With improvements in the management of major causes of neonatal mortality such as infection and asphyxia, birth defects are increasingly seen as a major cause of stillbirths and neonatal deaths. Preventing birth defects-related mortality would contribute to further reduction in child mortality in countries and contribute to achievement of MDG-4. In view of this, the World Health Assembly adopted WHA Resolution 63.17 in May 2010, which identified actions to address birth defects to impact stillbirths and neonatal mortality. In response, the South-East Asia Regional Office of WHO proposed to develop a Regional Strategy for prevention and control of birth defects in consultation with Member States and partner agencies.

A Regional programme managers’ meeting on prevention and control of birth defects was held from 20 to 22 March 2012 in Bangkok, Thailand. Presentations were made to summarize the global, regional and country situations. Key technical areas related to evidence for prevention of birth defects, birth defects surveillance, communication and advocacy were discussed. The draft Regional strategic framework for prevention and control of birth defects was reviewed and discussed. Based on the understanding developed in the meeting the national programme managers developed tentative action plans for prevention of birth defects for the next two years and five years.

Prevention and control of birth defects in South-East Asia

Report of Regional Programme Managers’ meeting

Bangkok, Thailand, 20-22 March 2012

World Health Organization
Regional Office for South-East Asia
World Health House
Indraprasta Estate
Mahatma Gandhi Marg
New Delhi-110002, India
Prevention and control of birth defects in South-East Asia

Report of Regional Programme Managers’ meeting

Bangkok, Thailand, 20-22 March 2012
Acknowledgement

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## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>AIIMS</td>
<td>All India Institute of Medical Sciences</td>
</tr>
<tr>
<td>BDRI</td>
<td>Birth Defects Registry of India</td>
</tr>
<tr>
<td>CCI</td>
<td>Carter Consulting, Inc.</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>ICBD-SR</td>
<td>International Clearinghouse for Birth Defects Surveillance and Research</td>
</tr>
<tr>
<td>ICMR</td>
<td>Indian Council of Medical Research</td>
</tr>
<tr>
<td>MDG</td>
<td>Millennium Development Goal</td>
</tr>
<tr>
<td>NNPD</td>
<td>National Neonatal-Perinatal Database</td>
</tr>
<tr>
<td>NTD</td>
<td>Neural tube defect</td>
</tr>
<tr>
<td>PA</td>
<td>Pernicious anaemia</td>
</tr>
<tr>
<td>PHG Foundation</td>
<td>Foundation for Genomics and Population Health</td>
</tr>
<tr>
<td>SEA</td>
<td>South-East Asia</td>
</tr>
<tr>
<td>UL</td>
<td>Tolerable upper intake level</td>
</tr>
<tr>
<td>WHA</td>
<td>World Health Assembly</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WHO-SEARO</td>
<td>WHO–Regional Office for South-East Asia</td>
</tr>
<tr>
<td>WIFS</td>
<td>Weekly iron–folic acid supplementation</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary health care</td>
</tr>
<tr>
<td>PHFI</td>
<td>Public Health Foundation of India</td>
</tr>
<tr>
<td>QA</td>
<td>Quality assurance</td>
</tr>
<tr>
<td>RH</td>
<td>Reproductive health</td>
</tr>
<tr>
<td>RPR</td>
<td>Rapid programme review</td>
</tr>
<tr>
<td>SRH</td>
<td>Sexual and reproductive health</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually transmitted infections</td>
</tr>
<tr>
<td>WP</td>
<td>Western Pacific</td>
</tr>
<tr>
<td>YFHS</td>
<td>Youth-friendly health service</td>
</tr>
</tbody>
</table>
Background

The United Nations Millennium Development Goal (MDG) 4 commits world leaders to reduce child mortality globally and at the country level, and specifically to reduce the under-five mortality rate by two-thirds, between 1990 and 2015. The number of under-five deaths worldwide has declined from more than 12 million in 1990 to 7.6 million in 2010. Nearly 21,000 children under five died every day in 2010—about 12,000 fewer per day than in 1990. Since 1990 the global under-five mortality rate has dropped 35%—from 88 deaths per 1000 live births in 1990 to 57 in 2010. Northern Africa, Eastern Asia, Latin America and the Caribbean, South-East Asia, Western Asia and the developed regions have reduced their under-five mortality rate by 50% or more.
In South-East Asia alone, the under-five mortality dropped 55%, from 71 deaths per 1000 live births in 1990 to 32 deaths per 1000 live births in 2010. The rate of decline in under-five mortality has accelerated—from 1.9% a year over 1990–2000 to 2.5% a year over 2000–2010.

Although substantial progress has been made towards achieving MDG 4, the rate of child deaths is not falling quickly enough to reach the target of a two-thirds reduction. Despite the fact that most child deaths are preventable, many countries still have unacceptably high levels of child mortality and have made little or no progress in recent years.

**Birth defects and infant mortality**

Owing to improvements in the management of neonatal infection and asphyxia, birth defects are increasingly seen as a major cause of stillbirths and neonatal deaths. Preventing birth defect-related mortality would contribute to further reductions in child mortality in countries, whether they have achieved the MDG target already or need to accelerate progress for achieving the MDG 4 target.

In addition, an increasing number of infants with potentially disabling conditions, who would previously have died undiagnosed, now survive and require medical and supportive interventions.

**World Health Organization response**

The World Health Assembly (WHA) adopted WHA Resolution 63.17 in May 2010, which identified actions to address birth defects as an important cause of stillbirths and neonatal mortality and recognized the high number of stillbirths and neonatal deaths occurring worldwide and the large contribution of neonatal mortality to under-five mortality.

Among priority actions identified, the Resolution urges Member States to raise awareness among all relevant stakeholders about the importance of birth defects as a cause of child morbidity and
mortality and to set priorities, commit resources, and develop plans and activities for integrating effective interventions. These include comprehensive guidance, information and awareness-raising to prevent birth defects, and care for children with birth defects, integrated into existing maternal, reproductive and child health services and social welfare for all individuals, as well as effective interventions to prevent tobacco and alcohol use during pregnancy.

The Resolution also calls upon the World Health Organization (WHO) Director-General to support Member States to develop and include national plans for implementation of effective interventions to prevent and manage birth defects within their national maternal, newborn and child health services, strengthen health systems and primary care, include improved coverage of vaccination against diseases such as measles and rubella, address tobacco and alcohol use among pregnant women and women trying to conceive, implement food fortification strategies for the prevention of birth defects, and promote equitable access to such services.

South-East Asia Region response
In the present scenario with improving health statistics in many South-East Asian countries, the time is ripe to initiate programmes that address preventable birth defects. For example, the prevalence of neural tube defects (NTDs) can be dramatically reduced if women have an adequate intake of folic acid before and during early pregnancy. This can be accomplished at low cost by fortifying a widely consumed food staple, such as wheat, corn flour or rice with folic acid, or it can be provided via supplements containing folic acid in areas where fortification is not yet available.

Similarly, impaired mental development due to iodine deficiency can be prevented at relatively low cost through the iodization of salt. Congenital rubella syndrome can be prevented through the immunization of children and women. Public health education and preventive health-care services can reduce the prevalence of Down syndrome by offering antenatal screening for aneuploidies and
counselling about the possible impact of marriages between relatives, and can address the in-utero effects of alcohol and tobacco use by encouraging abstinence for women who are pregnant or planning a pregnancy.

Improvements in the care of children with birth defects can be made even with limited resources. Affordable medications, surgical treatments, and community-based rehabilitation can improve the quality of life for these children. This care can be made accessible through existing primary health services, which can make referrals to, and receive support from, secondary and tertiary care facilities.

To initiate any preventive programme, the first step is to generate epidemiological data regarding birth defects. However, the availability of epidemiological data on birth defects in the WHO Member States in South-East Asia (SEA) is quite limited. Review of available data and information on prevalence of birth defects and on the availability of preventive and management strategies for birth defects in Member States needs to be carried out to understand the present situation.

WHO Regional Office for South-East Asia (WHO-SEARO) organized a Regional Expert Group Meeting on birth defects in December 2011, convening international, regional and country experts to review and discuss regional situation analysis birth defects and a draft regional strategic framework for prevention and control of birth defects. A report on the Expert Group Meeting can be found at the WHO-SEARO website (http://www.searo.who.int/LinkFiles/Publications_SEA-Birth-Defects.pdf).

WHO-SEARO convened the Regional Programme Managers Meeting in March 2012 in Bangkok, Thailand with the objectives to review the current situation, disseminate global evidence and experience on prevention of birth defects and advocate for development of national strategies in the Member States.

Participants in the Regional Programme Managers Meeting included representatives from nine SEA Region Member States, as well as the
WHO Collaborating Centre, the All India Institute of Medical Sciences (AIIMS), international nongovernmental organizations, the United Nations Children’s Fund (UNICEF), the US Centers for Disease Control and Prevention (CDC), the International Clearinghouse for Birth Defects Surveillance and Research (ICBD-SR), subject experts, and staff from WHO country office, WHO-SEARO and WHO-headquarters. The meeting programme is at Annex 4. The detailed list of participants is at Annex 5. Prior to the meeting of the programme managers, a questionnaire was prepared and shared with the Member States to collect information on birth defects, current status of policies and programmes on prevention of birth defects and explore strategies to tackle the problem.
Day 1

Inauguration

Dr Samlee Plianbangchang, Regional Director, WHO-SEARO, welcomed participants and delivered the inaugural address. He stated that prevention of up to 60% of birth defects is possible by a number of effective interventions that are available, but it requires a sustained political will and commitment. Despite insufficient information on birth defects at present, planning and implementation can be started, and refined subsequently as better information from surveillance becomes available.

Dr Plianbangchang briefly outlined the WHO-SEARO birth defects prevention initiative
that includes the expert group meeting held in December 2011, development of regional and national strategies for prevention of birth defects, and the surveillance training proposed in April 2012. He welcomed the collaboration of CDC and ICBD-SR and stressed the importance of working with partners and with multidisciplinary and multisectoral approaches.

He stated that birth defects not only lead to foetal loss and deaths but that they can impact and undermine countries’ social and economic development. Because birth defects prevention and control is a complex problem, it is useful to initially address issues that can be tackled quickly. He emphasized the importance of national strategy development, including development of capacity and infrastructure, the need for ethical, legal and socio-cultural sensitivity, and that strategies should be specific to the country context. He stressed that countries will not be starting work from scratch. Rather, they already have varying levels of experience and expertise in birth defects prevention that can be upgraded progressively. He also said that the meeting can be used as a platform for increasing country cooperation and critical exchange of information. Dr Plianbangchang concluded his remarks by saying there is an urgent need to move forward, and he wished participants success with the meeting. His address is at Annex 1.
Dr Apichai Mongkol, Deputy Permanent Secretary, Ministry of Public Health, Thailand, welcomed the meeting participants. He began by stating that although there are global estimates on under-five deaths, there are limitations in vital registration in developing countries, which is why there is lower reporting of birth and deaths, and that it is important to improve reporting of vital events and birth defect surveillance. There are several effective birth defects prevention programmes that include rubella vaccination, salt iodization, and control of alcohol and tobacco use. Dr Mongkol also stated that a programme on prevention and control of birth defects should be integrated into primary health-care services and a functional referral system should backup the primary health-care efforts.

Thailand has introduced neonatal screening and a national birth registry has been started. Folate supplementation has been initiated in hospitals, but it should be extended to community levels, and fortification of foods with folic acid is the way forward. There are multiple factors responsible for birth defects, which require adoption of an integrated approach in existing priority programmes. Dr Mongkol emphasized the importance of the meeting and wished participants success in their discussions.

Dr Coleen Boyle, Director of the National Center on Birth Defects and Developmental Disabilities at CDC, welcomed participants and stated that the WHA has identified birth defects as a global problem and that prevention and control of birth defects is critical to achieve MDG 4. She said that CDC shares this priority and that the meeting represented an important landmark to prevent and control birth defects in the Member States of the SEA Region.

Deaths attributed to birth defects are a contributor to high under-five mortality. In addition there is lifetime disability in those who survive and birth defects affect their quality of life. She detailed several birth defects prevention and control efforts, including the necessity of surveillance. She emphasized that surveillance and research have shown the role of folic acid fortification and supplementation in
Preventing folic acid-preventable NTDs. There is a need for a global initiative to prevent folic acid-preventable NTDs and to expand fortification of food with folic acid, as well as to develop and support birth defects surveillance. She also said that partnerships are needed to adopt an integrated approach with a focus on middle- and lower-income countries where the burden of birth defects is unacceptably high.

Dr Boyle stressed CDC’s support of the efforts of WHO-SEARO, including the development of the regional strategic framework for birth defects prevention, increasing countries’ surveillance capacity through a training course to be held in Colombo, Sri Lanka in April 2012. She also stated CDC’s commitment to collaborate with WHO-SEARO on birth defects prevention and control initiatives in the future, to reduce mortality and morbidity from birth defects through application of evidence-based policies and programmes, and accelerating their implementation.

Dr Neena Raina, Regional Advisor for Child and Adolescent Health, WHO-SEARO then introduced participants and reviewed the objectives of the meeting. She stated that the purpose of the meeting was to advocate and develop strategic approaches for prevention and control of birth defects in SEA Member States of WHO, and specifically to:

1. Discuss the draft Regional Situation Analysis on birth defects in Member States;
2. Identify opportunities for implementing interventions for prevention of birth defects;
3. Obtain inputs from the Member States on the draft regional strategy on prevention and control of birth defects; and
4. Explore possibilities of regional and national networks of institutions on birth defects.

Dr Coleen Boyle of CDC and Dr IC Verma, Director, Centre of Medical Genetics, New Delhi India were assigned as Co-Chairs for
Day 1 and Dr Arvind Mathur, Medical Officer–Making Pregnancy Safer, WHO-SEARO as the Rapporteur.

**Session 1**

**Global and regional overview of birth defects prevention activities**

*WHO research strategy for birth defects in public health: a nutrition perspective*

Dr Luz Maria De-Regil, Epidemiologist, Department of Nutrition for Health and Development/WHO-HQ, introduced WHO’s research strategy for nutrition-preventable birth defects, and discussed WHO’s evidence-informed 9-step process for guidelines development.

Dr De-Regil stated that WHO recommends that all women, from the moment they begin trying to conceive until 12 weeks of gestation, take a folic acid supplement for prevention of NTDs. Women who have had a foetus diagnosed as affected by a neural tube defect or have given birth to a baby with an NTD should receive information on the risk of recurrence, be advised on the protective effect of periconceptional folic acid supplementation and be offered high-dose supplementation. A review of five trials, involving 6105 women (1949 with a history of a pregnancy affected by a NTD and 4156 with no history of NTDs) shows the effect of daily folic acid supplementation in doses ranging from 0.36 mg (360 μg) to 4 mg (4000 μg) a day, with and without other vitamins and minerals, before conception and up to 12 weeks of pregnancy, in preventing the recurrence of these conditions.

The WHO Guideline-suggested scheme for intermittent iron and folic acid supplementation in menstruating women recommends the following:

- Supplement composition: Iron: 60 mg of elemental iron and folic acid: 2800 μg (2.8 mg)
- Frequency: One supplement per week
Duration and time interval between periods of supplementation: 3 months of supplementation followed by 3 months of no supplementation after which the provision of supplements should restart. If feasible, intermittent supplements could be given throughout the school or calendar year.

Target group: All menstruating adolescent girls and adult women.

Settings: Populations where the prevalence of anaemia among non-pregnant women of reproductive age is 20% or higher.

The rationale of providing seven times the recommended daily dose to prevent NTDs is the limited experimental evidence demonstrating that this dose can improve red blood cell folate to concentrations that have been associated with a reduced risk for NTDs.

She introduced the WHO–Food and Agriculture Organization guidelines on food fortification with micronutrients. Fortification of staple foods (i.e. wheat flour) can improve the nutritional status of a large proportion of the population, requires no changes in dietary patterns and no individual decision for compliance. She stressed that when appropriately implemented, food fortification is an effective, simple, and inexpensive strategy for supplying vitamins and minerals.
to diets. The Guideline focuses on key nutrients, i.e. iron, folic acid, zinc, vitamin B12 and vitamin A.

Dr De-Regil explained that wheat and maize fortification with folic acid increases the intake of folate by women and can reduce the risk of neural tube and other birth defects. Fortification can also be integrated with other interventions in the efforts to reduce vitamin and mineral deficiencies and that fortification is most effective if mandated at the national level.

Dr De-Regil concluded with a brief reference to the Evidence-informed Policy Network (EVIPNet) and the WHO/CDC logic model for micronutrient interventions in public health.

**CDC’s global activities for birth defects prevention**

Dr Coleen Boyle reviewed CDC’s global activities for birth defects prevention, identifying four priority areas:

- Prevention of folate deficiency
- Prevention of congenital heart defects
- Prevention of alcohol exposed pregnancy
- Enhancing newborn screening data and programmes

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**CDC’s Global NTD Elimination Efforts**

- **Global Initiative to Eliminate Folic Acid-Preventable Neural Tube Defects (GIENTD)**
  - Reduce infant and child mortality and childhood morbidity resulting from NTD-affected births worldwide
  - Contribute to the achievement of the *Millennium Development Goal 4* (under-five mortality)
  - Support the 63rd World Health Assembly resolution on birth defects
She gave examples of CDC’s global efforts in Viet Nam, Lebanon, Central American countries, collaborations with ICBD-SR and the March of Dimes, and technical assistance provided on haemoglobinopathies in African countries.

Dr Boyle stated that global elimination of folic acid-preventable NTDs should be an important part of MDG 4, consistent with WHA Resolution 63.17 (May 2010). She said that there are an estimated 300,000 babies born annually with NTDs, the majority of which can be effectively prevented with adequate folic acid intake, leading to CDC’s focus on this initiative. CDC has identified the SEA Region as a priority region and activities are beginning in other regions as well.

She said that key CDC strategies are to work with multiple partners, educate and inform about the benefits of birth defects prevention, and to establish programmes and strategic partnerships. Partnerships are also proposed to enhance surveillance capacity and existing efforts, such as through the CDC Field Epidemiology Training Program. This programme can be an important resource for training and capacity development for countries.

Dr Boyle concluded by outlining CDC’s collaborative efforts with WHO-HQ and WHO-SEARO, including the development of a regional strategic framework and efforts to help build regional surveillance capacity, in SEA Region.

**Overview of birth defects in the South-East Asia Region**

Dr Neena Raina presented that while some Member States in the SEA Region have already achieved the MDG 4 targets and several are on course, there are Member States that are not likely to reach it. Neonatal mortality has remained relatively high and accounts for 52% of under-five mortality. With reductions in infant mortality caused by infectious and vaccine-preventable diseases, birth defects are emerging as a significant cause of death. Prevention of birth defects will contribute to further progress towards achievement of MDG 4. Dr Raina said that in terms of numbers, the highest burden of birth
defects is in the SEA Region because of its huge population and the large annual cohorts of deliveries that take place in countries such as India, Indonesia and Bangladesh. Not enough is known about actual burden of birth defects in the Region because countries do not have hospital- or population-based data or information.

Dr Raina emphasized that adolescent girls should be the focus for birth defects prevention. She stated that WHO-SEARO has prepared and shared WIFS guidelines and that countries such as in India have implemented new WIFS-related policies and decisions. However, she stated that the limitation is that currently available Iron – folic acid supplements contain 500 μg (or less) folic acid in most SEA Member States. Therefore adjustments are needed to increase it to 2800 μg as per recent WHO guidelines to prevent folate insufficiency related NTDs.

She stated that Bhutan, Maldives, Sri Lanka and Thailand have made progress regarding rubella vaccination. Routine rubella vaccination needs to be strongly supported with advocacy, since elimination of rubella-related birth defects is a highly effective intervention and can be quickly implemented.
Dr Raina said that the WHA Resolution 63.17 (May 2010) provides critical and broad guidance and that a national “nodal person” is required to mainstream and package multidisciplinary and multisectoral efforts together to make sure that the recommendations are effectively implemented. She also stressed that single, disconnected interventions are unlikely to produce results if not coordinated or mainstreamed with other programmes and interventions. She also stressed the need for implementation research and for the improvement of national birth registration.

She also discussed the problem of lack of available data on birth defects and the associated problem of convincing policymakers to act on a real but sometimes overlooked public-health problem. She stated that the March of Dimes estimates on birth defects are very crude and have not been yet endorsed by WHO. She also emphasized that folate insufficiency related-NTDs can be eliminated, which could be a strong advocacy entry point for inclusion in the global and national noncommunicable disease prevention and maternal health efforts. Some infectious disease related-birth defects are also candidates for advocacy and support, such as rubella and congenital syphilis.

**Session 2**

**WHO-SEARO Member States’ presentations on current situation and opportunities**

Prior to the meeting, a questionnaire was prepared and shared with the Member States to collect information on birth defects, current status of policies and programmes on birth defects and explore strategies to tackle the problem. The participating programme managers came prepared with the presentation. Concurrent workgroup sessions were conducted in which two groups of countries presented on their current situation and opportunities related to birth defects prevention and control. Rapporteurs for the workgroup sessions presented a summary of the country presentations to the Plenary as follows. Detailed tables are provided in Annex 2.
**Birth registration**

Country reports on birth registration indicate a need to strengthen the vital registration systems. While a significant proportion of births is registered in most Member States, but registration of deaths and assignment of cause of death is inadequate in some Member States. Only Maldives, Nepal, Sri Lanka and Thailand register stillbirths. The percentage of women aged 35 and older at the age of childbirth ranges from a high of 15.5% in Sri Lanka to a “negligible” percentage in India. Consanguineous marriages are uncommon in most countries except for India where it is common in some populations such as Muslims (22%) and South Indians (20%) as presented by countries.

**Contribution of birth defects to mortality**

Most countries reported hospital-based data on the contribution of birth defects to neonatal mortality rates. In Thailand, birth defects contribute to 21% of neonatal deaths, with similar rates in Indonesia (19%). Where data are available, most other countries reported that birth defects contribute to about 10% of neonatal deaths. Country reports point to a critical need for surveillance and monitoring of the contribution of birth defects to perinatal and stillbirth mortality rates, as well as medical termination of pregnancies. Only three countries track perinatal deaths related to birth defects. In Thailand, birth defects contributed to 21% of perinatal deaths, with comparable rates in India (19.5%). Only India and Nepal track birth defects contributions to stillbirths.

**Most common birth defects**

The most common birth defects among WHO-SEARO countries are structural malformations—including cardiovascular defects—followed by NTDs. Six countries reported that Down syndrome is common. Thalassaemia is common in four countries—Bangladesh, India, Maldives and Myanmar. Bangladesh, Maldives and Myanmar reported a common occurrence of glucose-6-phosphate dehydrogenase deficiency. Bhutan, Myanmar, Nepal and Thailand reported that cleft lip and cleft palate are among the most common birth defects in
their countries. Ankyloglossia and limb defects appear to be unique common birth defects in Thailand, with congenital rubella syndrome being a unique common birth defect in Nepal.

**Source of data/information on birth defects in Member States**

Hospital-based surveys are the most common sources of information on birth defects among six of the countries. Only one, Thailand, has established a national registry as a source of birth defects data. India has sub-national registries that are used as a source. Only Sri Lanka has a national health information system that provides information on birth defects. Four countries have conducted disability surveys—India, Indonesia, Myanmar (done in 2009) and Thailand.

<table>
<thead>
<tr>
<th>Folic Acid Supplementation and fortification</th>
<th>Adolescents</th>
<th>Pregnancy and lactation</th>
<th>Periconceptional</th>
<th>Composition of tablets</th>
<th>Food fortification National/Sub-national</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indonesia</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>60 mg + 0.25 mg</td>
<td>Biscuits 89 provinces</td>
</tr>
<tr>
<td>Maldives</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>60 mg + 0.4 mg</td>
<td>No</td>
</tr>
<tr>
<td>Nepal</td>
<td>Yes</td>
<td>Yes</td>
<td>Private clinics</td>
<td></td>
<td>?</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>2013</td>
<td>YES</td>
<td>No</td>
<td>60 mg + 1 mg</td>
<td>10%</td>
</tr>
</tbody>
</table>

**Folic acid supplementation and fortification**

All countries reported providing folic acid supplementation to pregnant and lactating mothers. Most countries provide, or will start providing, folic acid supplementation to adolescents. Only Bhutan and Thailand provide periconceptional supplementation nationally. The composition of supplementation tablets varies from a low of 60 mg iron and 0.25 mg folic acid in Indonesia to highs of 200 mg iron in Myanmar.
and 1 mg folic acid in Sri Lanka. Thailand provides Triferdine tablet that contains iron, folic acid and iodine. Food fortification programmes also vary widely. Only Indonesia and India reported folic acid fortification (India reported fortification with folic acid, iron and iodine in some states). Bhutan, India, Myanmar and Thailand reported iodine fortification programmes.

**Pre-pregnancy care**
All countries reported some type of pre-pregnancy care providing rubella vaccines, interventions or education on the use of alcohol and tobacco (and exposure) among women and pregnant women, with the exception of Nepal, which does not provide alcohol or tobacco use interventions. Also, most countries reported providing education and awareness programmes on avoiding pregnancy for women 35 years and older, avoiding teratogens, and detection of Type 2 diabetes.

**Screening for birth defects**
Countries reported varying efforts to screen for birth defects. Bhutan, India, Maldives, Sri Lanka and Thailand reported antenatal screening at the national or subnational level, mostly for anaemia or haemoglobinopathies. Bhutan reported screening for NTDs at the National hospital only. Bhutan conducts ultrasonography only for confirming pregnancies. Ultrasonography, though available in most countries, is generally not used for antenatal screening of birth defects. Newborn screening is conducted in Bangladesh and India (for hypothyroidism), Sri Lanka and Thailand (for phenylketonuria and hypothyroidism). India, Maldives, Sri Lanka and Thailand conduct population screening and prenatal diagnosis for thalassaemia.

**Services in place for care of people with birth defects**
Almost all countries reported that there were services in place for care of people with birth defects, including family support programmes, corrective surgery, rehabilitation programmes and community rehabilitation programmes but these were inadequate to meet the needs.
**Genetic services**

Only a few countries reported having either the capacity or programmes for birth defects genetic services. Genetic screening and counselling is conducted at selected centers in India, Maldives (for thalassaemia), Sri Lanka and Thailand. India, Sri Lanka and Thailand also offer a selected list of genetic tests from designated laboratories.

**Challenges and needs**

Countries also expressed several common challenges and needs related to advancing national birth defects prevention and control at the national level:

- Standard implementation guidelines for the prevention and management of birth defects
- Strengthening of information on birth defects, including surveillance and dedicated registries, integration in existing national health information surveys
- Initiation and/or expansion of folate supplementation and food fortification programmes
- Laboratory support for birth defects diagnostics
- Capacity-building for autopsy in stillbirths
- Strengthen programmes for care for children born with birth defects
- Technical, financial and capacity-building support for surveillance and preventive intervention programmes
- Piloting and modelling before scaling-up of birth defects surveillance systems
- Sustained advocacy for policy on prevention and control of birth defects
- Technology transfer for food fortification
Session 3

Strategies for preventing birth defects and other congenital conditions: evidence, metrics, and programmes

Evidence for prevention

Dr Pierpaolo Mastroiacovo, Director, ICBD-SR, provided an overview of maternal risk factors, the evidence on prevention for birth defects and approaches to prevention.

He stated that three congenital conditions—birth defects (malformations, genetic conditions, developmental disabilities of prenatal origin), preterm birth/intrauterine growth restriction, and birth asphyxia—account for 25–55% of under-five mortality, and share many risk factors. For the prevention of congenital conditions there are preventive approaches that mitigate “lifestyle”-related risk factors, like physical activity and body weight management (underweight, overweight, obesity), avoidance of use of alcohol, tobacco, illicit drugs (e.g. cocaine, amphetamines) and over-the-counter medications. On the other hand there are approaches that promote protective factors and contribute to reduction in prevalence of birth defects such as family planning, intake of healthy nutrition, micronutrients and vitamins (e.g. iron, iodine, B-vitamins), prevention and management of chronic diseases like diabetes, asthma, hypertension; and prevention of infectious diseases like syphilis, rubella and varicella in mothers. In addition, there are other factors such as environmental pollution (indoor and outdoor) and workplace or psychosocial stressors, previous pregnancy outcomes and genetics that contribute to causation of birth defects.

Dr Mastroiacovo introduced four pillars for effective prevention: incentive (adherence to moral or policy basis for action), evidence (scientific basis for action), strategies (broad categories for action) and tools (such as screening, interventions and monitoring and evaluation) for birth defects prevention. Strategies should be based on scientific evidence and interventions should be chosen on the basis of high impact.
Dr Mastroiacovo stated that modifiable risk factors can be prioritized on the basis of the strength of evidence through multiple studies of different designs. Such evidence provides the magnitude of risk, which includes the “relative risk” (how many times higher is the risk among those exposed compared to unexposed) and the “absolute risk” (actual chance of birth defect among those exposed) - the higher the risk, the higher the number of affected babies. Through this kind of assessment, diabetes, obesity and alcohol use and smoking are assessed as important modifiable risk factors. The adverse outcomes of these conditions are a high risk of preterm births and intrauterine growth restriction, in addition to birth defects. These also contribute to foetal loss including stillbirths.

Dr Mastroiacovo said that modifiable risk factors can also be assessed on the basis of frequency of exposure, or how common they are among women of childbearing age. In a US study, multivitamin nonuse, alcohol use, smoking, obesity and stress were the most prevalent risk factors. He also stated that modifiable risk factors should be assessed in relation to the types of birth defects they contribute to and other health outcomes. For example, smoking is related to subfertility, spontaneous abortion, ectopic pregnancy, placental pathology, preterm birth, etc. in addition to birth defects. Obesity outcomes are subfertility, spontaneous abortion, hypertension.
Prevention and control of birth defects in South-East Asia

and pre-eclampsia, gestational diabetes, stillbirth, preterm birth, etc., besides birth defects.

He stated that many maternal deaths can be prevented by addressing multiple risk factors, as risk factors cluster and interact with each other. Therefore, a common approach to multiple risk factors should be used. Modifiable risk factors should be assessed for the effectiveness of interventions and the potential for high impact. When planning health interventions, it is important to look at the quantity, intensity and equality of interventions. Quantity means the population impact and the number of people who benefit from the intervention; intensity is the effort to provide the benefit over time; and equality is the just distribution of benefit, without socio-economic disparities. He then introduced the “Health Impact Pyramid”, a conceptual framework for public-health action that helps compare a range of interventions that have population- or individual-level impact. He highlighted fortification as a population-based effort with the potential for high impact.

Dr Mastroiacovo discussed the effectiveness of public-health interventions specifically related to folic acid supplementation versus folic acid fortification. Studies showed that recommendations for folic acid supplementation had limited or no measurable effect on rates of NTDs in several European countries and other regions, which could be because of poor compliance. These findings contrasted with studies that showed that folic acid food fortification and compliant supplementation reduced the risk of NTDs in many countries.

He also discussed the experience of Italy in providing birth defects prevention training and tools for primary health-care professionals that included “cascading” training courses for primary-care providers, development of guidelines and preconception care integrated in existing primary-care services, contributing to the continuum of care.

Dr Mastroiacovo summarized his presentation by saying that prevention and surveillance are strictly linked. He emphasized the use of evidence for addressing global risk factors, such as the lack of use of
folic acid, infections, use of medications, smoking, alcohol consumption, diabetes and obesity for prevention of birth defects, preterm births, low birth weight, stillbirths, intellectual disability and others. He also said that data and information should be reliable, relevant and recent, and that there is a need for priorities, approaches and required personnel to be optimized as per the local needs and local settings.

**Discussion**

Discussion on Dr Mastroiacovo’s presentation focused on the definition of birth defects, which was defined as a defect that is present at the time of birth, e.g. structural defect or a functional defect that may manifest later in life. The need for packaging effective birth defects preventive interventions was discussed, with the focus on preventing and controlling specific risk factors and multiple adverse outcomes. The need for monitoring and evaluating key outcomes was also emphasized.

**Surveillance for birth defects**

Dr Lorenzo Botto, Chair of ICBD-SR, presented on measurement and metrics for evaluating evidence, setting priorities, and the need to focus surveillance efforts related to birth defects prevention.

He emphasized that for surveillance to be meaningful the data needs to be reliable, relevant and recent. This is consistent with WHA Resolution 63.17 (May 2010) on birth defects prevention, that emphasizes the need to develop and strengthen birth registration and surveillance of birth defects. Dr Botto stated that surveillance is the key that unlocks many of the other goals of the Resolution:

- Information and evidence helps raise awareness (of burden and potential for prevention);
- Surveillance of risk factors and outcomes helps assess coverage of effective prevention and target populations at risk or unreached population groups;
- Surveillance systems can be the basis for etiologic studies and prevention activities.
He explained that surveillance provides evidence of a problem and its possible solutions, or interventions, and provide information on the effect of implementation of the interventions. Surveillance should also be ongoing and efforts should be made to constantly improve the quality of information. He emphasized that teamwork is essential for successful and sustained surveillance efforts.

Birth defects surveillance has two broad scenarios. First and historically, birth defect surveillance was strengthened after the tragic experience of thalidomide — a fairly sudden “epidemic” of severe limb anomalies due to a medication used during pregnancy. A birth defects surveillance system is meant as a safety net to provide early detection of these outbreaks and prompt identification of the causes. Secondly, whereas managing this acute scenario is still a stated goal of many programmes, arguably an even greater usefulness is management of the “chronic burden of disease” related to preventable birth defects. An example is surveillance that was the basis for several case control studies in the USA evaluating the efficacy of folic acid. This surveillance provided the data to evaluate the decrease in NTDs after folic acid fortification.

Another key point is that quality surveillance helps to “maximize value” of interventions, as public health systems are most often
driven by considerations of quality and cost which determine the value. Consciousness of quality helps reduce variability in systems, thus reducing waste of resources and also promoting integration and teamwork. Regarding teamwork, Dr Botto cautioned that both surveillance expertise and clinical expertise are required for effective surveillance, but they are difficult to combine. For this reason, fostering teamwork from the planning stage is crucial and requires well-coordinated training.

Dr Botto mentioned that a ICBD-SR/WHO/CDC Birth Defects surveillance training programme was conducted in Geneva, Switzerland in October 2011, and that a WHO-SEARO Birth Defects Surveillance workshop was planned for Colombo, Sri Lanka in April 2012, as well as in Geneva, Switzerland in October 2012.

Dr Botto summarized his presentation saying that a global approach to surveillance is necessary and that local solutions must be evolved. A global approach is needed for consistency and local solutions are needed for effectiveness and sustainability. Excellent surveillance systems are possible anywhere, even in resource poor settings, provided that there is rigour and sustained effort. He also stated that an overriding principle is that surveillance has to be purposeful. In terms of surveillance, easier problems to tackle are NTDs, orofacial defects, and gastoschisis, while limb anomalies, heart defects and micro-deletions may be harder to tackle. He suggested that countries start with simple systems and build on them.

**Discussion**

Participants discussed their concern that low-birth-weight cases were “submerging” the problem of birth defects. They suggested that these two issues are best addressed together through a credible intervention package as an integral part of the national health system.

Participants also noted that multiple risk factors and the huge variety of birth defects tend to overload health workers who must collect the data. Reliability and use or analysis of the data is also a
concern. They also discussed the need to consider basic information on medical termination of pregnancy, stillbirths and early neonatal mortality as a starting point for surveillance, supported by more in-depth information from secondary and tertiary centres, and the surveillance system can be subsequently built from there. Participants from India noted that the private sector is enthusiastic in contributing to birth registry efforts but that there is a lot of indifference from the government sector.

**Day 2**

Co-chairs for Day 2 sessions were Dr Lorenzo Botto and Dr Siraporn Sawasdivorn, Director, Queen Sirkit National Institute of Child Health, Department of Public Services/Thailand Ministry of Public Health. Dr Madhulika Kabra, AIIMS/Division of Genetics, Department of Paediatrics, served as Day 2 Rapporteur.

Dr Vijay Kumar, SWACH Foundation, India, began the proceedings with a summary of Day 1 proceedings.

**Session 3 (continued)**

**Integration of birth defects prevention in existing public health programmes**

Dr Vijay Kumar presented on the rationale and opportunities for integration of birth defects prevention in existing public-health programmes. He began with an overview of the global burden of birth defects. Every year, an estimated 8.1 million children – 6% of the total births worldwide – are born with a serious birth defect of genetic or partially genetic origin. Additionally, hundreds of thousands more are born with serious birth defects of post-conception origin, including maternal exposure to environmental agents (teratogens) such as alcohol, rubella, syphilis and iodine deficiency that can harm a developing foetus.
Dr Kumar stated that birth defects are under-recognized and under-reported, can be life-threatening, result in long-term disability, and negatively affect individuals, families, health-care systems and societies. He also detailed the various causes of birth defects.

There are several reasons why birth defects have not yet received policy-makers’ attention. First, policy-makers are not aware of the heavy toll and very high life-long burden of such defects because there is a reliance on hospital data only, a lack of population-based data, and poor vital registration. Second, there is a lack of engagement by the public-health community with families impacted by birth defects. There is also a misperception that costly high-technology interventions are required to prevent and control birth defects. The programmes are already too busy addressing the simpler causes of child mortality and health systems are already overburdened. There is also a lack of policy commitment to integrate the care required for effective birth defects prevention, as well as integrated care implementation “bottle-necks” that exist in many health systems. Finally, there is a lack of coordination within and outside the health sector.

Dr Kumar identified existing opportunities for prevention of birth defects in public-health programmes in the SEA Region. These include strong maternal and child health programmes in Member States, established adolescent health programmes and family planning services, as well as iodine deficiency prevention programmes, strong immunization programmes, recently initiated noncommunicable diseases prevention programmes and efforts to eliminate congenital syphilis. He said that the region is “not starting from zero” and that there is a need to keep building steadily based on capacity at all levels, including with families and communities.

Dr Kumar highlighted the importance of preconception care in the prevention of birth defects. Preconception care is comprised of interventions that aim to identify and modify biomedical, behavioural and social risks to a woman’s health or pregnancy outcome through
prevention and management. He also discussed the need for a “continuum of care” ensuring that healthcare is provided across the lifecycle through strong public-health programmes and beyond—engaging families and communities—that can ensure that all women and babies are healthy. Unfortunately, in many countries there is no continuum of care and progress is slow. In particular there is a gap in the continuum of care for adolescent girls and women before pregnancy.

He detailed several features of an effective, integrated intervention package. The package should be based on epidemiology and evidence, employ appropriate technology for interventions, be applied on a wide scale, be affordable and acceptable in different cultural contexts and deliver multiple interventions. The package that delivers multiple interventions needs to be advocated and sustained. There should be a priority on immediate impact (“low-hanging-fruit priority”), with greater attention to specific groups in the population who need to be targeted and a balance of “push and pull” factors (demand creation and service delivery). Finally, the package should be inclusive and should evolve according to national capacity and local situations.
Among effective interventions, Dr Kumar addressed the prevention of NTDs due to folate insufficiency. He said that fortification of foods to benefit the entire population is an excellent intervention but will take time. On the other hand, daily iron and folic acid during pregnancy provides adequate quantities of folic acid, but in most countries in the Region the weekly iron and folic acid supplements have only 500 µg (or less) of folic acid, which is not enough to prevent the problem. Among other interventions, Dr Kumar discussed preconception- and periconception-period activities such as family planning, preconception screening and counselling, optimizing diet before and during pregnancy, preventing and treating teratogen-induced conditions and infections, and optimizing maternal health related to diabetes. For interventions during pregnancy, he discussed activities to address tobacco consumption and exposure, alcohol consumption, maintaining ideal weight, treating syphilis and malaria. In addition he discussed antenatal and prenatal screening and foetal treatment, such as anaemia and syphilis. For after-delivery interventions, he talked about risk assessment efforts that include family history and genetic risks, social assessment, family violence, poverty, psychological stressors, occupational or environmental hazards, behaviour risks—such as alcohol, tobacco or drugs—nutrition risks, and assessment of mental health and stress. He also identified several health promotion approaches.

In summary, Dr Kumar emphasized that we need to adopt a life course continuum of care approach for long-term control of risk factors to have impact on the overall health of women and children beyond the prevention and control of birth defects. We also need a dual strategy where there is an immediate visible gain, such as the elimination of folate deficiency-related NTDs, and a longer-term goal of prevention and control of other risk factors. An integrated package is needed urgently that can be advocated on a sustainable basis to inform the policy and a buy-in from the partners.
Session 4

Evidence-guided birth defects preventive strategies

Food fortification and safety of folic acid fortification

Dr RJ Berry, Medical Officer, CDC, presented the evidence base, potential for adverse outcomes, the mechanisms by which folic acid might lead to adverse outcomes and issues of high intake of folic acid.

Since 1991, when folic acid was first recommended to prevent NTDs, several governmental and independent advisory agencies have conducted evidence-based reviews of the literature and issued reports on the safety of mandatory fortification of staple foods with folic acid. Each of these earlier reviews included comprehensive literature searches and objective presentations of the findings. All involved agencies concluded that mandatory fortification of staple foods was safe and effective, and recommended that a plan to fortify selective staple foods with folic acid be implemented in their respective countries.

The studies reviewed the source of blood folate (food folate and folic acid), the intake required to achieve higher blood folate concentrations, randomization of use of folic acid (such as multivitamin-users vs non-users), and study design limitations.

Sources of folic acid include mandatory fortification of food staples, which is a major source relevant to developing new fortification policies for populations; limited use of ready-to-eat breakfast cereals in many areas of the world; and supplements containing folic acid, which are a major source in the United States but limited in other areas of the world.

CDC has also reviewed studies related to the safety of folic acid. Many relevant human studies have been published between January 2007 and March 2011 related to various adverse effects and their mechanisms.
Dr Berry explained that for potential mechanisms, CDC reviewed the indirect effects of folic acid on masking and vitamin B12 deficiency and DNA methylation and synthesis and detailed these processes. He discussed the history of masking and how this issue emerged related to the state of medical knowledge about megaloblastic anaemia in the 1940s and the impact of changes in the therapy of megaloblastic anaemia at that time.

In summarizing the review of masking studies, Dr Berry reported that of 255 case reports contained in 23 articles:

- 155 cases had neurological manifestations, which are the same as those that are complications of pernicious anaemia (PA);
- Most had a diagnosis of PA before being switched to folic acid;
- There was no way to confirm that patients with undiagnosed PA were involved;
- There was no way to distinguish between pre-existing damage from PA and damage attributed to use of high-dose folic acid;

Dr Berry then addressed the issue of concern of DNA methylation and synthesis where it is hypothesized that folic acid could both
prevent and promote cancer. He described a review of folate and DNA methylation from CDC that is now published.\(^1\) The review concludes that there is no evidence of harm to date, but it is biologically plausible and further research is needed.

He clarified the issue of the direct effects of high intake of folic acid on anaemia, cognition and childhood problems in populations where mothers have a low vitamin B12 status during pregnancy. In looking at the progression of nerve damage in vitamin B12-deficient patients, Dr Berry explained that there is no known evidence that folic acid at current intake levels has masked vitamin B12 deficiency or harmed individuals with vitamin B12 deficiency or pernicious anaemia.

In discussing the Institute of Medicine’s definition of the tolerable upper intake level (UL): “Maximum daily intake levels at which no risk of adverse health effects is expected for almost all individuals in the general population — including sensitive individuals — when the nutrient is consumed over long periods of time, Dr Berry described how the UL is not a limit and not a level where potential risk begins. It applies only to synthetic folic acid, and the UL for folic acid is not based on direct toxicity, but is an attempt to prevent a vitamin B12 deficiency. Furthermore, the UL does not apply to other potential adverse effects. These Recommended Dietary Allowances and Estimated Average Requirements for folate are based on classical deficiency, not on the prevention of NTDs.

He then discussed the reports on high intake of folic acid and cognitive decline. He stated that elevated blood homocysteine concentrations, low blood folate concentrations or low folate intake have been associated with increased rates of dementia in most studies, including randomized controlled trials, but not in all. Patients with low vitamin B12 status but relatively high blood folate concentrations scored more poorly on memory tests. But the question is whether

this is due to folic acid interference with vitamin B12 metabolism in some way or to the presence of preclinical PA in supplement takers who can absorb folates but not vitamin B12. He noted that 97% of those with normal vitamin B12 and high blood folate concentrations had evidence of increased cognition. He said we can conclude that there is no evidence of harm and some evidence of benefit, but data are conflicting.

Dr Berry also reviewed in detail the studies on high intake of folic acid (antenatal), including a study on insulin resistance in children exposed during pregnancy (Yajnik, India). In summary, he said that with respect to the Yajnik (India) study, the data are observational (i.e. not a randomized design) and should not be used to make causal inferences. Regarding a study on antenatal micronutrient supplementation (Stewart, Nepal), the data are from a follow-up of a randomized control trial, in which antenatal use of folic acid was randomized and thus provides better evidence.

Dr Berry also noted that, other than issues related to vitamin B12, cancer has historically generated the most concern related to folic acid intake. The preponderance of the evidence suggests that levels of folic acid intake resulting from food fortification are not associated
with an increase in cancer risk. More recently some concern has been expressed that folic acid supplementation during late pregnancy is associated with an increase in asthma among offspring, but the data are inconclusive.

In his summary and conclusions, Dr Berry emphasized that folic acid fortification is intended to prevent NTDs. It is unlikely for the usual intake to exceed the UL and to result in high blood folate concentrations unless supplements containing folic acid are consumed. In addition, there is a need to evaluate the strength of evidence in newly published studies and for continued monitoring and research. He highlighted the fact that no data exist to indicate that intake of folic acid causes harm at levels recommended to prevent NTDs or those in fortified foods, but that the data are not yet clear with intake of supplements of more than 400 µg per day. Finally he highlighted that an estimated 150000 NTDs each year could be prevented worldwide through adequate fortification of food staples with folic acid.

**WHO Guideline on intermittent iron and folic acid supplementation**

Dr Luz Maria De-Regil presented on issues related to folate supplementation. Anaemia is a multifactorial disorder that requires a multipronged approach for its prevention and treatment. It can impact cognitive performance, behaviour, physical growth, immune status and morbidity from infections, physical capacity and work performance. Furthermore, folate insufficiency contributes to the burden of NTDs.

Many countries are using WIFS as a part of their national policy to address anaemia and folate-related neural tube defects, particularly for vulnerable women. If the population has higher than 40% prevalence of anaemia then supplementation is an important intervention. Iron requirements are different at different stages of life. The current recommendation for iron supplementation is intermittent supplementation once, twice or three times per week. This approach has fewer side effects and results in higher compliance.
Intermittent supplementation also can be delivered as a community-based approach and the risk of iron excess is low.

Dr De-Regil reviewed the WHO Nutrition Guideline Development Process and stated that WHO is in the process of reviewing and revising WIFS recommendations. Preliminary review and assessment of the experience has shown better results with WIFS. The current recommendation is that weekly supplement should contain 60 mg iron in the form of ferrous sulphate and 2800 μg folic acid, although evidence for the effective dose of folic acid for weekly supplementation is limited at present. Daily folic acid supplementation is effective for reducing the risk of NTDs. Information on disease outcomes, adherence, side effects, economic productivity and work performance is scarce and the evidence about the effects of intermittent supplementation on them is unclear. Upon confirmation of pregnancy, women should receive standard antenatal care that includes daily supplementation with 60 mg iron and 400 ug of folic acid during pregnancy and the first three months postpartum.

In summary, Dr De-Regil said that iron and folic acid supplementation should be integrated into national programmes for adolescent and reproductive health, with surveys done to establish a baseline assessment of status and other interventions. Upon confirmation of pregnancy, women should receive standard antenatal care including daily iron supplementation and folic acid supplementation, depending on their anaemia status. The quality assurance process is important to guarantee that supplements are manufactured, packaged and stored in a controlled and uncontaminated environment.

Dr De-Regil also recommended that the selection of the most appropriate delivery platform be context-specific, with the aim of reaching the most vulnerable populations and ensuring a timely and continuous supply of supplements. Furthermore, the implementation of a behaviour change communication strategy to communicate the benefits of the intervention and management of side effects is essential.
Discussion
Participants noted that food fortification and food supplementation are complementary strategies. They echoed Dr De-Regil’s points that it is important to have a quality assurance programme to get the best results and that the delivery platform should be context-specific for the same purpose. Participants also raised the issue that in settings where malaria is a problem, the use of iron supplementation can be harmful. However, there is no option when the anaemia is common since there is no other intervention that is effective.

Prevention of thalassaemia
Dr IC Verma, Centre of Medical Genetics, New Delhi, India, presented on issues related to prevention of thalassaemia. He commented that although research on birth defects was presented 20 years ago, but only in the past two years has there been a focus to eliminate NTDs and to control birth defects in the SEA Region. Dr Verma detailed haemoglobinopathies and thalassaemia in South-East Asian countries, with Maldives having the highest rates at 6.4% followed by 5.6% in Thailand.

Thalassaemia prevention programmes are needed to address the high frequency of the disorder, to provide optimal treatment by limiting the cases, to avoid fatalities from untreated thalassaemia

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**Public health framework Required for thalassemia**

1. Assess the prevalence/incidence;
2. Monitor quality of life of people with thalassemia;
3. Quantify impact of thal on disability, mortality, & healthcare system, esp. hospital-based care;
4. Identify preventable causes of health problems among thalassemics
5. Identify barriers to optimal treatment

and to avoid expensive treatment (estimated at US $3000 per year per child). He said that prevention efforts are cost-effective, reduce the burden on patients, families and health services, and are simple to employ in good public-health practice.

Dr Verma outlined a public health framework for thalassaemia. First it is necessary to assess the prevalence/incidence of thalassaemia, monitor the quality of life of people with the illness and quantify its impact on disability, mortality and the health-care system, especially hospital-based care. Efforts are needed to identify preventable causes of health problems among thalassaemics as well as barriers to optimal treatment. It is important to ensure access to cost-effective and affordable screening, diagnostic and specialty health services and to establish systems for screening outcomes. There is a need to evaluate the effectiveness, accessibility and quality of health services for thalassemics. Finally, programme- and policy-makers should be informed about cost-effective strategies to prevent thalassaemia, and also educate and empower family members who are caregivers for thalassemics.

Elements of a public-health framework for prevention also have been articulated by WHO. These include political and financial support, improving curative services, prenatal diagnostics in future pregnancies of affected couples, prospective antenatal screening, community carrier screening, premarital counselling, and a network of centers and national/regional working groups.

Dr Verma explained the issues of screening and diagnosis. The carrier state has no disadvantage, but the risk of thalassaemia arises when both partners are carriers. The homozygous state is very severe and eventually fatal with no curative therapy. Foetal diagnosis is available and safe. Dr Verma emphasized that the experience so far clearly indicates that testing must be voluntary, and that mandatory measures should be discouraged.

He pointed out several problems with premarital screening, primarily that marriage is a complex social phenomenon and marriage
partners are selected based on strong personal preference, family or traditional reasons. When a planned marriage is called off it can cause social embarrassment and create a stigma for young people and their families. Most successful thalassaemia prevention programmes depend on pre-natal diagnosis of affected foetus.

In conclusion, Dr Verma emphasized that prevention of thalassaemia is a necessity: it limits the number of affected people who need treatment, curtails the economic burden on health services, and reduces the socioeconomic burden on families. As primary prevention measures, premarital screening, pregnancy screening and prenatal diagnosis should be done depending upon local conditions.

**Discussion**

Participants agreed that there can be tremendous saving through a prevention programme and that screening is highly cost-effective. In some countries delays in implementing screening programmes have been related to the issue of medical termination of pregnancies, which many countries now permit.

**Newborn screening**

Dr Madhulika Kabra, WHO CC, AIIMS, New Delhi reviewed newborn screening efforts in the SEA Region, and in detail in India. Newborn screening is a comprehensive and sometimes complicated system that includes secondary prevention, education, screening, diagnosis, management, follow-up and evaluation. Newborn screening is sustained within public-health systems and often challenged by economic, political and cultural considerations. Dr Madhulika reviewed the status of mortality rates in South-East Asian countries, highlighting low neonatal deaths where there is some type or level of newborn screening.

Dr Madhulika discussed barriers to establishing and maintaining newborn screening in developing countries, such as poor economies, unique sociocultural issues, the high number of home deliveries, absence of laboratories and trained personnel, non-availability and cost of treatment, inadequate political will and awareness, lack of
Dr Madhulika presented the “11T system” for newborn screening, which includes:

1. Technology (equipment)  
2. Training (Personnel)  
3. Taking (Specimen collection)  
4. Transportation  
5. Testing  
6. Treating  
7. Telling (Reporting)  
8. Totalling (Cost)  
9. Tracking (Confirmation)  
10. Teaching (Counselling)  
11. Tracking (Follow-up)

In initiating a newborn screening programme, Dr Madhulika advised first piloting a model programme to assess the feasibility and cost-effectiveness. The difficulties in initiation need to be tackled by the creation of a task force.

In deciding which conditions to screen, the programme should address an important health problem, there should be existing facilities for diagnosis and treatment, and screening should focus on a recognizable latent or early symptomatic state with a suitable test or examination. The test or examination should be cost-effective, acceptable to the population and its natural history should

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**How do you decide which conditions should be screened?**

- Should be an important health problem.
- Facilities for diagnosis and treatment should be available.
- Recognizable latent or early symptomatic state.
- There should be a suitable test or examination.
- The test or examination should be acceptable to the population.
- The natural history should be adequately understood.
- Agreed policy on whom to treat as patients.
- Cost Effective.

*Wilson and Jungner – WHO, 1968*
be adequately understood. Examples of such conditions include phenylketonuria and haemoglobinopathies. After the pilot programme is established, it is important to have results discussed in a common forum with the involvement of professionals, policy-makers and media. In addition, there should be advocacy and education efforts. Training of health personnel for the management of these disorders is also an essential component. Dr Madhulika also highlighted issues related to the need for integration of newborn screening programmes with existing health-care systems.

Dr Madhulika emphasized the need to assess “lessons learned” from ongoing programmes. Existing programmes should have methodical record-keeping, allow for rapid evaluation, and development of policies and legislation. In addition, advisory groups involving experts, and advocacy programmes and media campaigns should be developed, along with active management and follow-up and quality control.

She concluded with a briefing on newborn screening in India. There is no national programme, but a multicentric study is being carried out with the support of the Indian Council of Medical Research (ICMR), a national agency.

**Session 5**

**Communication and advocacy strategies**

Mr Burke Fishburn, Consultant, Carter Consulting, Inc.(CCI), presented on communication and advocacy strategies related to birth defects prevention. He began by making a case for strategic planning for communication and advocacy and using available tools. It is important to understand the theoretical or scientific basis for health communications which are to influence individual and community decisions. It is helpful also to understand that health communication is an “art” that combines many scientific disciplines.

Health communication and advocacy activities should be placed in the context of a broader strategy for public health change. As
an example, Mr Fishburn pointed to the role of communication and advocacy in the WHO–CDC logic model for micronutrient deficiency.

Mr Fishburn reviewed the potential use of CDCynergy, an online health communication planning tool, which also emphasizes the need for strategic planning before communication activities are implemented. It is also important to build in a process of monitoring and evaluation in order to assess the progress and impact of communication activities. There is a micronutrient edition of CDCynergy, and other editions provide case studies relevant to birth defects prevention, such as folic acid fortification/supplementation.

Mr Fishburn suggested a number of practical issues to be considered when implementing communication and advocacy strategies for birth defects prevention. First, it is important to identify and target audiences or potential stakeholders. Second, we should access appropriate communication modalities and technologies and not be bogged down by the production of ineffective materials that are not in sync with the overall strategy and not well designed.
Packaging of communication and advocacy interventions is very important, specifically a multisectoral approach for birth defects prevention efforts, comprising a number of effective interventions such as family planning, preconception care, food fortification, supplementation, tobacco control etc. The challenge is to package the interventions so that a change can be brought about at the policy or programme level to address a group of causative factors. Packaging is also about creating a “brand” for birth defects prevention that grabs and holds policy-makers’ and the public’s attention and creates support.

Mr Fishburn also noted that it is important to identify champions — high-level, high-profile leaders who can individually communicate and advocate for birth defects prevention. He summarized by saying that communications and advocacy should be a component of national planning for birth defects prevention and control and that effective health communications strategies employ various health behaviour theories. There should be a component that advocates for policy-makers’ investment in birth defects prevention. Countries need to consider whether there is a need for a new or separate birth defects communication strategy versus integrating the strategy into existing health communications strategies. Regardless, this consideration will depend on the country situation and needs.

Role of Regional and National networks
Dr Vinod Paul, Chief, Division of Neonatology, Department of Paediatrics/AIIMS and nodal officer for WHO Collaborating Centre for research and training in newborn health, presented on the role of national and regional networks for newborn health and the need for research groups and research networks. He shared the history and background of the India National Neonatal-Perinatal Database (NNPD). The objectives of the NNPD cater to intramural (babies born in the hospital) and extramural (babies born outside the hospital and brought for treatment) groups:
Objectives of the database:

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<tr>
<th>Intramural group</th>
<th>Extramural group</th>
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<td>To study:</td>
<td>To describe the profile of morbidity and mortality of extramural neonatal admissions at the Network institutions.</td>
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<tr>
<td>- Causes of maternal, perinatal and neonatal deaths</td>
<td>- To use the data on neonatal-perinatal health generated through the Network for quality improvement of newborn care at the participating centres.</td>
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<td>- Incidence of low birth weight and prematurity</td>
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<td>- Incidence and outcome of birth asphyxia</td>
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<td>- Organisms causing infections in neonates</td>
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<td>- Antibiotic resistance pattern of neonatal infections</td>
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<td>- Incidence of other morbidity: hypothermia, respiratory distress, hyperbilirubinaemia, intraventricular haemorrhage, etc.</td>
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<td>- Prevalence and profile of birth defects</td>
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</table>

Dr Paul shared NNPD’s protocols for intramural live births (Protocol “A”), stillbirths (Protocol “B”) and extramural babies (Protocol “C”). He also presented the results from the NNPD work, including major neonatal outcomes, perinatal outcomes and respiratory morbidity trends.

He highlighted several NNPD achievements, noting that NNPD created a coalition of a professional body, academic institutions and ICMR, and brought together disparate institutions. It was able to develop and implement common protocols even without additional funds. It collected high-quality data; was sustained over multiple cycles; and was able to analyse, synthesize, publish and use the information. Furthermore, NNPD developed capacity for multicentre research and developed various protocols that established Indian standards of foetal growth, short-course treatment for newborn sepsis and delivery room management of meconium-stained neonates.

Major limitations of the NNPD are that its activities have not been continuous, it does not follow neonates after discharge, district sites
need further strengthening and there are unmet expectations for analyses of the data collected.

Dr Paul then described the experience with the Regional Neonatal Perinatal Database supported by WHO-SEARO and which involved selected institutions from Bangladesh, Indonesia, India, Nepal, Sri Lanka and Thailand. The goal of the database is to establish a SEA Region Neonatal-Perinatal Database Network for generating prospective information on neonatal/perinatal morbidity and mortality, aimed at collecting information on births at the selected institutions of excellence in different Member States of the Region, with the objective of generating and disseminating prospective data on neonatal-perinatal morbidity and mortality. He presented results from the database on intramural births (major neonatal, perinatal and maternal outcomes, demographic profiles, major neonatal morbidities and outcomes) and extramural admissions (major neonatal outcomes). Results and recommendations were reported in the meeting report of the Regional Network Meeting Strengthening Newborn Health Care, Education and Training Capacity organized in March 2011 at New Delhi.

In conclusion, Dr Paul emphasized the challenge of sustainability for research groups and research networks and discussed issues such as funding, meeting support, development and refining of new
protocols, initiating new studies and trials, publication of papers, and furthering research capacity.

**Discussion**

Participants expressed enthusiasm for the idea of networking for birth defects prevention and broad participation including the private sector. Participants also voiced the need to develop a network for birth defects so that databases can be strengthened. It was noted that in India, the government is starting a large network of 640 districts, with 350 having special-care newborn baby units in the district hospitals.

**Introduction and overview of Regional Strategic Framework on prevention and control of birth defects**

Dr Rajesh Mehta, Medical Officer for Child and Adolescent Health, WHO-SEARO, provided an overview of the draft Regional Strategic Framework on prevention and control of birth defects. The Framework was prepared by WHO-SEARO with support from CDC and CCI Consultant Mr Burke Fishburn, and was initially vetted at the Expert Group Meeting in December 2011. The draft document went through several iterations. Review, comment and endorsement of the Framework were key objectives of the Regional Programme Managers’ meeting.

WHO-SEARO is proposing five strategic directions in the Framework to reduce the prevalence of birth defects in the next five years (2012–2016). The Framework provides guidance to Member States to evolve national programmes and strategies for the prevention and control of birth defects to reduce morbidity and mortality among newborns, infants and children. The Framework also outlines areas of WHO-SEARO’s and partners’ support to Member States.

The rationale for the Framework is based on several factors. First, as indicated by MDG 4 progress reviews, child deaths are decreasing, but not quickly enough. It is also recognized that birth defects are a contributor to child deaths and a significant cause of stillbirths and neonatal deaths. Birth defects also cause a significant social and
economic burden. In addition, reducing birth defects is a major public health opportunity, and a WHO and global priority.

Dr Mehta outlined the proposed guiding principles of the Framework, which underpin the primary goal of significantly reducing birth defects to contribute to achievement of MDG 4 and beyond and reduction of folic acid-preventable NTDs in the SEA Region. One of the specific targets of the Framework is to reduce prevalence of folic acid-preventable NTDs by 50% in selected Member States in five years.

To achieve this goal and target, the Regional Strategic Framework focuses on the effective implementation of five overall Strategic Directions. These Strategic Directions guide Member States’ implementation of birth defects prevention and control activities and WHO-SEARO and partnership support. The Strategic Directions are:

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

Dr Mehta briefly discussed Framework implementation issues, saying that the success of efforts to prevent birth defects in the SEA Region depends on the effective planning and implementation of policies, programmes, surveillance, and monitoring and evaluation activities, as well as engagement in partnerships, networks, and
mobilization of resources and advocacy. The Framework recognizes that Member States in the Region are at different stages of health development and have different capacities and systems for planning and implementation of national birth defects prevention and control. It is also recognized that all the required activities may not be able to be undertaken at the same time.

Member States need to develop plans and activities that can be implemented in a phased manner in accordance with the needs and conditions of the evolving health systems. He said national implementation of the Framework will generally involve several well-defined steps:

(1) Designate a national focal point in the ministry of health;
(2) Establish a national coordination mechanism;
(3) Establish a national technical working group or task force;
(4) Develop and conduct a phased implementation national strategic plan;
(5) Develop and conduct a national communication strategy, including public education plans;
(6) Plan and conduct surveillance, monitoring and evaluation, including operation research;
(7) Strengthen programme management capacity.
Dr Mehta stated that after discussion and inputs from programme managers at the Regional Programme Managers meeting, the Framework would undergo revisions and reiterations and be implemented later in 2012.

Session 6

Workgroups
Dr Mehta assigned participants to three workgroups that were requested to review the Framework using a standard template. Each workgroup was asked to provide a general review of the Framework, including the rationale, guiding principles, goal and targets. Specific strategic directions were divided up for review among the workgroups.

Day 3
Dr Pierpaolo Mastroiacovo and Dr R R M L R Siyambalagoda, Deputy Director-General, Ministry of Health, Sri Lanka, acted as Co-Chairs for Day 3 proceedings. Dr Anita Kar, Director of Interdisciplinary School of Health Sciences, University of Pune, India served as Day 3 Rapporteur.

Dr Rajesh Mehta began the day by providing a summary of Day 2 proceedings. Then workgroups provided feedback and inputs from the previous day’s review of the Regional Strategic Framework. These inputs are reflected in the meeting’s Conclusions and Recommendations and will be included in future revisions to the Framework.

Session 7

Birth defects surveillance
Dr Lorenzo Botto presented on birth defects surveillance needs, the types of surveillance and using surveillance data for reporting on burden, development of policy/programme and its evaluation. He
provided the background information on ICBD-SR and the training programme on surveillance and prevention of birth defects and preterm births. He described the need for public health surveillance to do three things: provide information for action, maximize value and provide a global approach with local solutions. He described public health surveillance as a circular process that must be ongoing, timely, accurate and purposeful.

Surveillance provides information for birth defects prevention through policies and interventions, information on global risk factors (e.g. lack of folic acid use, infections, medications, smoking, diabetes and obesity) and the global burden of disease (e.g. birth defects, preterm births, low birth weight/Intra Uterine Growth Retardation, stillbirth and intellectual disability).

Dr Botto described the Awareness Project, which provides surveillance of birth defects risk factors under collaboration between ICBD, CDC, WHO and March Of Dimes, and reported on the status of the Awareness Project components. As one component, a review of toxoplasmosis seropositivity was conducted and included data from India, Indonesia, Nepal, Sri Lanka and Thailand, among others. In addition, a review of folic acid use prevalence during the periconceptional period was conducted using data available for Sri Lanka and Thailand.

<table>
<thead>
<tr>
<th>Elements of surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Define public health problem and purpose(s) of surveillance (e.g., baseline, trends)</td>
</tr>
<tr>
<td>2. Define area and population</td>
</tr>
<tr>
<td>3. Define information needs</td>
</tr>
<tr>
<td>a. Cases with associated information</td>
</tr>
<tr>
<td>b. Underlying population: denominator (e.g., births)</td>
</tr>
<tr>
<td>4. Develop process to get data (accurate, timely, ongoing)</td>
</tr>
<tr>
<td>5. Look for opportunities for integration</td>
</tr>
<tr>
<td>6. Analyse, use --- evaluate, improve, integrate -- restart</td>
</tr>
</tbody>
</table>
Dr Botto discussed the needs that should be met by a good surveillance system. The system should address a defined public health problem and have a clear purpose or purposes. The system should collect data in a defined area and population, meet defined information needs, and collect data on cases with associated information about the underlying population. Finally, a good system should have a developed process to obtain and analyse the data. He also stated the need for “form to follow function” and that a development of a surveillance system should start small with a clear vision and focus on high-quality data collection and analysis. An expansion can then be undertaken, but only after careful planning.

Dr Botto described hospital-based surveillance systems that collect data on cases and births from select hospitals in a defined area. These can be convenient and efficient, but also have problems because of referral patterns, bias and lack of representativeness. Population-based surveillance systems collect data on cases and births from entire resident populations. They are accurate and less prone to bias, but also resource-intensive and sometimes difficult to implement.

Dr Botto discussed passive, active and hybrid surveillance systems. In passive systems, sites report to centres. Such systems can be useful but can be incomplete and also difficult to check. In an active system, a centre sends staff to the field sites to find cases. An active system is resource-intensive because of staffing needed and, sometimes, the distances travelled. A hybrid system contains elements of both the other two systems. In deciding what kind of system to implement, you need to look at the number of staff needed for the programme, the programme funding required, and the legal authority to collect sensitive data and the reporting mechanism. However, the ideal system is a hybrid system. However, the real key to a successful surveillance system is to have a champion: a leader and staff at a site who are committed to the programme.

Public health surveillance provides massive opportunities by addressing considerable variations in practice, unacceptable rates of
preventable disease, disability, and death, enabling implementation of what we know works and avoiding the considerable waste on interventions that have limited value for the patient or the population.

Dr Botto concluded by saying that “High-value, high-quality surveillance is possible nearly everywhere.” Now, more than ever, better communication technology is available. High quality is also more available at an affordable cost. There is a need to plan carefully and promote teamwork through networking and to leverage existing local resources. High-value, high-quality surveillance provides a system to measure, learn, and improve. Dr Botto recommended starting small, piloting, achieving success and then growing.

Discussion
Participants discussed the use of demographic surveys as a tool to determine the scope of birth defects. Some said there is already a lot of relevant data in their countries (and causes of birth defects-related deaths can also be determined), and the data just need to be analysed and used. Participants said it is important to begin to review the data that already exists, starting with population-based data.

Country experience: organizing a birth defects registry – gains and challenges
Dr S Suresh of Mediscan, India, presented the Birth Defects Registry of India (BDRI). He informed that BDRI was established in 2001 by the Foetal Care Research Foundation. Initially it had the participation of a few hospitals and has since grown to a network of 750 enrolled hospitals.

In the first phase, BDRI’s mission is to: ascertain nationwide prevalence of birth defects; establish birth defects registries throughout India; provide guidelines and assistance to the upcoming centres for uniform methods of data collection; and collect, analyse and disseminate birth defects surveillance data. In the second phase, BDRI’s mission is to: reduce birth defects incidence; obtain support
through preventive and supportive strategies that create awareness and educate the public regarding birth defects; and form support groups.

Dr Suresh described BDRI’s registry methodology as being a hospital-based, passive reporting system that produces prevalence estimates. The denominator for data collection is live born babies plus intra uterine foetal demise (or) stillbirths and medical termination of pregnancy. The classification is based on ICD-10 (Q00.0 – Q99.9) and only includes structural and chromosomal anomalies.

Dr Suresh shared BDRI’s methods of functioning, online reporting system, coverage of selected hospitals in 27 states, and results of over 10 years analysing 900 000 births. In addition to other data, he briefed on the proportion of system anomalies and prevalence of the top 10 major anomalies with NTDs comprising almost 25% of all anomalies.

Dr Suresh indicated several limitations in the birth defects registries’ data collection. First, prevalence is under reported, probably due to the fact that minor anomalies are rarely reported
and that the passive reporting system approach may not reflect the population prevalence and is an estimate from a non-random sample of hospitals.

BDRI has to deal with a very large geographic area eventually and track 25 million births nationally each year. There is a need to create awareness for the need for birth defects registries and to motivate local leadership. There is a human resource shortage: large hospitals lack staff to conduct the registry, and hospitals are often unwilling to appoint staff exclusively for this registry, so it is left to students or resident staff who are usually rotating through assignments, resulting in a serious lack of continuity.

There is also a technical knowledge gap. There is a large knowledge deficit about anomalies, obstetricians do not have the necessary skills, and there are very few dysmorphologists, perinatal pathologists and geneticists. There is also a problem of “blind/generic labelling” (e.g. all short long bones are labelled “achondroplasia” and blind labelling of “multiple congenital anomalies”). There is the challenge of the attitude of health professionals: they claim to have no time to fill out forms and are overburdened and do not see the personal benefit of supporting a registry. There is also the challenge of sustaining interest after the initial excitement phase and eventual transfer of personnel. There is a need for continuous advocacy for reporting birth defects by organizations.

Dr Suresh spoke about the final challenge being the need to “spark a fire” and keep it burning, identifying responsible professionals, whether obstetricians, foetal medicine specialists, paediatricians, dysmorphologists etc, as well as coordinating a team effort and the need “to rise above personal prejudices”.

**Experience of birth defects registry in Thailand**

Dr Siraporn Sawasdivorn stated that in 2008 a national birth defects registry in Thailand was established and a national meeting was
organized. Associated with the national perinatal society, the registry participants met every 2–3 months and led efforts to establish a national programme for prevention of birth defects, which was launched in 2011. The programme provides for birth defects diagnosis, treatment, rehabilitation and prevention and is directed through all health-care delivery channels. Thus far they have focused on five priority birth defects: Down syndrome, cleft lip and cleft palate, limb anomalies, NTDs and Duchenne muscular dystrophy. The programme goal is to cover at least 50% of the population in the first year.

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**Thailand Birth Defects Registry (BDR)**

- Dec. 2008: established “Working Group for Thailand BDR”
  (Thailand Society of Birth Defects + Thai Perinatal Society)
- Oct. 2009: participated in “4th International Conference on Birth Defects & Disabilities in Developing World”, New Delhi, India

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Dr Sawasdivorn emphasized that now a birth defect registry is coupled with a national prevention programme and thus together they are likely to be more successful. She discussed the birth defects registry process, which involves 20 hospitals and is combined with payment systems. The registry tracks 20 common conditions selected which represent 70% of the problems. She detailed some limitations of the registry system and said that new digital communication may overcome some of the problems.
Dr Hilary Burton, Director of the Foundation for Genomics and Population Health (PHG), United Kingdom, presented an overview of the PHG health needs assessment toolkit that can be used for birth defects prevention planning.

Birth defects prevention is a part of a wide portfolio of PHG, a foundation that is a part of Cambridge University comprising a multidisciplinary group of experts. She said the needs assessment toolkit developed by PHG could help in planning for prevention and control of birth defects. Accessible online, the toolkit addresses the needs and inequalities of a population emphasizing a continuum approach and effectiveness and cost-effectiveness of interventions. The toolkit process begins with an assessment of the status of birth defects prevention efforts and the burden of the problem, and yields information on resources that may be required to address the burden.

**Chapter: the Health Needs Assessment process**

A step-by-step guide

1. Authority
2. Forming the team
3. Clarifying aims and objectives
   - Target population
   - Scope: clinical topics, service topics
4. Identify resources
5. Define responsibilities
6. Define a time-frame
7. Review budget
8. Define and invite stakeholders

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2 PHG Health Needs Assessment Toolkit www.bornhealthy.org
Dr Burton summarized the content of the toolkit along with the step-by-step guide. Global and regional planning are important in birth defects prevention planning, but after this more generic approach it is important to do the country-specific planning. Country-specific information can serve as a starting point for doing strategic planning and is important for any situation analysis. The toolkit also provides for consideration of ethical, legal and social issues in the planning.

PHG has many supporting chapters and has worked in countries in South America such as Brazil, Argentina and Uruguay.

Dr Burton also said that stigmatization of birth defects is a key issue to consider in planning. She concluded by saying that PHG has chosen to work on the theme of “Born Healthy” rather than the potentially stigmatizing “birth defects” prevention.

Country action points presented by WHO-SEARO Member States

In this session, Member States presented their provisional plans for national birth defects prevention efforts. They were requested to identify key actions for each of the meeting’s session-wise thematic area that could be implemented over two- and five-year periods. Tables summarizing Member States’ presentations are at Annex 3.
Dr Neena Raina presented the conclusions and recommendations of the Regional Programme Managers meeting that were endorsed by the participants as follows:

**Conclusions**

- Delegates recognize that it is important to address prevention and control of birth defects to reduce foetal loss, child mortality and morbidity, and mitigate socioeconomic burden on affected families.
- The information on birth defects in the South-East Asia Region Member States is inadequate at present and efforts are required to strengthen the existing health information systems.
(Vital Registration System, Demographic Health Surveys, Health Management Information Systems, etc.) to integrate information on foetal deaths, stillbirths and birth defects as well as develop/strengthen dedicated mechanisms like birth defect surveillance and registries.

- Member States will need to prioritize a few birth defects based on epidemiology, amenability to prevention and systems capacity in the country. Neural tube defects are one such example, for which evidence-based cost-effective preventive intervention exists and is available in the form of folic acid fortification and supplementation.

- Member States are providing continuum of care for reproductive–maternal–newborn–child health and other programmes like nutrition, immunization and noncommunicable diseases programmes, within which there are opportunities to integrate interventions for birth defect prevention.

- Effective birth defect prevention requires a range of interventions from population-based strategies such as fortification and supplementation to individual-level interventions like counselling and screening.

- Packaging of birth defect prevention interventions will help in advocacy and improve synergy in existing public-health programmes. A preconception package that includes preventive interventions for birth defects will complete and strengthen the continuum of care across the life course.

- There are multiple risk factors that tend to cluster. This will necessitate adoption of a multisectoral approach. These risk factors are also associated with other adverse outcomes which if addressed would provide improvements in women’s, maternal, foetal, and child health.

- Delegates endorsed the proposed Regional Strategic Framework for prevention and control of birth defects as applicable in the Member States and feasible to implement, and they contributed to the improvement of the draft.
Delegates expressed the need to develop national strategies and plans for prevention and control of birth defects and the importance of policy and environmental approaches in the Member States.

Delegates supported the need to follow a public-health approach to implement interventions for prevention and control of birth defects with particular emphasis on primary health care and strong community engagement.

Delegates underlined the need for advocacy and social mobilization in support of birth defects programmes for which a national communication strategy would be useful.

Member States will need assistance for advocacy, resource mobilization, capacity-building for surveillance, human resource training, diagnostics, and programme planning and management.

Partnerships, networks and working groups at the regional, national and subnational levels will help to take the birth defects prevention and control programme forward. The need for research on evidence and implementation was emphasized.

Delegates commended the WHO-SEARO initiative to take forward the World Health Assembly Resolution in collaboration with National Center on Birth Defects and Developmental Disabilities, CDC.

Recommendations

For Member States

- A national focal point in the Ministry of Health should be appointed to coordinate the activities for prevention and control of birth defects. The national focal point should be assisted by a multidisciplinary working group with clear terms of reference.
Carry out a national policy review and develop strategic and implementation plans for prevention and control of birth defects.

NTDs, rubella haemoglobinopathies, congenital syphilis and hypothyroidism are eminently preventable. Selection of conditions should be made according to the country context.

Develop and implement a national communication strategy for advocacy and behaviour change.

Strengthen existing vital registration systems (including a focus on foetal losses and stillbirths) and other health information systems, develop a surveillance mechanism for birth defects, and establish national registries in a phased manner, as required.

Strengthen national capacity for surveillance, diagnostics, training and programme planning, review and management.

Partnerships should be built for developing a multisectoral approach for prevention of risk factors and food fortification. Coordination mechanisms should be established for sustaining the partnerships.

Mobilize appropriate resources, and create partnerships and networks to support programme for prevention and control of birth defects.

Prepare a monitoring and evaluation framework to strengthen programmes and to measure progress in implementation of preventive and control efforts on birth defects.

**Recommendations for WHO and partners**

- Support high-level advocacy and resource mobilization for birth defect programmes at regional and national levels.
- Provide support and guidance for developing national strategy and implementation plan for prevention and control of birth defects.
• Support capacity building needs of SEA Region Member States.
• Support development of regional–national networks to support implementation, monitoring and evaluation of birth defect programmes.
• Establish mechanisms to support national-level efforts like operationalization of birth defect surveillance and food fortification and supplementation with folic acid.
• Create opportunities for knowledge- and experience-sharing, and support research to support implementation of birth defect programmes.

Prevent Birth Defects – Ensure Quality of Life and Dignity

Closing remarks
Dr Coleen Boyle said that the meeting reflected the remarkable efforts of countries and the immense energy needed to confront the problem of birth defects through prevention and control. It is recognized that countries are at different stages of their efforts, and that CDC will provide technical guidance and support as requested/needed. She said that one of CDC Director Dr Tom Frieden’s constant themes is that a lot can be done through championing efforts in a finite period of time and that there are winnable battles. Birth defects prevention is a winnable battle. There is a clear need for targeted planning in the SEA Region, as well as strengthening surveillance to better understand the breadth and depth of the problem, building on what has been done already.

Dr Boyle stated that food fortification with folic acid, accompanied by folic acid supplementation where necessary, is a “sure win” for the Region, and that this can be communicated through advocacy
efforts. In conclusion she thanked the leadership and vision of WHO-SEARO, commended the engagement of all meeting participants, and recognized the high level of interest and energy generated at the meeting.

Dr Neena Raina said that, the meeting has signified a meaningful start, fruitful results and proves that a lot can be done over a short period of time. She acknowledged the CDC collaboration and support. She said that the Regional Strategic Framework would be revised and finalized incorporating the suggestions received in this meeting with a strong focus on prevention. She also said that after the regional birth defects surveillance workshop planned in Sri Lanka in April 2012, WHO-SEARO proposes to support the national-level action, workshops and meetings depending on the countries’ state of readiness. She said that WHO-SEARO can provide support to countries in several different ways, such as supporting high-level advocacy and resource mobilization, supporting and guiding development of national strategy, implementation plans and supporting capacity-building.

In conclusion, Dr Raina stated that champions for birth defects prevention are emerging in the Region and that she was confident the Region could embody the motto, “We came, we saw and we won”. She expressed thanks to all country representatives and experts, including CDC, ICBD-SR, PHG Foundation, the Micronutrient Initiative and UNICEF for their support.
Regional Director’s address
Dr Samlee Plianbangchang
Regional Director, South-East Asia

Dr Apichai Mongkol, Deputy Permanent Secretary, Ministry of Public Health, Thailand, Dr Coleen Boyle, Director, National Centre on Birth Defects and Development Disabilities, CDC, distinguished participants, distinguished representatives of partner organizations, colleagues, ladies and gentlemen, I welcome you all to this Regional Programme Managers’ Meeting where we will deliberate upon the issues relating to “prevention and control of birth defects” in the WHO South-East Asia (SEA) Region.

Every year, an estimated eight million children worldwide are born with birth defects due to their genetic endowment. Additionally, hundreds of thousands more are born with birth defects of post-conception origin. Birth defects are a global problem. Despite insufficient information, it must be admitted, however that there is a large burden of birth defects in the SEA Region. Experience from high-income countries has shown that up to 70% birth defects can be prevented. Evidence-based interventions are available for such prevention.

A large majority of birth defects is attributed to the poor health status of women during the periods of preconception and periconception. Improvement in the maternal status linked to iron, folic acid and iodine intake, and “awareness” of the impact of exposure to teratogens during antenatal period will significantly help reduce the number of “still births” and “birth defects”.

Ladies and gentlemen, taking cognizance of the situation, WHO Governing Bodies have paid their particular attention to the prevailing problem relating to birth defects. WHO has been requested to support
Member States in developing national capacity and plans for effective interventions to prevent and manage birth defects. In pursuance of the Governing Bodies’ request, the WHO Regional Office for SEA proposes to develop, in collaboration with Member States, a regional strategy for prevention and control of birth defects.

The Regional Expert Group on Birth Defects has advised that urgent action be taken on such prevention and control in the Region. A regional workshop has been planned for the next month to discuss building of country capacity, specifically in the area of surveillance of birth defects. I would like to place on record our grateful thanks to the Centers for Disease Control (CDC) Atlanta, United States of America and the International Clearinghouse for Birth Defects for their valuable contribution in prevention and control of birth defects.

Ladies and gentlemen, prevention and control of birth defects require multidisciplinary, multisectoral and multiple programme efforts. In WHO-SEARO, programmes such as Maternal and Reproductive Health; Nutrition; Immunization; and NCD are encouraged to work together in a coordinated manner for prevention and control of birth defects.

In countries, we are promoting multidisciplinary and multisectoral involvement of all concerned stakeholders in the development and implementation of national plans for prevention and control of birth defects. Birth defects can undermine health and well-being of people in a big way. Relevant interventions at national level are therefore really indicated. Political will and commitment are indispensable prerequisites for development and implementation of such interventions at national level. Due to the complexity of the problem, selection of some birth defects for cost-effective interventions would be a pragmatic and feasible approach.

In our attempt to support countries in the prevention and control of birth defects it has also to be kept in mind that there may have been substantial national efforts on the ground at least in some countries. Therefore, we should thoroughly study the country situations by
involving all sectors and institutions concerned in the process. Through these means, we may be able to elicit some useful information that can be used as the basis for our planning to support country capacity strengthening.

I am sure many countries may not need to start work from scratch. In our collaboration with Member States we should try to help enhance their existing capacity and infrastructure. Furthermore, when we move forward in our efforts to prevent and control birth defects some “ethical” aspects may surface for consideration. These aspects may lead to significant socio-cultural sensitivity that needs to be tackled with the utmost care – country by country, place by place.

I am pleased that the Regional Programme Managers’ Meeting is being held now. It will be an important step forward in supporting each and every country, keeping in mind, the local specific situations and circumstances. Country capacity may be strengthened through intercountry cooperation by exchange of information and experience. This regional meeting can be effectively used as a platform for promotion of such intercountry cooperation.

Ladies and gentlemen, I overwhelmingly thank all country participants; representatives from UNICEF, CDC, United States, and the International Clearing- house for Birth Defects; experts from Centres of Expertise in the Region; and all other attendees for having spared their valuable time to attend and participate in this meeting.

Let us together move forward with our combined wisdom and efforts towards effective prevention and control of birth defects, which can contribute to improved quality of life of populations in the SEA Region.

With these words, ladies and gentlemen, I wish the meeting all success, and I wish all of you an enjoyable stay in Bangkok.
### Annex 2

**Country situation:**

**Summary tables**

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Percentage of births registered</th>
<th>Percentage of deaths registered</th>
<th>Percentage of stillbirths registered</th>
<th>Percentage of women older than 35 years at delivery</th>
<th>Percentage of population who marry consanguinely</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bangladesh</strong></td>
<td>Project in progress</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>1 district: 10%</td>
</tr>
<tr>
<td><strong>Bhutan</strong></td>
<td>99.9%</td>
<td>NA</td>
<td>NA</td>
<td>4.5% (single facility)</td>
<td>Exists, but no data</td>
</tr>
<tr>
<td><strong>India</strong></td>
<td>National: 68% 7 states: 100%</td>
<td>63%</td>
<td>NA</td>
<td>Negligible</td>
<td>South Indian: 20% Muslims: 22%</td>
</tr>
<tr>
<td><strong>Indonesia</strong></td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Maldives</strong></td>
<td>99%</td>
<td>Yes</td>
<td>Yes</td>
<td>11%</td>
<td>Uncommon</td>
</tr>
<tr>
<td><strong>Myanmar</strong></td>
<td>65%</td>
<td>NA</td>
<td>NA</td>
<td>Yes</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Nepal</strong></td>
<td>Urban: 42% Rural: 34%</td>
<td>NA</td>
<td>3831 cases/year</td>
<td>7.8%</td>
<td>7%</td>
</tr>
<tr>
<td><strong>Sri Lanka</strong></td>
<td>97.2%</td>
<td>94%</td>
<td>Limited</td>
<td>15.5%</td>
<td>Uncommon</td>
</tr>
<tr>
<td><strong>Thailand</strong></td>
<td>98.4%</td>
<td>98.4%</td>
<td>4000 cases/year</td>
<td>12.8%</td>
<td>NA</td>
</tr>
</tbody>
</table>

NA: Not available

<table>
<thead>
<tr>
<th>Contribution of birth defects to select mortalities</th>
<th>Contribution of birth defects to neonatal mortality rate</th>
<th>Contribution of birth defects to perinatal mortality rate</th>
<th>Contribution of birth defects to stillbirths</th>
<th>Contribution of birth defects to medical termination of pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bangladesh</strong></td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Bhutan</strong></td>
<td>Single hospital: 10%</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>India</strong></td>
<td>9.6%</td>
<td>19.5%</td>
<td>9.9%</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Indonesia</strong></td>
<td>19%</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Maldives</strong></td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>50%</td>
</tr>
<tr>
<td><strong>Myanmar</strong></td>
<td>National: 3% Hospital-based: 0.6%</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Nepal</strong></td>
<td>7.9%</td>
<td>9.7%</td>
<td>11%</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Sri Lanka</strong></td>
<td>10.8%</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Thailand</strong></td>
<td>21%</td>
<td>21%</td>
<td>NA</td>
<td>NA</td>
</tr>
</tbody>
</table>

NA: Not available
### Most common birth defects

<table>
<thead>
<tr>
<th>Rank</th>
<th>Bangladesh*</th>
<th>Bhutan</th>
<th>India</th>
<th>Indonesia</th>
<th>Maldives</th>
<th>Myanmar</th>
<th>Nepal</th>
<th>Sri Lanka</th>
<th>Thailand</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>CHD</td>
<td>CHD</td>
<td>NTD</td>
<td>NA</td>
<td>CHD</td>
<td>Thai</td>
<td>Cleft</td>
<td>CHD</td>
<td>CHD</td>
</tr>
<tr>
<td>2</td>
<td>NTD</td>
<td>NTD</td>
<td>Down</td>
<td>NA</td>
<td>NTD</td>
<td>CHD</td>
<td>CHD</td>
<td>Chrom</td>
<td>Ank</td>
</tr>
<tr>
<td>3</td>
<td>Thal</td>
<td>Cleft</td>
<td>MD</td>
<td>NA</td>
<td>Thal</td>
<td>Clefts</td>
<td>NTD</td>
<td>NTD</td>
<td>Limb defects</td>
</tr>
<tr>
<td>4</td>
<td>Down</td>
<td>Chrom</td>
<td>Thal</td>
<td>NA</td>
<td>Down</td>
<td>CGI</td>
<td>CRS</td>
<td>Clefts</td>
<td>G6PD</td>
</tr>
<tr>
<td>5</td>
<td>G6PD</td>
<td>CH</td>
<td>NA</td>
<td>G6PD</td>
<td>Down</td>
<td>Down</td>
<td></td>
<td></td>
<td>G6PD</td>
</tr>
<tr>
<td>6</td>
<td>DMD</td>
<td>NA</td>
<td></td>
<td>G6PD</td>
<td>NA</td>
<td>NTD</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Based on March of Dimes (2006)

Ank: ankyloglossia  
CGI: congenital gastrointestinal conditions  
Chrom: chromosomal abnormalities, includes Down syndrome  
Cleft: cleft lip, cleft palate  
CH: congenital hypothyroidism  
CHD: congenital heart defects, includes cardiovascular system defects  
CRS: congenital rubella syndrome  
DMD: Duchene muscular dystrophy  
Down: Down syndrome  
G6PD: Glucose-6-phosphate dehydrogenase deficiency  
MD: metabolic disorders  
NA: Not available  
NTD: neural tube defects, including spina bifida  
Thal: thalassemia and pathological haemoglobin disorders

### Source of data/information on birth defects in the country

<table>
<thead>
<tr>
<th>Country</th>
<th>Registry: National or subnational</th>
<th>Hospital-based health information survey</th>
<th>Population-based health information survey</th>
<th>Special surveys</th>
<th>Surveillance system</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh*</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Bhutan</td>
<td>–</td>
<td>Yes</td>
<td>–</td>
<td>Pilot survey on mental disorders: CD</td>
<td>–</td>
</tr>
<tr>
<td>India</td>
<td>Sub-national</td>
<td>Yes</td>
<td>No</td>
<td>Disability: No</td>
<td>–</td>
</tr>
<tr>
<td>Indonesia</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Disability</td>
<td>–</td>
</tr>
<tr>
<td>Maldives</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>CD (STI, HIV, VPD)</td>
</tr>
<tr>
<td>Myanmar</td>
<td>Some hospitals have registries</td>
<td>Some</td>
<td>No</td>
<td>Disability (2009)</td>
<td>No</td>
</tr>
<tr>
<td>Nepal</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>–</td>
<td>No</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>Pilot</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Perinatal death reviews, CD</td>
</tr>
<tr>
<td>Thailand</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

* Based on March of Dimes (2006)

CD: communicable diseases  
HIV: human immunodeficiency virus  
STI: sexually transmitted diseases  
VD: vaccine-preventable diseases
### Folic acid supplementation and fortification

<table>
<thead>
<tr>
<th>Country</th>
<th>Adolescents</th>
<th>Pregnancy and lactation</th>
<th>Periconceptional</th>
<th>Composition of tablets</th>
<th>Food fortification: national/sub-national</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>NA</td>
<td>No</td>
</tr>
<tr>
<td>Bhutan</td>
<td>Yes</td>
<td>Yes: same dose daily</td>
<td>Yes: up to 3 months</td>
<td>Iron: 60 mg Folic acid: 0.5 mg</td>
<td>Yes: Only iodized salt coverage (100%)</td>
</tr>
<tr>
<td>India</td>
<td>Yes</td>
<td>60% coverage</td>
<td>No</td>
<td>Iron: 100 mg Folic acid: 0.5 mg</td>
<td>Yes: folic acid, iron, iodine</td>
</tr>
<tr>
<td>Indonesia</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Iron: 60 mg Folic acid: 0.25 mg</td>
<td>Yes: Biscuits with folic acid, iron and iodine: 89 provinces</td>
</tr>
<tr>
<td>Maldives</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Iron: 60 mg Folic acid: 0.4 mg</td>
<td>No</td>
</tr>
<tr>
<td>Myanmar</td>
<td>Yes: twice a day, partial coverage</td>
<td>Yes: daily</td>
<td>No</td>
<td>Iron: 200 mg Folic acid: 0.4 mg</td>
<td>Yes: Iodine</td>
</tr>
<tr>
<td>Nepal</td>
<td>Yes</td>
<td>Yes</td>
<td>Private clinics</td>
<td>NA</td>
<td>No</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>Starting in 2013</td>
<td>Yes</td>
<td>No</td>
<td>Iron: 60 mg Folic acid: 1 mg</td>
<td>10% coverage</td>
</tr>
<tr>
<td>Thailand</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Triferdine: Iodine, iron &amp; folic acid</td>
<td>Yes: Iodine No: Iron and folic acid</td>
</tr>
</tbody>
</table>

### Pre-pregnancy care

<table>
<thead>
<tr>
<th>Country</th>
<th>Rubella vaccine</th>
<th>Use of alcohol among women</th>
<th>Harmful use of tobacco and exposure during pregnancy</th>
<th>Education and awareness programmes</th>
<th>Detection of Type 2 diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>Yes: 2012</td>
<td>Banned</td>
<td>General</td>
<td>Avoid pregnancy &gt; 35 years</td>
<td>Urine test</td>
</tr>
<tr>
<td>Bhutan</td>
<td>Yes: Since 2006 (women &amp; children)</td>
<td>No programmes but awareness programs, high taxation</td>
<td>Strict legislation against tobacco</td>
<td>Avoidance</td>
<td>Yes</td>
</tr>
<tr>
<td>India</td>
<td>Yes: Some states</td>
<td>No: national Ban in one state</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Indonesia</td>
<td>Yes</td>
<td>Yes: ANC</td>
<td>Yes: ANC</td>
<td>Yes: secondary &amp; tertiary care</td>
<td>Yes: ANC</td>
</tr>
</tbody>
</table>

Prevention and control of birth defects in South-East Asia
## Pre-pregnancy care

<table>
<thead>
<tr>
<th>Country</th>
<th>Rubella vaccine</th>
<th>Use of alcohol among women</th>
<th>Harmful use of tobacco and exposure during pregnancy</th>
<th>Education and awareness programmes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maldives</td>
<td>Yes: Since 2007</td>
<td>General national campaign</td>
<td>General national campaign</td>
<td>Yes  Yes  Yes</td>
</tr>
<tr>
<td>Myanmar</td>
<td>Private sector</td>
<td>Health education</td>
<td>Health education</td>
<td>No  Yes  Yes: for DM during ANC</td>
</tr>
<tr>
<td>Nepal</td>
<td>Yes: 2012</td>
<td>Yes</td>
<td>No</td>
<td>Yes  Yes  Yes</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>Yes: Since 1994</td>
<td>No</td>
<td>Yes</td>
<td>Yes  Yes  Yes</td>
</tr>
<tr>
<td>Thailand</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes  Yes  Yes</td>
</tr>
</tbody>
</table>

ANC: antenatal care
DM: diabetes mellitus

## Screening for birth defects

<table>
<thead>
<tr>
<th>Country</th>
<th>Antenatal screening</th>
<th>Ultrasound screening</th>
<th>Newborn screening</th>
<th>Population screening for thalassaemia, etc.</th>
<th>Prenatal diagnosis</th>
<th>Medical termination of pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>No</td>
<td>Yes</td>
<td>Hypothyroidism</td>
<td>No</td>
<td>Sporadic</td>
<td>Yes</td>
</tr>
<tr>
<td>Bhutan</td>
<td>National: NTD</td>
<td>Only for confirming pregnancies</td>
<td>No</td>
<td>No (a few at national hospital)</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>India</td>
<td>Yes (Some states for Hbpathies)</td>
<td>Yes</td>
<td>No: Public Yes Private</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Indonesia</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Maldives</td>
<td>Yes</td>
<td>Yes</td>
<td>Selectively</td>
<td>Yes</td>
<td>Abroad* 120 days</td>
<td></td>
</tr>
<tr>
<td>Myanmar</td>
<td>No (Some for anaemia, infectious diseases)</td>
<td>Yes: Tertiary care &amp; private</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Nepal</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>28 weeks</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Not legal</td>
</tr>
<tr>
<td>Thailand</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes: PKU, hypothyroidism</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes: Up to 20 weeks though no law exists</td>
</tr>
</tbody>
</table>

Hbpathies: haemoglobinopathies
PKU: phenylketonuria

*For prenatal diagnosis of thalassaemia patients are referred abroad*
## Services in place for care of people with birth defects

<table>
<thead>
<tr>
<th>Country</th>
<th>Family support programmes</th>
<th>Corrective surgeries and/or rehabilitation programmes</th>
<th>Community rehabilitation programmes</th>
<th>Parent organizations</th>
<th>List of Stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Bhutan</td>
<td>None</td>
<td>Yes: “Camps” for cleft lip and palate 2/year</td>
<td>Yes</td>
<td>Disabled person Association for visually impaired</td>
<td>NA</td>
</tr>
<tr>
<td>India</td>
<td>Some</td>
<td>Medical colleges and tertiary care</td>
<td>NGOs/Civil Society</td>
<td>Yes</td>
<td>Multiple</td>
</tr>
<tr>
<td>Indonesia</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Maldives</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Myanmar</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes: Autism, cleft lip and cancer</td>
<td>Multiple</td>
</tr>
<tr>
<td>Nepal</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Thailand</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Multiple</td>
</tr>
</tbody>
</table>

## Genetic services

<table>
<thead>
<tr>
<th>Country</th>
<th>Genetic screening</th>
<th>Genetic counselling</th>
<th>Genetic laboratories</th>
<th>List of available genetic tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>No</td>
<td>No</td>
<td>Few</td>
<td>No</td>
</tr>
<tr>
<td>Bhutan</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>India</td>
<td>Yes: Support from Indian Council of Medical Research</td>
<td>Yes: 45 ICMR facilities</td>
<td>26 biochemical 28 molecular labs</td>
<td>Yes</td>
</tr>
<tr>
<td>Indonesia</td>
<td>No</td>
<td>No</td>
<td>Few</td>
<td>No</td>
</tr>
<tr>
<td>Maldives</td>
<td>Yes: for Thalassemia</td>
<td>Yes: for Thalassemia</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Myanmar</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Nepal</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Thailand</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
## Country action plans: Summary tables

### Annex 3

**Bhutan**

<table>
<thead>
<tr>
<th>Action Area</th>
<th>2 Years</th>
<th>5 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Integrate preventive interventions into existing public health programmes</strong></td>
<td>Rubella immunization (sustain and improve) through the Vaccine Preventable Disease Program</td>
<td>Strengthen further to near 100%</td>
</tr>
<tr>
<td></td>
<td>Periconceptional folic acid supplementation through reproductive health programme inclusion in adolescent health manual</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Advocacy on alcohol avoidance through the National Center for Disease Control and Prevention</td>
<td>Upscale and strengthen.</td>
</tr>
<tr>
<td><strong>Folic acid fortification</strong></td>
<td>Make it truly periconceptional (integrating it into the Maternal and Child Health programme)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adolescent folic acid supplementation/schoolchildren</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appraisal on folic acid fortification of food or sprinkles</td>
<td>Folic acid fortification of staple diet: rice, maize, possibly wheat and salt</td>
</tr>
<tr>
<td><strong>Thalassaemia</strong></td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Newborn screening</strong></td>
<td>Clinical screening of visible defects at birth in selected centers (referral hospitals)</td>
<td>Incorporate a section on birth defects in the Birth Registry (eventually, nationwide)</td>
</tr>
<tr>
<td></td>
<td>Plan and prepare for mandatory congenital hyperthyroidism screening (prevention vs. treatment)</td>
<td>Begin mandatory screening of common birth defects: congenital hyperthyroidism, congenital syphilis</td>
</tr>
</tbody>
</table>
### Bhutan

<table>
<thead>
<tr>
<th>Action Area</th>
<th>2 Years</th>
<th>5 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Communication strategy</strong></td>
<td>Form an expert/core group at the national level</td>
<td>Liaise and collaborate with regional networks (SEARO)</td>
</tr>
<tr>
<td></td>
<td>Advocacy on harmful aspects of alcohol use</td>
<td>Upscale</td>
</tr>
<tr>
<td></td>
<td>Advocacy on role of folic acid and benefits</td>
<td>Upscale</td>
</tr>
<tr>
<td><strong>National networks</strong></td>
<td>Include national referral hospitals (mainly for data)</td>
<td>Include selected district hospitals</td>
</tr>
<tr>
<td></td>
<td>Extend to Regional Hospital (only 3)</td>
<td>Collaborate with regional networks</td>
</tr>
<tr>
<td><strong>Birth defect surveillance</strong></td>
<td>At the National Hospital, start a birth defects registry</td>
<td>Extend to regional referral hospitals</td>
</tr>
</tbody>
</table>

### India

<table>
<thead>
<tr>
<th>Action Area</th>
<th>2 Years</th>
<th>5 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Integrate preventive interventions into existing public health programmes</strong></td>
<td>100% coverage of iodized salt</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Universal coverage of iron and folic acid to all pregnant mothers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Weekly iron and folic acid supplementation to adolescents</td>
<td>Upscaling of the programme</td>
</tr>
<tr>
<td><strong>Folic acid fortification</strong></td>
<td>Pilot project of food fortification</td>
<td></td>
</tr>
<tr>
<td><strong>Thalassaemia</strong></td>
<td>Pilot on universal screening of adolescents/women for thalassaemia trait</td>
<td>Thalassaemia prevention as part of national programme</td>
</tr>
<tr>
<td></td>
<td>Facility based antenatal thalassemia screening at state level institutions</td>
<td></td>
</tr>
<tr>
<td><strong>Newborn screening</strong></td>
<td>Population based pilot in 2-4 districts</td>
<td>Population-based roll-out in 10 districts</td>
</tr>
<tr>
<td></td>
<td>Newborn screening programme in 20 teaching institutions</td>
<td></td>
</tr>
<tr>
<td><strong>Communication strategy</strong></td>
<td>Raise awareness among pregnant women</td>
<td>Advocacy for including the strategy as a part of national programme in the next five year plan</td>
</tr>
<tr>
<td></td>
<td>Awareness among adolescents</td>
<td></td>
</tr>
</tbody>
</table>
### India

<table>
<thead>
<tr>
<th>Action Area</th>
<th>2 Years</th>
<th>5 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>National networks</td>
<td>Establish a network comprising 20 centres</td>
<td>Networking through Sick Newborn Care Unit at district level</td>
</tr>
<tr>
<td>Birth defect surveillance</td>
<td>Sentinel surveillance in tertiary care hospitals</td>
<td>Upscaling at district and subdistrict levels</td>
</tr>
<tr>
<td>Others</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Measles/mumps/rubella vaccine to be introduced in a phased manner</td>
<td>Upscaling of MMR vaccination</td>
</tr>
<tr>
<td></td>
<td>Multidisciplinary working group</td>
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<tr>
<td></td>
<td>Capacity building</td>
<td>Upscaling</td>
</tr>
<tr>
<td></td>
<td>Ongoing research</td>
<td>Research to be continued.</td>
</tr>
</tbody>
</table>

### Indonesia

<table>
<thead>
<tr>
<th>Action Area</th>
<th>2 Years</th>
<th>5 Years</th>
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</thead>
<tbody>
<tr>
<td>Integrate preventive interventions into existing public health programmes</td>
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<td></td>
<td>Establish teamwork for birth defects’ prevention at national level</td>
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<td>Establish a secretariat for birth defects’ prevention at national level</td>
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<tr>
<td></td>
<td>Advocacy for policy-makers at national level</td>
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<tr>
<td></td>
<td>Socialization of birth defects in multiple sectors and multiple disciplines for mobilization of resources, including role of rice fortification</td>
<td>Make policies, programmes and activities at national level</td>
</tr>
<tr>
<td></td>
<td>Syphilis prevention/treatment Implementation</td>
<td>Monitoring and evaluating for syphilis prevention/treatment implementation</td>
</tr>
<tr>
<td></td>
<td>Folic acid for adolescents and the newly married</td>
<td>Evaluating the use of folic acid by adolescents and the newly married</td>
</tr>
<tr>
<td></td>
<td>Increased capacity of knowledge of midwives in villages for signs of birth defects in antenatal clinic screening</td>
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<tr>
<td></td>
<td>Work with indoor air pollution/ cooking stove programme and collect data</td>
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<tr>
<td>Indonesia</td>
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<tr>
<td><strong>Action Area</strong></td>
<td><strong>2 Years</strong></td>
<td><strong>5 Years</strong></td>
</tr>
<tr>
<td><strong>Folic acid fortification</strong></td>
<td>Promoting the use of food fortified with folic acid and supplementary multivitamins with folic acid for adolescents, pre-pregnancy, pregnancy and family through mother classes, Maternal and Child Health handbook, Integrated Management of Child Health, Child and Family Centres</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Socialization on the role of rice fortification</td>
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</tr>
<tr>
<td></td>
<td>Review pilot programme for rice fortification</td>
<td>Expanding rice fortification (to be discussed after review)</td>
</tr>
<tr>
<td></td>
<td>Explore implementation of mandatory fortification</td>
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<tr>
<td><strong>Thalassaemia</strong></td>
<td>Thalassaemia screening to be discussed</td>
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<tr>
<td><strong>Newborn screening</strong></td>
<td>Advocacy for policy-makers at national level</td>
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<td></td>
<td>Socialization birth defects for healthcare providers</td>
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<td></td>
<td>Education and training for healthcare providers</td>
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<td>Strengthen programmes of newborn screening (e.g. congenital hypothyroidism)</td>
<td>Expanding newborn screening (to be discussed)</td>
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<td></td>
<td>Discuss for other screening</td>
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<tr>
<td><strong>Communication strategy</strong></td>
<td>Advocacy for policy-makers at national level</td>
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<tr>
<td></td>
<td>Advocacy and communication through media</td>
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<td></td>
<td>Advocacy with local government for prevention and control of birth defects</td>
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<td></td>
<td>Working Group on Maternal and Child Health Handbook (ongoing) to be utilized</td>
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<tr>
<td></td>
<td>Collaborating with Ministry of Social Affairs</td>
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</table>
### Indonesia

<table>
<thead>
<tr>
<th>Action Area</th>
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<th>5 Years</th>
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<tbody>
<tr>
<td>National networks</td>
<td>Establish teamwork for birth defects prevention at national level</td>
<td></td>
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<tr>
<td></td>
<td>Establish a secretariat for birth defects prevention at national level</td>
<td></td>
</tr>
<tr>
<td>Birth defect surveillance</td>
<td>Develop tools for collecting data from hospitals, public health clinics, community-based clinics (establish and strengthen)</td>
<td>Develop tools for collecting data from hospitals, public health clinics, community-based clinics (establish and strengthen)</td>
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<tr>
<td></td>
<td>Establish academic network for birth defects registration in major hospitals with paediatric, obstetric and neonatal societies</td>
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<tr>
<td></td>
<td>Explore documentation of birth defects in community and sentinel surveillance sites</td>
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### Maldives

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<thead>
<tr>
<th>Action Area</th>
<th>2 Years</th>
<th>5 Years</th>
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<tbody>
<tr>
<td>Integrate preventive interventions into existing public health programmes</td>
<td>• Development of a taskforce and national plan for prevention of birth defects in collaboration with other public health programmes with maternal and child health, nutrition, noncommunicable disease unit, tobacco control unit, sexually transmitted infections/ HIV and health promotion programme etc., and other stakeholders</td>
<td>• Address prevention and management of birth defects during the review of existing strategies/activities</td>
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<tr>
<td></td>
<td>• Start premarital counselling programme (piloting and expanding)</td>
<td>• Develop a policy for prevention and management of birth defects</td>
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<tr>
<td></td>
<td>• Preconceptional folic acid supplementation as per the recommendation</td>
<td></td>
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<tr>
<td>Folic acid fortification</td>
<td>Take the draft Micronutrient Policy forward</td>
<td>Import fortified food</td>
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<td></td>
<td>Check quality of iodized salt imported to the country as this salt is only available for households</td>
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<tr>
<td>Action Area</td>
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<td>5 Years</td>
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<tr>
<td><strong>Thalassaemia</strong></td>
<td>Preparation for prenatal diagnosis</td>
<td>• Start prenatal diagnosis in the country • Thalassaemia bill may get endorsed</td>
</tr>
<tr>
<td><strong>Newborn screening</strong></td>
<td>Development of national protocols</td>
<td>Establish newborn screening facilities at central level</td>
</tr>
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<td>Sensitization of health-care providers on birth defects through ongoing inservice education programmes</td>
<td>Establish newborn screening mechanism for other regions</td>
</tr>
<tr>
<td></td>
<td>Advocacy programmes for policy-level stakeholders (Tiny Hearts Association, Association of Retarded Citizens, etc.)</td>
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<tr>
<td><strong>Communication strategy</strong></td>
<td>• Develop and implement communication plan • Development of communication materials</td>
<td></td>
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<tr>
<td><strong>National networks</strong></td>
<td>Identify and establish network with relevant organization(s) from all over the country</td>
<td>Participate in the regional network</td>
</tr>
<tr>
<td><strong>Birth defect surveillance</strong></td>
<td>Policy endorsement to have a birth defect registry</td>
<td>Data analysis</td>
</tr>
<tr>
<td></td>
<td>Information on birth defects through vital registration systems</td>
<td>Collect evidence-based information</td>
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<tr>
<td></td>
<td>Establish National Birth Defect Registry in central and regional hospitals and expand further</td>
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<td></td>
<td>Improve the quality of collection of birth defect data in health facilities at all levels</td>
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<td>Action Area</td>
<td>2 Years</td>
<td>5 Years</td>
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<tr>
<td><strong>Integrate preventive interventions into existing public health programmes</strong></td>
<td>Female community health volunteers, maternity and child welfare services</td>
<td>Nutrition programmes</td>
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<tr>
<td><strong>Folic acid fortification</strong></td>
<td>With iron tablets</td>
<td>Salt fortification</td>
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<tr>
<td>Technology</td>
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<tr>
<td><strong>Thalassaemia</strong></td>
<td>Counseling</td>
<td>Lab setting</td>
</tr>
<tr>
<td><strong>Newborn screening</strong></td>
<td>NA</td>
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<tr>
<td><strong>Communication strategy</strong></td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td><strong>Birth defect surveillance</strong></td>
<td>Prioritizing BD, advocacy</td>
<td>Different regional levels</td>
</tr>
<tr>
<td>Pilot</td>
<td></td>
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<tr>
<td><strong>Other</strong></td>
<td>Assessment of socioeconomic impacts</td>
<td></td>
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<tr>
<td>Diagnostic facility setting</td>
<td></td>
<td></td>
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<tr>
<td>Sharing of experiences of Member States</td>
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<tr>
<td>Sri Lanka</td>
<td>Action Area</td>
<td>2 Years</td>
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<tr>
<td><strong>Integrate preventive interventions into existing public health programmes</strong></td>
<td>To strengthen and expand the National Working Committee on birth defects with defined terms of reference</td>
<td>To introduce action plans and implement at both national and sub-national levels</td>
</tr>
<tr>
<td></td>
<td>To develop a national strategic plan on birth defects prevention and control/national integrated birth defects programme</td>
<td>To develop strong links with other related programs e.g., noncommunicable diseases, tobacco/alcohol, nutrition</td>
</tr>
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<td></td>
<td>To mainstream pre-pregnancy Care Package within health sector</td>
<td>To develop a comprehensive care package for children with birth defects/Children with Special Health Care Needs, with full government commitment</td>
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<td></td>
<td>To strengthen maternal care package to address birth defects prevention</td>
<td>To strengthen genetic services, including counseling/services, research and genetic surveillance</td>
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<td>To include and strengthen the birth defects prevention strategies in school health programme</td>
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<tr>
<td><strong>Folic acid fortification</strong></td>
<td>To implement in Intermittent iron-folic acid supplementation – adolescents/menstruating women</td>
<td>To achieve country-wide coverage of Intermittent iron-folic acid supplementation</td>
</tr>
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<td></td>
<td>To assess feasibility of food fortification (rice) with folic acid and iron.</td>
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<tr>
<td><strong>Thalassaemia</strong></td>
<td>To introduce voluntary screening at strategic points, such as for school children, premarital and cascade screening</td>
<td>To achieve universal coverage</td>
</tr>
<tr>
<td></td>
<td>To assess feasibility of bone marrow transplantation</td>
<td>To establish a dedicated centre – bone marrow transplantation</td>
</tr>
<tr>
<td><strong>Sri Lanka</strong></td>
<td><strong>2 Years</strong></td>
<td><strong>5 Years</strong></td>
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<tr>
<td><strong>Newborn screening</strong></td>
<td>To strengthen and improve the quality of existing newborn screening</td>
<td>To introduce comprehensive newborn screening to cover other disease entities</td>
</tr>
<tr>
<td></td>
<td>To expand the existing congenital hypothyroid screening</td>
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<td></td>
<td>To develop a road map for newborn screening and management</td>
<td></td>
</tr>
<tr>
<td><strong>Communication strategy</strong></td>
<td>To identify areas for birth defects communication and to integrate with reproductive health communication strategy</td>
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<td></td>
<td>To develop a behaviour change communication package on birth defects</td>
<td></td>
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<tr>
<td><strong>National networks</strong></td>
<td>Networking local academic bodies and centers of excellences dealing with birth defects (prevention/control/rehabilitation) health and non-health</td>
<td></td>
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<tr>
<td></td>
<td>Data sharing with all relevant stakeholders for action</td>
<td></td>
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<tr>
<td><strong>Birth defect surveillance</strong></td>
<td>To introduce a birth defects surveillance mechanism and initiate birth defects registry</td>
<td>To achieve country-wide coverage</td>
</tr>
<tr>
<td></td>
<td>To piloting BD surveillance system in a representative district/s</td>
<td>To improve data quality and data linkage</td>
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<td></td>
<td>To conduct an epidemiological survey – profile/risk factors</td>
<td>To improve birth defects-specific data extraction &amp; utilization</td>
</tr>
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<td>To strengthen existing HIMS to report birth defects (hospitals and population based e.g., H509 (Maternal and Child Health Return) /Indoor Morbidity and Mortality Record/demographic health survey/laboratory</td>
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<tr>
<td><strong>Other: Ethics</strong></td>
<td>To establish ethics advisory committee on birth defects related areas</td>
<td></td>
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### Thailand

<table>
<thead>
<tr>
<th>Action Area</th>
<th>2 Years</th>
<th>5 Years</th>
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<tbody>
<tr>
<td><strong>Integrate preventive interventions in existing public health programs</strong></td>
<td>20 hospitals have birth defects registry</td>
<td>National birth defects registry</td>
</tr>
<tr>
<td></td>
<td>Triferdine use in pregnant women</td>
<td>Increase coverage Triferdine using in Pregnant and preconception (adolescent, etc.)</td>
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<tr>
<td></td>
<td>Holistic prevention and care in 20 provinces for five selected birth defects</td>
<td>Increase coverage of birth defects holistic prevention and care to all the country</td>
</tr>
<tr>
<td><strong>Folic acid fortification</strong></td>
<td>Noodle folic acid fortification</td>
<td>Rice fortification</td>
</tr>
<tr>
<td><strong>Thalassemia</strong></td>
<td>Increase coverage of screening pregnant women to 70%</td>
<td>Increase coverage screening pregnant women to 80%</td>
</tr>
<tr>
<td></td>
<td>Support system for prenatal diagnosis</td>
<td>Increase prenatal diagnosis center</td>
</tr>
<tr>
<td><strong>Newborn screening</strong></td>
<td>Increase coverage of NBS and provide treatment to positive cases</td>
<td>Establishment of efficient holistic care</td>
</tr>
<tr>
<td></td>
<td>Increase coverage of the existing screening of phenylketonuria (PKU) congenital hyperthyroidism to &gt;95%</td>
<td>Increase categories for screening: e.g. congenital adrenal hyperplasia</td>
</tr>
<tr>
<td><strong>Communication strategy</strong></td>
<td>Regular birth defects prevention communication to the public</td>
<td>Persistent regular birth defects prevention to the public</td>
</tr>
<tr>
<td><strong>Birth defect surveillance</strong></td>
<td>Pilot study of 5 birth defects</td>
<td>Country coverage of 5 diseases</td>
</tr>
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<td></td>
<td>Birth defects registry network</td>
<td>Neonatal database network</td>
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Annex 4

Agenda

- Present global situation of birth defects and rationale for developing strategies for prevention of birth defects.
- Present regional and country situation of birth defects and review the draft regional situation assessment report on birth defects.
- Sharing of evidence-based approaches for prevention of birth defects including food fortification and supplementation with folate.
- Present the need and mechanism for birth defects surveillance in countries.
- Discuss communication and advocacy strategy for prevention of birth defects in the Region.
- Discussions and consensus on development of the regional strategic directions for prevention and control of birth defects.
- Discussions on establishing regional and national networks of institutions on birth defects.
### Annex 5

#### Programme

#### Day 1: Tuesday, 20 March 2012

<table>
<thead>
<tr>
<th>Time</th>
<th>Agenda item</th>
<th>Lead/Presenter</th>
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<tbody>
<tr>
<td>0830 - 0900</td>
<td>Registration</td>
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<tr>
<td>0900 - 1000</td>
<td>Inauguration</td>
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<tr>
<td><strong>Session 1</strong>&lt;br&gt;1030 - 1130</td>
<td>Global and Regional overview of Birth Defects&lt;br&gt;• Burden of Birth Defects and Preventive Strategies: Global overview&lt;br&gt;• Global activities&lt;br&gt;• Regional situation&lt;br&gt;Discussions</td>
<td>Luz Maria de Regil (WHO/HQ)&lt;br&gt;Coleen Boyle (CDC)&lt;br&gt;Neena Raina (WHO/SEARO)</td>
</tr>
<tr>
<td><strong>Session 2</strong>&lt;br&gt;1130 - 1330</td>
<td>SEARO Member States’ presentations on current situation and opportunities&lt;br&gt;<strong>Group 1</strong>&lt;br&gt;Chairs: Luz Maria and R J Berry&lt;br&gt;• Bangladesh&lt;br&gt;• Indonesia&lt;br&gt;• Maldives&lt;br&gt;• Nepal&lt;br&gt;• Sri Lanka</td>
<td>Two concurrent group sessions&lt;br&gt;<strong>Group 2</strong>&lt;br&gt;Chairs: Coleen Boyle and I C Verma&lt;br&gt;• Bhutan&lt;br&gt;• India&lt;br&gt;• Myanmar&lt;br&gt;• Thailand</td>
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<tr>
<td>Rapporteur</td>
<td>Vijay Kumar</td>
<td>Burke Fishburn</td>
</tr>
<tr>
<td>1430 - 1515</td>
<td>Plenary Feedback from country presentations&lt;br&gt;Rapporteurs</td>
<td>Lorenzo Botto, PierpaoloMastroiacovo (ICBD-SR)</td>
</tr>
<tr>
<td><strong>Session 3</strong>&lt;br&gt;1515 - 1545</td>
<td>Review of strategies for prevention of birth defects:&lt;br&gt;• Maternal risk factors</td>
<td>Lorenzo Botto, PierpaoloMastroiacovo (ICBD-SR)</td>
</tr>
<tr>
<td>1615 - 1645</td>
<td>Review of strategies for prevention of birth defects: (Contd)&lt;br&gt;• Evidence on prevention&lt;br&gt;• Large-scale programmes for prevention&lt;br&gt;Discussions</td>
<td>Lorenzo Botto, PierpaoloMastroiacovo (ICBD-SR)</td>
</tr>
<tr>
<td>1645 - 1715</td>
<td>Integration of BD prevention in existing public health programmes: Rationale and opportunities</td>
<td>Vijay Kumar</td>
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### Day 2: Wednesday, 21 March 2012

<table>
<thead>
<tr>
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<tr>
<td>0900 - 0915</td>
<td>Welcome and review of Day 1</td>
<td>WHO-SEARO</td>
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| **Session 4** 0915 - 1030 | Evidence-guided birth defects preventive strategies  
  - Food fortification and Safety of folic acid fortification  
  - Supplementation with folate  
  Discussions                                                | R.J Berry (CDC)  
  Luz Maria de Regil (WHO)                                    |
| 1100 - 1145 | Evidence-guided birth defects preventive strategies (continued)  
  - Thalassaemia prevention  
  - Newborn screening  
  Discussions                                                | Experts  
  I C Verma  
  Madhulika Kabra                                           |
| **Country Action Points: Sessions 3 - 4** |                                                                 | Country teams                     |
| **Session 5** 1145 - 1215 | Communication and advocacy strategy for birth defects  
  Discussions                                                | Burke Fishburn (CDC/CCI)           |
| 1215 - 1245 | Role of Regional and National Networks  
  - Need for networks  
  - Models for networks  
  Discussions                                                | V K Paul                           |
| **Country Action Points: Session 5** |                                                                 | Country teams                     |
| 1245 - 1330 | Introduction and overview of Regional Strategic Framework on prevention and control of birth defects and introductions to group work | Rajesh Mehta                       |
| **Section 6** 1430 - 1530 | Review in Groups                                                            | Group work                        |
| 1600 - 1700 | Review in Groups                                                            | Group work                        |

**Chairs:** Lorenzo Botto and Sirarpon Sawasdivorn  
**Rapporteur:** Madhulika Kabra
<table>
<thead>
<tr>
<th>Time</th>
<th>Agenda item</th>
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<tbody>
<tr>
<td>0900 - 0915</td>
<td>Welcome and review of Day 2</td>
<td>WHO-SEARO</td>
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<tr>
<td>0915 - 1030</td>
<td>Feedback from Group Work: Inputs on Regional Strategic Framework</td>
<td>Rapporteurs</td>
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<td><strong>Session 7</strong></td>
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<tr>
<td>1100 - 1200</td>
<td>Birth Defects Surveillance</td>
<td>Lorenzo Botto, Pierpaolo Mastroiacovo (ICBD-SR)</td>
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<tr>
<td></td>
<td>• Surveillance needs</td>
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<td>• Types of surveillance</td>
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<td>• Using surveillance for reporting, policy/programme development and evaluation</td>
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<td>Discussions</td>
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<tr>
<td>1200 - 1230</td>
<td>Country Experience: Organizing Birth Defect Registry – Gains and challenges</td>
<td>India: S Suresh</td>
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<td></td>
<td>Discussions</td>
<td>Thailand:</td>
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<td><strong>Session 8</strong></td>
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<tr>
<td>1230 - 1315</td>
<td>Needs Assessment and Strategic Planning Tool for Birth Defect Programming</td>
<td>Hillary Burton</td>
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<td>Discussions</td>
<td>PHG Foundation</td>
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<tr>
<td>1415 - 1515</td>
<td>Country Action Points- Compilation</td>
<td>Country teams</td>
</tr>
<tr>
<td>1515 - 1615</td>
<td>Country Presentation of Action Points</td>
<td>Presentation by each country – 5 minutes</td>
</tr>
<tr>
<td>1615 - 1645</td>
<td>Closing: Conclusions and recommendations</td>
<td>WHO-SEARO and CDC</td>
</tr>
</tbody>
</table>
Annex 6

List of participants

Bangladesh
Dr Md Abdul Hoque
Programme Manager
MNH, DGHS
Mohakhami, Dhaka
Mobile: 01712185008

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With improvements in the management of major causes of neonatal mortality such as infection and asphyxia, birth defects are increasingly seen as a major cause of stillbirths and neonatal deaths. Preventing birth defects-related mortality would contribute to further reduction in child mortality in countries and contribute to achievement of MDG 4. In view of this, the World Health Assembly adopted WHA Resolution 63.17 in May 2010, which identified actions to address birth defects to impact stillbirths and neonatal mortality. In response, the South-East Asia Regional Office of WHO proposed to develop a Regional Strategy for prevention and control of birth defects in consultation with Member States and partner agencies.

A Regional programme managers’ meeting on prevention and control of birth defects was held from 20 to 22 March 2012 in Bangkok, Thailand. Presentations were made to summarize the global, regional and country situations. Key technical areas related to evidence for prevention of birth defects, birth defects surveillance, communication and advocacy were discussed. The draft Regional strategic framework for prevention and control of birth defects was reviewed and discussed. Based on the understanding developed in the meeting, the national programme managers developed tentative action plans for prevention of birth defects for the next two years and for five years.

Prevention and control of birth defects in South-East Asia

Report of Regional Programme Managers’ meeting
Bangkok, Thailand, 20-22 March 2012