WHO-EM/NCD/070/E

Summary report on the

First coordination meeting on the regional comparative breast cancer research programme

Sharm El-Sheikh, Egypt
21–22 January 2012

World Health Organization
Regional Office for the Eastern Mediterranean

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1. Introduction

A coordination meeting to initiate a regional comparative breast cancer research programme was organized by the World Health Organization (WHO) Regional Office for the Eastern Mediterranean in collaboration with Susan G Komen for Cure, in Sharm El-Sheikh, Egypt, on 21–22 January 2012. The objectives of the meeting were to discuss a plan of action for implementation of a regional comparative breast cancer research programme; review the proposed breast cancer information system database including its feasibility and possible limitations; agree on the collaborative process for data collection through the different participating regional cancer facilities; provide an opportunity for the piloting cancer facilities to share experiences and feasible approaches to overcome the expected challenges; and agree on the overall process of monitoring, evaluation, analysis and programme funding.

The meeting was attended by experts from the National Cancer Institute (Cairo University), National Cancer Research Programme (Iraq), King Hussein Cancer Centre (Jordan) and Lebanese Cancer Society, as well as by staff of the International Agency for Research on Cancer (IARC), International Atomic Energy Agency (IAEA), Susan G Komen for Cure and WHO.

The meeting was inaugurated by Dr Haifa Madi, Director, Health Protection and Promotion, WHO Regional Office for the Eastern Mediterranean and Dr Rola Shaheen, Middle East Adviser, Susan G. Komen for the Cure. In her address, Dr Madi referred to the regional strategy for cancer prevention and control, adopted by all countries of the Eastern Mediterranean Region in 2009, which called for a focus on early detection through integration in primary health care. She referred to the work of IARC, the specialized cancer research arm of WHO, which focused on conducting and coordinating research on the burden, causes, prevention and early detection of cancer worldwide. In her inaugural speech, Dr Rola stressed the need for a collaborative approach in order to create a world without breast cancer. This approach must include accurate documentation, national cancer registries, clinical trials, collaborative work, resource allocation and prompt intervention.

The first day consisted of technical presentations, country presentations on breast cancer statistics from the national cancer registry in Egypt, Iraq, Jordan and Lebanon, and presentations by partners on the role of stakeholders in fighting breast cancer. On the second day, IARC representatives provided practical training on utilizing the breast cancer information system database and a comprehensive review of the proposed questionnaire. Country representatives and statisticians discussed the feasibility, capabilities and limitations of the proposed questionnaire and suggested some possible modifications.

2. Summary of discussions

- The project was adopted by the 4 centres: National Cancer Institute (Egypt), National Cancer Research Programme (Iraq), King Hussein Cancer Centre (Jordan) and Lebanese Cancer Society.
- It was agreed that IARC will be responsible for data validation and cleaning. The WHO Regional Office will store clean data. Completed data forms will be forwarded to IARC on a monthly or bimonthly basis.

- It was agreed that IARC will develop an online system to simplify the process of data entry and follow-up of breast cancer patients, with one password for each country.
- In support of the above, statistical analysis and data management will be ensured for the 4 countries involved. Support will also be provided from WHO/IARC/IAEA to countries for data collection, training on analysis, disseminating publications and project advocacy.
- The feasibility of completing the comprehensive 4-page form was discussed, along with follow-up of patients.
- Data will be collected, retrospectively or prospectively based on country situation, and will include at least 300 consecutive cases per year.
- Both forms (long and short) were reviewed. Core items were approved by all 4 teams.

3. The way forward

- IARC will revise and share the final data collection form, along with a glossary of terms that will assist in completing the form.
- Given the fact that each centre has a role in managing the data collection process, it was agreed to develop an internal action plan for project implementation.
- A teleconference or videoconference will be held every 3 months to follow up the project implementation process.
- The second phase of the project should expand to include more centres from the Region. Komen expressed willingness to provide financial support for expansion.
- The process of conducting research will be accompanied and complemented by capacity-building in statistical analysis and data management at regional and country levels.