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EUROCHIP

European Cancer Health Indicator Project

EXECUTIVE SUMMARY OF THE FINAL REPORT

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SUMMARY OF THE PROJECT

1 BACKGROUND

In spite of concern about cancer, a cancer monitoring system covering all countries of the European Union has not yet been implemented. A large-scale Health Monitoring Program (HMP) to establish health indicators for the European Union and for all diseases was yet implemented, giving a reasonable way to reach this important European goal. Cancer surveillance holds a privileged position, compared to other diseases, in terms of sources for collecting data, matured experience and availability of data. Population-based cancer registries covering entire countries and millions of other Europeans, whose initial purpose was to collect data on cancer occurrence, are now progressively providing much more detailed information on cancer, including diagnostic criteria and therapeutic procedures at individual level. More information on social-economic health variables, both at aggregated and individual levels, is now becoming available in European networks and institutions. For these reasons the project on cancer on these topics may propose useful methods and standards for developing the European Health Information System.

The present project, EUROpean Cancer Health Indicator Project- EUROCHIP-, was conceived as a contribute to the HMP and to produce a comprehensive list of health indicators pertaining to the control and treatment of cancer, indispensable for the development of the set of European health surveillance indicators.

2 AIMS

EUROCHIP aimed to develop a comprehensive list of health indicators on cancer according to numerous European cancer experts. The list includes variables on risk factors' prevalence, pre-clinic activity, cancer occurrence, clinical follow-up, cancer recurrences, patient survival, diagnostic and therapeutic procedures, effectiveness of cancer care, outcome and care prevalence. The list includes both variables that had already been proposed by other HMP projects and new variables that are specific for cancer and had not been suggested from other HMP projects.

The present project will assess the internal consistency of all these data according to criteria of easy collection, reliability, comparability, and country representatives. Moreover, the gained experience in the development of cancer health indicators will be centralized. The final aim will be to make available a comprehensive list of indicators that would describe cancer in terms of burden, prevention activity, standards of care, and cure rates.

3 ORGANISATION

A complex organization was created to develop the list and achieve maximum consensus among the experts and institutions involved in cancer in Europe. This organization consisted of various groups with different roles.

- Steering Committee (5 persons) - SC: had a decisional role on many aspects of the project
- Panel of Experts (21 persons) - PE: included one expert for each EU member, and experts from cancer institutions and the major European cancer networks (IARC, EBCN, Cervix Network, EURO CARE, EUROPREVAL, OECD, ENCR, and NCI from US). The PE held a vital role in the project, discussing and preparing the list and organizing national groups of specialists
- National Groups of Specialists - NGS: were set up by the members of the “Panel of Experts” and consisted of groups at national level which discussed indicators from a national angle.
- Domain Groups of Specialists - DGS: were organized internationally with specialists in five major cancer domains from Europe. One group was created for each one of our study areas, i.e.: prevention, screening area, data registration and epidemiology, treatment and clinical aspects, social and macro-economic variables.
- Methodological Group - MG: dealt with methodological aspects related to the indicators included in the list.
- Working Team (6 persons) - WT: supported all groups from organizational point of view.

Final aim of the entire organization was, through an iterative method, to suggest health indicators, explain their meaning and the necessity of each chosen indicator. A preliminary list was prepared, commented and modified. A resulting new list was discussed again and defined in detail.

This complex organization resulted very useful in determining a large consensus and applicability on the EUROCHIP results. The experience of the National Groups of Specialists was used to promote actions for describing the difference in cancer within countries.

4 THE FORMS

A form to describe the indicators was prepared and used.

It is divided into three parts:

1. all characteristics of the indicators we decide to include in the list. This section was filled in for each indicator.
2. the operational definition of the indicators, information on possible sources and methodological issues (this part was expanded in a second form where the aspects of data collection, standardization and validity and others relevant were synthesized).
3. the availability of the given indicator in different countries.

5 METHOD OF DISCUSSION

EUROCHIP started work in January 2002 and ended in June 2003. More than 130 European experts in various cancer-related fields have so far been involved. During the first phase of the project one person in Public Health/Cancer from each of the participating EU countries was identified to select a group of persons involved in different fields to discuss and prioritize the relevance of a preliminary list of 134 cancer health indicators. The suggestions initially proposed by national working groups were then refined through a series of international meetings. The main elements of information required for each proposed indicator (i.e.: characteristics, operational definition, possible sources of data, methodological issues, and availability) were summarized on a standard form. A web-site was set up with all pertinent EUROCHIP information, and a methodology working group studied ways to standardize, collect and validate health indicator data.

The preliminary list was discussed by Groups of Specialists at national level and each group gave a rank of importance and priority to each indicator. The preliminary list included 158 indicators and the Panel of Experts, following Groups of Specialists' suggestions, provided a second list of only 101 indicators (during the process 57 indicators were eliminated). This new list was subdivided in 5 domains, each of which discussed in 5 international meetings. Once this part of the discussion was concluded, a new list was prepared and proposed to the discussion of the Panel of Experts concluding the work with a list of 52 indicators (26 at high priority, 15 of which proposed directly by EUROCHIP).

6 RESULTS

The list of indicators was grouped along three axes: (a) natural history of disease, (b) type of factor (demographic, socio-economic, health status, determinant of health, or health system-related) and (c) cancer site. Out of the indicators now present in the final list, some had already been proposed by other HMP projects, but a large number of new indicators was also identified. These were grouped into five separate domains: smaller meetings between experts in such domains from all Europe were held to comment on each indicator.

In synthesis EUROCHIP's main work and results are:

1. Contact and co-ordinate people involved in different fields from different countries to develop the complex organization of the project. 130 persons from all the European countries have been directly involved in the project (Annex B).
2. Organize several meetings in Europe: 4 Steering Committee meetings, 3 Panel of Experts meetings, 3 Methodological Group meetings, 8 National Groups of Specialists meetings and 5 Domain Groups of Specialists meetings (Chapter 4.1) .
3. Create forms to describe the indicators and their methodological aspects upon which all would agree (Chapter 5).
4. Develop a list of indicators and organize discussions on it.

Table 1. Number of indicators proposed by EUROCHIP, as by domain.

DOMAIN	HIGH PRIORITY	MEDIUM PRIORITY
Prevention	7 (2)	4 (2)
Epidemiology and cancer registration	7 (3)	-
Screening	4 (4)	7 (7)
Treatment and clinical aspects	5 (5)	3 (3)
Social and macro-economic variables	3 (1)	12 (4)
TOTAL	26 (15)	26 (16)

In brackets: number of new indicators proposed by EUROCHIP

5. Fill the forms for each indicator and provide an operational definition and proposals regarding methodological problems (Annex A).
6. Organize the web-site where EUROCHIP's material is presented (www.istitutotumori.mi.it/project/eurochip/homepage.htm).
7. Present the list to the audiences of national and international cancer congresses in order to improve consensus on the indicators (Chapter 4.2).
8. Publish articles on scientific journals- share methods and results.
(For Eurochip Posters and Communications, see Chapter 7)

The European Cancer Health Indicator Project (EUROCHIP) contributed significantly to the HMP producing a comprehensive list of cancer health indicators. This list will subsequently become the framework for a European health data-bank that will make possible the creation of the indicators.

The indicators of EUROCHIP's final list (Ch. 6), are:

1. Consumption of fruit and vegetables
2. Consumption of alcohol
3. Body Mass Index distribution in the population
4. Physical activity
5. Tobacco survey: prevalence of
 - a. tobacco smokers among adults
 - b. tobacco smokers among 10-14 year olds
 - c. ex-smokers
 - d. exposure to environmental tobacco smoke (ETS)
6. Exposure to sun radiation
7. Prevalence of occupational exposure to carcinogens
8. Population covered by high quality Cancer Registries
9. Cancer incidence rates, trends and projections
10. Cancer relative survival rates, trends and projections
11. Cancer prevalence proportions, trends and projections
12. Cancer mortality rates, trends, projections and person-years of life lost due to cancer
13. Stage at diagnosis: percentage of
 - a. cases with early diagnosis
 - b. cases with a metastatic test
14. Percentage of women that have undergone a mammography (breast cancer)
15. Percentage of women that have undergone a cervical cytology examination (cervical cancer)
16. Percentage of persons that have undergone a colo-rectal cancer screening test
17. Organized screening coverage
18. Delay of cancer treatment (pilot studies)
19. Percentage of radiation systems in the population
20. Percentage of diagnostic Computed Axial Tomographies (CTs) in the population
21. Compliance with best oncology practice
22. Percentage of patients receiving palliative radiotherapy
23. Gross Domestic Product
24. Total Public Expenditure on Health
25. Anti-tobacco regulations
26. Estimated cost for a cancer patient

7 FUTURE OF EUROCHIP

The overall aim of the European health information system on cancer is to carry out analyses of the cancer health indicators between-country and over-time. A steady stream of information should be generated to help reduce the risk of cancer, to promote optimal practice in cancer treatment, to improve survival with a high quality of life in cancer patients, and to reduce inequity and inequalities in cancer burden. This information will be valuable to plan the allocation of resources to cancer care. It will be available to professional policy makers, citizens and citizens' organisations in all member countries of the EU.

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