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EUROCHIP

European Cancer Health Indicator Project

FINAL REPORT

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ANNEX A: RESULTS. CANCER HEALTH INDICATORS DESCRIBED IN THE FORMS BY EUROCHIP

ANNEX B: LIST OF CANCER SPECIALISTS INVOLVED IN THE PROJECT

1. REPORT PRESENTATION

Chapter 2, ‘Summary of the project’, provides all essential information on the project.

The following issues are also explained in detail:

- organisational aspects of the project (Chapter 3). See Annex B for information on participants;
- activity schedule of each EUROCHIP group during the project (Chapter 4);
- first result: the final list of indicators subdivided by priority (Chapter 6);
- second result: the forms. We have prepared a descriptive and a methodological form to explain the indicators (Annex A). Chapter 5 specifies the meaning of each field of the descriptive Access form;
- continuation of the EUROCHIP project in the future (Chapter 8).

2. SUMMARY OF THE PROJECT

2.1 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.

2.2 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.

2.3 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.

2.4 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.

2.5 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).

2.6 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:

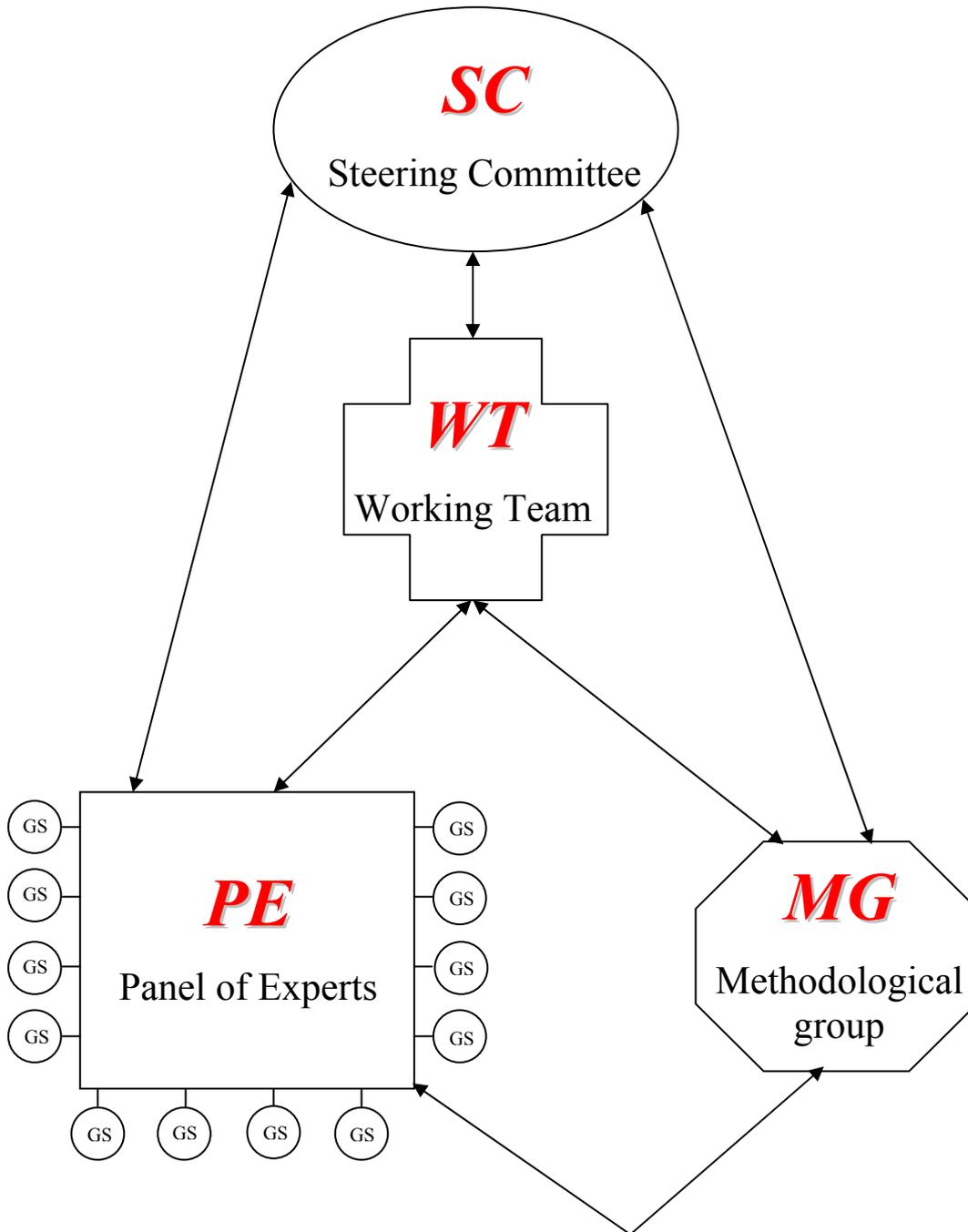
1. Consumption of fruit and vegetables
2. Consumption of alcohol
3. Body Mass Index distribution in the population
4. Physical activity
5. Tobacco survey: prevalence of
 - a. tobacco smokers among adults
 - b. tobacco smokers among 10-14 year olds
 - c. ex-smokers
 - d. exposure to environmental tobacco 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

2.7 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.

3. METHODS. PROJECT FRAMEWORK AND ROLES OF EACH GROUP

The framework below illustrates the structure of EUROCHIP’s organisation. The role of each group is presented in the next page.



GS: Groups of specialists at national level or international level (5 major domains)

3.1 THE ROLES OF EACH GROUP INVOLVED

SC: STEERING COMMITTEE

1. Help set up other groups;
2. Suggest possible health indicators;
3. Guide the work of the PE and MG;
4. Give comments on PE, MG and WT suggestions;
5. Validate reports on month 9th and 18th.

WT: WORKING TEAM

1. Organise meetings;
2. Contact each participant;
3. Co-ordinate a mailing list;
4. Inform the SC about news and mails;
5. Organise available material on indicators;
6. Integrate the results produced with those of other projects included in the HMP;
7. Prepare a report on month 9th and 18th.

PE: PANEL OF EXPERTS

1. Suggest and explain health indicators;
2. Check the availability of indicators;
3. Propose and contact specialists for national meetings to discuss the list, and check for the availability of the indicators;
4. Try to integrate the cancer indicator list in the HMP.

MG: METHODOLOGICAL GROUP

1. Discuss methodological problems of the indicators and their operational definitions;
2. Comment the level of standardisation of the indicators;
3. Propose methods to test the validity of the indicators;

GS: NATIONAL GROUP OF SPECIALISTS

1. Discuss the priority level of the indicator according to the national value;
2. Inform about the aims and the results of EUROCHIP

DGS: DOMAIN GROUP OF SPECIALISTS

1. Discuss about the indicators according to the domain
2. Propose indicators that had not yet been considered

For participants, by country, see Annex 1.

4. METHODS. ACTIVITY SCHEDULE

Table 2 presents the schedule of the meetings carried out during the project while Table 3 presents the national or international conferences in which EUROCHIP was or will be presented orally or by posters. Table 4 shows the working plan for this first period.

4.1 MEETINGS

Table 2. Meetings.

	DATE	Group	PLACE
1	25-11-2001	Steering Committee (Informal meeting)	Arona (I)
2	29-01-2002	Steering Committee	Luxembourg
3	21-02-2002	Panel of Experts	Milan (I)
4	22/23-04-2002	Working Team	Genova (I)
5	22-04-2002	Group of specialists. Austria	Innsbruck (A)
6	02-05-2002	Group of specialists. United Kingdom + Ireland	London (UK)
7	08-05-2002	Steering Committee	Naples (I)
8	13/14-05-2002	Group of specialists. Italy + Austria + France + Germany	Maiori (I)
9	16-05-2002	Group of specialists. Belgium + Netherlands + Luxembourg	Maastricht (NL)
10	17-05-2002	Group of specialists. Portugal	Lisbon (P)
11	16-05-2002	Group of specialists. Sweden	Stockolm (S)
12	21-05-2002	Group of specialists. Greece	Athens (GR)
13	25-05-2002	Group of specialists. Spain	Madrid (E)
14	29/30-05-2002	Panel of Experts	Arona (I)
15	24/27-09-2002	Methodological Group (workshop)	Milan (I)
16	1-10-2002	Workshop of the project 'I Tumori in Italia'. Project related with EUROCHIP for italian aspects of the indicators	Rome (I)
17	3-10-2003	Working Team	Milan (I)
18	14/15-10-2002	Meetings with the members of the EUROCORE-EUROPREVAL Steering Committees	Lyon (F)
19	25-10-2003	Methodological Group	Rome (I)
20	03/08-11-2002	Meetings with the EUROCORE members about EUROCHIP indicators	Milan (I)
21	12/13-11-2002	Domain group of specialists. Cancer registration + epidemiology	Murcia (E)
22	20-11-2002	Domain group of specialists. Screening	Edinburgh (SCO)
23	21/22-11-2002	Domain group of specialists. Clinical aspects and treatment	Edinburgh (SCO)
24	5/6-12-2002	Domain group of specialists. Social and macro-economic variables	Paris (F)
25	12/13-12-2002	Domain group of specialists. Prevention	Amsterdam (NL)
26	21/22-01-2003	Methodological Group	Milan (I)
27	10/11-02-2003	Meetings with the members of EUROCORE/ENCR about EUROCHIP indicators	Lyon (F)
28	13-02-2003	Steering Committee	Milan (I)
29	4/7-03-2003	Meetings with the members of EUROCORE about EUROCHIP indicators	Milan (I)
30	7-03-2003	Meetings with the members of EUROCORE and ENCR about EUROCHIP indicators	Lyon (F)
31	13/14-03-2003	Panel of Experts	Maiori (I)
32	17/18-03-2003	Meetings with the members of EUROCORE and ENCR about EUROCHIP indicators	Lyon (F)
33	6/10-04-2003	Workshop of the project 'I tumori in italia'. Project related with eurochip for italian aspects of the indicators	Rome (I)
34	5/7-05-2003	Workshop of the project 'I tumori in italia'. Project related with eurochip for italian ASPECTS OF THE INDICATORS	Rome (I)

4.2 CONFERENCES

Table 3. Conferences in which the EUROCHIP project was or is presenting.

	DATE	ORGANIZATION	PLACE
1	19/22-3-2002	AIRT (Associazione Italiana Registri Tumori)	Trento (I)
2	27-28/06/2002	EUROCARE and ENCR (European Network Cancer Registration)	Tampere (FIN)
3	24-26/09/2002	AIE (Italian Association of Epidemiology)	Naples (I)
4	28/30-11-2002	EUPHA (European Public Health Association)	Dresden (D)
5	3/4-04-2003	AIRT (Associazione Italiana Registri Tumori)	Biella (I)
6	28/30-05-2003	Groupe pour l'epidemiologie et l'enregistrement du cancer dans le pays de langue latine	Havana (Cuba)
7	9/11-06/2003	NAACCR (North America Association of Central Cancer Registries)	Honolulu (US)
8	1/4-10-2003	SEE (Sociedad Española de Epidemiología)	Toledo (E)
9	21-10-2003	Surveillance epidemiologique des cancers: etat des lieux, enjeux et perspectives	Paris (F)
10	20/22-11-2003	EUPHA (European Public Health Association)	Rome (I)

4.3 WORKING PLAN

Table 4. Time-table showing the activity in the first period of the EUROCHIP project

DATE	WORK
Jan 2002	- The Steering Committee (SC) discusses the organisation of EUROCHIP, programmes the creation of a Panel of Experts, plans future steps and criteria for the compilation of the indicators' list
Feb 2002	- The Working Team contacts all designated members for the Panel of Experts. First Panel of Experts meeting takes place: specific aims of the project are commented.
Mar 2002	- A preliminary list of indicators is prepared from the available lists of the HMP projects and international data banks. - The Panel of Experts establishes 5 National Groups of Specialists. - The Working Team composes a preliminary form to be filled in with each indicator.
Apr 2002	- The Working Team includes fields to the preliminary form (i.e.: definition, meaning, use, caveat).
May 2002	- All the National Groups of Specialists are operative. During the meetings it is their task to discuss the preliminary list and assign to each indicator a priority-level from 0 (low priority) to 3 (high priority). New indicators are chosen to substitute some from the list. - The Panel of Experts presents the work of the Group of Specialists and applies a new rank for each indicator: from A (high priority) to E (indicator pertinent to other groups).
Jun 2002	- The Steering Committee plans future meetings. - The Working Team prepares the interim report. - The Panel of Experts indicates Specialists for the 5 cancer Domains Groups.
Jul 2002	- The Working Team organises future international meetings. - The Methodological Group starts its activity. - An updated list of indicators is presented on the web.
Sep 2002	- Second phase of EUROCHIP: 5 Domain Groups of Specialists are organised. The 5 Domain areas are: prevention, screening, cancer registration and epidemiology, social and macro-economic variables, treatment and clinical aspects. - The Methodological Group works on the indicators of the rank A and defines a methodological form to be filled in.
Oct 2002	- The descriptive and methodological forms of the indicators are dispensed to be filled in. - The Working Team organises future international meetings.
Nov 2002	- Domain Groups of Specialists Meetings take place.
Dec 2002	- Meetings of Remaining 2 Domain Group of Specialists are carried out. - The Working Team compares the results of EUROCHIP with those from other HMP.
Jan 2003	- The Methodological Group finalises its work also taking into account the new methodological problems suggested by the Domains Group of Specialists.
Feb 2003	- The Working Team organises the last Panel of Experts's meeting - The Steering Committee agrees on a publication plan and on the next steps after EUROCHIP-1
Mar 2003	- The list is completed by the Panel of Experts
Apr 2003	- The final list and all forms for each indicator are prepared for the final report - The list is presented at several cancer congresses and is being prepared for publication on specialised papers.

5. METHODS. THE FORM PROPOSED BY EUROCHIP TO DESCRIBE INDICATORS

The form is divided into three sections:

4. ***DESIRED INDICATOR***: with all characteristics of the indicators we wish to include in the list. Consequently, this section shall be filled in for each indicator.
5. ***METHODOLOGY***: including an operational definition of the indicators, information on possible sources and methodological issues.
6. ***AVAILABILITY***: showing availability in different countries.

Throughout the work, it is recommended that the two fields “*Code*” and “*Acronym*” are not modified.

All remaining fields can be modified, providing that “*Version*”, “*Date*” and “*By*” fields are updated.

The underlined fields allow for multiple answer.

In the following pages, the form is presented with a field description for all three sections.

Code
Priority
Group
Date
By

Name of indicator
Acronym
Rank

D
E
S
I
R
E
D

I
N
D
I
C
A
T
O
R

Cancer type
By cancer site Yes No

Relevance for Prevention Screening Diagnosis Treatment Surveillance End results

Category Demographic and socio-economic factors Health status Determinant of health Health system

Generic definition

Rationale

Utility

Caveat

Unit of measurement

Sex M F M and F separately M+F together Not collectable

By age class Yes No Not collectable

Modalities of classification

M
E
T
H
O
D
O
L
O
G
Y

Operational definition:

NUMERATOR:

DENOMINATOR:

How can we get the information?

NUMERATOR:

DENOMINATOR:

METHODOLOGICAL PROBLEMS

Data collection Y N
Quality check Y N
Standardization Y N
Available methods to estimate indicator Y N

A
V
A
I
L
A
B
I
L
I
T
Y

	By Nation	By Subnational areas	By Sex	By Age	By Temporal trends	Not collectable
Not requested / not collectable	<input type="checkbox"/>					
Austria	<input type="checkbox"/>					
Belgium	<input type="checkbox"/>					
Denmark	<input type="checkbox"/>					
Finland	<input type="checkbox"/>					
France	<input type="checkbox"/>					
Germany	<input type="checkbox"/>					
Greece	<input type="checkbox"/>					
Ireland	<input type="checkbox"/>					
Italy	<input type="checkbox"/>					
Luxembourg	<input type="checkbox"/>					
Netherlands	<input type="checkbox"/>					
Portugal	<input type="checkbox"/>					
Spain	<input type="checkbox"/>					
Sweden	<input type="checkbox"/>					
United Kingdom	<input type="checkbox"/>					

Databanks where indicator is available

References

Notes

5.1 “DESIRED INDICATOR” SECTION

FIELD	DESCRIPTION
<i>Code</i>	Identification number of indicator (in correspondence with the number present in the index list (Annex A)). NON MODIFIABLE
<i>Priority</i>	Priority (HIGH or MEDIUM) assigned by the Panel of Experts
<i>Group</i>	EUROCHIP group or other HMP project or other organization to which the indicator is referring
<i>Date</i>	Date of compilation of this version of the form
<i>By</i>	Name of the author/s or Group who compiles the form
<i>Name of indicator</i>	Name of the indicator
<i>Acronym</i>	Acronym of the indicator as given by the Working Team NON MODIFIABLE
<i>Rank</i>	Indicating the rank given to the indicator by Panel of Experts. “H1” means HIGH PRIORITY and EUROCHIP GROUP “H2” means HIGH PRIORITY and OTHER GROUP “M1” means MEDIUM PRIORITY and EUROCHIP GROUP “M2” means MEDIUM PRIORITY and OTHER GROUP
<i>Cancer type</i>	Cancer sites to which the indicator is referring.
<i>By cancer site</i>	Cancer site amongst these choices: <i>Yes</i> The indicator has to be collected by each cancer site indicated in the “Cancer type” field <i>No</i> The indicator has not to be collected by cancer site
<i>Relevance for</i>	Follows the natural disease history: <i>Prevention, Screening, Diagnosis, Treatment, Surveillance, End results.</i>
<i>Category</i>	Follows categories proposed by ECHI project: <i>Demographic and socio-economics factors, Health Status, Determinant of health and Health System</i>
<i>Generic definition</i>	Generic and non operational description of the indicator. Formal and concise statement aimed to introduce the indicator that is being dealt with
<i>Rationale</i>	Purpose of indicator. What is the aim of this indicator?
<i>Utility</i>	Possible area of application for the indicator
<i>Caveat</i>	Any possible problem that could arise in relation to the indicator
<i>Unit of measurement</i>	Synthesized unit of measurement
<i>Sex</i>	Sex classification amongst these choices: <i>M</i> Indicator for males only <i>F</i> Indicator for females only <i>M and F separately</i> Indicator for males and females separately <i>M+F together</i> Indicator without sex distinction <i>Not collectable</i> Sex classification is not possible
<i>By age class</i>	Age grouping amongst these choices: <i>Yes</i> Indicator needs age grouping <i>No</i> Indicator does not need age grouping <i>Not collectable</i> Age grouping is not possible
<i>Modalities of classification</i>	Modalities (other than age and sex) by which data should be collected

5.2 “METHODOLOGY” SECTION

FIELD	DESCRIPTION
<i>Operational definition</i>	Formula for calculating the indicator with distinction between numerator and denominator quantities
<i>How can we get the information?</i>	Sources where data can possibly be found the for the numerator and the denominator of the operational definition
<i>Methodological problems</i>	Methodological problems on: <ul style="list-style-type: none"> <i>Data collection</i> Are there any data collection problems that have not yet been solved? (Y/N) <i>Quality check</i> Are there any quality check problems that have not yet been solved? (Y/N) <i>Standardization</i> Are there any standardization problems that have not yet been solved? (Y/N) <i>Available methods</i> Are there any available methods to estimate the indicator? (Y/N)

5.3 “AVAILABILITY” SECTION

FIELD	DESCRIPTION
<i>Availability</i> * MANDATORY	To assess if the indicator is available at national (<i>By nation column*</i>) and/or subnational level (<i>By subnational areas column</i>) and weather the data are also available <i>by sex, age and temporal trends</i> .
<i>Databanks where indicator is available</i>	Addressesto the databanks where information is already present at national level
<i>References</i>	References useful for describing the indicator and its availability
<i>Notes</i>	In this field any type of problem can be raised.

6. RESULTS. THE LIST OF HEALTH INDICATORS FOR CANCER PROPOSED BY EUROCHIP

The discussion on the list of indicators was organized mainly following the natural history of the disease, with specific cancer sites used as a proxy of particular phases of the disease and the type of factor proposed by the ECHI project.

The indicators are proposed by the following three axes of classification:

1. Major axis of classification: the natural history of cancer
 - a. Prevention domain: Causes & Risk factors, Preclinical disease
 - b. Occurrence domain: Symptoms-Diagnosis-Treatment
 - c. Outcome domain: Clinical follow-up, Recurrences, Rescue treatments, Palliation, Death

2. Axis correspondent to the recommended ECHI classification of health indicators:
 - a. Demographic and socio-economic factors
 - b. Health determinants
 - c. Morbidity/general health status/mortality
 - d. Health system performance, health care resources
 - e. Health expenditure

3. The other axis is the type of cancer for which indicators are required:
 - a. **All cancers combined without non melanoma skin cancers** for relevance with
 - cancer burden and cancer trends
 - total cost of cancer care
 - incidence and mortality
 - b. **Major cancers**
 - **Lung** for relevance with prevention (tobacco smoking (very limited for asbestos)) and preventable deaths estimation
 - **Breast** for relevance with monitoring screening programmes (mortality and incidence) and to evaluate care (tamoxifen)
 - **Colorectal** for relevance with evaluation of early diagnosis (and screening programmes) and care, and for diagnosis delay
 - **Prostate** for relevance with future cancer burden trends and future resources utilization
 - c. Other major cancers
 - **Stomach** for relevance with monitoring the decreasing trends (ethnic-nationality differences)
 - **Head and neck-larynx, oropharynx** (specifying ICD-9 code) for relevance with prevention and care, treatment for organ preservation and quality of life
 - **Melanoma** for relevance with prevention (early diagnosis-stage migration)

d. Other cancers

- **Kaposi** as sentinel cancer
- **Mesothelioma** as sentinel cancer
- **Testis** for relevance with treatment
- **Haematopoietic malignancies: Lymphomas** for relevance with treatment and health services (H-), for trends (NH-) and for treatment (Leukaemia)
- **All childhood tumors (0-14 years)** for relevance with surveillance. We have to choose the sites particularly related with treatment and burden.
- **Cervix** for relevance with screening. We need information on incidence and mortality (Note: corpus vs cervix uteri misclassification)

Classes *a* and *b* are at high priority.

For a description of each indicator present in the following lists: See Annex A.

Table 5. List of indicators proposed by EUROCHIP. By domain.

1Pr ^a PREVENTION	2Ep ^a EPIDEMIOLOGY & CANCER REGISTRATION	3Sc ^a SCREENING	4Tr ^a TREATMENT & CLINICAL ASPECTS	5Mv ^a MACRO SOCIAL AND ECONOMIC VARIABLES
<p><u>Lifestyle</u></p> <p>01. Consumption of fruit and vegetables *</p> <p>02. Consumption of alcohol *</p> <p>03. Body Mass Index distribution in the population *</p> <p>04. Physical activity *</p> <p>05. Tobacco survey *: prevalence of</p> <p>a. tobacco smokers among adults</p> <p>b. tobacco smokers among 10-14 year olds</p> <p>c. ex-smokers</p> <p><u>Environment & Occupational risk</u></p> <p>d. exposure to environmental tobacco smoke (ETS)</p> <p>06. Exposure to sun radiation</p> <p>07. PM10 (particulate matter = 10μ³) emissions *</p> <p>08. Indoor exposure to radon</p> <p>09. Prevalence of occupational exposure to carcinogens</p> <p>10. Exposure to asbestos: mesothelioma incidence and mortality trends</p> <p><u>Medicaments</u></p> <p>11. Prevalence of use of hormonal replacement treatment drugs *</p>	<p>1. Population covered by high quality Cancer Registries</p> <p>2. Cancer incidence rates, trends and projections *</p> <p>3. Cancer relative survival rates, trends and projections *</p> <p>4. Cancer prevalence proportions, trends and projections *</p> <p>5. Cancer mortality rates, trends, projections and person-years of life lost due to cancer *</p> <p>6. Stage at diagnosis: percentage of</p> <p>a. cases with early diagnosis</p> <p>b. cases with a metastatic test</p>	<p><u>Screening examinations</u></p> <p>1. Percentage of women that have undergone a mammography (breast cancer)</p> <p>2. Percentage of women that have undergone a cervical citology examination (cervical cancer)</p> <p>3. Percentage of persons that have undergone a colo-rectal cancer screening test</p> <p><u>National evaluation in HMP of organized mass screening process indicators</u></p> <p>4a. Organized screening coverage</p> <p>4b. Screening recall rate</p> <p>4c. Screening detection rate</p> <p>4d. Screening localized cancers</p> <p>4e. Screening positive predictive value</p> <p>4f. Screening benign/malignant biopsy ratio</p> <p>4g. Screening interval cancers</p> <p>4h. Screening specificity</p>	<p><u>Health system delay</u></p> <p>1. Delay of cancer treatment (pilot studies)</p> <p><u>Resources</u></p> <p>2. Percentage of radiation systems in the population</p> <p>3. Percentage of diagnostic Computed Axial Tomographies (CTs) in the population</p> <p>4. Percentage of Positron Emission Tomographies (PETs) on population (for future)</p> <p>5. Percentage of magnetic resonances on population (for future)</p> <p><u>Treatment</u></p> <p>6. Compliance with best oncology practice</p> <p><u>Palliative care</u></p> <p>7. Use of morphine in cancer patients</p> <p>8. Percentage of patients receiving palliative radiotherapy</p>	<p><u>Social indicators</u></p> <p>01. Educational level attained *</p> <p>02. Income by decile *</p> <p>03. Gini's index *</p> <p><u>Macro economic indicators</u></p> <p>04. Gross Domestic Product *</p> <p>05. Total Social Expenditure *</p> <p>06. Total National Expenditure on Health *</p> <p>07. Total Public Expenditure on Health *</p> <p>08. Anti-tobacco regulations</p> <p>09a. Public expenditure for cancer prevention on anti-tobacco activity</p> <p>09b. Total expenditure for population-based cancer registries</p> <p>09c. Total expenditure on organized cancer screening programmes</p> <p>09d. Public expenditure on cancer drugs *</p> <p>09e. Total expenditure on cancer research</p> <p>09f. Estimated cost for a cancer patient</p> <p><u>Demographic indicators</u></p> <p>10. Age distribution in 2010, 2020 and 2030 *</p> <p>11. Life-table quantities *</p>

Notes:

^a Domain code

* Connected with other HMP projects

In **bold** indicators at high priority

Each indicator is identified by an internal code formed by "Domain code.Indicator Number"

Table 6. List of indicators proposed by EUROCHIP. By priority, source and implementation cost.

		HIGH PRIORITY	MEDIUM PRIORITY
LOW COSTS or NO NEW COSTS	Indicators already available	Population covered by high quality Cancer Registry Cancer incidence rates, trends and projections * Cancer survival rates, trends and projections * Cancer prevalence proportions, trends and projections * Cancer mortality rates, trends, projections and person-years life lost due to cancer * Gross Domestic Product * Total Public Expenditure on Health *	Exposure to asbestos: mesothelioma incidence and mortality trends Education level attained * Income by decile * Gini's index * Total Social Expenditure * Total National Expenditure on Health * Age distribution in 2010-20-30 * Life-table quantities *
	Sources already available	Organized screening coverage Anti-tobacco regulations	National evaluation in HMP of the organized screening process indicators Screening recall rate, Screening detection rate, Screening localized cancers, Screening positive predictive value, Screening benign/malignant biopsy ratio, Screening interval cancers, Screening specificity
MEDIUM COSTS	Databank updates	Prevalence of occupational exposure to carcinogens	PM10 (particulate matter = 10 μ^3) emissions *
	Surveys	Health survey Consumption of fruit and vegetables * Consumption of alcohol * Body Mass Index distribution in the population * Physical activity * Tobacco survey *: prevalence of current tobacco smokers among adults, prevalence of tobacco smokers among 10-14 year olds, prevalence of ex-smokers, prevalence of exposure to environmental tobacco smoke (ETS) Exposure to sun radiation Percentage of women that have undergone a mammography (breast cancer) Percentage of women that have undergone a cervical cytology examination (cervical cancer) Percentage of persons that have undergone a colo-rectal cancer screening test Other surveys Percentage of radiation systems on population Percentage of diagnostic Computed Axial Tomographies (CTs) on population Proportion of patients treated with palliative radiotherapy Estimated cost for a cancer patient	Other surveys Prevalence of use of hormonal replacement treatment drugs * Percentage of Positron Emission Tomographies (PET) on population (for future) Percentage of magnetic resonances on population (for future) Use of morphine in cancer patients Public expenditure for cancer prevention on anti-tobacco activity Total expenditure for population-based Cancer Registries Total expenditure on organized cancer screening programmes Public Expenditure on cancer drugs * Total expenditure on cancer research
HIGH COST	CRs	Stage at diagnosis: percentage of cases with early diagnosis and with a metastatic test Delay of cancer treatment: pilot studies Compliance with best oncology practice	
	Other		Indoor exposure to radon

* Connected with other HMP projects

7. RESULTS. EUROCHIP POSTERS AND COMMUNICATIONS

- Micheli A, Capocaccia R, Martinez C, Mugno E, Coebergh JW, Baili P, Verdecchia A, Berrino F, Coleman M. *Cancer control in Europe. A proposed set of European Cancer Health Indicators*. European Journal of Public Health 2003; 13 (supplement): 1x-1x
- Micheli A, Navarro C, Baili P, Martinez C, Cherie-Challine L, Garau I, Gatta G, Izarzugaza I, Moeller T, Oberaigner W, Paci E, Sankila R, Tyczynski J, Velten M, Chirlaque MD. *The EUROCHIP Project: in Murcia to define indicators for the future of the cancer epidemiology*. LAS CLARAS. Cuadernos del centro cultural Las Claras. Fundacion Cajamurcia. N° 5 Febrero 2003
- Micheli A, Baili P, Quaglia A, Paci E, Ponti A, Marinacci C, Mugno E, Amati C, Massimiliani E, Bianchi N, Cifalà A, Lenz H, Terracini B. *EUROCHIP: un progetto per lo studio del cancro nelle popolazioni europee*. Atti della 7° Riunione dell'Associazione Italiana Registri Tumori (AIRT) – Biella, 3-4 april 2003 – Oral presentation
- Micheli A, Coleman M, Baili P, Mugno E, Capocaccia R, Verdecchia A, Martinez C, Berrino F, Coebergh JW. *EUROCHIP: New European indicators describing cancer*. Final Program & Abstracts of the Annual meeting and workshops of the North American Association of Central Cancer Registries (NAACCR) – Honolulu, 7-14 June 2003 - Poster

8. FUTURE. EUROCHIP-2 THE ACTION

EUROCHIP-2 is a proposal for a Europe-wide multidisciplinary multi-annual project which aims to define an organisational and logical model that will effectively fight inequalities in cancer, in Europe. It aims to improve access to and organisation of information and knowledge on cancer in all European countries. In doing so, it will add value to each individual country allowing comparison with Europe as a whole and forming a basis for political action on health. Starting point of the project is the network established by EUROCHIP-1; it is our aim, however, to improve and enlarge this network, also involving other cancer networks.

8.1 A NEW PROJECT: EUROCHIP-2 FOR ACTION

EUROCHIP-2 aims to improve access, organisation and integration of information and knowledge on cancer for all EU countries in order to take more a effective action.

Specific aims of EUROCHIP-2 are:

- ◆ To maintain and extend the system of cancer networks created within the EUROCHIP-1 project into a larger network involving all 25 European countries, new health institutions and other chronic disease networks.
- ◆ To liase with sources of cancer data (e.g. CR networks, the EURO CARE-high resolution study network, EUROSTAT, the HIS/HES system, other networks involved with smoking, vegetable and fruit consumption etc) to induce these primary fonts to standardise their information collection, presentation and quality control procedures as recommended by EUROCHIP, CAMON and ECHI-2.
- ◆ To encourage the setting-up of data collection in areas where information is unavailable.
- ◆ In collaboration with ECHI-2, to improve existing European data-banks with cancer information.
- ◆ To check quality and standardisation of cancer data already available and data becoming available during the project.
- ◆ To analyse the behaviour of various indicators in relation to their utility as determinants of clinical outcomes, possibly leading to modifications.
- ◆ To integrate cancer information with information on other chronic diseases.
- ◆ To identify deficiencies in European health systems.
- ◆ To encourage action based on EUROCHIP-2 findings to reduce inequalities in cancer surveillance and control.
- ◆ To make available EUROCHIP-2 findings to the European health portal.

EUROCHIP-2 shall:

- Produce results at two levels: for European Union as a whole and for individual countries.
- Focus on problems and inadequacies of individual countries in order to suggest policy changes at country level. Meanwhile, action to improve data quality and standardisation, will be taken.
- Organise activity in a process of continuous re-evaluation, i.e.: taking a global view of the information system, involving promotion of data collection on one hand, and analysis of already available data and evaluation promoting political action on established inequalities on the other hand.

8.2 METHODS

The methods of EUROCHIP-2 will build on those ones that proved successful with the current study of EUROCHIP. Two important aspects of the method of EUROCHIP-2 are organisation and execution.

8.2.1 ORGANISATION

The organisation created for EUROCHIP-1 will be maintained and expanded. EUROCHIP-2 will therefore be consisting in: (a) an International Steering Committee with a co-ordinating role, (b) a Working Group on analyses and reports; (c) a National Specialist Group in each country dealing with national issues and including professionals involved in cancer (e.g.: medical oncologists, radiotherapists, surgeons, epidemiologists, economists, sociologists, health planners etc.); (d) a Domain Specialist Group operating at European level dealing on different aspects of cancer (i.e.: prevention, registration and epidemiology, screening, treatment, and social and economic determinants); (e) a Methodology Group examining problems relating collection, standardisation, and validation of data; and (f) a Panel of Experts, responsible for the International strategy of EUROCHIP-2 and for all operational decisions. The Panel of Experts will include delegates from each National Specialist Group, Domain Specialist Group, Methodology Group, and all major networks and institutions directly or indirectly involved in cancer (e.g. IARC, OECD, ANCR, EUROCARE, EUROPREVAL, EBCN).

The Panel of Experts will decide the strategy of EUROCHIP-2 in co-ordination with other international groups concerned with health surveillance; it will follow recommendations from ECHI-2, and will work in co-operation with networks from other chronic diseases.

8.2.2 APPLICATION

The results of EUROCHIP-1 will create the basis for the application of EUROCHIP-2; the classification of ECHI-2 and other groups that study chronic diseases be also be taken into account. The ongoing process for each indicator involves the following phases:

- Phase 1: Identification of sources of data pertaining to health indicators. Verify that data are collected as indicated by EUROCHIP-1.
- Phase 2: Collection, validation, standardisation of data and unification in a single database.
- Phase 3: Analysis of data from the unified database pertaining to a given health indicator in relation to other factors.
- Phase 4: Identification of problems at international and national level (e.g. general health inequalities and those pertaining to access and availability).
- Phase 5: Assessment of health indicators' impact on the promotion of effective political action.

The concrete application of EUROCHIP-2 can be described by “modular” and “process” approaches which can be represented on three axes. The first axis would correspond each time one of EUROCHIP's cancer health indicators, the second axis stands for all countries involved in the study, and the third axis refers to the various phases of application of the process for that indicator. For the given health indicator, EUROCHIP-2 may be promoting a certain phase (or phases) of the process in certain countries, while in other countries it may be promoting another phase (or phases). The “module” may therefore vary for each indicator. EUROCHIP-2 could act directly and promote a phase, or co-operate with other networks or cancer data bodies to execute a given phase.

With “Incidence”, for instance, phases may vary markedly from one country to another, as follows: (a), where the population is fully covered by cancer registration and cancer incidence is available phases 4 and 5 would be promoted. (b) where only a limited portion of the population is covered by cancer registration, steps to implement national registration would be encouraged – so phases 3, 4 and 5 would be promoted. For a country (c) with no cancer registration and with no available accurate incidence data, phase 1 would be activated.

This apparently complex procedure of application reflects the significant diversity among European countries with respect to the implementation of the structures for cancer control. It also allows us to add value to each country and to all countries together.

What we refer to as “process” is the simultaneous vision of all phases. Only by a simultaneous approach can one assess the validity of each indicators at all stages of their application and, from learned experience, enforce changes in the module in correspondence to those countries where earlier phases are being implemented.

All participating countries will be thereby able to benefit both from the data comparison and the experience of other countries. In EUROCHIP-2 it is our aim to involve as many countries as possible.

8.3 CONCLUSIONS

The beginning of EUROCHIP-2 could be set from July 2003, in coincidence with the end of EUROCHIP-1. An application for funds for the project has been presented for the European Union Public Health's "Call for proposals 2003". The application stresses the general proposals of the present paper, within the budgetary limits of the Call. It is our intention to apply for an international three-year multidisciplinary finance. We emphasise that EUROCHIP-2 focuses on fighting inequalities in cancer. Its aim is to improve information and knowledge on cancer. It will add value to each country's and all Europe's action through data comparison. The starting point is EUROCHIP-1 network and it will improve and enlarge this network of cancer networks by including both Member and Candidate Member States. The international group of experts engaged by EUROCHIP-2 will liaise with networks, international agencies, institutions, ministries of health and medical association to promote action, collect and analyse data, and disseminate results. EUROCHIP-2's final goal is to encourage the transition between the acquisition of new knowledge on cancer and the implementation of new therapies and other initiatives.

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