

Report on the

**Regional meeting on haemoglobinopathies
and genetic diseases in the Eastern
Mediterranean Region**

Amman, Jordan
27–30 June 2011

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1. INTRODUCTION

Most countries of the Eastern Mediterranean Region face major challenges in providing comprehensive and up-to-date health services in rapidly advancing fields such as genetics. This includes haemoglobinopathies, such as sickle-cell disease and thalassaemia, which are significant health issues in many countries of the Region. Advances in science and the understanding of these diseases have led many countries in the world to develop national management guidelines for common genetic diseases, including haemoglobinopathies. Adherence to these guidelines and the simultaneous development of the needed infrastructure for the management of genetic diseases and haemoglobinopathies has resulted in greatly improved health outcomes among people with haemoglobinopathies in these countries. While some countries in the Region have shown tremendous improvement in outcomes for people with haemoglobinopathies and other genetic diseases, others have not been so successful.

In order to strengthen regional and national capacity for the prevention and management of common genetic diseases and haemoglobinopathies in the Eastern Mediterranean Region, the World Health Organization (WHO) Regional Office for the Eastern Mediterranean, in partnership with the Centers for Disease Control and Prevention (CDC), USA, organized a regional meeting, from 27–30 June 2001, in Cairo, Egypt, to consult Member States on the development of a regional strategy for genetic diseases and country guidelines for the management of haemoglobinopathies. The objectives of the meeting were to: review country experiences and national capacity for the prevention and management of genetic diseases and haemoglobinopathies in the Eastern Mediterranean Region; discuss and agree on essential components of a regional strategy on genetic diseases; and build national and regional capabilities in developing national action plans for the prevention and management of haemoglobinopathies and genetic diseases, training on public health surveillance and epidemiological analysis, and training on screening and community health education.

The meeting was attended by participants from Bahrain, Egypt, Iraq, Jordan, Lebanon, Morocco, Oman, Pakistan, Palestine, Qatar, Saudi Arabia, Sudan, Syrian Arab Republic, Tunisia, United Arab Emirates and Yemen, as well as the Thalassaemia International Federation. The contribution of the Thalassaemia International Federation to the recommendations that were produced by the meeting is gratefully acknowledged. The programme and list of participants are included as Annexes 1 and 2, respectively.

The meeting was inaugurated by Dr Diaff Allah Allouzi, representative of H.E Professor Wajih M. Owais, Minister of Higher Education and Scientific Research/Acting Minister of Health, Jordan, and Dr Hussein A. Gezairy, WHO Regional Director for the Eastern Mediterranean.

In his opening speech, Dr Gezairy said that genetic diseases and haemoglobinopathic disorders constitute one of the major public health challenges in the Region. He observed that the high rates of haemoglobinopathies and genetic diseases in countries can be partially attributed to the high rate of traditional consanguineous marriages, which account for 20%–50% of all marriages, with first cousin unions amounting to 20%–30% of all marriages. Young age of marriage and low educational levels were associated with large family sizes,

which may increase the number of affected children in families with autosomal recessive conditions, he noted.

Dr Gezairy highlighted that there had been some success stories in the Region. The countries of the Gulf Cooperation Council have reported a significant reduction in the incidence of haemoglobinopathies following the effective implementation of premarital screening programmes, coupled with newborn and school screening, along with community education. He pointed out that the meeting was the first in a series of initiatives to address regional needs and improve regional resources in this area.

2. TECHNICAL PRESENTATIONS

2.1 The regional meeting on haemoglobinopathies and genetic diseases: objectives and expected outcomes

Dr Haifa Madi, WHO/EMRO

Haemoglobinopathies and genetic diseases constitute a serious health problem and a major cause of disability and death. About 5% of the world's population carry the genes of sickle-cell anaemia, and genetic and congenital abnormalities occur in around 2%–5% of all live births. Haemoglobinopathies in countries of the Eastern Mediterranean Region exhibit high population carrier rates, which range from 2%–7% for beta-thalassaemia, 2%–50% for alpha-thalassaemia and 0.3%–30% for sickle-cell disease.

Other congenital disorders include Down Syndrome, one of the most common chromosomal abnormalities in the Region, with an incidence per 1000 live births of 1.8 in Egypt, 1.7 in Libya and 1.1 in Bahrain, while congenital hypothyroidism among live births was 1:2666 in Saudi Arabia and 1:1433 in Islamic Republic of Iran.

The economic burden of haemoglobinopathies is high. In Pakistan, the average cost of iron-chelating therapy in transfusion-dependent thalassaemia patients is US\$ 4400, or 10 times the average annual income. Annual treatment costs are currently 4% of government health expenditures. In Jordan, the annual cost of treatment is estimated to be about US\$ 10 million.

Challenges in the Eastern Mediterranean Region include:

- Consanguineous marriages account for 20%–50% of all marriages, with first cousin unions amounting to 20%–30% of all marriages.
- The young age of marriage and low educational levels results in high fertility.
- Religious and social reservations exist regarding interventions during pregnancy.
- Haemoglobinopathies and genetic diseases are not prioritized in public health plans.
- Only limited preventive programmes exist and there is a lack of accurate data.
- The public is largely unaware of genetic risks and the possibilities of prevention.
- Genetic education of health professionals is deficient at both undergraduate and postgraduate levels.

WHO has adopted two World Health Assembly resolutions on haemoglobin disorders: resolution WHA59.20 on sickle-cell anaemia, adopted by the Fifty-ninth World Health Assembly in May 2006; and resolution WHA63.17 on birth defects, including sickle-cell disease and thalassaemia, adopted by the Sixty-third World Health Assembly in May 2010.

The Regional Office for the Eastern Mediterranean has initiated several strategies and interventions to address the prevention and control of genetic and congenital diseases in the Region. This includes: premarital, newborn, antenatal and school screening programmes; community education; support for genetic laboratory services; and establishing a registry for congenital abnormalities and hereditary diseases.

2.2 Global situation, burden, morbidity and mortality

Dr Azfar-E-Alam Siddiqi, CDC

The global estimate for annual births with birth defects of genetic or partially genetic origin is 7.9 million births (6% of total births worldwide). A multicentre study of the incidence and rate of development of iron-related organ dysfunction among 405 patients with chronically-transfused thalassaemia and sickle-cell disease, found that observed death rates were three times the US mortality statistics for gender and race by age group. The thalassaemia death rate was 2.2/100 person years, while the rate among sickle-cell disease patients was 7/100 person years. Thalassaemia patients died at a younger age than those with sickle-cell disease. However, haemoglobin disorders are not included in WHO's disease burden estimates and those estimates available are necessarily incomplete and speculative.

2.3 Regional situation: findings from the country survey

Dr Ibtihal Fadhil, WHO/EMRO

The high rates of consanguinity and haemoglobinopathies in the Eastern Mediterranean Region mean that there is a need to build on World Health Assembly resolutions WHA.59.20 and WHA63.17 and to update regional efforts for reorganization of community genetic services.

In a situation assessment conducted in 2009, eight countries responded to the assessment on genetic services status (Afghanistan, Bahrain, Egypt, Iraq, Morocco, Palestine, Somalia and Sudan), while 17 countries responded to the assessment focused on haemoglobinopathy services (Bahrain, Egypt, Iraq, Jordan, Kuwait, Lebanon, Morocco, Oman, Pakistan, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syrian Arab Republic, Tunis and Yemen). Further data were extracted from published data and personal communications.

The main findings were: 47% of respondents reported existing national guidelines; 50% of respondents reported newborn screening; 88% of respondents reported parent and adult carrier counselling; and 88% of respondents reported guidelines for management of complications.

Based on the regional situational analysis, the Regional Office has proposed developing a regional strategy for genetic diseases control. The core components of this will be:

- commitment of policy-makers
- availability of epidemiological data and research
- establishment of surveillance and registries of congenital and genetic diseases
- integration of genetic services, mainly screenings and genetic counselling, into existing health care facilities (primary health care)
- screening programmes at different levels
- infrastructure development and capacity-building
- increased genetic literacy of the population by all available means
- establishment of a regional network and exchange of resources
- improved management and rehabilitation for affected individuals and families.

2.4 Haemoglobinopathies in developing countries

Dr Androulla Eleftheriou, Thalassaemia International Federation

The Thalassaemia International Federation is a non-profit, nongovernmental and patient-driven organization with a mission to develop national control programmes for the prevention and management of thalassaemia in affected countries and the vision of equal access to quality health care for every patient.

The specific objectives of the Federation are to: establish and/or promote patient/parent support groups in every affected country; educate patients, parents, health professionals and the community at large; develop networks of collaboration with official health agencies and organizations at the international, European and national levels; and propose, initiate, contribute to and support the development of health-related policies, position papers and consultations.

Low- and middle-income countries face particular challenges when addressing noncommunicable diseases such as financial instability, poverty and illiteracy, poor governance and corruption, and a lack of accountability of governments and systems, including health systems.

In addition, the presentation covered initiatives, meetings and resolutions adopted by the Federation to prevent and control thalassaemia. The presentation also outlined the clinical aspects of different types of thalassaemia and other haemoglobinopathies.

2.5 Newborn screening: 2011 update

Dr Hani K. Atrash, CDC

Newborn screening as a comprehensive system of care includes private and public medical practitioners, laboratory personnel, administrative and follow-up personnel, educators, family members and other interested individuals (politicians). Almost all four million infants born every year in the US are screened for phenylketonuria (PKU), congenital hypothyroidism, congenital adrenal hyperplasia, galactosaemia and sickle-cell disease.

The criteria for newborn screening are:

- the screening programme should respond to a recognized need
- the objectives of screening should be defined at the outset
- there should be a defined target population
- there should be scientific evidence of screening programme effectiveness
- the programme should integrate education, testing, clinical services and programme management
- there should be quality assurance, with mechanisms to minimize potential risks of screening
- the programme should ensure informed choice, confidentiality and respect for autonomy
- the programme should promote equity and access to screening for the entire target population
- programme evaluation should be planned from the outset
- the overall benefits of screening should outweigh the harm.

2.6 Newborn screening for haemoglobinopathies

Dr Althea Grant, CDC

Newborn screening has had a major impact on preventing morbidity and mortality, especially for sickle-cell disease. The primary purpose of newborn screening for haemoglobinopathies is to identify clinically-significant haemoglobinopathies. The golden standard is the ability to detect thalassaemia and sickle-cell disease. Secondary targets are also important for public health, education and prevention. Carrier identification and counselling provide opportunities for prevention.

2.7 Clinical management: Current practices and developing technologies

Dr Miguel R. Abboud, WHO Temporary Adviser, WHO/EMRO

The main goals of newborn screening are to reduce mortality rates due to pneumococcal sepsis and incidence of complications such as splenic sequestration. The required examination laboratory tests are:

- complete physical examination
- complete blood counts, liver profile, electrolytes, creatinine, microalbuminuria, ferritin level, calcium metabolism including vitamin D, pulmonary function tests: routinely or as clinically indicated
- hepatic ultrasonography after three years of age
- hip radiograph and echocardiography after six years of age
- ophthalmological evaluation by a trained ophthalmologist: patients with SD disease after six years of age; patients with SS disease after 10 years of age
- academic performance
- adherence to treatment and appointments.

2.8 Surveillance and analysis: Concept, why and how

Dr Azfar-E-Alam Siddiqi, CDC

Public health surveillance is a core component of public health practice. The main aspects of surveillance are collection, analysis and interpretation of health data. These are essential to the planning, implementation and evaluation of public health practice. The timely dissemination of data to those who need to know and the application of such data to prevention and control programmes are very important. The purpose of evaluating a surveillance system is to ensure that problems of public health importance are being monitored efficiently and effectively.

2.9 Surveillance and analysis: Role of the laboratory

Dr Althea Grant, CDC

Laboratory services play a key role in newborn screening and diagnosing genetic disorders, as these vary in severity and it is not always possible to depend on clinical symptoms to identify affected individuals. There is therefore a need for laboratory confirmation and case definition. This is classified as:

- High: laboratory-confirmed;
- Probable: laboratory screening with algorithm using International Classification of Diseases (ICD) coding for administrative datasets that includes treatments, procedures and complications to increase confidence;
- Possible: could be either positive or negative.

2.10 Community genetic services in Eastern Mediterranean Region: Impediments, needs and proposed strategies

Dr Hanan Hammamy, WHO Temporary Adviser, WHO/EMRO

The five most serious and prevalent birth defects, which constitute about 25% of all disorders, are: haemoglobin disorders (thalassaemia and sickle-cell anaemia); Down syndrome; neural tube defects; congenital heart defects; and G6PD deficiency.

Around 70% of birth defects are preventable, and this prevention can be achieved through:

- Primary prevention: preconception/premarital testing and counselling.
- Secondary prevention: screening testing and management.
- Tertiary prevention: surgical interventions.

The goal of community genetic activities in the Eastern Mediterranean Region is to prevent congenital disorders at the population level and, at the same time, to provide genetic services (diagnosis, counselling and care) in the community for individuals and families.

2.11 Management models of follow-up and care: The role of public health

Dr Althea Grant, CDC

The model of care for sickle-cell disease involves the following procedures: newborn screening; parental education; penicillin prophylaxis; vaccinations (pneumococcal conjugate vaccine); transcranial Doppler screening; transfusion; iron chelation; and hydroxyurea.

Comprehensive care for thalassaemia can be defined as the following:

- blood transfusions: every 2–4 weeks for thalassaemia major;
- iron chelation therapy: deferoxamine (standard therapy given overnight through a needle/pump under the skin) and deferasirox (daily pill);
- fetal haemoglobin inducers;
- folic acid supplements;
- splenectomy;
- stem cell transplant.

2.12 Public awareness/education and policy development

Dr Samir Faouri, WHO Temporary Adviser, WHO/EMRO

Control and prevention of genetic diseases programmes, when effectively implemented, can reduce the frequency of homozygous and double states, morbidity and psychosocial trauma. The objectives of population, premarital and preconception screening are to:

- identify carriers for a particular gene defect;
- identify individuals with a genetic predisposition to a disease;
- provide genetic counselling for prevention of birth of an affected child;
- provide genetic counselling to prevent or delay disease development.

Future strategies for control of these disorders should be to: determine the frequency and distribution of genetic disorders in the population; construct databases of genetic disorders; establish care and counselling facilities; establish programmes for carrier detection; provide appropriate counselling; increase awareness of genetic defects; develop better understanding of the molecular pathology of genetic disorders; and provide continuous updates of related information.

3. COUNTRY PRESENTATIONS

3.1 Bahrain

The Ministry of Health began a campaign to control sickle-cell disease in the 1980s. It has included: education and public awareness campaigns; screening of different categories, such as carriers and students; and premarital, prenatal and newborn screening. Newborn screening is followed by genetic counselling. National newborn screening for haemoglobinopathies started in 2007 and is fully funded from the national budget. The testing

is done at the central laboratory in Salmaniya hospital. A comprehensive health education programme has also been launched to increase public awareness of the diseases.

3.2 Egypt

A national prevention programme has not yet been established. A newborn screening programme for congenital hypothyroidism started in 2000 and was expanded gradually to cover all Egyptian governorates by the end of year 2003. The genetic counselling programme started in 2002, but the community genetic service is currently only available at 11 clinics. Paediatricians at these clinics are managing cases through genetic counselling, while technical consultation is offered through supervisory visits to the genetics clinics by university professors of genetics.

3.3 Iraq

In Iraq, there are 19 hereditary blood diseases centres, with a total of 13 500 patients. Services are provided free of charge, including regular blood transfusion and iron chelating therapy. National guidelines for management and prevention of haemoglobinopathies have been developed. Premarital screening for haemoglobinopathies is performed by haematology autoanalyser tests.

3.4 Jordan

Since 2004, premarital screening test has been mandatory by law and national guidelines have been developed. It is implemented through: education of the public; training of the health sector; availability of prescreening genetic counselling; quality control of the screening test and interpretation of results; couples counselling; and availability of other relevant diagnostic tests. Newborn screening mainly targets phenylketonuria and congenital hypothyroidism. It is planned to introduce favism (G6PD) in the near future.

3.5 Lebanon

The haemoglobinopathies service is a mainly vertical one provided by the Chronic Care Centre, founded in 1994. It is dedicated to the free treatment of chronic diseases and is the only center to provide specialist care for thalassaemia patients. The main challenges are the absence of national guidelines and a newborn screening programme, and a lack of funds and trained staff.

3.6 Morocco

National guidelines are available for the management of patients with haemoglobinopathies. However, there is no national newborn screening programme. Genetic counselling is available for couples who request it and relatives at high risk (after the birth of at least one affected child). A limited number of health providers have been trained for educational and genetic counselling for hereditary diseases.

3.7 Oman

A national programme for the prevention and management of haemoglobinopathies in Oman was established in 1999. It has developed standardized protocols. Neonatal screening for haemoglobinopathies is not included in the newborn screening programme. This is because counselling and education takes place at the primary care level through individual and group sessions, along with the distribution of pamphlets.

3.8 Pakistan

Although national guidelines for prevention and management of haemoglobinopathies have been developed, they have not been implemented. Twenty-six different nongovernmental organizations work independently in various cities, mainly providing blood transfusions and free iron chelating therapy. There is no national newborn screening programme for haemoglobinopathies due to financial constraints and the absence of infrastructure and trained personnel.

3.9 Palestine

A national control programme has been in place for beta thalassaemia and sickle-cell anemia since May 2000. The Ministry of Health/Thalassaemia Patients' Friends Society introduced legislation on premarital testing. There is no programme of neonatal screening, while the antenatal programme is only for suspected cases and families with a history of thalassaemia or sickle-cell anaemia. Educational activities are undertaken for improving awareness and prevention. These activities target students, patients and patients' relatives.

3.10 Qatar

A national haemoglobinopathies project has been recently adopted and is due to start soon. It consists of: the Qatar National Haemoglobinopathies Registry; education for health care professionals and the public; implementation of Thalassaemia International Federation guidelines; and epidemiological and translational research. Neonatal sickle-cell screening, in collaboration with Heidelberg University Hospital, started in 2007, while premarital screening started in December 2010.

3.11 Saudi Arabia

National guidelines for the prevention and management of haemoglobinopathies have been developed. These include a thalassaemia and screening programme. The guidelines also recommend patient education on self-manageable aspects of their disease and the counselling of parents of a child with a haemoglobinopathic disease. A national programme for newborn screening is in place.

3.12 Sudan

There are no existing national guidelines for prevention and management of haemoglobinopathies. However, there are guidelines for the prevention and management of sickle-cell anaemia. These guidelines are implemented in the sickle-cell clinic in Khartoum. There is no newborn screening programme or provision of health education by either the Federal Ministry of Health or nongovernmental organizations. Counselling and education are provided at the time of follow-up at the clinic.

3.13 Syrian Arab Republic

National guidelines for haemoglobinopathies have been implemented since 1997 and were updated in 2008. The service is provided through nine specialized health units distributed across the country. Newborn screening is in place and focuses only on families known to contain carriers or patients with sickle-cell disease or thalassaemia. Premarital screening is part of marriage documentation.

3.14 Tunisia

There are no national guidelines for the prevention and management of haemoglobinopathies or newborn screening programme. Haemoglobinopathies screening takes place only among families at risk and before marriage to a person at high risk. Counselling and education of young patients and their parents takes place at the time of diagnosis and follow-up care, and is mainly provided by physicians.

3.15 United Arab Emirates

There are three genetic centres providing services for haemoglobinopathies: the Genetic and Thalassaemia Centre in Dubai, the Faculty of Medicine and Health Sciences in Al-Ain and the National Screening Centre for Women and Child Health in Abu Dhabi. The elements of the haemoglobinopathies prevention programme include a neonatal screening programme, premarital screening (mandatory at the national level since 2008), screening of pregnant woman during antenatal care visits, screening at age one year, and screening at schools and universities.

3.16 Yemen

There are no national guidelines for the prevention and management of haemoglobinopathies or newborn screening programme. This is due to a lack of funding and staff. Health education is targeted only at those at risk of developing the diseases.

4. CONCLUSIONS

Participants in the meeting came to a number of key conclusions for national health-care decision-makers and providers in the Eastern Mediterranean Region. These are summarized as follows:

- Haemoglobinopathies in countries of the Eastern Mediterranean Region exhibit high population carrier rates, ranging from 2%–7% for beta-thalassaemia, 2%–50% for alpha-thalassaemia and 0.3%–30% for sickle-cell disease.
- High rates of haemoglobinopathies and genetic diseases in Eastern Mediterranean Region countries can be attributed partially to the high rate of traditional consanguineous marriages which currently account for 20%–50% of all marriages, with first cousin unions amounting to 20%–30% of all marriages.
- Haemoglobinopathies and genetic diseases are not always recognized as priorities in public health planning.
- Although assessment has been partially done in some countries, there is an urgent need to analyse the situation in detail.
- In some countries there are no national guidelines for the prevention and management of haemoglobinopathies and/or no national newborn screening programme.
- In those countries where guidelines exist, they have either not been implemented or lack adequate funding and trained personnel.
- There is no regional strategy for genetic diseases control in the Eastern Mediterranean Region. The need for a strategy is essential.
- There is a great demand for the definition and implementation of a surveillance framework for haemoglobinopathies and genetic diseases in the Eastern Mediterranean Region.
- Most countries in the Eastern Mediterranean Region lack the proper infrastructure and training programmes for the capacity-building of health staff in the area of haemoglobinopathies and genetic diseases.
- Management of haemoglobinopathies and genetic diseases is not integrated into primary health care in the countries of the Eastern Mediterranean Region.

5. RECOMMENDATIONS

To Member States

1. Given the limited data available on the national and regional level of haemoglobinopathies and genetic diseases, country situation assessments should be updated and a regular registry of national data established to reflect the burden and impact of haemoglobinopathies and common genetic disorders.
2. National action plans should be developed and/or revised by the country team in collaboration with all stakeholders, with the technical support of the WHO Regional Office for the Eastern Mediterranean during the development stages. When the plan has been finalized, a draft should be forwarded to the Regional Office.
3. The Regional Office should collaborate with partners, such as the Thalassaemia International Federation, to review and edit existing guidelines to tailor them to regional needs, culture and capacities.
4. A centre of excellence should be identified by participants in their respective countries to be a potential WHO Collaborating Centre, working in collaboration with

the existing WHO Human Genetics Collaborating Center in Saudi Arabia to expand their services to meet regional needs.

5. A regional network of experts, called the Regional Haemoglobinopathies Forum, should be formed to share experiences, training and resources, and to monitor progress in countries.

To WHO Regional Office for the Eastern Mediterranean

6. A regional strategy on prevention and care of haemoglobinopathies and common genetic disorders should be developed to develop and strengthen the prevention and care of haemoglobinopathies and genetic disorders.
7. The core components of the regional strategy should be as follows:
 - Introduction and justification
 - Situation analysis
 - Objectives and targets
 - Strategic directions:
 - political commitment
 - public awareness and education of health-care providers
 - reorganization of services (infrastructure)
 - surveillance
 - population screening
 - networking and collaboration
 - monitoring and evaluation.
8. Guidelines should be developed on the screening, prevention and management of haemoglobinopathies and common genetic disorders, building on existing guidelines.
9. Further training should be organized, jointly with Member States, in three priority areas: newborn screening; prevention and management of haemoglobinopathies at all levels of care; prevention and management of birth defects/congenital disorders in registry and preconception care services.
10. A regional taskforce should be developed to review and adapt existing guidelines.
11. A regional follow-up meeting should be organized to monitor progress, subject to availability of resources.
12. Acknowledging the leadership of WHO in addressing the impact of noncommunicable diseases at the UN High-Level Meeting on Noncommunicable Diseases in September 2011, haemoglobinopathies and common genetic disorders should be included as an official part of the noncommunicable diseases programme.

Annex 1

PROGRAMME

Monday, 27 June 2011

- 08:30–09:00 Registration
- 09:00–09:30 Opening session
Welcome address by Dr Hussein A. Gezairy, Regional Director, WHO/EMRO
Address by H.E Professor Wajih M. Owais, Minister of Higher Education and Scientific Research, Acting Minister of Health, Jordan
Introduction of attendees, election of officers and adoption of Agenda
- 09:30–10:15 Objectives and expected outcomes of the Meeting, *Dr Haifa Madi, WHO/EMRO*
- 10:15–10:45 Global situation, burden, morbidity and mortality, *Dr Azfar-E-Alam Siddiqi, CDC*
- 10:45–11:15 Regional situation/findings from country survey, *Dr Ibtihal Fadhil, WHO/EMRO*
- 11:15–12:00 Haemoglobinopathies in developing countries, *Dr Androulla Eleftheriou, TIF*
- 12:00–14:30 Country presentations: Bahrain, Egypt, Iraq, Lebanon, Oman, United Arab Emirates
- 14:30–16:00 Country presentations: Jordan, Palestine, Qatar, Saudi Arabia, Yemen
- 16:00–17:00 Country presentations: Morocco, Pakistan, Sudan, Tunisia

Tuesday, 28 June 2011

- 09:00–9:45 Country presentations: Islamic Republic of Iran, Somalia, Syrian Arab Republic
- 9:45–10:30 Newborn screening: 2011 update, *Dr Hani K. Atrash, CDC*
- 10:30–11:30 Newborn screening for haemoglobinopathies, *Dr Althea Grant, CDC*
- 11:30–12:30 Clinical management: Current practices and developing technologies, *Dr Miguel R. Abboud, WHO Temporary Adviser*
- 12:30–13:00 Surveillance and analysis: Concept, why and how, *Dr Azfar-E-Alam Siddiqi, CDC*
- 13:00–14:30 Surveillance and analysis: Role of the laboratory, *Dr Althea Grant, CDC*
- 14:30–15:00 Community genetic services in the Eastern Mediterranean Region: impediments, needs and proposed strategies, *Dr Hanan Hammamy, WHO Temporary Adviser*
- 15:00–15:45 Management models of follow-up and care: The role of public health, *Dr Althea Grant, CDC*
- 15:45–16:30 Public awareness and education and policy development, *Dr Samir Faouri, WHO Temporary Adviser*

Wednesday, 29 June 2011

09:00–09:15 Group work session: Instructions, expectations and outcomes, *Dr Ibtihal Fadhil, WHO/EMRO*

09:15–10:30 Group work: Developing recommendations for regional activities

11:00–13:00 Group work plenary: Presentation of recommendations

14:00–16:00 Individual country work on developing country specific plan of action

Thursday, 30 June 2011

09:00–11:00 Country presentations of action plans

11:30–12:00 Panel discussion on the UN High-Level Meeting on Noncommunicable Diseases

12:00–13:00 Concluding remarks and summing up.

Annex 2

LIST OF PARTICIPANTS

BAHRAIN

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