings. In the context of privacy and confidentiality, clear guidelines about photography are to be followed in the surveillance systems to ensure privacy, confidentiality and data security.

**Discussion**

- When there are isolated defects, photographs should be taken only of the part of the body affected.
- The standard approach is to get consent for a picture right from the beginning.
- Standard photographs can be effectively used to train field workers and assist them in their role as surveyors, in the form of a field atlas.
- To ensure confidentiality, photographs collected in electronic format should be transferred in the system in an encrypted format with password protection.

**Partnerships and funding**

*(Dr Arvind Mathur, WHO Regional Office for South-East Asia)*

It is important to identify partners and their role in supporting the implementation of surveillance programmes. Partners include health providers, community workers,
programme managers, civil society, nongovernmental organizations, professionals and organizations as well as industry. They can support the surveillance programmes by developing goals, policies and funding plans, providing access to data, and providing long-term sustainability. Industry, for example, can play a role in food fortification and the availability of certain dosages of folic acid.

Birth defects surveillance: population coverage

(Dr Diana Valencia, CDC, Atlanta)

It is important to understand the different types of surveillance system. Member States need to decide which type of surveillance would work best in their country context. From the start, it is essential to decide the needs, set goals and objectives, set case definitions, identify available resources and assess existing legislation and policy support for birth defects surveillance.

Surveillance can be used to monitor acute and chronic occurrences of birth defects as well as for evaluation of prevention programmes. In acute events such as a sudden outbreak, surveillance is used to estimate how many cases occur and where. In chronic events, surveillance can inform overall burden of selected congenital anomalies. In evaluation strategies, it can be used to find out whether or not the prevention programmes work, and for considering the continuity of programmes/interventions. In addition, it is important to use the experience and lessons learnt from
existing surveillance systems in the countries, such as measles, acute flaccid paralysis, adverse event following immunization, neonatal tetanus, food and nutrition, and metabolic syndrome surveillance (in Thailand).

The two main methodological approaches for birth defects surveillance are population-based and hospital-based surveillance. Population-based surveillance captures the burden of birth defects within a population, which can provide “true” prevalence of birth defects. To avoid repetition in reporting (double counting), each patient should have a unique patient identification number. When a mother is a resident of a geographic area but delivers outside the area, this birth outcome will be counted in population-based surveillance.

There are advantages and disadvantages to population-based surveillance. As all resident births are included in the population-based surveillance, the prevalence estimates are usually more accurate as the denominator is better defined. The findings can be generalized to the general population. Reporting of defects is not limited to the time of birth, as conditions diagnosed beyond the newborn period are also included. However, population-based surveillance requires more resources (staff and funds), more time to establish, and there is potential duplication of information. It is suggested to start population-based surveillance in a small geographic area initially.

Hospital-based surveillance captures the cases that are born within participating hospitals located in a defined geographical area. Hospital-based surveillance cannot
provide “true” prevalence of birth defects because home deliveries are not counted. Mothers who are normally resident outside the geographic area but deliver in participating hospitals are included. There are some advantages to hospital-based surveillance, such as the need for fewer resources, the simpler protocols required and the generation of high-quality data. It is particularly useful in countries where most of the births occur in hospitals, as in Sri Lanka. There are disadvantages to hospital-based surveillance, however. Prevalence estimates can be unreliable as the target population is limited to those born in participating hospitals. There is also a risk of referral and selection bias.

Discussion

- Population-based surveillance is ideal, but due to resource limitations it is not possible in some countries. Therefore, it may be more practical to use hospital-based surveillance to know prevalence and trends over time.

- If hospital delivery is almost universal, hospital-based surveillance can be assumed as population-based surveillance.

- It was suggested to start with population-based surveillance where newborn screening exists, as in Sri Lanka and Thailand.

- In India, the proportion of health-facility delivery is around 75%. Having hospital-based surveillance could be the best option to start with, although the remaining 25% of home deliveries will be missed.

- As there are a lot of migrants in Thailand, there are some issues regarding birth defects cases born from migrant/non-Thai mothers. If the non-resident women are not served by prevention programmes (such as folic acid supplementation) then their delivery will affect the evaluation of the preventive programmes. In Thailand, all the babies born get a birth certificate regardless of their mother’s residency status. Babies born from non-resident mothers should not be counted in the denominator for statistical purposes.

- It is important to understand the concepts of prevalence, denominator and numerator. Comparison with other regions or year-by-year requires valid, high-quality data; however, if differences over time or across areas are of less interest than other things such as services, then estimating the prevalence will not be an issue.
• Besides hospital-based or population-based surveillance, a hybrid surveillance system can also be considered.
• When the denominator is the total number of births, it is necessary to add stillbirths into the estimation. If that is not feasible, the denominator would be live births only.

Case ascertainment

(Dr Joe Sniezek, CDC, Atlanta)

Case ascertainment can be active, passive or hybrid (a combination). An active system means using qualified people to go and find the case, either from multiple data sources or abstract information from various records. A passive case ascertainment system means asking people to send and report data, while a hybrid system is a combination of active and passive reporting systems. There are benefits and limitations to each system.

An active system may improve case detection, case reporting and data quality. However, this system requires considerable resources as well as personnel. In a passive system, fewer resources and personnel are required; however, data are less complete, it is reliant on people to send data, and allows the possibility of underestimation or overestimation of data. Hybrid case ascertainment potentially requires fewer resources and personnel, but similar drawbacks can occur as in the passive and active systems.
It is important to have champions – people who commit to and support the programme. They can be maternal, newborn, child and adolescent health staff, village health workers and professional workers (nurses or physicians) as well as the ministries of health.

**Discussion**

- Type of case ascertainment system can depend on the availability of funds and commitments.
- If hybrid case ascertainment is applied, only selected birth defects are checked.
- Champions can also be identified at the managerial level, some of whom may be engaged in national planning meetings where they can contribute to the programmes.
- To establish the surveillance system it is recommended to have a legal mandate and good monitoring system. It is necessary to use an individual or institution that can monitor, update information, mentor and provide feedback. The institutions chosen must be trusted ones, having interest and capacity in academic and research all over the country.

**Case finding and description formats**

*(Dr Joe Sniezek, CDC, Atlanta)*

Birth defect cases can be obtained from single or multiple data sources, however it is recommended to seek cases from multiple sources. Single data sourcing for birth defects is usually less time consuming, but fewer numbers of birth defects cases can be identified. Using multiple data sources, more cases can be detected and case ascertainment can be improved, however more time is required.

In a hospital-based reporting system, the delivery units, pediatric units, surgery units, vital records and neonatal care units can be used as sources for identifying cases of birth defects. In a population-based reporting system, the hospital-based sources, treatment clinics, rehabilitation clinics, genetic laboratories, foundations and associations that help children born with birth defects, databases of health insurance companies, and vital records can be used as sources for case finding. In multiple data sources, there is a possibility of double reporting or duplication which can be avoided by creating unique patient or hospital identification numbers.
There are two methods for describing birth defects in data collection forms: verbatim and checkbox. The verbatim method requires writing a detailed description of the case. This will ensure detailed information for accurate diagnosis of the birth defect at a later stage. The checkbox method depends on the person who fills in the form, and is most useful when used in combination with the verbatim method.
Inclusion criteria

(Dr Diana Valencia, CDC, Atlanta)

There are several criteria to be considered for inclusion of birth defects cases in a survey, such as age of diagnosis, pregnancy outcome (live birth/stillbirth), gestational age at delivery, birth weight and mother’s residency. Each country should decide which criteria they want to include in their surveillance programme.

- What birth defects will be included?
- Up to what age of diagnosis will a case be included?
- What pregnancy outcomes will be included?
- What gestational age at delivery or birth weight will be included?
- Why should maternal residency be considered?

The most important criterion to decide is which birth defects will be included in surveillance: all major birth defects, only selected defects, or whether minor defects will also be included. The availability of resources and capacity are important factors in the decision. It is easiest to start with a small number of recognizable major external birth defects and, later on, more defects can be added once the surveillance system is established. Internal birth defects can be considered for inclusion where there is enough capacity for diagnosis with laboratory or radiological diagnostic facilities. Thailand, for example, has started with five birth defects and will add more once surveillance on those five defects is in place.

The age criteria for inclusion could be newborn (or up to 7 days), or up to 1 year or more, depending on capacity. The higher the cut-off age, the greater the possibility of identifying additional anomalies.
Regarding pregnancy outcomes, surveillance could include live births alone or also include stillbirths and other outcomes, such as elective termination of pregnancy (induced abortions). Inclusion of many types of pregnancy outcome can ensure more completeness of data and case detection, but requires additional capacity, ability and resources. Some countries may have difficulty including stillbirths that occur before 28 weeks’ gestation and termination of pregnancy. When including live births and stillbirths, more than 50% of cases of spina bifida and anencephaly can be captured, while more than 90% of cases are missed when only in live births are included in surveillance.

In terms of birth weight, the cut-off criteria could be 500 g or 1000 g. In Maldives, for example, it is possible to detect a birth weight of 500 g as vital registration exists. Maternal residency is an important criterion when considering population-based surveillance.

Participants were asked to discuss the inclusion and exclusion criteria for hypothetical hospital-based surveillance programmes.

Discussion

- Including spontaneous abortion in birth defects surveillance would be useful for research purposes, but may not be feasible for programmatic purposes. For calculating actual prevalence, all pregnancies must be counted; however, information on stillbirths and induced and spontaneous abortion is incomplete in many countries.

- Neural tube defects (excepting spina bifida occulta) can be identified within a few days after birth, and there is no need to follow up for data collection at a later age.

- Stillbirths are defined differently across the countries. In Thailand, the cut-off is 25 weeks while in India it is 20 weeks gestation; other countries define it between 20–22 weeks gestation or 500 g birth weight.

- Autopsy of stillbirths is done in some countries. In India, it is only done in selected hospitals. In Myanmar, autopsy depends on parental consent.

- Referral and urban hospitals should be considered for selection when initiating hospital-based surveillance. However, many referral hospitals may not be the birthing/maternity hospitals.

- In a mandatory surveillance system all hospitals would be included, while in a voluntary system it is advisable to decide certain criteria for selection of participating hospitals.
Core ascertainment variables

(Dr Joe Sniezek, CDC, Atlanta)

When deciding the types of birth defects for surveillance programmes, it is important to decide which variables will be collected and how. Using existing data sources for collecting information on birth defects is a good idea in the beginning. Data sources within the hospitals include delivery (labour) rooms, pediatric wards, neonatal intensive care units, laboratory and vital records. Core variables to be collected depend on the goals and objectives of the surveillance programme of the country. It is suggested to focus on collecting only essential data, because there is a tendency to add more and more data that do not get used.

Examples of survey data and variables for birth defects were shared. The abstraction form for birth defects with essential core variables, which is available in the surveillance manual, was discussed.

Discussion

- There should be consensus on the minimum indicators to be collected uniformly across the country for specified birth defects. If some countries want to go further, they can add more indicators. Risk factors are also important for epidemiology purposes.
The information collected should be considered in relation to a defined denominator to have meaningful use e.g. outcome at birth such as live birth and stillbirth.

Length, head circumference and chest circumference of baby are usually recorded as part of the routine newborn examination. However, there is no published evidence of any relationship between length and head circumference of baby to birth defects. Therefore, it might be better to categorize these as optional variables.

The gestational age of small babies might be difficult to determine; therefore, best estimates of gestational age can be filled in.

Maternal address is important for providing information on prevalence in geographic areas. Residency during the first trimester can also provide a clue to some risk factors.

When setting up the surveillance system it is suggested to focus on a small set of core indicators. Look at the data that is already available in the hospital registration system, and then decide on the minimum additional variables.

If there are too many variables to be recorded, doctors may not fill all the form.

It would be useful to link newborn health information and birth defects together, and to include maternal risk factors that are common to both.

In the long-run, birth defects and newborn health data should be mainstreamed in the management information systems that exist in many countries.

In Sri Lanka, facility delivery is almost universal, and the data collection system is advanced compared to other countries. Therefore, indicators on risk factors can be added.

In Thailand, information on birth defects is collected under two systems: the national birth registry (civil registration) and birth defects association registry. The birth registry provides the additional information on the form of father and mother’s names, and baby’s birth weight. The form used by the birth defects association registry, for five common birth defects, is four pages long.
• India is proposing a birth defects registry, as there are several existing surveillance programmes. Core variables and risk factors would be incorporated.

• Indonesia can start to develop their surveillance system using the form provided in the manual. Until now, hospitals are the source of data. Available data are not fully transferred to the central registry at national ministry of health, which only receives the number and types of birth defects. There are more than 2000 hospitals throughout the country, but only around 24% of these send a report to the central registry.

• There is a list of related risk factors available in the manual that can be used by countries. Risk factor analysis is important, but it is very complicated. Each risk factor should have a clear definition e.g. obesity – what is the definition, prepregnancy obesity or not.

Data collection and management

*(Dr Diana Valencia, CDC, Atlanta)*

To improve birth defects surveillance, the quality of surveillance data must be ensured. Data definition and what is expected from the surveillance should be understood before starting data collection. Standard guidelines and a protocol should be defined so as to reduce variability, and surveillance teams should be established to ensure that the process works well.
Completeness, accuracy and timeliness of data are the essential elements for ensuring the quality of any surveillance system. Completeness is defined as the extent to which data are all-inclusive and comprehensive, including case ascertainment. Completeness of case ascertainment can be done by conducting a hospital audit, linking the cases with vital records and other specialized centres. Accuracy means that information is exact, correct and valid. It can be achieved by doing re-abstraction, clinical review and data entry verification. Timeliness is used to set a timeframe for the date of diagnosis, date of abstraction and date of reporting. For example, when the established protocol is to report the case within a week, then data should be sent within that timeframe. The data flow protocol shows how data collected at hospitals or clinics are transferred up to regional/national level in the surveillance programme.

Standardization is an important element of data collection. It provides uniformity for the use of a structured data collection form as well as on the classification and coding of birth defects. The data can be collected either by paper-based form or in an electronic-based format. Using a paper-based form is less expensive, but more errors can occur compared to electronic data collection formats. In hospital-based surveillance, each participating hospital should follow the same guidelines/protocol for data collection and reporting. This will avoid duplication, ensure detailed description of birth defects, and ensure timely and systematic reporting and analysis of data. For protection and security, electronic data should be transmitted as encrypted and restricted password-protected access given only to limited programme managers.
The latest version of Epi Info 7 developed by CDC is easily downloadable and available free of cost. In Epi Info, it is easy to create a form for data collection and analysis. The form and pictures of selected birth defects are available in Epi Info 7 software as well as on its Android-based application. Data collected is encrypted and can be easily transferred to the central registry using an internet connection.

**Data analysis**

*(Dr Pierpaolo Mastroiacovo, Director, ICBDSR)*

In birth defects surveillance, “prevalence” is used rather than “incidence rate” to measure birth defect occurrence. Determining incidence of birth defects is impractical because it requires evaluation of all the outcomes of conception including live births, stillbirths, terminations of pregnancy and spontaneous abortions. Thus, for practical reasons, it is suggested to use birth prevalence that includes live births and stillbirths as the denominator. Termination of pregnancy is not included in the denominator, because the total number of terminations may be very small compared to the total number of births and its exclusion has little impact on the estimate.

Case studies on calculating prevalence were discussed and practiced. Comparison across sites and over time cannot be made by comparing the number of cases, but by comparing the prevalence of birth defects. A case study comparing the birth prevalence of neural tube defects pre- and post-fortification in the USA from 1999 to 2007 showed...
the relation between the implementation of fortification of folic acid with the decline of neural tube defect rates.

There may be differences in prevalence among the ethnic groups. This can be due to differences in food staples or eating behaviours, or possibly due to genetic mutation. When implementing folic acid fortification, when a significant reduction is not seen in a certain population there is probably a genetic cause. Thus, it is sometimes important to collect information on different ethnic groups to evaluate the prevention programme.

**Clinical review of birth defects**

*Dr Pierpaolo Mastroiacovo, Director, ICBDSR*

The clinical review of birth defects focused on several types of birth defects including spina bifida and limb reduction defects, as well as omphalocele and gastroschisis. Four types of spina bifida were explained including the etiology, pathogenesis and clinical appearance. In multiple neural tube defects, spina bifida and anencephaly may occur together in which case both defects should be coded separately. Spina bifida occulta, a failure of neural arches to unite, is a minor defect and should not be counted in neural tube defects surveillance. The neural tube is formed in the embryo during the first days after conception; however, many women do not know that they are pregnant before the end of the first trimester. Anything that occurs after 28 days (end of week 5 of gestation) cannot cause or prevent neural tube defects.
Limb reduction defects are defined as the absence or severe hypoplasia of an upper limb or part of limb, including finger. Mild hypoplasia does not characterize a limb reduction defect, but is a minor anomaly. There are three categories of limb reduction defect: transverse, longitudinal and intercalary. Transverse defects mean absence of the distal part of a limb bone horizontally, at any level. Longitudinal defects mean partial or total absence of a limb bone vertically. Intercalary defects mean absence of intermediate part of limb bone with the proximal and distal part present. Pictures on limb reduction defects were shown and discussed.
The difference between gastroschisis and omphalocele was explained. In gastroschisis, the abdominal opening is positioned at the umbilical cord insertion. In omphalocele, the abdominal content is herniated through an enlarged umbilical ring and the umbilical cord is inserted in the distal part of the membrane covering the defect. Sometimes it is difficult to recognize cases of omphalocele when the membrane covering the defect has ruptured.

**Overview of birth defect coding**

*(Dr Pierpaolo Mastroiacovo, Director, ICBDSR)*

The important process of coding of birth defects starts at the field level. The field staff collects data and provides a description of birth defect cases. The data are then entered into the surveillance system and sent to the central registry, which conducts final review and analysis. This process involves a number of professionals, and requires accuracy and the use of standardized methods.

The International Statistical Classification of Diseases and Related Health Problems, tenth Revision (ICD-10) is the standard coding system. ICD-10 is the international standard diagnostic classification system for all general epidemiological purposes, health data management purposes and clinical use. It is developed by WHO, revised periodically and available in 42 languages. ICD-10 uses a simple alphanumeric coding
scheme. ICD-10 Chapter XVII (Q00-Q99) includes malformations, deformations and chromosomal anomalies, while some other birth defects are found in other chapters. There are some limitations to ICD-10 Chapter XVII, in that it is not as accurate as desired for congenital anomaly surveillance. Some chapters, particularly on malformations, are not precise enough to be used for etiological study: no distinction is made between major and minor malformations; it is not specific enough for some anomalies; many syndromes are not included; and there is erroneous nomenclature, such as Robin syndrome.

International coding extensions such as the Royal College of Paediatrics and Child Health (RCPCH) modification or the CDC extension, ICD-10-Clinical Modification (CM), can be used to reduce these limitations. For example, encephalocele of other sites is coded as Q01.8 in ICD-10-CM. In the RCPCH extension, Q01.80 is used for parietal encephalocele, Q01.81 for orbital encephalocele, Q01.82 for nasal encephalocele, and Q01.83 for nasopharyngeal encephalocele. Creating a new unique scheme is not recommended as it will create further difficulties. It should be kept in mind that the risk of distortion of the information from infant to coded data is great.

A good clinical description and documentation, including photographs, can minimize the distortion and maximize the accuracy of coding. Guidelines should be available for clinicians to aid accurate description of birth defects. Photographs are easy to take and have a low cost, however training is required and there is the issue of
confidentiality and privacy. If taking photographs is not possible, then drawing sketches is a good option.

Ideally, all birth defects should be coded regardless of whether they are minor or major. Coding minor defects requires more work, although it can provide clues for underlying conditions. Evidence shows that children with minor defects have a higher risk of internal defects. Coding the defects is not enough, however. It is also important to understand and code the certainty of diagnosis for dissemination of accurate
information. The degree of certainty depends on the description made by clinicians. The final coding for each defect will be “confirmed” or “possible”.

When a birth defect is diagnosed by prenatal diagnosis only, without the possibility of postnatal confirmation, the unconfirmed diagnosis should be excluded from the analyses. Prenatally diagnosed cases need to be explicit and clear.

Using a database format for storage, the description should be as wide as possible; hierarchical (storing major defects first, then minor); use a mark or associated field to identify major or minor defects; and store description in an anatomical order (cranio to caudal) following the ICD-10 order. For each case, it is suggested to use a field to code the clinical presentation such as isolated congenital anomalies, multiple congenital anomalies or syndromes. Additional fields can be added when a more precise coding of syndromes is preferred.

Discussion

• The use of ICD-10 depends on the country capacity. Based on the existing surveillance system, countries should decide from which level they start using the coding system. How to streamline and integrate ICD-10 into the system needs to be considered at the same time. A list of selected birth defects as well as providing the code and pictures at the field level can be a starting point.

• Almost all countries in the Region have used ICD-10 to some extent. Bangladesh has been conducting “training-of-trainers” for doctors and nurses. Bhutan, Indonesia and Maldives have been using ICD-10. India and Nepal have been using it in public hospitals. Myanmar receives a grant to conduct training for the use of ICD-10 in hospitals. Thailand has been using ICD-10 with modifications similar to the RCPCH extension.

• There are 10 fields available for coding the birth defects in one child. Therefore, when a child has more than one, it is possible to code all the defects.

• In Thailand’s birth registry, a checklist on anomalies is available.

• Pilot projects should be designed as realistically as possible and commitment for scaling-up and sustainability should be ensured.
• Bangladesh is planning to develop a surveillance tool at the community level by using photographs. When community health workers report cases, a trained paramedic will go to the field and see the patients. For the pilot surveillance project, new paramedics will be recruited. At the same time, capacity-building of the nurses and hospital staff will be conducted.

• Birth defects have been integrated in the regional neonatal–perinatal database.

Data dissemination

(Dr Diana Valencia, CDC, Atlanta)

Utilization of data collected and analysed in a surveillance system is an important step. Data are transformed into intelligent information that can be used for several purposes, including advocacy at the policy level. For effective dissemination of surveillance information, it is essential to identify the target audiences with whom the information is intended to be shared. Data can be disseminated in several ways and forms: in writing, electronically, or verbally. The written form can be a scientific publication, report, pamphlet, news release or letter. Electronic forms include web pages, social media (Twitter or Facebook) and list serve. Verbal dissemination can be done through health-care providers and outreach community health workers, both of which play a crucial role.
Participants discussed what type of information and messages can be used to convey messages to inform policy-makers and the public (including families) that birth defects are a serious and preventable public health issue. The role of the media and how it can create awareness in a country were discussed. The media can act as a double agent, and must be used cautiously after careful sensitization. Studies show that health-care providers play important role in conveying personal messages to the patient; it is therefore important to educate health-care providers to be able to convey messages effectively.

**Developing country action plans for birth defects surveillance**

Representatives from the participating countries worked together in country teams to develop possible set of activities over the next two years. The proposed country action plans are contained in Annex 3.

**Feedback on the surveillance manual**

During the workshop, participants provided useful feedback on the birth defects surveillance manual. The following suggestions were made.

- To add one general template on the consent form.
- To add more references at the end of each chapter.
- To add other risk factors, such as radiation and teratogen agents, as an appendix.
- To have mixed groups for the training, due to the possible different backgrounds of participants. It is useful to have different skills and expertise to set up a core team for birth defects surveillance.
- To give the objectives of each session at the beginning of the day, and to summarize at the end of the day.
- To provide background materials before the meeting, to prepare participants.
- To include some success stories from the countries.
• To share among the participants an example on how to communicate with parents.
• To develop a “Frequently Asked Questions” section, based on questions asked during the workshop.
• To add guidelines on how to conduct the review session.
• There is some information missing in the form in the surveillance manual, such as maternal risk factors, maternal illnesses and cause of death. There also is confusion regarding the “unknown sex” variable on the form.

The feedback provided will be used to strengthen the birth defects surveillance manual.
Annex 1

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Annex 2

Agenda

- Inaugural session
- Share an overview of the draft of surveillance toolkit
- Presentation of global overview of birth defects
- Presentation of regional overview of birth defects
- Presentation on the prevention, prioritization, and modifiable risk factors for birth defects
- Present and discuss the logic models for planning activities for birth defects surveillance
- Present and discuss the legislation, privacy and confidentiality issues of birth defects surveillance
- Present the role of partnerships and funding
- Present and discuss the various methodological approaches for birth defects surveillance including population coverage, case ascertainment, case finding and description formats, inclusion criteria, core ascertainment variables, data collection and management, and data analysis.
- Present clinical review of some birth defects
- Present, discuss and practice the birth defects coding
- Present and discuss dissemination of surveillance data and findings
- Develop country action plans
### Annex 3

**Country action plans**

1. **Identify nodal unit/nodal person for birth defects surveillance (in health ministry or institution)**

<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
</table>
| Bangladesh   | Programme Manager, Maternal and Neonatal Health, Directorate General of Health Services (DGHS) identified as focal person for birth defects.  
From institutions:  
1. Professor Md Shahidullah, Bangabandhu Sheikh Mujib Medical University (BSMMU).  
2. Dr Emdadul Haque, International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B). | Ministry of Health and Family Welfare | Identified     |
| Bhutan       | Involve the three regional hospitals                                                | Programme Manager of Reproductive Health Programme  
Institutions/hospitals as technical advisers  
Pediatricians  
Obstetricians/gynaecologists  
Staff in charge of labour rooms | October 2013                        |
| India        | Nodal unit at national coordinating institution  
- Health ministry representative  
- Geneticist/pediatrician trained in genetics  
- Programme Manager (preferably appointed from health ministry)  
- Data entry operator | Ministry of Health and Family Welfare  
Two WHO collaborating centres at AIIMS | 6 months                       |
<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indonesia</td>
<td>Meeting(s) will be held for policy-level staff of health ministry and senior management of Health Protection Agency</td>
<td>Reproductive Health Unit – Health Protection Agency</td>
<td>July 2013</td>
</tr>
<tr>
<td>Maldives</td>
<td>Meeting(s) will be held for policy-level staff of health ministry and senior management of Health Protection Agency</td>
<td>Reproductive Health Unit – Health Protection Agency</td>
<td>July 2013</td>
</tr>
</tbody>
</table>
| Myanmar     | 1. Nodal person – Programme Manager (Nutrition)  
2. To form Technical Working Group:  
• Senior pediatrician, Central Women’s Hospital, Mandalay  
| Nepal       | Family Health Division, Ministry of Health and Population  
Institute of Medicine                                                                                                                                                                                                | Director, Family Health Division Dr Laxman Shrestha  | September 2013|
| Sri Lanka   | Multisectoral working committee on prevention and control of birth defects established.  
Deputy Director General (Public Health Services II) identified as the focal point for entire birth defects programme.  
National Programme Manager, Maternal & Child Morbidity & Mortality Surveillance Unit of Family Health Bureau recognized as the nodal person. | Already completed                                    |               |
### Country: Thailand

<table>
<thead>
<tr>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
</table>
| Queen Sirikit National Institute of Child Health Department of Health, Ministry of Public Health | 1. Draft policy  
2. Communicate to stakeholders  
3. Implement policy  
4. Financial support  
5. Database linkage | 1 year |

### 2. Identify resources: funds, human resources, tools and partners

<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>Funds need to be identified; small grants received from WHO for national strategic planning workshop and developing tools for surveillance. Funds needed for capacity-building on surveillance at national level. BSMMU and ICDDR,B are on board. BRAC will be partner in population-based surveillance</td>
<td>Ministry of Health and Family Welfare BSMMU WHO ICDDR,B</td>
<td>September–December 2013</td>
</tr>
<tr>
<td>Bhutan</td>
<td>Ministry of Health WHO for funds</td>
<td>Programme managers of Reproductive Health Programme Department of Public Health Ministry of Health</td>
<td>October 2013</td>
</tr>
<tr>
<td>India</td>
<td>WHO Government of India Indian Council of Medical Research (for research objectives)</td>
<td>Two WHO collaborating centres at AIIMS</td>
<td>6 months</td>
</tr>
<tr>
<td>Country</td>
<td>Recommended actions</td>
<td>Responsibility</td>
<td>Timeframe</td>
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</tr>
<tr>
<td>Indonesia</td>
<td>Funds: WHO SEARO, the proposal has been developed and submitted to WHO SEAROHR: establish task forces in hospital level, conduct training for the task force. Tools: adapt the surveillance manual into country context (included booklet for diagnostic major BD)</td>
<td>MOH, Directorate of Child Health, National task forces</td>
<td>Funds expected received by the end July 2013 National TOT should be conducted by Sept 2013 Tools should be ready by mid of August</td>
</tr>
<tr>
<td>Country</td>
<td>Recommended actions</td>
<td>Responsibility</td>
<td>Timeframe</td>
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</tbody>
</table>
            3. Tools: protocols, forms, software.  
            4. Partners: Ministry of Health and Population, hospitals, professional organizations, WHO. | Director, Family Health Division    | December 2013 |
|           |                                                                                                                                                     | Dr Laxman Shrestha                  |                |
| Sri Lanka | Funding: Government of Sri Lanka, WHO.  
            Partners: professional organizations (SLCP, PSSL, SLCOG, CCPSL, CFPSL, SLCO, geneticists, etc.) and provincial health-care administrators/hospital heads.  
            National consultation already conducted to provide human resource for MCMMS unit. | National Programme Manager          | August 2013    |
|           |                                                                                                                                                     | Ministry of Health and Family Welfare |                |
| Thailand  | 1. Department of Health  
            2. Bureau of Policy and Strategy  
            3. Permanent Secretarial Office of Ministry of Public Health  
            4. National Health Security Office  
            5. Ministry of Interior | Ministry of Public Health           | 1 year         |
|           |                                                                                                                                                     | National Health Security Office      |                |
### 3. Steps to reach consensus on birth defects surveillance mechanism

<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>National Strategic Planning Meeting</td>
<td>Nodal person from Ministry of Health and Family Welfare HMIS DGHS WHO</td>
<td>August 2013</td>
</tr>
<tr>
<td>Bhutan</td>
<td>Coordination between stakeholders. Advocacy.</td>
<td>Reproductive Health Programme</td>
<td></td>
</tr>
<tr>
<td>India</td>
<td>National consensus meeting for national neonatal–perinatal database/birth defects registry including participating institutions. Two institutions from each region of the country. Representatives from four districts identified by Government of India.</td>
<td>Ministry of Health and Family Welfare WHO collaborating centres at AIIMS</td>
<td>6 months</td>
</tr>
<tr>
<td>Indonesia</td>
<td>National consultation to develop the mechanism. Development of tools (form, guidelines and protocols) and endorsement. Propose the developed mechanism to policy-level and relevant stakeholders for endorsement.</td>
<td>Health Protection Agency</td>
<td>January–July 2014</td>
</tr>
<tr>
<td>Maldives</td>
<td>National consultation to develop the mechanism. Development of tools (form, guidelines and protocols) and endorsement. Propose the developed mechanism to policy-level and relevant stakeholders for endorsement.</td>
<td>Health Protection Agency</td>
<td>January–July 2014</td>
</tr>
<tr>
<td>Country</td>
<td>Recommended actions</td>
<td>Responsibility</td>
<td>Timeframe</td>
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</tr>
<tr>
<td>Nepal</td>
<td>Meeting with authorities of: Family Health Division, Child Health Division, Health Management Information System (HMIS) (Ministry of Health and Population), Professional organizations</td>
<td>Director of Family Health Division, Ministry of Health and Population Institute of Medicine</td>
<td>December 2013</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>Technical committee on birth defects established, National consultation already conducted.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thailand</td>
<td>Meeting with stakeholders to evaluate surveillance mechanism.</td>
<td>Provide relevant information on different types of birth defects.</td>
<td>1 year</td>
</tr>
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</table>
### 4. Develop a national mandate for birth defects surveillance and prevention: policy/legal

<table>
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<tr>
<th>Country</th>
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<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>A national technical committee will be formed to review the policies/legislations and make recommendations.</td>
<td>Ministry of Health and Family Welfare and all other stakeholders</td>
<td>August–December 2013</td>
</tr>
</tbody>
</table>
| Bhutan | 1. Develop national planning meeting.  
2. Find out the prevalence of five major birth defects:  
   - neural tube defects  
   - anencephaly  
   - limb deformities  
   - gastroschisis and omphalocele  
   - hypospadias (in hospital-based).  
3. Develop policy for immediate referral and treatment of cases.  
4. Develop policy to take informed consent.  
5. Carry out the surveillance for 1 year, then extend. | Ministry of Health  
Programme managers of reproductive health programmes | October 2013 |
| India | Advocacy to Government of India policy-makers to combine with Rashtriya Bal Suraksha Karyakram (RBSK).                                                                                                                  | Representatives from all participating institutions                                                        | 1 year            |
| Indonesia | Can be discussed during the national consultation planned for August 2013.  
At present, birth defect prevention strategies are included in the draft National Reproductive Health Strategy (2013 – 2017).  
The micronutrient policy also address interventions required for birth defects prevention (the policy is in the process of endorsement).  | Health Protection Agency                                                                                   | January–July 2014 |
<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
</table>
| Maldives     | Can be discussed during the national consultation planned for August 2013  
At present, birth defect prevention strategies are included in the draft National Reproductive Health Strategy (2013 – 2017).  
The micronutrient policy also address interventions required for birth defects prevention (the policy is in the process of endorsement). | Health Protection Agency                | January–July 2014 |
| Myanmar      | Develop a national strategy for prevention and control of birth defects                                                                                                                                             | Technical Working Group National consultant | 2013               |
| Nepal        | Meeting with authorities of:  
• Family Health Division  
• Child Health Division  
• HMIS (Ministry of Health and Population)  
• Professional organizations.                                                                                                                              | Director of Family Health Division, Ministry of Health and Population Institute of Medicine | December 2013      |
| Sri Lanka    | National consultation already conducted. Birth defects prevention and control workplan developed. Surveillance mechanism agreed upon. Legal immunity to be worked out.                                             | National Programme Manager              | December 2013      |
| Thailand     | Hospital-based surveillance in 20 hospitals. Develop online software. Training on case identification, and entering and verifying data.                                                                            | Ensure uniform implementation           | 1 year             |
## 5. Communication and social mobilization

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<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>Advocacy workshop at divisional level</td>
<td>Nodal person and Management Information System, DGHS WHO and other development partners</td>
<td>January–June 2014</td>
</tr>
</tbody>
</table>
| Bhutan     | 1. Advocacy: use of media such as TV and print.  
2. Educate mothers in antenatal clinics and obstetric wards, as surveillance will be hospital-based.                                                                 | Ministry of Health Obstetricians/gynaecologists, pediatricians, obstetric unit in charge             | 1. September 2013  
2. October 2013 |
<p>| India      | Inclusion of messages in existing advocacy material for antenatal, perinatal and maternal and child health package. Communication through various media regarding importance of detection of birth defects and possibility of prevention. | To be decided in consultation with Ministry of Health and Family Welfare                              | 1 year                       |</p>
<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myanmar</td>
<td>• Advocacy</td>
<td>• Central Health Education Bureau</td>
<td>Late 2014–2015</td>
</tr>
<tr>
<td></td>
<td>• Capacity-building of basic health services</td>
<td>• Nutritionists</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Social mobilization of community leaders, local authorities, volunteers</td>
<td>• Clinicians</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Mass media</td>
<td>• Partners</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Inter-personal communication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nepal</td>
<td>Family Health Division in consultation with National Health Education, Information and Communication Centre. Professional organizations.</td>
<td>Director, Family Health Division</td>
<td>June 2014</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>Strategies, activities and target groups identified. To conduct proposed communication and social mobilization activities.</td>
<td>National Programme Manager</td>
<td>November 2013</td>
</tr>
<tr>
<td>Thailand</td>
<td>Created registry network. Annual meeting “sharing lessons learned and knowledge management”.</td>
<td>Timely report every trimester. Provide feedback on accuracy of case identification.</td>
<td>1 year</td>
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</table>
## 6. Surveillance training

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<thead>
<tr>
<th>Country</th>
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<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>Identify potential trainers and provide training-of-trainers. Training for the district- and subdistrict-level providers.</td>
<td>As above Professional organizations ICDDR,B</td>
<td>December 2013–March 2014</td>
</tr>
</tbody>
</table>
| Bhutan           | 1. Training of all obstetricians/gynaecologists, pediatricians, neonatal units and obstetric units in charge of birth defects surveillance in three regional hospitals.  
2. Training of all health staff working in delivery wards of the three regional hospitals and neonatal wards on identification and reporting selected birth defects. | 1. Reproductive Health Programme, Department of Public Health, Ministry of Health  
2. Three focal persons (pediatricians or obstetricians/gynaecologists) appointed during the national training  | 1. September 2013  
2. October 2013                                                                 |                                                                              |
<p>| India            | After the national consultation meeting, surveillance training for staff in participating institutions.                                                                                                              | Both WHO collaborating centres at AIIMS                                           | 7–8 months                  |
| Indonesia        | Training will be given for the selected hospital and programme staff.                                                                                                                                               | Health Protection Agency                                                        | 2014                        |
| Maldives         | Training will be given for the selected hospital and programme staff.                                                                                                                                              | Health Protection Agency                                                        | 2014                        |</p>
<table>
<thead>
<tr>
<th>Country</th>
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<th>Timeframe</th>
</tr>
</thead>
</table>
| Myanmar | 1. Capacity-building of member institutions:  
- Database trainings  
- Birth defect surveillance.  
2. First data summary 3 months after implementation.  
3. Regular quarterly meetings.  
4. Development of checklist for monitoring and supportive supervision. | Training-of-trainers team  
Perinatal-neonatal networking group. | 1. Third quarter 2013 and first quarter 2014  
2. First/Second quarter 2014  
3. From first quarter 2014 onwards  
4. Fourth quarter 2013 or first quarter 2014 |
| Nepal | Identification of partner hospitals and staff of those hospitals. | Dr Laxman Shrestha, Dr Mahaseth, Deepak Dahal WHO Regional Office for South-East Asia | May 2014 |
| Sri Lanka | To conduct training workshop for designated medical officers of participating hospitals. | National Programme Manager  
Hospital authorities | January 2014 |
| Thailand | In 20 hospitals. | Integration with existing birth registry | 1 year |

7. Plans for pilot implementation of birth defects surveillance: design, implementation and evaluation

<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
</table>
| Bangladesh | Develop protocol for population-based surveillance.  
Institutional Review Board approval.  
Training of staff on data collection tools.  
Design data management system.  
Data entry. | Nodal person at the Ministry of Health and Family Welfare.  
WHO  
ICDDR,B  
BSMMU  
UBC | September 2013–December 2015 |
<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
</table>
| Bhutan    | 1. Hospital-based surveillance involving the three regional hospitals.  
2. All birth defects in babies born in the three regional hospitals will be reported.  
5. Data collection by paper-based method.  
6. Complete abstraction forms sent to national surveillance programme. | Reproductive Health Programme Manager  
Technical person/focal person for birth defects | October 2013–October 2014 |
| India     | Two parallel activities:  
1. Surveillance system for magnitude of selected birth defects (common abstraction form without risk factors). All medical colleges in phased manner with inclusion of four districts (from RBSK) to start.  
WHO collaborating centres at AIIMS.  
Representatives of selected institutions. | 1 year |
| Indonesia | Identify institution for piloting.  
Design the programme in consultation with all relevant staff and organizations.  
Obtain/arrange resources required.  
<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maldives</td>
<td>• Identify institution for piloting.</td>
<td>Technical Working Group</td>
</tr>
<tr>
<td></td>
<td>• Design the programme in consultation with all relevant staff and organizations.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Obtain/arrange resources required.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Start data collection.</td>
<td></td>
</tr>
<tr>
<td>Myanmar</td>
<td>• Hospital-based, four tertiary maternity hospitals and one referral hospital.</td>
<td>Health Protection Agency</td>
</tr>
<tr>
<td></td>
<td>• Inclusion criteria: external major structural anomalies (neural tube defects, cleft lip and palate, gastrointestinal, omphalocele, gastroschisis, imperforate anus, limb anomalies, Down's Syndrome).</td>
<td></td>
</tr>
<tr>
<td>Nepal</td>
<td>• Training health staff of partner hospitals.</td>
<td>Family Health Division, Ministry of Health and Population Institute of Medicine</td>
</tr>
<tr>
<td></td>
<td>• Supply of logistics.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Printing of forms.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Supply of software.</td>
<td></td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>• Develop data formats.</td>
<td>National Programme Manager Hospital authorities Professional colleges</td>
</tr>
<tr>
<td></td>
<td>• Develop a web-based surveillance system.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Pilot the proposed surveillance mechanism in two selected districts.</td>
<td></td>
</tr>
<tr>
<td>Thailand</td>
<td>• 20 hospitals based in 15 provinces, cross-sectional, descriptive.</td>
<td>Ensure uniform implementation</td>
</tr>
<tr>
<td></td>
<td>• Training on how to identify cases, enter and verify data.</td>
<td></td>
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</tbody>
</table>

Timeframe:
- Myanmar: 2013
- Nepal: June 2014
- Sri Lanka: January, 2013
- Thailand: 1 year
8. Analysis of data

<table>
<thead>
<tr>
<th>Country</th>
<th>Recommended actions</th>
<th>Responsibility</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>Ongoing</td>
<td>ICDDR,B BSMMU</td>
<td>August–December 2015</td>
</tr>
</tbody>
</table>
| Bhutan      | 1. All completed abstraction forms from three regional hospitals to be sent to national surveillance centre under Reproductive Health Programme.  
           | 2. Completed abstraction forms sent on monthly basis (end of the month).            | National focal persons                           | October 2013–October 2014|
| India       | National coordinating centre                                                       | Ministry of Health and Family Welfare WHO collaborating centres at AIIMS Representatives of selected institutions | 3 years                 |
| Indonesia   | Analyse the data which have been collected                                          | Health Protection Agency                         | 2015                    |
| Maldives    | Analyse the data which have been collected                                          | Health Protection Agency                         | 2015                    |
| Myanmar     | Linking with HMIS                                                                   | HMIS                                            | 2014–2015               |
| Nepal       | Entry of forms and verification Data to be send to Family Health Division/Ministry of Health and Population | Family Health Division/Ministry of Health and Population |                         |
| Sri Lanka   | To be done at central level                                                         | National Programme Manager                      | December 2014           |
| Thailand    | Hospital-based surveillance Live birth prevalence                                   |                                                 | 1 year                  |
### 9. Dissemination of information

<table>
<thead>
<tr>
<th>Country</th>
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<th>Responsibility</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Bhutan</td>
<td>Stakeholders meeting</td>
<td>Ministry of health</td>
<td>2 years</td>
</tr>
<tr>
<td>India</td>
<td>Report, publications, advocacy material</td>
<td>Ministry of Health and Family Welfare WHO collaborating centres at AIIMS Representatives of selected institutions</td>
<td>1–3 years</td>
</tr>
<tr>
<td>Indonesia</td>
<td>Develop a report and disseminate the result to all relevant stakeholders</td>
<td>Health Protection Agency</td>
<td>2016 June</td>
</tr>
<tr>
<td>Maldives</td>
<td>Develop a report and disseminate the result to all relevant stakeholders</td>
<td>Health Protection Agency</td>
<td>2016 June</td>
</tr>
<tr>
<td>Myanmar</td>
<td>Review meeting Evaluation workshops</td>
<td>Technical Working Group</td>
<td></td>
</tr>
<tr>
<td>Nepal</td>
<td>Meeting with partner hospitals, stakeholders, professional organizations</td>
<td>Family Health Division/Ministry of Health and Population</td>
<td>July 2015</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>To all relevant stakeholders</td>
<td>National Programme Manager</td>
<td>December 2014</td>
</tr>
<tr>
<td>Thailand</td>
<td>Report data online Annual report</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Country logic frame

<table>
<thead>
<tr>
<th>Country</th>
<th>Resources</th>
<th>Activities</th>
<th>Outputs</th>
<th>Short- and long-term outcomes</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ministry of Health and Family Welfare, WHO, other partners</td>
<td>Advocacy workshop at divisional level</td>
<td>Sensitization of decision-makers, health-service providers, professionals, elites</td>
<td>Target audience sensitized</td>
<td>Change in policy and positive environment for birth defects</td>
</tr>
<tr>
<td>WHO-SEARO</td>
<td>Training-of-trainers on surveillance system</td>
<td>Group of facilitators</td>
<td>Local-level training</td>
<td>Effective implementation of surveillance</td>
<td></td>
</tr>
<tr>
<td>WHO-SEARO/CDC</td>
<td>Participation in birth defects workshop in Cebu</td>
<td>Understanding and dissemination global and regional context of birth defects</td>
<td>Reflected in country birth defects initiatives</td>
<td>Birth defects surveillance and reporting</td>
<td></td>
</tr>
<tr>
<td>WHO Country Office</td>
<td>Inclusion in biennium 2014–2015</td>
<td>Implementation of activities for birth defects</td>
<td>Surveillance system Routine system for birth defects</td>
<td>Birth defects surveillance and reporting</td>
<td></td>
</tr>
<tr>
<td>Country</td>
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<td>Short- and long-term outcomes</td>
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</tr>
<tr>
<td>Bhutan</td>
<td>Ministry of Health and WHO (financial)</td>
<td>Training of staff (midwifery/neonatal) on birth defects surveillance and clinical diagnosis of major defects</td>
<td>Birth defects registry and data collection</td>
<td>Know the prevalence or disease burden</td>
<td>Identification of birth defects, quick referral and treatment</td>
</tr>
<tr>
<td></td>
<td>Tools of data/analyses (software)</td>
<td>Appoint three regional focal persons</td>
<td>Birth defects registry and data collection</td>
<td>Identify risk factors</td>
<td>Better quality data on birth defects</td>
</tr>
<tr>
<td></td>
<td>Ministry of Health and donor agency</td>
<td>National advocacy on TV (media), print or health education</td>
<td>Public awareness on birth defects</td>
<td>Enhance knowledge</td>
<td>Reduced prevalence of birth defects</td>
</tr>
<tr>
<td>India</td>
<td>Human resources</td>
<td>• Identification of objectives and stakeholders</td>
<td>Implementation</td>
<td>Produce report for advocacy</td>
<td>Reduction in birth defects</td>
</tr>
<tr>
<td></td>
<td>Identify existing resources</td>
<td>• Plan hospital-based surveillance protocols</td>
<td>Prevalence data</td>
<td>Publications</td>
<td>Decrease in neonatal mortality rate, infant mortality rate and under-5 mortality rate</td>
</tr>
<tr>
<td></td>
<td>Infrastructure</td>
<td>• Identification of participating hospitals and champions</td>
<td>Risk factors</td>
<td>Development of preventive policies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tools</td>
<td>• Training</td>
<td>Feasibility and upgradable model Programme</td>
<td>Referral system for identified families</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Standard operating procedures</td>
<td>• Initiation in phased manner</td>
<td></td>
<td>Nationwide implementation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Funding</td>
<td>• QA</td>
<td></td>
<td>Ongoing sustained system</td>
<td></td>
</tr>
<tr>
<td>Country</td>
<td>Resources</td>
<td>Activities</td>
<td>Outputs</td>
<td>Short- and long-term outcomes</td>
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<td></td>
</tr>
<tr>
<td>Indonesia</td>
<td>Funds</td>
<td>National meeting, Task force establishment, National training-of-trainers</td>
<td>Consensus gained, National network of institution for birth defects, Taskforce members trained</td>
<td>Short-term: birth defect surveillance implemented in 10 nodal hospitals, Short-term: birth defect prevalence in 10 nodal hospitals, Long-term: policies for reduction in birth defects</td>
<td></td>
</tr>
<tr>
<td>Indonesia</td>
<td>Champion, government, partner, stakeholders</td>
<td>Develop national strategic plan on birth defects, Propose legislation</td>
<td>National meeting, Task force establishment</td>
<td>Short-term: birth defect prevalence decreased, Reduction in under-5 mortality rate, Long-term: policies for reduction in birth defects</td>
<td></td>
</tr>
<tr>
<td>Indonesia</td>
<td>Programme support to collect data</td>
<td>Monitoring and evaluation, Analysis of data</td>
<td>National meeting, Task force establishment</td>
<td>Short-term: birth defect prevalence decreased, Reduction in under-5 mortality rate, Long-term: policies for reduction in birth defects</td>
<td></td>
</tr>
<tr>
<td>Indonesia</td>
<td>Legislative support to collect data</td>
<td>Advocacy</td>
<td>National meeting, Task force establishment</td>
<td>Short-term: birth defect prevalence decreased, Reduction in under-5 mortality rate, Long-term: policies for reduction in birth defects</td>
<td></td>
</tr>
<tr>
<td>Country</td>
<td>Resources</td>
<td>Activities</td>
<td>Outputs</td>
<td>Short- and long-term outcomes</td>
<td>Impact</td>
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<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Maldives</td>
<td>Funding sources</td>
<td>Identify goals</td>
<td>Established hospital-based surveillance system</td>
<td>• Short-term: surveillance programme established in selected hospitals</td>
<td>• Reduction in the prevalence of preventable congenital anomalies</td>
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<td></td>
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<td></td>
<td>• Awareness/sensitization created among relevant stakeholders</td>
<td>• Reduction in under-5 mortality rate</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>• Develop policies</td>
<td>• Improved quality of life of affected children</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>• Families receive counselling and referral mechanism established</td>
<td></td>
</tr>
<tr>
<td>Infrastructure</td>
<td>Identify relevant stakeholders</td>
<td>Develop reports and recommendations</td>
<td>Long-term: policies for food fortification</td>
<td>Reduction in preventable malformation</td>
<td></td>
</tr>
<tr>
<td>Programme manager and staff</td>
<td>Policy advocacy and sensitization of stakeholders</td>
<td>Identify risk factors</td>
<td>Establishment of services to manage congenital anomalies</td>
<td></td>
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<tr>
<td>Partners</td>
<td>Develop and implement surveillance protocol and guidelines</td>
<td></td>
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<tr>
<td>Government/nongovernment</td>
<td></td>
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<tr>
<td>Participating hospitals</td>
<td>Select sites</td>
<td></td>
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<tr>
<td>Legislative support to collect data</td>
<td>Training</td>
<td></td>
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<tr>
<td></td>
<td>Procure tablets/camera</td>
<td></td>
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</tr>
<tr>
<td>Country</td>
<td>Resources</td>
<td>Outputs</td>
<td>Short- and long-term outcomes</td>
<td>Activities</td>
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</tr>
<tr>
<td>Myanmar</td>
<td>Tool for data collection and analysis</td>
<td>Funds</td>
<td>Consensus obtained</td>
<td>Establish surveillance system</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Funds</td>
<td>Capacity-building</td>
<td>Assess data quality</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Monitoring and evaluation</td>
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<td></td>
<td></td>
<td>Funds</td>
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<td>Expand the programme nationwide</td>
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<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>National planning workshop</td>
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<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Training on birth defects surveillance system</td>
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<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Development of guidelines</td>
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<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Strategic plan in place</td>
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<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Long-term: food fortification</td>
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<tr>
<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Awareness raised</td>
<td></td>
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<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Updated data and recommendations</td>
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<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Programme is functioning</td>
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<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Financial allotment</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Funds</td>
<td></td>
<td>Incorporate into WHO biennium workplan</td>
<td></td>
</tr>
</tbody>
</table>

**Impact**

- Short-term: national surveillance system for birth defects visualized
- Long-term: national surveillance system for birth defects visualized
- Tools for data collection and analysis
- Monitoring and evaluation
- Implementing partners
- Tools

**Outcomes**

- Consensus obtained
- Capacity-building
- Strategic plan in place
- Long-term: food fortification
- Updated data and recommendations
- Programme is functioning
- Financial allotment

**Activities**

- Establish surveillance system
- Assess data quality
- Monitoring and evaluation
- Expand the programme nationwide
- National planning workshop
- Training on birth defects surveillance system
- Development of guidelines
- Strategic plan in place

**Outputs**

- Consensus obtained
- Capacity-building
- Strategic plan in place
- Awareness raised
- Updated data and recommendations
- Programme is functioning
- Financial allotment

**Resources**

- Tool for data collection and analysis
- Monitoring and evaluation
- Implementing partners
- Tools

**Country**

- Myanmar

**Impact**

- Reduction in neural tube defects
- Reduced neonatal mortality rate
- Infant mortality rate
- Under-5 mortality rate

**Outcomes**

- Short-term: national surveillance system for birth defects visualized
- Long-term: food fortification
<table>
<thead>
<tr>
<th>Country</th>
<th>Resources</th>
<th>Activities</th>
<th>Outputs</th>
<th>Short- and long-term outcomes</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nepal</td>
<td>WHO MoH</td>
<td>Training of staff</td>
<td>Birth defects registry and data collection</td>
<td>Prevalence of birth defects Risk factors for birth defects</td>
<td>Identification of birth defects Treatment and referrals Quality of life</td>
</tr>
<tr>
<td></td>
<td>Tools Logistics support</td>
<td>Birth defects registry</td>
<td>Collection of data</td>
<td>Initiation of programme Expansion of surveillance</td>
<td>Awareness Preventive programmes</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>WHO Government of Sri Lanka</td>
<td>Finalize the implementation of birth defects surveillance e.g. formats and training</td>
<td>Completion of the pilot</td>
<td></td>
<td>Availability of data on prevalence of selected birth defects in piloted area</td>
</tr>
<tr>
<td></td>
<td>WHO Government of Sri Lanka</td>
<td>Scaling-up of birth defects surveillance</td>
<td>System established island-wide</td>
<td></td>
<td>Availability of data country-wide</td>
</tr>
<tr>
<td>Thailand</td>
<td><strong>Funding:</strong> Department of Medical Services, Ministry of Public Health</td>
<td>Develop birth defects surveillance system</td>
<td>Implementation of birth defects surveillance</td>
<td>Short-term: change in knowledge, attitudes, awareness</td>
<td>Improved health outcomes</td>
</tr>
<tr>
<td></td>
<td><strong>Staff:</strong> Queen Sirikit National Institute of Child Health</td>
<td>Data collection and analysis</td>
<td>Translation, utilization and dissemination of surveillance data and information</td>
<td>Intermediate-term: change behaviours and practices, data for policy direction</td>
<td>Improved survival/reduced morbidity</td>
</tr>
<tr>
<td></td>
<td><strong>Partnerships:</strong> 20 hospitals</td>
<td>Capacity-building</td>
<td></td>
<td>Long-term: prevention of birth defects</td>
<td></td>
</tr>
</tbody>
</table>

## Nepal
- **Country:** Nepal
- **Resources:** WHO, MoH
- **Activities:** Training of staff
- **Outputs:** Birth defects registry and data collection
- **Short- and long-term outcomes:** Prevalence of birth defects, Risk factors for birth defects
- **Impact:** Identification of birth defects, Treatment and referrals, Quality of life

## Sri Lanka
- **Country:** Sri Lanka
- **Resources:** WHO, Government of Sri Lanka
- **Activities:** Finalize the implementation of birth defects surveillance e.g. formats and training
- **Outputs:** Completion of the pilot
- **Impact:** Availability of data on prevalence of selected birth defects in piloted area

## Thailand
- **Funding:** Department of Medical Services, Ministry of Public Health
- **Staff:** Queen Sirikit National Institute of Child Health
- **Partnerships:** 20 hospitals
### Challenges expected for BDs surveillance in the country

- Create awareness, sensitization of policy makers, policy commitment
- If it is not made mandatory by policy makers, it may not be sustained
- Competing priorities with infectious diseases and newborn illness
- Resources: funds, manpower
- Capacity building amongst primary health workers (including continuity of training)
- Inclusion in the routine information system for national scale up
- Integration of preventive interventions in existing health system
- Lack of available services for identified BD including limited laboratory services (genetic lab)
- Fortification of food with folic acid
- Extra workload for the health staffs in the neonatal/delivering wards may inaccurately or incompletely fill the forms
- Consistency of quality data entry by personnel
- Resignation of champion on the nodal hospital
- Low IT literacy
- Insufficient IT connections & equipment
- No Newborn screening program yet

### Support needed for BDs surveillance at country level

- Technical support
- Resource allocation
- Training materials such as manuals, guidelines, or atlas will be needed for training to be conducted in the country for other staffs.
- Information Technology
- Financial support
- Implementation
- Data analysis
The South-East Asia strategic framework on prevention and control of birth defects (2013–2017) underlines the importance of developing birth defects surveillance mechanisms to determine the burden and evaluate the preventive programmes as these get implemented in countries. A regional workshop on birth defects surveillance was organized by the Queen Sirikit National Institute of Child Health, Thailand, with the support of the WHO Regional Office for South-East Asia and the Centers for Disease Control and Prevention (CDC), Atlanta, USA. It was attended by national nodal persons on birth defects, national programme managers responsible for surveillance in Member States, representatives of the Regional Network for Newborn Health and Birth Defects, and WHO staff from country offices (Bangladesh and Indonesia). The meeting was facilitated by experts from the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR), CDC, and the WHO Regional Office for South-East Asia. The birth defect surveillance package developed by WHO, CDC and ICBDSR was used. Participants reviewed the principles of surveillance and practised specific skills on birth defects surveillance. It was agreed that countries need to define the primary purposes of birth defects surveillance and decide on the surveillance mechanisms to be used based on the country context and capacity. Major and external birth defects will be prioritized for inclusion in birth defects surveillance. Tentative action plans for national birth defects surveillance mechanisms were developed by country teams.