WHO-EM/NUT/235/E

Report on the

Technical consultation to establish national birth defect registries in countries of the Eastern Mediterranean Region

Cairo, Egypt
21–26 May 2005

World Health Organization
Regional Office for the Eastern Mediterranean

WHO-EM/NUT/235/E

Report on the

Technical consultation to establish national birth defect registries in countries of the Eastern Mediterranean Region

Cairo, Egypt
21–26 May 2005

World Health Organization
Regional Office for the Eastern Mediterranean
Cairo
2005

Document WHO-EM/NUT/235/E/09.05/22

CONTENTS

1. INTRODUCTION

A technical consultation to establish national birth defect registries in countries of the Eastern Mediterranean Region was held by the WHO Regional Office for the Eastern Mediterranean (WHO/EMRO) on 21–26 May, 2005 in Cairo, Egypt. The objectives of the consultation were to review the current status of national birth defect registries in countries of the WHO Eastern Mediterranean Region and to develop a plan of action for establishing national birth defect registries with focus on neural tube defects.

The meeting was inaugurated by Dr Ramez Mahaini, Coordinator, Family Health and Women's and Reproductive Health, who delivered a message from Dr Hussein A. Gezairy, WHO Regional Director for the Eastern Mediterranean. In his message, Dr Gezairy recalled that several years previously, the Regional Office had recognized the public health problems posed by micronutrient deficiencies among the populations of the Region and, in collaboration with partner organizations, had supported introduction of a wide-ranging set of interventions targeted against the commonly encountered micronutrient deficiencies—iron, vitamin A and iodine deficiencies. These interventions had met with varying degrees of success.

The possibility of fortifying wheat flour with iron as another tool for the control and prevention of iron deficiency and its anaemia was given serious consideration by the Regional Office and its partner organizations in the mid 1990s. A few countries adopted the strategy at the national level while several others explored its relevance through pilot projects. Subsequently, folic acid was added to the fortification process for the purpose of reducing the risk of neural tube defects and possible reduction in risks for other birth defects. Member States adopting this approach did not have baseline information on the prevalence of folic acid deficiency or an ongoing mechanism to detect birth defects, particularly neural tube defects. At present, national level fortification of wheat flour with iron and folic acid existed in 7 countries, while large and small-scale projects had been completed or were under way in 6 other countries.

Dr Gezairy noted that assessments of the impact of flour fortified with iron in some countries had yet to yield the information of its desired beneficial effect upon the population. Expert opinion indicated that the full benefit of an iron fortification programme could only be discerned after a sufficient period of time had elapsed between the initiation of the programme and its assessment. This optimum period of time for countries in the Region had yet to be established, but scientific evidence showed that the impact of folic acid supplementation was comparatively easier to detect, either through biochemical assessment at the individual level, or through the assessment of birth defects, particularly neural tube defects, as a population indicator. He stressed that neural tube defects constituted just one of the areas that indicated the need for national birth defect registries.

Although there had been significant progress in improving the birth outcome and health of infants and young children in countries of the Region, as reflected in the sustained decline in the infant and under-five child mortality rates, he noted that corresponding improvement in neonatal health had not been proportionate. The Regional Office had continued to emphasize

to countries the need to improve neonatal health care, and an important component of the Regional Office's effort had been to provide support to the development of neonatal birth registration procedures in countries and to effective utilization and interpretation of data generated at different levels of the infant and child health care system. In the areas of micronutrient deficiency prevention and control activities and improving neonatal health outcomes, the Regional Offices had benefited from the strong technical support provided by the Centers for Disease Control and Prevention in Atlanta.

The Regional Director ended by stating that the objectives of the technical consultation were to review the present status of national birth defect registries in countries of the Eastern Mediterranean Region and to develop a plan of action for establishing national birth defect registries with focus on neural tube defects. The consultation was to attempt to combine the experience of programme managers from the areas of reproductive health and nutrition to develop a sustainable system for monitoring birth defects, and in the process to be able to determine the public health impact of folic acid supplementation.

Dr Hani K. Atrash, Associate Director for Programme Development at the National Center on Birth Defects and Development Disabilities, Centers for Disease Control and Prevention (CDC), next addressed the consultation, noting that the meeting marked a new phase of collaboration between the Regional Office and CDC. Dr Atrash highlighted the importance of the step they were taking and anticipated future benefits from the development of registries in preventing health problems. He emphasized the importance of recognizing the needs of babies, infants and children with disabilities and helping them to lead normal, productive lives.

Dr Robabeh Sheikholeslam (Islamic Republic of Iran), Dr Safaa Abdel Fattah Ahmed (Egypt) and Ms Aisha Al-Romaihi (Qatar) shared the Chair on a rotating basis. Ms Lina Chichakli served as Rapporteur. The meeting agenda, programme and list of participants are included as Annexes 1, 2 and 3, respectively.

2. OBJECTIVES AND METHODOLOGY

Ms Lilas A. Tomeh

Micronutrient deficiency is a serious public health problem in the Eastern Mediterranean Region. The most noted deficiencies are in iron, folic acid, vitamin A and zinc and it is because of problems caused by their lack that strategies and interventions in the areas of dietary diversification, supplementation and fortification are needed.

The Region has a history of flour fortification beginning with a 1995 technical consultation to develop guidelines for the control of iron deficiency which was organized by the Regional Office and UNICEF. This was a move towards improved, innovative supplementation programmes, promoting active dietary approaches, appropriate public health measures and initiating fortification of wheat flour. In 1996, a workshop to examine the practical implication of flour fortification and build consensus on regional standards was held by the Regional Office, UNICEF and the Micronutrient Initiative (MI). Two years later a

workshop on flour fortification for the control and prevention of micronutrient deficiencies in the Region was held by the Regional Office and UNICEF to build on consensus developed at the 1996 meeting. At present, countries are at different stages in the flour fortification process. Some are at the planning stage but have not initiated programmes; others have initiated their programmes and others have ongoing flour fortification programmes.

There are limitations of iron status indicators; baseline information on iron deficiency is lacking for countries undertaking flour fortification, and the impact of iron fortified flour on the prevalence of anaemia is limited to only two studies. There is close collaboration between CDC and the Regional Office in the control and prevention of micronutrient deficiencies through standardized methodologies, technical and financial support for the prevention of micronutrient deficiencies in the Region, the improvement of communication strategies and technical and financial support to selected countries.

A further intervention is the addition of folic acid to wheat flour since folic acid as a preventive measure against the development of neural tube defects. However, there is neither baseline information on the prevalence of folic acid deficiency in the Region nor information on the prevalence of neural tube defects. This lack of information indicates the need for birth defect registries.

The objectives of the consultation are to review the present status of national birth defect registries in countries of the Region and to develop a plan of action for establishing national birth defect registries focusing on neural tube defects in countries. To this aim, the consultation would commence with plenary sessions on technical issues with ample time devoted to discussion and national experiences. There would be case study activities and a site visit to the National Population Centre in Cairo. This would be followed by group work, from which the conclusions and recommendations of the consultation would emerge.

The expected outcomes of the meeting are to harmonize the experience of programme managers from reproductive health, child health and nutrition sectors, and identify a sustainable and applicable national birth defects registry to detect neural birth defects in countries of the Region. Further expected outcomes are to assess the impact and prevalence of folic acid deficiency in the population of the Region, to be able to determine the public health impact of folic acid supplementation and fortification.

3. OVERVIEW OF NEONATAL HEALTH IN THE REGION

Dr Ramez Mahaini

Each year, about 4 million newborns die worldwide before they are four weeks old—98% of these deaths occur in developing countries. Around 16% of all newborn deaths occur in the Eastern Mediterranean Region. Newborn deaths now contribute to about 40% of all deaths among children under five years of age, and more than half of infant mortality worldwide. The above figures do not include the 3.3 million stillbirths per year. Data on stillbirths are even scarcer than those on newborn deaths. This is not surprising, as only 14% of births in the world are registered. Both live births and deaths of newborns go

underreported; fetal deaths are even more likely to go unreported, particularly early fetal deaths. It is clear that the Millennium Development Goal for reducing child mortality will not be reached without substantial advances in promoting neonatal health by making greater efforts to implement the scientific and cost-effective interventions.

WHO defines neonatal mortality rate as “number of deaths of live born infants, occurring during the period, which commences at birth and ends 28 completed days after birth per 1000 live births”. Perinatal mortality rate is defined as “number of deaths of fetuses weighing at least 500 grams (or when birth weight is unavailable, after 22 completed weeks of gestation or with a crown-heel length of 25 cm or more) plus the number of early neonatal deaths occurring during the first seven days of life, per 1000 total births”. While the burden of neonatal deaths is very substantial, it is in many ways only part of the problem, as the same conditions that contribute to it also cause severe and often lifelong disability. For example, over a million children who survive birth asphyxia each year develop problems such as cerebral palsy, learning difficulties and other disabilities. For every newborn baby who dies, at least another 20 suffer birth injury, infection, complications of preterm birth and other neonatal conditions. Their families are usually unprepared for such tragedies and are profoundly affected.

The World Health Report 2005 estimated that around 610 000 children die every year in the first weeks of life in the Region, compared to 3 910 000 newborns that die worldwide every year. The average neonatal mortality rate for the Region as a whole was calculated at 32.7 per 1000 live births in 2004. However, there are great variations and disparities in neonatal mortality levels between countries of the Region, with a wide range from 5 per 1000 in Bahrain to 54 per 1000 live births in Pakistan. The neonatal mortality rate is also expected to be much higher in other countries like Afghanistan, Djibouti and Somalia.

A handful of preventable and treatable conditions are responsible for a significant portion of all newborn deaths. In the Eastern Mediterranean Region these include the following conditions: severe infection (28%), prematurity (22%), birth asphyxia (20%), neonatal tetanus (12%) congenital disorders (9%), diarrhoea (4%) and others (5%). However, it should be appreciated that the underlying reasons for the death of newborn babies are largely the cause of death and disability of their mothers, and are closely linked to women’s status, education, nutrition and health care in pregnancy, childbirth and post-partum.

Distance from health services, cost (direct fees as well as the cost of transportation, drugs and supplies), multiple demands on women’s time and women’s lack of decision-making power within the family are all factors that prevent women in developing countries from getting the life-saving health care they and their newborn babies need. The poor quality of services, including poor treatment by health providers, can also make some families reluctant to use services.

The health and survival of newborn children is closely linked to that of their mothers. First, because healthier mothers have healthier babies; second, because where a mother gets no or inadequate care during pregnancy, childbirth and the postpartum period, this is usually also the case for her newborn baby. In addition to the 4 million babies who die each year

before reaching their first month of life, millions more are disabled because of inadequately managed pregnancies and births. Today the knowledge of how to prevent and manage pregnancy-related complications exists and there is increasing recognition that pregnant women should be assisted by skilled health personnel, particularly during and immediately following childbirth. Unfortunately, in the Eastern Mediterranean Region, only 60% of pregnant women receive antenatal care and 53% are attended during delivery by skilled health personnel. As a result, despite the decline of the under-five child mortality rate by 22% from its level in the year 1990, over 60% of infant deaths in the Region still occur in the first four weeks of life.

Immunization of women against tetanus, hygienic conditions for delivery, warmth, immediate breast-feeding, resuscitation when necessary, early detection and treatment of infections and screening for inborn errors of metabolism, are all important factors that can save the lives of newborn babies.

Doctors, nurses, midwives, and other health care workers at first referral level are usually responsible for the care of newborns with problems after birth. Therefore, upgrading their knowledge and skills in neonatal health care can lead to a significant reduction in perinatal/neonatal death. Development of evidence-based, authoritative clinical guidelines with basic laboratory facilities, selected essential drugs and supplies can equip the skilled health care providers with necessary tools for quality neonatal health services. In some settings, large health centres that provide childbirth care and have the capacity to care for sick or small newborn babies are important to deliver necessary treatment for newborn babies with serious complications.

Educating women and their families about the risk of neonatal complications and about the appropriate action should danger signals be identified, early identification of newborn babies with complications and their prompt referral to appropriate medical care, as well as effective motivation of women and their families to agree with these referrals, can all drastically improve the situation. As well, provision of appropriate education about the health hazards of marriage between cousins, and the significance of premarital medical examination, maternal health care in pregnancy and child birth and neonatal screening of inherited diseases are also important factors towards promoting the health of newborn babies, and hence reducing infant and child mortality.

Analysis of relevant data reported by countries to the Regional Office indicates that neonatal mortality rate has a significant statistical correlation with skilled birth attendance rate ($r = 0.912$), maternal mortality ratio ($r = 0.847$), and female illiteracy rate ($r = 0.738$).

Since the Nairobi Conference in 1987, the Regional Office has advocated the principles and necessary interventions for the implementation of the Safe Motherhood Initiative as a priority public health issue in countries of the Region. In 1988, the Regional Committee for the Eastern Mediterranean discussed and “noted with concern the high levels of maternal and infant deaths in some countries of the Region”, and adopted resolution EM/RC35/R.9 “Maternal and infant mortality in the Eastern Mediterranean Region—socioeconomic implications and urgent need for control”. In 1990, the Regional Committee adopted

resolution EM/RC37/R.6, in which all countries of the Region were requested to aim at reducing maternal mortality by 50% by 2000 and to adopt all possible measures to achieve this target. Two approaches were determined in this resolution to improve maternal health, namely, securing the availability of one trained birth attendant in every village and urban quarter, and reinforcing the technical support provided to Member States to achieve the goals of safe motherhood.

The Regional Office adopted the Safe Motherhood Initiative as a priority strategy to protect and promote maternal and neonatal health in countries of the Region. Since then, the Regional Office has adopted the Safe Motherhood Initiative as a priority strategy to protect and promote maternal and neonatal health in the Region. Close technical and financial support have been maintained to strengthen and expand safe motherhood activities in countries of the Region. As a result, maternal health care delivery indicators were significantly improved in the past decade. The percentages of pregnant women and deliveries attended by skilled personnel increased from 28% to 60% and from 36% to 53%, respectively.

The launch of WHO's Making Pregnancy Safer (MPR) initiative in 2000 was a significant step forward towards reducing maternal and neonatal ill health in Member States. The adoption of the MPR strategy is expected to accelerate the reduction of maternal and neonatal morbidity and mortality through improvement of the availability, accessibility and utilization of the essential maternal and neonatal health services and improvement of quality of these services.

The Regional Office also supported the national programmes on safe motherhood through a series of intercountry consultations, meetings, workshops and international training to improve the knowledge and skills of national health programme managers and health staff in the field of maternal and neonatal health. The following are examples.

- The Mother–Baby Package: in 1995, the Regional Office introduced the Mother–Baby Package, which describes the effective minimum interventions of the four pillars of Safe Motherhood, namely: antenatal care, essential obstetric care, post-partum and neonatal care and family planning. The package was translated into Arabic and other spoken languages, and was used in Member States.

- Data use for decision-making in maternal and perinatal health care: this project is aimed at introducing the technical know-how for using available data in ensuring maternal and perinatal health care coverage and quality. The Regional Office initiated this project in 1998 in collaboration with CDC. The project training materials on data use for decision-making in maternal and perinatal health care were developed by the Regional Office and were disseminated to countries of the Region.

- Directory for reproductive health research: the project is aimed at establishing a data-base on reproductive health, including maternal and neonatal health research for enabling exchange of related experience between and within countries of the Region; and encouraging the utilization of data, when available, in reproductive health

programme development and implementation. This project is being implemented in close collaboration with WHO headquarters.

- Total quality management in maternal and perinatal health care: this project is aimed at developing the managerial skills of national health staff at the district and peripheral levels through integrating total quality management approaches in maternal and perinatal health care. The project was started in 1999. Regional training guidelines were developed by the Regional Office in collaboration with CDC in 2000, were field-tested in Member States in 2001 and were finalized and disseminated to countries of the Region in 2003.

- Pan Arab Project for Family Health: the implementation of Pan Arab Project for Family Health (PAP-FAM), which is executed by the League of Arab States, in collaboration with the Regional Office along with other concerned agencies, made significant progress in updating a database on family health related issues, including maternal health. PAP-FAM surveys were completed in Algeria, Djibouti, Lebanon, Morocco, Syrian Arab Republic, Tunisia and Yemen. Meanwhile, similar surveys have been already agreed to be implemented in Libyan Arab Jamahiriya, Mauritania, Somalia and Sudan.

- United Nations Population Fund strategic partnership programme (UNFPA/WHO): increased attention was addressed to upgrade the technical know-how of the health workers of making pregnancy safer services, and hence improve the quality and management of these services in countries of the Region. The Regional Office selected a number of WHO guidelines of Integrated Management of Pregnancy and Childbirth (IMPAC) and initiated their translation into Arabic and expanded their dissemination to Member States. The following guidelines were included: “Beyond the Numbers”, “Pregnancy, Childbirth, Postpartum and Newborn Care: a guide to essential practice”, “Managing Complications of Pregnancy and Childbirth” and “Managing Newborn Problems”, “Improving Access to Quality Care of Family Planning: Medical Eligibility Criteria for Contraceptive Use”, “Selected Practice Recommendations for Contraceptive Use”, and “Decision-Making Tool for Family Planning Clients and Providers”. The Regional Office has also formulated a plan of action to introduce and technically backstop adaptation of these guidelines in countries with high maternal mortality levels in 2005.

Several important challenges lie ahead. There is widespread lack of awareness about the Millennium Development Goals announced in the Millennium Declaration in 2000, even among maternal and child health programme managers, and the adoption of the goals has not translated into action to achieve them. National policies on maternal and neonatal health are still lacking in most of the countries.

If the current maternal and child mortality trends in the Region continue, the Millennium Development Goals are unlikely to be achieved, unless commitments, intensive efforts and national plans are made and translated into action, including the allocation of resources. Such efforts and plans should target the strengthening of health systems, expansion

in the coverage of effective integrated interventions and recognition of the essential role of community participation.

The tendency to fund vertical disease-specific programmes has dramatically shifted resources from maternal and child health. This tendency may lead to neglect of integrated strategies that aim both to strengthen the health system and to build capacity of the human resources that are essential to support and sustain progress towards the Millennium Development Goals.

Current levels of health expenditure, especially in the low-income countries in the Region, which are those with the highest child and maternal mortality, are insufficient to support strategies and actions necessary to achieve the Millennium Development Goals. The serious reduction in WHO allocations to child and maternal health at regional level has also adversely affected the scaling up of the implementation of effective related interventions.

Maternal and child health-related data and information are still scarce in most countries of the Region. Even when available, these data are either of poor quality or their use in decision-making and planning is remarkably limited.

Human resources development for maternal and child health in the Eastern Mediterranean countries requires further attention. The inadequate pre-service (basic) education of health providers overburdens the health system with a continuing need to improve and update health providers' knowledge and skills. Low quality in-service training of health providers and high turnover of trained staff are also major obstacles to providing good quality health services to children and mothers, particularly where they are most needed.

The future steps to be taken were indicated in the 51st Session of the Regional Committee for the Eastern Mediterranean in 2004, which noted with concern the high levels of maternal and child mortality in some countries of the Region and adopted resolution (EM/RC51/R.4). The resolution urged Member States who have not already achieved the targets set by the Millennium Development Goals for improvement of maternal and child health, including neonatal health care to:

- develop national maternal and child health policy documents and strategies necessary to achieve the Millennium Development Goals;
- expand upon the achievements already made by countries in implementing the effective interventions of Making Pregnancy Safer and ensuring the availability of one skilled birth attendant/midwife per village;
- strengthen existing national surveillance systems to identify mortality and morbidity trends in mothers and adopt evidence-based interventions, including community-based interventions;
- establish a national maternal mortality committee to review and monitor maternal deaths in the country;
- incorporate public health approaches related to maternal health into the formal teaching curricula of medical and paramedical schools.

The resolution also requested WHO to:

- support further the scaling up of effective interventions; in order to improve maternal health in the Eastern Mediterranean Region and assist the Member States to achieve the Millennium Development Goals;
- assist Member States to conduct in-depth assessment of maternal mortality;
- report periodically to the Regional Committee on progress in moving towards the Millennium Development Goals relating to maternal and child health.

4. TECHNICAL PRESENTATIONS

4.1 Principles of developing public health surveillance systems

Dr Hani K. Atrash

Public health surveillance is the ongoing, systematic collection, analysis and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know. The final link of the surveillance chain is the application of these data to prevention and control. A surveillance system includes a functional capacity for data collection, analysis and dissemination linked to public health programmes.

In 1965 WHO expanded the definition of public health surveillance to include disease control and prevention. In 1968 the 21st World Health Assembly applied surveillance to diseases rather than individuals, broadened the concepts of surveillance to include problems other than communicable disease, such as childhood lead poisoning, leukaemia, congenital malformations, abortions, injuries and behavioural risk factors. The purposes of public health surveillance are to assess public health status, define public health priorities, evaluate programmes and inform and conduct research.

In order to plan a surveillance system several steps must be taken: objectives need to be established; health events that need surveillance must be determined; methods developed; use of analysis and interpretation assured; the system evaluated; and proper attention given to ethical and legal issues.

In order to set the objectives, it is necessary to consider why the surveillance is taking place and what information is required. To determine the events that need surveillance, both qualitative and quantitative approaches are needed. The qualitative approach includes professional consensus, public interest and opinion and political interest and priority while the quantitative criteria include the frequency (incidence, prevalence, mortality, years of potential life lost), severity (case–fatality ratio, hospitalization rate, disability rate), cost (both direct and indirect cost) preventability, communicability and public interest.

When developing the methods used, it is necessary to consider the attributes of the system, remembering that many individuals will be involved. The system must be feasible, acceptable, sensitive, flexible, timely and with a high predictive value positive. The system

needs to be developed so that it can successfully meet identified needs without becoming excessively costly or burdensome. Case definition includes criteria for person, place, time, clinical or laboratory diagnosis and epidemiological features. It also includes degrees of certainty (suspected rather than confirmed), and high sensitivity and specificity are desirable. There should be a balance between the desire for high sensitivity and the effort needed to track false positive cases. Case definitions develop over time. Data can be collected from many sources with varying content, quality, availability, access and cost. Timelines must be set against quantity and quality of data.

Sources of data are diverse. In some cases routinely collected data may be sufficient whereas in others analysis of routinely collected data will supplement information from active case finding. For infectious diseases, surveillance activities have traditionally relied on notifiable disease reporting systems based on legally mandated reporting of cases to state and local health officials. Among existing data sources are vital records and administrative systems such as hospital discharge surveys, police records, school records and billing systems. New data can be obtained through the modification of existing systems, risk factor and health interview surveys, as well as sentinel reports.

Vital statistics are one of the cornerstones of surveillance. They are often the only health-related data available in a standard format for the entire population or for estimating rates for small geographic areas. Vital statistics are often the information collected at the time of birth and death and their usefulness depends on the characteristics of the health event being monitored, the procedures used to collect, code, and summarize relevant information. They are most useful for conditions that can be ascertained easily at the time of birth or death.

The term sentinel has been applied to key health events that may serve as an early warning or danger signal, clinics or other sites where health events are monitored and networks of health care providers who agree to report information on one or more health event. Sentinel sites and providers are especially useful for health events related to occupational exposures, such as mesothelioma and exposure to asbestos. They can provide timely information on a wide range of health conditions that is not available from other sources. In developing countries, the Expanded Programme on Immunization uses sentinel hospitals and clinics in 25 target cities, and sentinel providers, hospitals and clinics are used to monitor conditions not routinely monitored.

Data collection tools, whenever possible, should be generally recognized formats. There should be awareness of the use of identifiers so that there is an assurance of confidentiality and privacy while there is also the ability to link data to other information. Field testing is essential to ensure feasibility as well as acceptability to individuals and units participating in the surveillance system. Modification of the system is much easier during the field testing stage before it has been implemented on a wide scale.

A determination of the appropriate analytic approach to data should be an integral part of the planning of any surveillance system. Identifying the information needed helps to ensure that the proper data items are collected and that those unnecessary are not collected. The ability to use surveillance for its various purposes requires careful analysis and interpretation.

Data are not information but can be analysed to provide information which leads to knowledge and wisdom. It is important to know the limitations of the data and to realize when inaccuracies preclude more sophisticated analysis. Analysis and interpretation should proceed from the simplest to the most complex, beginning with time, person, place and their interactions and proceeding to estimate rates: crude specific and standard. Data should be summarized and displayed using graphs and tables, and the findings interpreted focusing on aspects that might lead to improved control of the condition.

Information must be presented in a compelling manner so that decision-makers at all levels can readily see and understand its implications. What and how to present information depend on the audiences and how they may use the information and a presentation must always include results, interpretation and recommendations for action. The information is being communicated for action to take place so it should be disseminated to those who have contributed and those who need to know.

Options for communication include publications, electronic, media and public forums. The information needs to be marketed in a way that ensures it is visible to those who need to know and focus placed on the single overriding communication objective (SOCO). What is new, who is affected and what works best are the most important components of the message. In order to evaluate the effect, evaluation efforts should address two considerations: whether it has been communicated to those who need to know and whether it has had a beneficial effect upon the problem or condition of interest.

The purpose of evaluating a surveillance system is to ensure that problems of public health importance are being monitored efficiently and effectively. Planning must therefore include ongoing, regular reassessment of the objectives and methods. Evaluation must be adapted according to need; specific attributes gain importance depending on the condition under surveillance (sensitivity, specificity, cost, etc). The three most important steps in evaluation are to describe clearly the health events under evaluation, the reasons for the surveillance and the ways the system has actually been used to help prevent and control disease or injury.

Sensitivity of the system is reflected by the proportion of cases that are detected and its ability to detect outbreaks. It can be affected by factors such as health care utilization of cases, correct diagnosis, reporting of cases. Sensitivity may change as a result of heightened awareness, new diagnostic tests and changes in surveillance methods. Predictive value positive (PVP) is the proportion of persons identified as case patients who actually have the condition. This affects the amount of resources required to investigate cases, the detection of epidemics and appropriate or inappropriate interventions being made. Clear and specific case definitions enhance PVP. It is estimated by dividing true positive cases by true positive cases added to false negative.

A further system attribute to be evaluated is the simplicity, structure and ease of operation. This can be assessed through examining the amount and type of information gathered, the number and type of reporting sources and the methods of transmitting data and information. It is necessary to take in the staff training requirements, the types and extent of

data analysis, amount of computerization, the methods of distributing reports and the amount of time spent on operating the system. The acceptability of a system to organizations should also be evaluated. Flexibility of the system is important as is its timeliness and its representativeness and lack of bias.

One major concern when establishing a surveillance system is ethical issues. The scale and significance of public health surveillance demand ongoing attention to ethics as well as to science. Ethics should not be regarded as an afterthought, or worse, an obstacle to professional practices, but as an element vital to its foundation and goals.

Legality also needs to be taken into consideration. Those presenting the results of the surveillance have to be prepared to stand by them, to place each data set in the public domain as soon as the first results are published and, if the findings are revolutionary, be prepared for a hostile reaction.

Developing countries have both unique needs and unique opportunities, since the system is a part of organized government services with fewer impediments to implementation. Developing countries may have a limited number of health care providers and diagnostic laboratories but fewer sources of data and better quality assurance. Acute diseases and injuries are the major health problems and surveillance techniques for these are already well-developed. Health objectives are more difficult to identify in developing countries but should focus on the current health status and anticipated health needs. Population-based surveillance is important in developing countries because of access to health facilities and in health status; vital event registration is the most important single addition to existing surveillance systems in developing countries.

4.2 Rationale for birth defects surveillance and monitoring

Dr Lowell E. Sever

Ultimately the aims of epidemiology focus around disease prevention, and this is the rationale for birth defects surveillance and monitoring.

Public health surveillance data can be used in assessment of the population’s health status, the areas in which more research is needed and the identification of problems. It is also required for policy development, defining and developing programmes, and for assurance, monitoring and evaluating programmes.

The key steps in establishing birth defects surveillance programmes are through defining the objectives and purposes of the programme, considering legal issues, engaging external support, leveraging resources and considering record linkage.

The purposes of birth defects surveillance programmes are epidemiological, planning and prevention, educational and social, health care and human services and clinical. The data are used in prevalence and epidemiologic studies, mortality assessment, needs assessment for services, referral to clinics and services, programme evaluation and clinical research.

A system has to be regarded as a scientific endeavour and users should understand and be assured of its usefulness. Ethical and legal considerations must be taken into account. The information can be applied to new areas and used to educate the public and policy-makers. The system needs to be flexible so that it takes from other systems and can also change them and it has to be cost-effective. Furthermore, the system has to be both acceptable to those organizations and persons who are to participate in the system and sensitive, allowing detection of cases and of possible outbreaks of disease.

In order to evaluate the surveillance programme the PVP (proportion of persons identified as case patients who actually have the condition) has to be determined, as well as the representativeness and timeliness. Finally the system needs to be stable with the ability to collect, manage and provide needed data without failure.

4.3 Setting up birth defects surveillance systems: the basics

Dr Lowell E. Sever

The first component of a surveillance system is its objectives, because the system cannot be planned before it has been decided what it is to cater for. Following this, the features to be decided are the case definitions, the population under surveillance, period of time for the collection of data, which data are to be collected, the data sources to be used, how they are to be transferred and how stored. All of these components need to be established before the system can be put into place.

There are also a number of questions that have to be answered before the system can become operational.

Who is to analyse the data?
How are the data to be analysed and how often?
How are the data to be reported and how often?
To whom are the reports to be distributed?
How often are the reports to be distributed?
Who is responsible for taking action on findings from the surveillance system?
What are the guidelines for taking action?

There are several design issues involved: the population at risk must be identified as must the outcomes or risk factors to be included and their definition, case ascertainment methods and confidentiality and the need for personal identifiers. Other design issues to be faced before proceeding are the data items and methods of collection, the data coding, analysis and reporting requirements and the follow-up study procedures.

Statistics are useful to surveillance programmes for summarizing and comparing surveillance data, assessing the potential role of chance or random variability and controlling the effects of extraneous factors. They can be expressed in terms of ratios, proportions and rates. A ratio is a fraction with no specified relationship between the numerator and denominator which allows a comparison to be made, such as the sex ratio (male:female), and the fetal death ratio (number of fetal deaths:live births). Proportion is when the numerator is

included in the denominator and may be expressed as a percentage. The range is therefore from zero to one and can be expressed thus: A/(A+B), for example prevalence which is always a proportion.

Different organizations, such as European Surveillance of Congenital Anomalies (EUROCAT), International Clearinghouse, etc. have different definitions which it is important to know when assessing data. The characteristics of each individual person may vary but the frequently required ones are:

- age
- sex
- race and ethnicity
- socioeconomic status
- occupation
- religion
- marital status.

4.4 Setting up birth defects surveillance systems: case definition and ascertainment

Dr Lowell E. Sever

A question that has to be answered when setting up a birth defect surveillance system is what conditions should be included in surveillance. Possible defects are:

- structural birth defects (major malformations and minor malformations)
- ICD-9 codes 740.0-759.9
- neurological/metabolic conditions
- prenatally diagnosed conditions
- developmental disabilities
- fetal alcohol syndrome
- prematurity related conditions
- congenital infections
- neoplasms.

A structural birth defect can be defined as an anomaly of body structure that is present at birth and is assumed to be of prenatal origin. The defects are classified into a major birth defect (medical, social, and cosmetic and therefore affecting the quality of life, morbidity and mortality) versus minor defects. They are also classified into the type of morphogenetic error (e.g. neural tube defect, oral cleft) and into single primary defect versus multiple malformations.

A further classification is pregnancy outcome classification into live births, which takes into account all gestational ages and birth weights and other gestational age and/or birth weight criteria, fetal deaths which includes stillbirths, spontaneous abortions less than 20 weeks, and elective terminations.

Neural tube defects are among the most serious and common birth defects in many countries. Each year in the United States an estimated 2500 babies are born with these defects, and many additional affected pregnancies result in miscarriage or stillbirth. The most common neural tube defect is spina bifida, a leading cause of childhood paralysis. A second is anencephaly, a fatal condition in which a baby is born without a normally developed brain. This is a fatal condition but some live-born infants may survive for a short time. The anterior portion of the neural tube does not close and the brain either fails to develop completely or is entirely absent. Pregnancies affected by anencephaly often result in miscarriages. Spina bifida and anencephaly usually make up about 90% of neural tube defect cases. Encephalocele, a disease in which portions of the baby's brain protrude outside the skull in a skin covered sac accounts for the remaining 10%. The child usually survives but with marked disabilities as the mental capacities do not develop normally. Myelomeningocele is the most severe type of spina bifida. A sac composed of meninges, cerebrospinal fluid, spinal cord and spinal nerves protrudes through the bone defect. The defect needs to be surgically repaired. Children with this defect frequently develop hydrocephalus, an abnormal accumulation of cerebrospinal fluid in the brain. If this condition is not treated immediately after birth, severe brain damage can occur.

In order to describe the distribution of health outcomes it is necessary to establish case definitions of what constitutes a "case" and use it consistently for quantitative description and analysis over time, facilitating accurate monitoring of clinically relevant conditions and comparison among populations. Therefore case definition criteria include diagnoses, residence, time period, pregnancy outcome, gestational age and the age at which the defects were recognized.

The population studied should include the geopolitical area, whether it is specialized (e.g. hospital-based), if it is an at-risk group, such as veterans, factory workers or active military and the specific outcome, such as cystic fibrosis. Population-based surveillance identifies a population under study and is usually defined by geopolitical boundaries and establishes the denominator from which the cases come.

Case ascertainment or identification is the process of identifying who, where, when and of what, from existing sources and using established case definitions: embryos, fetuses, neonates, infants and children who have a birth defect. The method is through examination of every baby born, a review of medical records, identifying medical records for review with hospital discharge and using existing discharge or outpatients' data. It is important that wherever possible there be legislative mandate for hospital or physician reporting, linkage of multiple data sources, vital statistics and other data sources, such as prenatal analysis and genetic clinics.

Case finding can be done through vital records, hospital records, administrative databases, special data sources, prenatal diagnoses centres, and clinical examination. The process of ascertainment can be active whereby a team or an individual seeks cases by going into the field to find cases, passive whereby reporting is required and cases are reported to the surveillance programme or a combination of both. Active case ascertainment requires more effort by the surveillance programme, is more expensive but generally results in more

complete and accurate data. Passive requires less effort and is cheaper but the data is likely to underestimate the occurrence of disease in the population.

4.5 Birth defects surveillance in the United States

Dr Hany Atrash and Dr Lowell Sever

In the United States, one in every 33 babies is born with a major birth defect each year. Birth defects are the leading cause of mortality with more than 5600 infant deaths each year, and 30% of admissions to paediatric hospitals suffer from birth defects. The 17 most significant birth defects cost the country US$ 8 billion annually.

The Birth Defects Prevention Act of 1998 authorizes the Centers for Disease Control and Prevention (CDC) to collect, analyse and make data available on birth defects, to operate regional centres for applied epidemiologic research on the prevention of birth defects and to inform and educate the public about the prevention of birth defects. The Children's Health Act was signed into law on 10 October, 2000. It established the National Center on Birth Defects and Development Disabilities (NCBDDD) within the CDC by April 2001. It required the Secretary to carry out programmes to collect data on birth defects and developmental disabilities, operate regional centres for epidemiological research and provide information and education to the public about the prevention of such defects and disabilities. The NCBDDD focuses on birth defects and paediatric genetics, developmental disabilities and health and fetal alcohol syndrome.

In 1968 the Metropolitan Atlanta Congenital Defects Program started at CDC. This established a standard for surveillance. There are now 38 operational and 9 programmes in the planning stages throughout the United States. The purposes of the programmes are to detect time trends and epidemics, quantify morbidity or mortality, evaluate community concerns, stimulate epidemiological research, evaluate the need for and facilitate access to services, guide and assess the progress of intervention and prevention and to provide information for advocacy.

The challenges for surveillance are its balance of quality and timeliness, consistent diagnosis, confidentiality, ability to share data and duplication of data. The Metropolitan Congenital Defects Program uses trained abstractors to actively search newborn hospitals, paediatric hospitals and other sources. It prompts for in-depth review, beyond initial information, of birth defects, preterm infants, low-birth-weight infants, stillbirth, neonatal death, newborn surgery and all newborns in high risk or special care nurseries. Data are collected on special forms which are then coded and classified and quality control evaluates completeness and accuracy through re-abstraction of records, reviews of new computerized discharge summary indices, linkage with prenatal records and special projects. The data are analysed quarterly for changes in birth defects' rates, observed numbers are compared to expected numbers based on prevalence data during the previous two years and the information is provided to local and state health officials and to national and international programmes

Important outcomes have been the use of multivitamins and the reduction in neural tube defects that led to studies on folic acid and recommendations for folic acid fortification and

supplementation as well as the recommendation that women should be counselled considering prenatal diagnosis.

In 1996 the Centers for Birth Defects Research and Prevention (CBDRP) and National Birth Defects Prevention Study (NBDPS) were established. The CDC coordinates the Centers' activities and participates in the National study. the study has three main components: to identify and collect information on cases and controls, to interview mothers of case-and-control infants using a computer-assisted telephone interview in Spanish or English and to collect a cheek cell sample for the infant and both parents in order to identify genetic factors that may affect the risk of birth defects. The information gathered will provide a valuable resource for the study of genetic susceptibility to environmental exposures. Unprecedented statistical power will enable scientists to study the epidemiology for some rare birth defects for the first time and the compiled data and banked DNA will facilitate future research as new hypotheses and improved technologies emerge.

An important example of a birth defects registry can be seen in the Texas Birth Defects Registry which collects demographic and medical information about more than 13 000 pregnancies affected by birth defects in Texas each year. The information is extensive, consistent and covers all geographic areas of Texas. The data are used by concerned citizens, families, teachers, community leaders, medical and clinical personnel, social workers and planners, universities, private and government researchers and students at all levels. The data are accessed without identifiers to protect the privacy of individuals. They can be used to investigate reports of high rates of birth defects (clusters), by the media in national coverage of birth defects to give in-depth information, by genetic counsellors to plan educational outreach activities and to participate in the National Birth Defects Prevention Study. Data from the Texas Registry has shown that if every woman of childbearing age took enough folic acid every day up to 75% of neural tube defects could be prevented.

4.6 Overview of IMMPaCt

Mr Laird Ruth

In 2000, CDC received congressional funding to support work in international micronutrients. AS a result, the International Micronutrient Malnutrition Prevention and Control Program (IMMPaCt) at CDC has been working with partners for the past five years to improve the wellbeing of vulnerable populations worldwide to eliminate micronutrient deficiencies or hidden hunger. Despite worldwide efforts to combat vitamin and mineral deficiencies, hidden hunger persists. For example, vitamin A deficiency is linked to blindness in approximately half a million children every year. Improved vitamin A nutrition could prevent up to 2.5 million deaths annually among children under five years as vitamin A deficiency in children also increases the risk of dying from measles, malaria or diarrhoea. Iodine deficiency is the leading cause of preventable mental retardation. As many as four to five billion people, or up to 80% of the world's population suffer from iron deficiency which results in anaemia, poor pregnancy outcome, learning deficits and reduced working capacity. Furthermore, consequences of folate deficiency during pregnancy can result in low birth weight, cervical dysplasia, neural tube defects and other malformations. Neural tube defects (open spina bifida, anencephaly, and encephalocele) lead to stillbirths, neonatal deaths or a

lifetime of disability. Neural tube defects affect at least 500 000 newborns annually worldwide.

Over the past five years IMMPaCt has collaborated with many partners in order to conduct workshops on survey methods, fortification monitoring systems, communication, and programme planning. IMMPaCt also provides training tools such as CDCynergy, which is a CD-Rom based tool that provides a framework for planning, implementing, managing, and evaluating health communication programmes within a public health context. Another training tool is MAPit, (Micronutrient Action Plan–instructional tool), an interactive tool that provides an overview of micronutrient programmes, with emphasis on assessment, analysis, and monitoring and evaluation. To help strengthen the quality of micronutrient surveys, RightSize, a computer based training tool, was developed. Through the context of a case study, RightSize teaches users about the principles and methods of cluster surveys to assess micronutrient status of populations. All three IMMPaCt training tools were exhibited and extremely well received at the ITANA conference in Nairobi, Kenya. Any quantity of these CDs can be ordered from the CDC website free of charge.

In 2002, the IMMPaCt programme joined forces with the Micronutrient Initiative to cultivate another global effort to improve micronutrient status of populations. Using lessons learned from the success of Universal Salt Iodization, the Universal Flour Fortification Initiative aims to bring together essential partners like wheat and flour producers, distributors and marketers, and public health agencies to pave the way for fortification of all industrially produced flour with at least iron and folic acid, and whenever possible, with additional vitamins.

Worldwide an estimated 500 000 children with neural tube defects are born each year. Around 200 000 of these birth defects could be prevented through increased consumption of folic acid. Folic acid can also help prevent anaemia and may possibly help prevent breast cancer, colon cancer and heart disease. In the United States, neural tube defects affect approximately 3000 pregnancies each year. To prevent these defects, recommendations were issued in the United States that all women capable of becoming pregnant consume 400 micrograms of folic acid daily, the fortification of cereal grain products with folic acid was mandated to increase women’s daily intake.

One important strategy to increase access to folic acid for women of reproductive age is through flour fortification. Supplementation programmes for pregnant women sometimes do not provide women with access to supplements until after conception. This is too late for preventing many birth defects. However, widespread use of flour fortified with folic acid could reach women before they become pregnant without requiring them to change their behaviour by ingesting a supplement.

Supplements can be difficult to deliver to target populations and even where education and promotion of supplementation is conducted adequately, side-effects and simply forgetting to take the supplement may reduce compliance considerably. Therefore it is important to have a multifaceted strategy for increasing folate status which includes supplementation, fortification, as well as eating a balanced diet that provides folate.

Monitoring of flour fortification can help explain trends in birth defects if the flour is fortified with folic acid. It is necessary to know the percentage of households that purchase fortified flour, and the percentage of women of childbearing age that consumes fortified flour sufficiently. In places where birth defects surveillance is conducted it is important to determine whether the population has access to fortified flour and whether women of childbearing age actually consume flour fortified with folic acid.

There are important factors to consider in order to show impact on micronutrient status. A sufficient amount of fortified flour must be made available to the population, flour must be fortified at adequate levels, and the fortification must be of good quality in order to detect its impact. Newly introduced flour fortification programmes take time to fully implement and only a few mills may be supplying fortified flour. In addition, the mills that supply fortified flour may only distribute the flour to a small geographic location. It is critically important for the population in the birth defect surveillance area to have regular and continued access to flour fortified with folic acid and/or folic acid supplements. Otherwise, there will not be a reduction in neural tube defects to monitor. For example, in order to see an improvement in iron status it is necessary to have at least 80%–90% population coverage over time. It is also extremely important to promote fortified products and educate women of childbearing age about the reasons why they should purchase flour fortified with folic acid, particularly where they can choose non-fortified flours.

The recent national nutrition survey conducted in Afghanistan is an example of why consumption patterns are so important for a birth defect surveillance system. In the survey, only 23% of the households surveyed were in urban areas. This is very important when looking at flour fortification and salt iodization. Not surprisingly, when looking at wheat purchasing behaviours, the majority, or 73% of urban households reported buying flour from the market compared to 25% of rural households. Conversely, 81% of rural households used locally milled flour compared to only 39%, of urban households. In addition, a much greater proportion of urban households reported purchasing bread from the market. If fortified flour is only going to urban areas or is only fortified at large roller mills, or is being made into bread, the beneficial effects from fortification in rural areas will be far less than in urban areas. Therefore, it is important to consider the distribution of fortified flour when interpreting surveillance data on birth defects.

To further illustrate this point, Kabul had the most established iodized salt coverage at the time of the survey. There was a dramatic and significantly higher iodized salt coverage in Kabul than in the other clusters. This was more than likely related to the fact that three or four factories had been producing iodized salt that was distributed mainly in and around Kabul at the time of the survey. The Afghanistan survey is just one example of coverage monitoring that can assist in examining the data compiled by a neural tube deficiency surveillance system. Part of a surveillance system for birth defects can include survey data that monitors coverage and impact of a fortified product.

In conclusion, through proper fortification programmes, the benefits of folic acid fortification of flour are clear. Fortification of the United States food supply with folic acid has resulted in a 26% reduction in neural tube defects. In addition, paediatric anaemia rates

have steadily declined in the United States due in large part to the wide availability of iron fortified foods for young children.

5. NATIONAL EXPERIENCES

5.1 Neonatal screening programme of Egypt

Dr Safaa Abdel Fattah

The neonatal screening programme started as a pilot study in April 2000 in three governorates, Qalubeya, Damietta and Kharbia, and then extended nationwide over six successive stages by December 2003 so that it now reaches all 27 governorates. At present the programme covers only one disease, congenital hypothyroidism, although there are plans for the addition of phenylketonuria (PKU) and galactocaemia in the near future.

The objectives of the screening programme for congenital hypothyroidism are to decrease the incidence of associated mental retardation and to provide facilities for the diagnosis and management of discovered cases. The programme has seven main pillars: training; implementation and supervision; laboratory analysis; treatment and follow-up; health education; and information system and research. The steps involved in implementing the programme were:

- establishment of a central neonatal screening committee;
- defining the goal, strategies and protocol for the programme;
- designing and implementing a three day training course for the primary health care nurses and laboratory technicians in different governorates;
- preparing a curriculum and a manual for the training;
- establishment of a central and governmental supervising system for the programme;
- provision of the primary health care units and laboratories with necessary supplies and equipment;
- defining specialized health insurance clinics for treatment of discovered cases and providing them with necessary equipment and personnel;
- preparing and implementing a plan for health education and raising public awareness in different governorates.

Accurate timing of the events in the programme is crucial. The dry blood spot samples have to be taken in the primary health care units every Saturday and Tuesday. The samples are then transferred on the same day to the directorates and on the next day (Sunday and Wednesday) to the laboratories. Analysing the samples and recording the results takes place within 24 hours (Monday and Thursday) which means that if it is necessary to take a second sample it is done within 48 hours after the first was taken (Tuesday or Saturday). This means that the confirmatory serum sample is taken within three to five days from the initial dry blood spot sample if needed and that treatment of confirmed cases takes place within the first 14 days of life.

The samples are tested for thyroid-stimulating hormone (TSH) using enzyme-linked immunosorbent assay (ELISA) technique. The cut-off is 15 µU/mL and samples below this are considered negative and the neonates are normal. Those with TSH between 15 and 40 µU/mL are considered susceptible and need a second dry blood spot test. Neonates with TSH above 40 µU/mL are positive for hypothyroidism and need serum confirmation. If the serum TSH and serum FT4 are positive for hypothyroidism the confirmed cases are transferred to the special health insurance clinic where they receive further investigation and are treated according to the protocol of management. The cycle takes 7 days at most, which allows for treatment before the critical 14 days when the brain would be affected by the low thyroxin level.

Community health education has been another important component of the programme and has taken place through meetings with nongovernmental organization members and mass media professionals, preparation and dissemination of information, education and communication materials, including newborn screening campaigns, on the television, radio and through posters, fliers and information cards.

The service is offered freely as part of the basic benefit package of the mother and child health services and the community is now aware of its importance as shown by the rising coverage percentage (83% in 2004).

By the end of 2004 there were:

- 2230 primary health care facilities offering neonatal screening facilities;
- 3 218 486 tests done for neonatal screening (April 2000–December 2004);
- 14 laboratories for neonatal screening nationwide;
- 25 health insurance clinics for congenital hypothyroidism nationwide.

In 2001 the total number of births was 479 437 and 277 samples were taken. From these there was positive recall for a second dry blood test of 376. The number of venous samples was 124 and the number of treated cases was 100.

5.2 Islamic Republic of Iran: flour fortification programme with focus on fortification with folic acid

Dr Robabeh Sheikholeslam

About 40 years ago, Hibbard and Smithells linked folate deficiency in pregnancy with neural tube defects. Smithells then led a series of observational and intervention studies which showed that improving folic acid status early in the pregnancy of mothers who had previously had a child with neural tube defects reduced the recurrence in that pregnancy.

Since then it is generally recognized that folic acid has several health benefits such as the reduction of birth defects by approximately 30% to 40%, lowering of plasma homocysteine—a newly identified risk factor for cardiovascular disease and strokes, as well as the reduction of total mortality (each increment of five micro moles of homocysteine is associated with a 49% increase in mortality).

A folate fortification pilot project was started in Bushehr province in 2000.There was midterm evaluation in 2003 and the expansion of the programme to Sistan va Baluchistan. The premix is made locally and a semi quantitative test or the Spot test is performed at the production level as is sampling by the food control personnel. At the central provincial food laboratory the semi quantitative test is confirmed using a spectrophotometer. The programme has received encouragement of the director and promotion from the Regional Office.

The premix component of the current fortification programme in the Islamic Republic of Iran is 200 g of premix to 1000 kg of flour which means that 300 g of bread should contain: folic acid 300 µg (75% RDA) and Fe 6 mg (40% RDA). The steps in a fortification programme are to:

- determine the nutrient status of the population (many studies are available);
- choose an appropriate nutrient and food vehicle (folic acid and flour seem reasonable choices);
- establish the acceptability and stability of the fortified vehicle (flour is accepted; people with celiac disease on a wheat free diet would not be reached, but this could be part of their individual management);
- assess the bioavailability of the nutrient from the vehicle;
- carry out a controlled field trial;
- implement a regional or national fortification programme.

5.3 Status of the birth defect registry in Jordan: successes and constraints

Dr Sana'Al-Hait

Fortification of foods has been taking place in Jordan since 1996 with the introduction of iodized salt and, in April 2002 flour fortification with iron and folate took place. In 2006 flour will be further fortified with vitamins B1, B2, B12, niacin, zinc, folate and iron.

In 2002, a national survey throughout Jordan showed that among women of childbearing age, iron deficiency stood at 40.6% while iron deficiency anaemia was at 22.5%.

Table 1. Birth defects notified to the government hospitals in Jordan, 1995–2002

Birth defect	Percentage of the total notified
Neural tube defect	11.7
Anencephaly	5
Hydrocephallous	7.4
Congenital dislocated hip	3.6
Congenital heart disease	9
Cleft lip and palate	4.8
Chromosomal abnormality	1.8

Among infants under five years of age, iron deficiency was 26.1% and iron deficiency anaemia 10.1%. The survey also showed a level of vitamin A deficiency of 15.2% among infants under the age of five and 46% among children aged 6–17 years. Between 1995 and 2002, government hospitals reported 1765 cases of birth defects distributed (Table 1).

During this period there was increased awareness about genetic and congenital disorders among the public, which resulted in the Ministry of Health making certain services available at the Primary Care Research Unit:

- 1995: chromosomal analysis available;
- 1998: unit for phenylketonuria and genetic conselling;
- 2004: section for control of genetic and congenital disorders.

There is a shortage of staff with little available workforce, however at the University of Jordan in 1996 a prenatal diagnosis became available and as from 2001 a geneticist was also available. At the University of Science and Technology in 1997, genetic and chromosomal analysis also became available.

Over the past 10 years, a number of reports on congenital malformations in Jordan have been carried out showing that congenital malformation was seen as the reason for 19.9% of perinatal mortality with the highest rate of perinatal mortality for mothers of 35 or over and those of parity five or higher. The three leading causes of infant death were conditions originating in the perinatal period, congenital deformities and acute respiratory diseases.

Table 2 shows the findings of a neural tube defects retrospective study of 119 cases at the University of Jordan between 1992 and 2002. The study showed a previous case history of miscarriage of 50% and 15% of malformed babies. Most of the mothers were under 30 years of age and in the majority of cases this was the second or third pregnancy.

One of the problems in Jordan is that the change in ministers usually instigates a change of policy so that there is little continuity. However there has been implementation of some premarital and neonatal screening free of charge. A national registry for genetic and congenital disorders was suggested in 1995 and again in 1998. It was proposed in 2005 but so far has not materialized.

Table 2. Neural tube defects, 1992–2002

Birth defects	Percentage
Low meningomyelocele	76.5%
Anencephaly	10.0%
Encephalocele	6.7%
Meningocele or lipoma	6.8%
Lower limb paralysis or paresis	78.6%

The constraints connected with the establishment of a national birth defect registry are:

- poor teamwork;
- lack of appreciation by second line directors;
- multiple health service sectors (Ministry of Health, military universities, UNWRA and the private sector;
- absence of a special budget;
- scarce records with an absence of utilization of the International Classification of Diseases (ICD);
- preoccupation of health authorities in other priorities (rubella, typhoid and brucella epidemics).

However, despite these difficulties there are areas which indicate that a national birth defect registry could be started:

- establishment of a multidisciplinary committee including all health sectors in Jordan;
- a task force including focal points from all governorates;
- affiliation of the registry to the WHO and Ministry of Health genetics programme.

The registry would require a special budget, a simple notification sheet, manpower for secretarial and computer work, facilitation of a communication channel, such as telephone and e-mail and annual reassessment and monitoring.

5.4 The neonatal screening programme in Lebanon

Dr Khaled Yunis

Newborn screening is a routine intervention in most industrialized countries and is fast becoming established in developing regions of the world. Recommendations for screening policy vary between countries depending on local economic, political, and medical factors and public health organization. In Lebanon there is a lack of a national programme for neonatal screening. In the recent past only, and based on recommendations by the Lebanese government and the Paediatric Society, screening for PKU and hypothyroidism was included as part of the routine information that needs to be available in the individual infant’s health record. However, overall screening strategies in the country are left to individual practices at the physician and organization levels.

Several barriers, such as the lack of health care infrastructure, limited resources, weak government capacity and regulation, as well as shifted priorities due to poverty and the unstable political context stand in front of the establishment of a national screening programme. These obstacles also impede the development of systems for high quality routine statistics that provide a consistent and continuous system of assessment. In this context, the input of the private sector (academic institutions, nongovernmental agencies and private hospitals) is crucial.

In 1998, the national collaborative perinatal neonatal network was created by a group of collaborating physicians and researchers from different health care institutions. The objective

of this medical and public health research network is to improve maternal, perinatal and neonatal health in Lebanon by developing accurate, scientific systems for routine data collection, capable of identifying health problems and of setting national health priorities. Medical and sociodemographic data are collected daily on mothers and newborns admitted to 16 hospitals located in Beirut and the rural areas of Lebanon. The network database covers, to date, information on over 61 000 newborn infants and their mothers, and carries, in addition to the database, several multicentre independent research projects.

Trained research assistants, nurses and midwives collect data on all live and stillborn admissions to the national collaborative perinatal neonatal network centres through two baseline, standardized questionnaires which can be amended as needed so that the system can maintain a degree of flexibility.

At the American University of Beirut Medical Center a systematic screening programme for PKU, congenital hypothyroidism and glucose-6-phosphate (G6PD) deficiency has been implemented since 1997. Published results of the screening for the period 1997–2001 show a high incidence of congenital hypothyroidism in the newborn population of the order of 1:1823 as compared to worldwide rates ranging between 1:3000 and 1:4000. The incidence of G6PD was 1.2% whereas the observed incidence of PKU was relatively low.

Preterm infants (less than 32 weeks gestation) at the American University of Beirut are screened for retinopathy of prematurity following guidelines by the American Academy of Paediatrics. Universal newborn hearing screening is rapidly becoming routine practice in industrialized countries because hearing loss is among the most common congenital disorders, with prevalence rates reportedly at 1.4–4.0 infants per 1000 live births and because of the considerable health and economic burden hearing loss carries. The prevalence of hearing loss in Lebanon is unknown but is estimated at 3–4 infants per 1000 live births. Hospitals in the country performing neonatal screening typically screen infants who are at high risk for hearing loss only. For example at the American University of Beirut Medical Center, newborn infants admitted to the neonatal intensive care unit are screened for hearing impairment using otoacoustic emissions and auditory brainstem response. Recently a study was undergone at the American University of Beirut Medical Center with the collaboration of the NCPNN to determine the feasibility of the universal newborn hearing screening in a hospital-based setting and to develop guidelines for optimizing a screening and follow-up programme that could be used by the American University of Beirut Medical Center and other hospitals in the country. Over a period of eleven months all infants born at the centre were tested. The rate of hearing loss was relatively high (approximately 3.5 per 1000 live births). Parental refusal was noted in 11% of the cases, with parental fear of the test being the main reason behind the refusal. This study indicated that universal newborn hearing screening is warranted and is feasible in a hospital-based setting provided that equipment, training, support staff and management plans are established. The main challenges for the implementation of such a screening programme remain the lack of awareness of parents and the failure of parents to return for follow-up testing after hospital discharge when an infant has failed or missed a screening during hospital stay.

Congenital malformations account for a substantial proportion of perinatal death. They also constitute a major cause of morbidity in surviving children and result in a large number of years of life lost. In Lebanon, little has been published on the occurrence of congenital malformations and nationwide prevalence rates are lacking. In the absence of population-based surveys and of a national birth defects surveillance system, hospital-based studies constitute an important source of information. With the objective of assessing the incidence of congenital malformations in Lebanon and its association with consanguinity, the NCPNN is carrying out a nationwide study of consanguinity and congenital malformations. Preliminary results show an incidence rate at birth of 29 per 1000 live births, with cardiovascular malformations being the more common type, followed by muscoskeletal then urogenital, then chromosomal malformations. Prevalence of congenital malformations can be seen in Table 3 while Table 4 shows the distribution of cardiovascular malformations.

Table 3. Prevalence of congenital malformations

Type of malformation	Number	Percentage of live births
Cardiovascular	94	11.0
Musculoskeletal	60	7.1
Urogenital	32	3.8
Chromosomal	17	2.0
Gastrointestinal	14	1.6
Neurological	14	1.6
Cleft lip and/or palate	13	1.5
Eye, ear, face and neck	9	1.1
Respiratory	5	0.6
Other	17	2.0
Total	247	29

Table 4. Distribution of cardiovascular malformations

Type of malformation	Number	Percentage of live births
Patent ductus arteriosus (PDA)	48	5.6
Patent foromen ovale (PFO)	31	3.6
Atrial septal defect (ASD)	19	2.2
Ventricular septal defect (VSD)	18	2.1
Malformation of the mitravaortic valves	8	0.9
Single ventricle	5	0.6
Malformation of the tricuspid/pulmonary valves	5	0.6
Coarctation of the aorta	3	0.4
Pulmonary stenosis (PS)	3	0.4
Tetralogy of fallot (TOF)	3	0.4
Transposition of greater vessels (TGV)	2	0.2
Other	4	0.5
Total		11.0

In parallel, the national collaborative perinatal neonatal network, in collaboration with the faculty of Health Sciences at the American University of Beirut has conducted a study exploring the prevalence and characteristics of preconceptional folic acid intake among pregnant Lebanese women. The preconceptional supplementation of folic acid is found to decrease risk of neural tube defects by as much as 60% to 70%. Preliminary results show that only 6.2% of women do take preconceptional folic acid, the intake being associated with high socioeconomic status. Of first pregnancies 80% are planned among the study population, and pregnancies happen within the first year after marriage. This makes intervention programmes aiming at the prevention of birth defects through preconceptional folic acid intake feasible among the Lebanese population.

5.5 Improving maternal and child nutrition: experience of the Qatar Foundation

Ms Aisha Al-Romaihi

The Qatar Foundation for education, science and community development was founded in 1995 by His Highness the Emir Sheikh Hamad bin Khalifa Al-Thani. The Foundation is an independent, private, non-profit and chartered organization. Its mission is to develop abilities and raise the quality of life through investments in human resources, technology and modern facilities and to form partnerships with international institutions such as WHO and CDC. The vision of the Foundation is to develop and utilize human potential and to build an education city with branches of world class institutions.

The programmes and institutions cater to all stages of life. The learning centre supports children with learning disabilities such as attention deficit disorders. Nutrition Awareness Month is the first continuous nutrition health communication education programme in Doha with some form of evaluation process. It comprises nutrition sessions targeted towards primary school through to college students and focuses on healthy diet. There are also “ask the dietician” sessions for staff and students.

The Qatar Foundation not only looks at the traditional aspects of health and nutrition promotion but also tries to use creative means to involve the students in their schools and their diet via the nutrition art project which seeks to improve child nutrition and health through the environment. Qatar Academy and The Learning Centre established one of the first food policies in schools, as follows:

- no food brought from home;
- no chocolate or crisps;
- no caffeine;
- no nuts;
- no soda or high sugar drinks;
- shared cafeteria space;
- recipes of the menu are adjusted;
- services students with special dietary needs;
- menus are based on food pyramid guidelines;
- continuous change of services based on student requirements.

Through rigorous control of the caterers and menus the diet needs of the students are catered for, and if they need to follow a special diet they do not feel any stigma psychologically.

Other programmes under the Qatar Foundation are the social development centre which is looking at the socioeconomic groups within the population with the aim of reducing unemployment rates by providing educational workshops to those who require them. There are also several projects in healthcare such as the renal dialysis where the fees for both nationals and non-nationals are covered and renal transplants where financial aid is offered to those who require a transplant.

The Qatar Diabetes Association (QDA) has conducted several workshops targeting women and children suffering from diabetes. Currently the foundation has a joint project with the QDA and the Supreme Council for Family Affairs (Qatar) to promote the health of women less than or equal to 18 years of age in the Qatar population. The Qatar Leadership Academy is a primary and secondary school which is also developing a nutrition curriculum for the students.

Community health and nutrition promotion is an ongoing process and the Friends of the Environment Centre helped develop the national nutrition promotion week focusing on maternal and infant nutrition. This is an annual programme composed of several aspects of nutrition that concern the welfare of mothers and their children, such as breast-feeding versus bottlefeeding.

The National Health Authority was established in 2005 to replace the Ministry of Health and have all private and public hospitals as well as primary health care centres and a specialty teaching hospital under its umbrella. It is working on a national nutrition survey to develop food based dietary guidelines in a collaborative effort with the University of Westminster. Projects regarding nutrition will be focused in schools in Qatar and collaborative projects with the health education centre in the national health authority deal with nutrition and include multimedia approaches to health and specifically to nutrition awareness.

There is no registry for birth defects or neural tube defects in Qatar. However, there is an annual health statistics report produced by the main general hospital stating the incidence of cases of various diseases. These data are usually vague and not specific to types of birth defect. More research is required to pinpoint the magnitude of the prevalence of birth defects in the state.

Flour fortification has been established in Qatar. State legislature has made fortification with iron and folic acid mandatory. However the public are unaware of the steps the state has made in this regard and do not realize the consequences of consuming fortified foods.

The specialty teaching hospital, under the national health authority is very interested in establishing a state birth defects registry and making other developments in the field of genomics and research with the possible support of Weil Cornell Medical College.

5.6 National congenital anomalies registry in the United Arab Emirates

Dr Hajer Al-Hosani

In the United Arab Emirates the rate of infant mortality decreased from 11.37 per 100 live births in 1990 to 8.1 per 1000 live births in 2002. However the proportion of infant mortality due to congenital anomalies showed an increasing trend; this proportion was 86.1% in 2002 compared to 30% during the 1980s.

The high proportion of infant mortality due to congenital anomalies meant that the establishment of a national congenital anomalies registry was a high priority in the United Arab Emirates. Congenital anomalies represent a special category of disorders characterized by their earliest onset and limited chance for complete recovery. Their prevention is based on real knowledge of the baseline prevalence of different congenital anomalies, their cause and risk factors. Therefore there is a real need for a registry.

The objectives of the registry are to determine the baseline birth prevalence of different types of congenital anomalies, to highlight the topic for the medical community in order to improve the quality of diagnosis and recording, to establish a priority list of preventive efforts and to use the surveillance function of the registry.

The national congenital anomalies registry is population based, covering all births in the United Arab Emirates and was established in all medical districts in 1999. By congenital anomalies structural defects of fetal development with the necessity of medical treatment are meant, so minor anomalies such as hydrocele and preauricular are excluded. The system is ongoing with permanent registration for the collection storage and analysis of personal, demographic, and medical data on affected neonates and infants.

The study period is from birth until the age of one year (stillbirth, live birth). The sources of information for the registry are all maternity obstetric units (99% of deliveries are in hospital), paediatric clinics (neonatal, general and surgical), mother and child health and primary health care centres and the genetic laboratory. The unit of recording is to index cases with isolated and multiple congenital anomalies. The classification of cases is according to the codes of the international classification of diseases (ICD 10) with slight modification in multiple congenital anomalies. There have been two types of notification form for data collection, the first being used between 1999 and 2002 and the second, more recent one that also contains more common hereditary disorders selected from the hereditary registry.

A total of 222 313 births have been included since the implementation of the national congenital anomalies registry and the prevalence rate of congenital anomalies according to the pregnancy outcome from 1999 to 2003 was 12.32.

In the United Arab Emirates there are preventive genetic counselling programmes with:

- a neonatal screening programme for PKU, Cong hypothyroidism, sickle cell diseases and congenital hyperplasia;
- congenital anomalies register;

- genetic clinic; genetic laboratory; premarital counselling programme.

The risk factors are maternal age, pregnancy care, rubella, self medication, smoking and folic acid.

There are a number of constraints, such as under ascertainment of cases of malformation because the doctors in some hospitals are not interested in registration. The registry includes only live born children and rarely stillborn. There are also problems concerning the notification form which is incomplete in some cases for head form, consanguinity and hospital of birth. There is lack of etiology in most cases. Some forms have concerned babies of over one year of age. Furthermore, there is a shortage of staff, especially in the field of coding, statistics and epidemiology. A final obstacle is the inability to connect with one of the supranational organizations of congenital restraints registries.

Some conclusions have been drawn from the implementation of the registry. Firstly, the observed incidence rate of births with congenital anomalies was slightly less than the global figure due to under ascertainment of malformed cases resulting from incomplete cooperation between the national congenital anomalies registry and lack of autopsies of stillbirths and neonatal deaths. Ascertainment can be increased by multiple-source case finding, such as birth certificates, hospital activity analysis register, perinatal death certificates and genetic clinics.

It is also recommended that efforts to overcome the problems of under ascertainment through form filling and diagnosis of congenital anomalies by enhanced awareness and increased experience of health professionals and nurses, especially in medical districts where underreporting is an obvious concern by continuous short courses, practical workshops and lectures. Doctors should also be encouraged to be more interested in sharing in the registry by continuous feedback, contact, follow-up and acknowledgement.

Accuracy should be encouraged through comparison of defects recorded in the registry with those in hospitals. There is also a need to develop health education strategies, for example premarital and preconception supplementation of folic acid. Finally it is important to evaluate the registry and connect it to supranational organization of congenital anomalies registry programmes such as the International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS) and European Registration of Congenital Anomalies and twins (EUROCAT).

5.7 UNWRA’s experience in introducing folic acid supplementation

Dr Haifa Madi

The United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) programme revolves around reducing mortality and morbidity. UNWRA serves refugees in five locations, Lebanon, Syrian Arab Republic, West Bank, Gaza and Jordan. The total fertility rate is dropping and was as low as 3.5% in 2004. The number of women registered during the first trimester is increasing and over 99% of women are delivered by trained personnel.

In Palestine, infant mortality is on the increase due to the current situation. It dropped in all locations except the Syrian Arab Republic, where neonatal mortality increased from 20 per 1000 in 1997 to 22.9 per 1000 in 2003. This could be due to an increase in the caesarean section rate (reaching almost 70%) or the conditions in hospitals, most of which do not have neonatal intensive care units. Of newborn deaths in the Syrian Arab Republic, over 81% occur during the neonatal period, as opposed to approximately 19% during the post-neonatal period.

Almost 29% of infant deaths are due to congenital anomalies, including cardiovascular. Congenital malformations are the second leading cause of infant death in 2004.

The UNWRA health programme consists of several different components: medical care, health care and promotion, antenatal, natal, postnatal, family planning, infant and child health care, school health services, nutrition, sexually transmitted diseases, and gender mainstreaming.

Antenatal care includes preconception folic acid supplementation. Upon first registering their pregnancy women are given a full comprehensive physical and obstetric examination and blood tests. They are provided with iron and folic acid from the time of registration until the time of delivery. They are also given family planning counselling, dental screening and testing for hypertension and diabetes. During natal coverage, the women considered to be at risk are referred to hospitals. Utilization of maternity units in Gaza is decreasing, as more people are using hospitals.

At the postnatal stage there are early visits with family planning counselling, surveillance of the outcome of the pregnancy and maternal mortality surveillance (started in the early 1990s through confidential verbal autopsy). Women suffering from anaemia, diabetes and hypertension are examined. All staff are trained on counselling, which has contributed to a 10% increase in contraception prevalence over the past five years.

The infant and child health care covers complete and comprehensive examinations to detect any anomalies or any other problems. It also covers immunization, screening for anaemia at one year of age, growth monitoring for the first three years, and surveillance of infant and child mortality through in-depth inquiry.

There is a startlingly high prevalence of anaemia among women and children as well as vitamin A deficiency. Tracking of children is managed through the use of the blue register in which all infants are registered through the month of their birth so that they can be followed and tracked to ensure complete immunization. Services in UNWRA are well integrated and there are no vertical programmes. UNWRA started the preconception folic acid supplementation by orienting the staff at the health centres on the benefits of the programme. A pamphlet to inform the population of the benefits was also designed and distributed. Counselling on folic acid is done during premarital counselling and during family planning counselling and achievements are monitored at the health centre level through the management health information system.

The main objective in providing folic acid is to prevent neural tube defects. Folic acid supplementation to all women one to two months before conception and during the first three months of the pregnancy could prevent from 50% to 70% of some kind of defects especially spina bifida and anencephaly. This also reduces the risk of giving birth to a child with oro-facial clefts.

6. FIELD VISIT TO THE NATIONAL INFORMATION CENTRE: EGYPT

The National Information Centre (NICHP) is responsible for all information technology: data collection and analysis, internet and system support etc. Its activities include networking, training, geographic information system design and development and health online.

NICHP headquarters is connected to 27 governorates. There is a dial-up connection between NICHP and the governorates. The services running on the network include messaging, backup files, the web and e-mail. There is one data collection centre, the health information system.

Another activity of NICHP is training, and it is responsible for all the information technology courses, computer courses, and medical and statistical courses. These courses are targeted at physicians, medical technicians, and administration. The geographic information system unit is hosted inside the NICHP. It provides a standardized geographic database to produce decision-support maps.

The system design and development include the management of health information system which is the backbone of the Ministry of Health and Population. It also includes the executive information system. It provides decision-makers with indicators that provide them with the information to assess the situation and follow up. The collected indicators include demographic and curative indicators, etc. They are collected and presented according to the levels, the year and type.

There is a unit for the National Cancer Registry in the NICHP. It collects all the data from all the cancer centres, a total of eight in Egypt, through the network. The future vision for this is that all cancer-related data can be collected to be used to get information on health insurance, curative information, etc.

The NICHP website is. www.mohp.gov.eg.The main sections of the website include:

- health directory of health centres such as hospitals and specialized centres including pharmacies;
- description of the Ministry of Health and Population;
- directory of health organizations in Egypt;
- statistical section illustrating main indictors such as vital statistics (the statistics are updated annually);
- health services;
- health education;

- drug services (based on the essential drug list);
- search section (such searching for health facilities, specialists, blood banks, etc).

In the second phase the website will be available in English. The data from the blood bank is entered by the blood bank daily throughout the governorates. In the blood bank section you can search for blood banks by blood type or by location.

The health information system (HIS) generates different types of data. The data include managerial data and health data. The data flow goes from health unit to the district level, where they are computerized and sent to governorate and central level through electronic networking. The health data include vital statistics (birth and cause of death), health services data and disease surveillance (for communicable and noncommunicable diseases). The birth data are collected monthly and then sent to the upper level.

Death certification forms were updated in 1999 to include a new medical section which includes items such as smoking, injuries, cancer and maternal mortality. Guidelines were prepared for the use of the certificate and for the use of ICD 10. Doctors, clerks and data entry staff are trained on using the new death certificate and the coding system. A death certificate is not issued without a birth certificate. For birth certificates, a doctor's notification of the birth is needed.

A number of key factors underlie the Centre's success.

- unified registers and unified forms
- training on the use of data and forms
- timing of data flow
- quality control of data
- agreement on reports and indicators for assessment
- full cooperation between maternal child health director and information unit
- regular meetings to increase cooperation and problem solving
- feedback to all levels
- support and encouragement

7. DISCUSSION

During the first stages of the consultation a great deal of the discussion was centred around the decision as to whether focus should be placed on surveillance or on registry. This led to an amount of debate on terminology which became a common theme.

Several views were given since some participants felt that registry was a part or tool of surveillance and that if the focus was placed on registry it would be addressing only one aspect of surveillance. Similarly it was felt that monitoring did not include action and was therefore another component of surveillance which was defined as going a step further and acting on what has been seen through monitoring. It was pointed out that the process of public health surveillance as defined by the CDC was a very broad public approach that included a

number of functions and outcomes. The key was that surveillance was a public health activity that included the processes of data collection, analysis, interpretation and action, whereas monitoring did not go any further than the interpretation stage. It was also stressed that in public health, surveillance was a process that did not involve only watching but that included learning from that which was observed, acting upon it and then evaluating those actions. Another word that needed to be defined was tracking, which could be confused with surveillance, but which the majority of the participants felt meant to keep an account of. The question was asked whether, if registry was an aspect of surveillance it was different from a database, and it was agreed that a database was part of a registry, representing the outcome of the process of identifying, collecting and recording data.

The difference between screening and surveillance was also defined. It was explained that a group of apparently well people, which in the case of establishing a birth defect registry would be all newborn babies, would be tested for particular defects. This was screening. Following the testing those tested positive that were thought to have a disease would move from screening to diagnosis. After the screening and diagnosis it is those infants that have the disease or risk factors that go into the surveillance programme.

The view was also given that registry grew out of surveillance, or was another of its functions and that registry used surveillance data. A further opinion was that within the region, registries would have to be the element focused upon because many countries would not yet be ready to set up complete surveillance systems. This led to the comment that home deliveries posed a challenge to establishing registry or surveillance and the general expression of the opinion that there was a definite scarcity of information in the Region. However, the view was also expressed that simply because deliveries were made at home did not necessarily mean that the vital registration system was not good but that it was the quality of the data that was important and that the quality of data was a problem everywhere since it usually depended on form filling, and whether staff were properly trained or not. This naturally led to the whole concept of training, communication and even further to the message finally delivered to those who needed to know the information gathered and disseminated through surveillance.

Training and community health care were aspects of health care that were described during discussions. In the Islamic Republic of Iran, health houses in rural areas were run by health centres and that there was an existing network of training that operated in a cascade format. UNWRA provided home visits and community services for pregnant Palestinian women so that the woman and her family were supported and given information.

With respect to maternal and child health, the Regional Office started a project on data collection and use in 1997 and at that time countries were trained on establishing systems with the focus on maternal health, but there was currently a shift towards neonatal health. It was stressed that high quality surveillance systems required documentation and training, that the Region did have personnel and that people needed to be properly trained in order to ensure good quality data. It was pointed out that filling in forms in order to get information was an additional burden on health providers, especially when the questionnaires were long and detailed. This led to the feeling that informing people on the value of the information they

would be supplying was important and giving them feedback so that they saw how they were participating in preventing diseases. It would motivate health workers to take part in the surveillance.

Communication seemed to be the key and the comment was made that communication was an art. It was also stated that it was a relatively new concept in the Region but that communication was a skill that was one of the components of the Regional Office's training workshops and that communication skills were needed by everyone, from managers to health providers. Often information was available but the various department of the health care system did not communicate it, or share it, because they were unaware of what was happening in another department. Discussions on this concept also stressed that the public needed to be made aware of the different conditions or diseases and the tests and treatments that were available to detect and combat them so that they asked for them and volunteered information.

It was felt that policy-makers also needed to be made more fully aware and that could only be done through increased communication. The role of the media was discussed and the importance they could play in educating the public and the decision-makers. Marketing the concept of a birth defect registry to countries was seen as important. Marketing was seen as an ongoing part of the system of surveillance itself. Messages had to be passed on to the public and they should be packaged as news and delivered at the optimum time to receive attention.

Resources were a subject that came up frequently during discussion. Different types of resources were considered; human resources seemed to be available but often the financial resources to pay for them were not. The opinion was given that training the workforce did not have to be expensive but that allocation of funds by ministries to something like national birth defect registries would be seen as something of a luxury when set against other more pressing health problems in a Region where there were many diseases. It was felt that governments needed to be educated to see that birth defects were part of public health and treated as one of the basic services. It was stressed that surveillance should be institutionalized and every death of every woman, infant and child investigated. One opinion given was that the registry would also be of use in that it would shed light on other areas of disease and indicate trends that could prevent illness and prompt changes in lifestyle.

The data variables to be used were discussed. It was agreed that there would be certain core variables and that the NBDPN guidelines could be consulted for these. However, it was also recognized that each country would have its own priorities and the variables used for its system would reflect that. At the same time it was suggested that the group maintain close contact so that they could consult together and the hope was expressed that they might move towards national and then a regional registry.

A familiar theme within discussion was the necessity of gaining the attention and support of policy-makers so that screening was mandatory and part of the public health system. Advocacy was felt to be the issue. This would mean it received a proper portion of the budget. The cost-effectiveness of screening, detecting and treating a child with a defect rather than allowing that problem to go undetected and merely postponing the time when that child would be a long-term burden on the government, society and the family unit was something

which participants felt needed to be communicated to policy-makers. This was also felt to be true of foods' fortification and of supplements. The opinion was expressed that where the issue of supplements was concerned, in order to save money, they should be supplied to all married women proceeding from the ones most likely to become pregnant to the ones for whom this is least likely.

Ethical considerations and the need to protect the privacy of the individual while implementing and carrying out a surveillance system that would benefit the society as a whole received a lot of attention from the participants. The use of identifiers in order to be able to track cases and ensure they received the necessary treatment, medical and social support was discussed but it was recognized as imperative that the identifiers used were kept absolutely separate from the data. This was seen as an area which would also be affected by legal considerations.

Discussion on food fortification, flour fortification with iron and folic acid in particular, and supplements was extensive. One of the subjects that came up was how to ensure that women received the correct levels of folic acid before conception so that neural tube defects caused by the lack of these nutrients in the first two weeks after conception could be avoided. It was agreed that the optimum time would be from marriage but that women who had previously given birth to a child with a neural tube defect were a priority group for supplements.

Doubt was expressed that women were receiving the recommended levels of 400 micrograms of folic acid despite flour fortification, so it was deemed important that fortification and supplementation should go side by side. Following the presentation on birth defects surveillance in the United States, the problem of ensuring that the fortified flour reached a particular group of women was discussed. One example is the case of the Hispanic community who continued to purchase the flour they were familiar with and which was not fortified, either because of tradition or due to economic reasons.

The participants focused on the reduction in the prevalence of birth defects that could be directly related to folic acid supplementation. Reference was made to the British MCR trial on women who had previously had a child with a neural tube defect. The study showed a 70% reduction of recurrent risk of neural tube defects for women who took folic acid.

7. GROUP WORK

The participants worked as a single group with facilitators directing and making note of the suggestions and decisions made. Topics under discussion were objectives, marketing and partners, target population, data sources and case ascertainment, data variables, data collection, data management and analysis, data interpretation, outcomes and data dissemination and policy. Each country representative brought up issues concerning his own country and core ideas relevant to the whole group were identified. The objectives were to address:

- cultural aspects of important disabilities and the need for intervention;
- concrete communication policy and programme;
- evaluation of interventions (educational, clinical and public health);
- basis for education campaigns, including provider education and family campaigns.

Preconception care focus was thought to be an important focus, given the current international interest, for marketing and finding partners. It was also felt important to monitor the impact and to include religious leaders. The targeted population differed widely in each country but those mentioned were governorates, hospitals, national committees and segments of subpopulations.

The data sources and case ascertainment would be through a combination of active and passive methods. It was felt important to use the present systems and existing information already available on medical records as much as possible where they existed, to modify birth notification forms, to train abstractors to identify cases and to include an auditing component. The Regional Office added that birth attendants could be trained to identify and report birth defects at the time of delivery.

The core data variables as recommended in the NBDPN guidelines issued to the participants (pages 4–10) were agreed upon, as well as others that might be appropriate to the Region, such as gestational diabetes, country and city of origin, religion and consanguinity. Data collection should be through forms and actual collection through abstractors.

Points concerned with data management and analysis were:

- where the surveillance system should be housed (hospital or central office);
- where the data should be kept;
- how the data should be kept;
- how the data should be entered;
- who should manage the data;
- how the data should be moved from one place to another;
- system operations;
- who should do the analysis, how often and what type of analysis should be carried out;
- what staff would be needed (programme manager, epidemiologist, statistician, IT specialist, administrative support, communications specialist).

It was suggested that data interpretation should be through a committee that would receive the reports and interpret findings. The committee should include policy staff. All the countries had similar strategies for data dissemination and policy:

- target the information and market it to various stakeholders;
- annual reports;
- reports could begin with short bullet points and become increasingly technical;
- issue periodic bulletins to various decision-makers, physicians and media;
- use national fortification alliance to bring in members from various sectors;
- doctors, health care professionals and government officials should be informed;

- education and curricula about birth defects should be established in education systems;
- evaluate the process;
- involve the public and stakeholders and link them together in the process;
- data can be used at the dissemination event to show that there is a problem;
- convene the central committee to discuss the next steps necessary to plan interventions;
- symposium;
- mass media;
- include health education;
- at the end of the dissemination event explain to the public how to prevent neural tube defects and focus on folic acid;
- explain how fortification has affected the results.

Possibilities of outcomes to be included were:

- the link to newborn screening through including positive screens in the registry;
- use WHO classification ICD-10;
- birth defects beyond neural tube defects;
- genetic diseases;
- no age constraint;
- include the top five disorders beyond structural malformations or defects;
- focus on prevalent conditions.

8. RECOMMENDATIONS

Member States and WHO

1. Work together to create a network of “interested parties” for ongoing communications/updates and support on the prevention of birth defects. The aim should be to establish the Eastern Mediterranean Birth Defects Prevention Network (EMBDPN). Other active partners, such as UNICEF and UNFPA should be involved.

2. Set a 10-year regional goal of having high quality data systems for birth defects surveillance, with skilled personnel, by 2015.

WHO

3. Sustain support for capacity building and systems development in birth defects surveillance, including advocacy, training and information-sharing workshops, evaluation of data systems leading to “certification” and development of guidelines to help establish uniform systems across the Region.

4. Support translation of the NBDPN Guidelines for Conducting Birth Defects Surveillance into Arabic.

5. Expand the Reproductive Health Research Network to include birth defects.

Annex 1

AGENDA

1. Welcome and opening address
2. Objectives and mechanics of the technical consultation
3. Overview on neonatal health in the Region
4. Principles of developing public health surveillance systems
5. Rationale for birth defects surveillance and monitoring
6. Setting up birth defects surveillance systems: the basics
7. National neonatal screening programme
8. Flour fortification programme with focus on fortification with folic acid
9. Technical presentations on national neonatal screening programmes
10. Working sessions in groups
11. Group presentations and discussions
12. Conclusions and recommendations
13. Closing ceremony

Annex 2

PROGRAMME

Saturday, 21 May 2005

12:30–13:00	Registration
13:00–14:15	Inauguration Message from Dr Hussein A. Gezairy, WHO Regional Director for the Eastern Mediterranean Introduction of participants Election of Chairperson and Rapporteur Review of agenda and programme
14:15–14:30	Objectives and mechanics of the technical consultation/*Ms Lilas Tomeh, EMRO*
14:30–15:00	Overview on neonatal health in the Region/*Dr Ramez Mahaini, EMRO*
15:00–16:15	Principles of developing public health surveillance systems/*Dr Hani Atrash, CDC*
16:15–16:30	Facilitators and organizers meeting about the consultation process, handouts, structure of sessions etc.

Sunday, 22 May 2005

08:30–10:15	Principles of developing public health surveillance systems/*Dr Hani Atrash, CDC*
10:15–11:30	Rationale for birth defects surveillance and monitoring/*Dr Lowell Sever, WHO Temporary Adviser*
11:30–13:30	Setting up birth defects surveillance systems: the basics/*Dr Lowell Sever, WHO Temporary Adviser*
13:30–14:15	National congenital anomaly registry/*Dr Hager Al-Hosani, WHO Temporary Adviser*
14:15–15:00	National neonatal screening programme in Egypt/*Dr Safaa Abdel Fattah, WHO Temporary Adviser*
15:00–15:45	Flour fortification programme with focus on fortification with folic acid/ *Dr Robabeh Shiekholeslam, WHO Temporary Adviser*

Monday, 23 May 2005

08:30–09:15	Neonatal screening programme in Lebanon/*Dr Khaled Yunis, WHO Temporary Adviser*
09:15–10:30	Preconception folic acid administration—experiences of UNRWA's health programme/*Dr Haifa Madi, UNRWA, Jordan*
10:30–11:15	Improving maternal and child nutrition—the experiences of Qatar Foundation/*Ms Aisha Al-Romaihi, WHO Temporary Adviser*
11:15–12:00	Status of birth defect identification in Jordan—successes and constraints *Dr Sanaa Saqf El-Hait, WHO Temporary Adviser*
12:00–15:30	Setting up birth defects surveillance systems/*Dr Lowell Sever, WHO Temporary Adviser*

Tuesday, 24 May 2005

08:30–13:30	Case Study 1: Field visit—vital statistics/MCH Information System, Ministry of Health and Population, Cairo, Egypt
13:30–15:30	Case Study 2: Birth defects surveillance in the United States: CDC activities / State activities/*Dr Hani Atrash and Dr Lowell Sever*

Wednesday, 25 May 2005

08:30–08:45	Instructions on group work
08:45–14:30	Group work: Establishing general objectives, structure and optional approaches to establishing national birth defect registries and surveillance systems in countries of the Eastern Mediterranean Region
14:30–15:30	Presentation of group work

Thursday, 26 May 2005

08:30–09:30	Overview of IMMPaCt—International Micronutrient Malnutrition Prevention and Control/*Mr Laird Ruth, CDC*
10:00–11:00	Conclusions and recommendations
11:00–11:15	Closing ceremony

Annex 3

LIST OF PARTICIPANTS

Temporary Advisers

EGYPT
Ms Lina Chichakli
Cairo

Dr Safaa Abdel Fattah Ahmed
Paediatric Consultant Healthy Mother and Healthy Child Project
Cairo
Email: safahussein@hotmail.com

Dr Zein El-Abedin Taher
Healthy Mother and Healthy Child Project
Ministry of Health and Population
Cairo
Email: zeintaif2002@yahoo.com

Ms Alison Thomas
Cairo

ISLAMIC REPUBLIC OF IRAN
Dr Robabeh Sheihkoleslam
Director General, Nutrition Department
Ministry of Health and Medical Education
Teheran
Email: i_shey@yahoo.com

JORDAN
Dr Sanaa Saqf El-Hait
National Focal Point for Genetic, Congenital Disorders and Birth Defects
Ministry of Heath
Amman
Email: pnsa61@yahoo.co.uk

Dr Haifa Madi
Deputy Director of Health
Chief Health Protection and Promotion
United Nations Relief And Works Agency (UNRWA)
Amman
Email: h.madi@unrwa.org

LEBANON
Dr Khaled Yunis
Associate Professor of Paediatrics
Director of Newborn Services
American University of Beirut Medical Centre
Beirut
Email: kayunis@aub.edu.lb

QATAR
Ms Aisha Al-Romaihi
Head of Nutrition
Materials and Contracts Department
Qatar Foundation for Education Science and Community Development
Doha
Email: aalromaihi@qf.org.qa

UNITED ARAB EMIRATES
Dr Hajer Al-Hosani
Director of Maternal and Child Health
Ministry of Health
Abu-Dhabi
Email: hager@emirates.net.ae

UNITED STATES OF AMERICA
Dr Lowell E. Sever
Professor of Epidemiology
University of Texas School of Public Health
Houston
Email: Lowell.E.Sever@uth.tmc.edu

Other organizations

Centers for Disease Control and Prevention (CDC)
Dr Hani K. Atrash
Associate Director for Programme Development
National Center on Birth Defects and Development Disabilities
Centers for Disease Control and Prevention
Atlanta
UNITED STATES OF AMERICA
Email: Hatrash@cdc.gov

Mr Laird Ruth
Micronutrient Specialist
IMMPaCt Program
Division of Nutrition and Physical Activity
Centers for Disease Control and Prevention
Atlanta
UNITED STATES OF AMERICA
Email: lruth@cdc.gov

WHO Secretariat

Dr Kunal Bagchi, Regional Adviser, Nutrition, WHO/EMRO
Dr Ramez Mahaini, Regional Adviser, Women and Reproductive Health, WHO/EMRO
Ms Lilas Tomeh, Technical Officer, Nutrition, WHO/EMRO
Dr Hossam Mahmoud, Medical Officer, Making Pregnancy Safer, WHO/EMRO
Mr Ahmed Elarousy, Senior Technical Assistant, WHO/EMRO
Ms Nashwa Nasr, Secretary, WHO/EMRO