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EUROCHIP

European Cancer Health Indicator Project

INTERIM REPORT
ON THE FIRST PHASE OF EUROCHIP
01/08/2002

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1. PRESENTATION OF THE CURRENT REPORT

The chapter ‘Summary and introduction’ provides the main information about the project.

The present report also explains in detail:

- The organisational aspects of the project (see the Annex 1 for information on participants);
- The activity schedule of each EUROCHIP group in the first phase of the project;
- First result: The form. We have prepared a form to be filled to explain the indicators. An annex specifies the meaning of each field. The form has been prepared by the Access program and it is now available on the web;
- Second result: the actual list of indicators;
- Annexes 2-6 reports several contributions from participants:
 - Annex 2. Report of the Group of Specialists from the UK and Ireland.
 - Annex 3. Report of the Group of Specialists from Greece.
 - Annex 4. Report of the Group of Specialists from Austria.
 - Annex 5. Report of the Group of Specialists from Denmark.
 - Annex 6. A contribution by Dr. Mike Richards (UK). Questions and Priorities

2. SUMMARY AND INTRODUCTION

2.1 AIM

The European Cancer Health Indicator Project (EUROCHIP) is one of the projects funded by the European Commission for the Health Monitoring Program (HMP). EUROCHIP is aimed to develop a comprehensive list of health indicators on cancer according to the agreement of numerous European cancer experts. The list will include variables on the prevalence of risk factors, 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 will include both variables already proposed from other HMP projects (a connection between EUROCHIP and these projects will be promoted) and new variables specific for cancer not yet suggested from the HMP projects.

2.2 THE ORGANISATION

A complex organisation was created to develop the list and achieve the maximum consensus among experts and institutions involved in cancer in Europe. This organisation is composed by various groups with different roles.

- **STEERING COMMITTEE (5 persons):** has a decisional role on the many aspects of the project
- **PANEL OF EXPERTS (21 persons):** includes one expert for each EU member, and some experts from cancer institutions and the major European cancer networks (IARC, Breast network, Cervix Network, EUROCORE, EUROPREVAL, NCI, OECD, ENCR, and IARC). PE has the main role to discuss and prepare the list and to organise the national groups of specialists.
- **NATIONAL GROUPS OF SPECIALISTS:** are set up by the members of the “Panel of Experts” and they include members at national level. They have the role to discuss the indicators from the national point of view.
- **DOMAIN GROUPS OF SPECIALISTS:** are organised at the European level with European specialists in five major cancer domains (prevention, screening, data registration and epidemiology, macro-health variables, and clinical aspects and treatment).
- **METHODOLOGICAL GROUP:** concerned with methodological aspects related to the indicators included in the list.
- **WORKING TEAM (5 persons):** supports the work of other groups from organisational point of view.

The final aim of the entire organisation is to suggest health indicators (with a maximum consensus) and explain the meaning of and reason why each indicator is necessary, throughout an iterative method. A preliminary list was prepared, commented and modified, producing a second list, that substitutes the first one. The second list was considered for a second step of discussion and so on.

2.3 RESULTS

This first part of the project was dedicated:

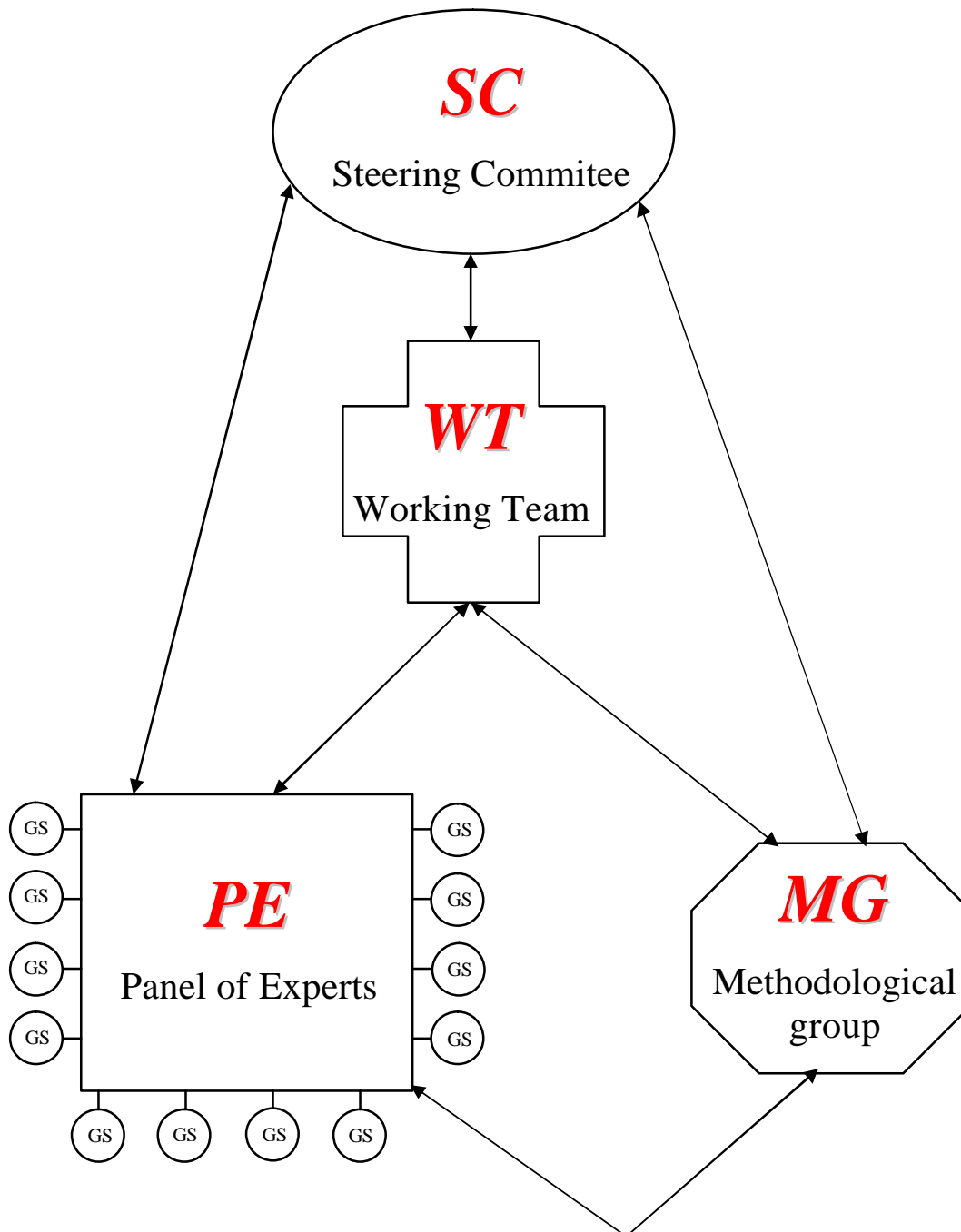
1. To contact and co-ordinate people involved in different fields from different countries to develop the complex organisation of the project. Up to now 102 persons from all the European countries have been directly involved in the project.
2. To organise several meetings in Europe: 3 meetings of the Steering Committee, 2 meetings of the Panel of Experts and 8 meetings of the Groups of Specialists.
3. To create an agreed form to describe the indicators. This form has been already used.
4. To develop a preliminary list of indicators and organise the first step of discussions on it. 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, according to the suggestions coming from the Groups of Specialists, provided a second list of only 101 indicators (during the process 54 indicators have been eliminated). Among these 101 indicators, 31 resulted already studied from other HMP projects and 16 were new indicators at high priority, not studied yet.
5. To organise a web-site where the EUROCHIP material is presented (www.istitutotumori.mi.it/project/eurochip/homepage.htm). A mailing list has been also carried on. In this way people have the opportunity to comment the list.

Next steps of the project are:

- a) To fill the form of each indicator providing the operational definition and proposals regarding methodological problems. We will start from the indicators at the highest priority.
- b) To discuss the list with the groups of specialists from the 5 domains at the European level.
- c) To present the list at the national and international congresses on cancer and on scientific journals in order to improve the consensus on the indicators.

3. FRAMEWORK OF THE PROJECT AND ROLES OF THE GROUPS

This following framework illustrates the structure of the organisation of EUROCHIP. In the next page the roles of these groups are presented.



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

3.1 ROLES OF GROUPS

SC: STEERING COMMITTEE

1. Select members of 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 not yet considered

For the participants of each group see Annex 1.

4. SCHEDULE OF THE ACTIVITY

Table 1 presents the schedule of the meetings carried out during the first part of the project. Table 2 shows the schedule of the meetings during the following months. Table 3 gives the working plan for this first period.

4.1 MEETINGS

Table 1. Meetings already hold.

	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	22-04-2002	GROUP OF SPECIALISTS. AUSTRIA	Innsbruck (A)
5	02-05-2002	GROUP OF SPECIALISTS. UNITED KINGDOM + IRELAND	London (UK)
6	08-05-2002	STEERING COMMITTEE	Naples (I)
7	13/14-05-2002	GROUP OF SPECIALISTS ITALY + AUSTRIA + FRANCE + GERMANY	Maiori (I)
8	16-05-2002	GROUP OF SPECIALISTS BELGIUM + NETHERLANDS + LUXEMBOURG	Maastricht (NL)
9	17-05-2002	GROUP OF SPECIALISTS. PORTUGAL	Lisbon (P)
10	16-05-2002	GROUP OF SPECIALISTS. SWEDEN	Stockolm (S)
11	21-05-2002	GROUP OF SPECIALISTS. GREECE	Athens (GR)
12	25-05-2002	GROUP OF SPECIALISTS. SPAIN	Madrid (E)
13	29/30-05-2002	PANEL OF EXPERTS	Arona (I)

Table 2. Meetings to be held.

	DATE	GROUP	PROBABLE PLACE
1	Sept 2002	METHODOLOGICAL GROUP	Milan (I)
2	Oct – Nov 2002	DOMAIN GROUP OF SPECIALISTS CANCER REGISTRATION + EPIDEMIOLOGY	Murcia (E)
3	Oct – Nov 2002	DOMAIN GROUP OF SPECIALISTS PREVENTION	Amsterdam (NL)
4	Oct – Nov 2002	DOMAIN GROUP OF SPECIALISTS SCREENING	Athens (GR)
5	Oct – Nov 2002	DOMAIN GROUP OF SPECIALISTS CLINIC AND TREATMENT	Edinburgh (SCO)
6	Oct – Nov 2002	DOMAIN GROUP OF SPECIALISTS MACRO-HEALTH VARIABLES	Paris (F)
7	Nov 2002	PANEL OF EXPERTS	Sicily (I)
8	Dec 2002	METHODOLOGICAL GROUP	
9	Jan 2003	ALL PARTICIPANTS	

4.2 WORKING PLAN

Table 3. Time-table showing the activity in the first period of the EUROCHIP project

DATE	WORK
Jan 2002	- The Steering Committee (SC) starts his work. SC discusses the EUROCHIP organisation, it composes the Panel of Experts and plans the future steps of the EUROCHIP work and the criteria for the composition of the list of indicators
Feb 2002	- The Working Team contacts the members of the Panel of Experts. In the first Panel of Experts meeting specific aims of the project are commented.
Mar 2002	- A preliminary list of indicators is ready (it is composed by the available lists of the HMP projects and international data banks). - The Panel of Experts members start to organise National Groups of Specialists. - The Working Team composes a preliminary form.
Apr 2002	- The Working Team specifies characteristics (definition, meaning, use, caveat) for each indicators in the preliminary form.
May 2002	- All the National Groups of Specialists are operative. During the meetings their task is discussing the preliminary list and assign a priority-level from 0 (low priority) to 3 (high priority) to each indicator. New indicators are chosen to substitute some indicators present in 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 the future meetings. - The Working Team works on the present interim report. - The Panel of Experts indicates Specialists for the 5 cancer Domains Groups.
Jul 2002	- The Working Team organises the future international meetings. - The Methodological Group starts its activity. - The actual list of indicators is presented on the web.
Sep 2002	- The second phase of EUROCHIP will start: 5 Domain Groups of Specialists will select the best indicators for each domain. The 5 Domain areas will be: prevention, screening, cancer registration and epidemiology, macro-health variables, clinic and treatment. - The Methodological Group will work on the indicators of the rank A. - The Working Team will compare the results of EUROCHIP with those from other HMP. - The list will be presented during the congresses about cancer and published on specialised papers.
Oct-Nov 2002	- The task of the 5 Domain Groups of Specialists will be: providing operational definitions of the indicators and identifying methodological problems. The list and the range will be discussed anyway. - The forms of the indicators will be dispensed to be filled in. The results obtained will be discussed.
Dec 2002	- The Methodological Group will work on new methodological problems as suggested by the Group of Specialists. - The list will be going to be completed.

5. THE FORM PROPOSED BY EUROCHIP TO DESCRIBE INDICATORS

The form is divided into three sections:

1. **DESIRED INDICATOR**: including all characteristics of indicators we wish to have. Consequently, this section shall be filled for each indicator.
2. **METHODOLOGY**: including the operational definition of the indicator we wish to have, information on possible sources and methodological issues.
3. **AVAILABILITY**: including information on the availability in different countries.

Two fields are not modifiable: *Code* and *Acronym*.

The other fields are all modifiable providing that fields *Version*, *Date* and *By* are updated.

The fields underlined are with multiple reply.

In the following pages the form is presented with the description of all fields by the three sections.

Code
Version
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

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
NUMERATOR:

Operational definition:
DENOMINATOR:

How can we get the
NUMERATOR:

DENOMINATOR:

REQUESTS TO METHODOLOGICAL GROUP OI

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

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

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

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>Version</i>	Number of version of the form given by the group in the field “BY”
<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 OPEN TO MODIFICATION
<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 the Group in the field “BY”. The final rank will be agreed on by the Panel of Experts
<i>Cancer type</i>	Follows the 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>	Synthesised 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 we can possibly find the data for the numerator and the denominator of the operational definition								
<i>Requests to methodological group on</i>	Questions for the Methodological Group: <table style="width: 100%; border: none;"> <tr> <td style="padding-left: 20px;"><i>Data collection</i></td> <td>Are there any data collection problems that have not yet been solved? (Y/N)</td> </tr> <tr> <td style="padding-left: 20px;"><i>Quality check</i></td> <td>Are there any quality check problems that have not yet been solved? (Y/N)</td> </tr> <tr> <td style="padding-left: 20px;"><i>Standardization</i></td> <td>Are there any standardization problems that have not yet been solved? (Y/N)</td> </tr> <tr> <td style="padding-left: 20px;"><i>Available methods</i></td> <td>Are there any available methods to estimate the indicator? (Y/N)</td> </tr> </table>	<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)
<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 whether the indicator is available at national (<i>By nation</i> column*) and/or subnational level (<i>By subnational areas</i> column) and whether the data are also available <i>by sex, age</i> and <i>temporal trends</i> . The various national sources will be mentioned in an appendix in correspondence to each indicator available
<i>Databanks where indicator is available</i>	Indication of the databanks where information is already present at national level
<i>References</i>	References useful for describing the indicator
<i>Notes</i>	In this field any type of problem can be raised by the BY field authors

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

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 expenditures

3. The other axis is the Type of cancer for which indicators are required:
 - a. All cancers combined
 - b. Major cancers (in terms of incidence or prevalence):
 - Lung
 - Breast
 - Colorectal
 - Prostate
 - Stomach
 - Head and neck (especially relevant for Southern Europe)
 - Melanoma
 - c. Sentinel cancers:
 - Kaposi
 - Mesothelioma (for etiology)
 - Testis
 - Hodgkin
 - ALL childhood cancers (for treatment)
 - Cervix (for etiology and early diagnosis)

In the *Table 4* of the 6.1 chapter the list of indicators is presented with the priority rank as given by National Group of Specialists. Ranks are as follows:

3	Most important	1	Low priority
2	Second priority	0	Not supported for use as an indicator

In the last column of *Table 4* the ranks given by the Panel of Experts (PE) are presented. The Panel of Experts applied the following ranking:

A	Direct indicator – Important – With or without any problem	C	Potentially useful but with presenting a great deal of problems
B	Indirect indicator – Important – With or without any problem	D	Very low priority – Irrelevant
E	Already available by other groups	Code	The indicator is inserted in the indicator with this <i>code</i>

In *Tables 5.a-5.g* the indicators are grouped by Panel of Experts ranking and attributed to the 5 Domains of Groups of Specialists.

6.1 TABLE OF INDICATORS

Table 4. List of indicators with suggestions from Group of Specialists and Panel of Experts.

Table 4	UK+IRE	I+A+F+D	BENELUX	SWEDEN	PORTUGAL	GREECE	SPAIN	PE
1. Prevention domain: Prevalence of major estimates								
1.01. Tobacco								
1.01.1. Adult daily smokers	3	3	0	3	3	2	3	A
1.01.2. Childhood daily smokers	3	3	0		3	2	2	1.01.1
1.01.2a Routine surveys on childhood smoking						3		1.01.1
1.01.3. Tobacco sales	1	2	0	2	2	3	2	B
1.01.4. Tobacco price	1-2	2	0	1-2	1	3	1	B
1.01.5. Anti-tobacco advertising	0	0	0	1	0	0	0	1.01.6
1.01.5a Money spent on anti-tobacco-advertising			0			2		1.01.6
1.01.6. Tobacco legislation on smoking prohibition in public places	2	2	0	1-2	1	1-2	1	B
1.01.7. Smoking cessation services	2	2	0			1-2	1	1.01.6
1.01.8. Age starting smoking							3	1.01.1
1.01.9. Ex-smokers							3	1.01.1
1.02. Dietary factors								
1.02.1. Daily consumption of Fruit & Vegetables	3	3	0	2	2	3	3	A and E
1.02.2. Daily consumption of Vegetable Fibre	0	0	0	1	1	0	0	C and E
1.02.3. Daily consumption of Meat	1	1	0	1	1	1	1	C and E
1.02.4. Daily consumption of Processed meat	0	0	0	1	0	0	1	C and E
1.02.5. Daily consumption of Alcohol	3	3	0	2-3	3	2	3	A and E
1.02.6. Sales of organic produce						2		D
1.02.7. Indirect indicators								
1.02.7.1. Diabetes mortality	0	0	0	2-3	0	1	0	D
1.02.7.2. Alcoholic cirrhosis mortality	0	0	0	2-3	0	1	1	D
1.03. Weight Profiles								
1.03.1. BMI	2	3	0	2-3	3	2	3	A and E
1.04. Physical activity								
1.04.1. Active vs sedentary occupations	0	0	0	1	0	0	0	E
1.04.2. Indicator of physical fitness	2		0			2		E
1.04.3. Physical activity at work							2	E
1.04.4. Physical activity at leisure time							2	E
1.05. Air pollutants								
1.05.1. Determinants								
1.05.1.1. Vehicle density	0	0	0	1	0	0	0	D
1.05.1.2. Industrial density	0	0	0	1	0	0	0	D
1.05.2. Actual measurements								
1.05.2.1. PM10 emissions	1	2	0	1	1	1	2	B and E
1.05.2.2. NO2 emissions	0	0	0	1	0	1	0	D
1.05.2.3. SO2 emissions	0	0	0	1	0	1	0	D
1.05.2.4. O3 emissions	0	0	0	1	0	1	0	D
1.05.2.5. PAH Emissions						2		D
1.05.3. Effects								
1.05.3.1. Prevalence of asthmatic disease	0	0	0	1	0	0	0	D
1.05.4. Radon exposure in households	1-2	2	0			1	0	C
1.05.5. Radiation exposure						2		D
1.05.6. Electromagnetic field exposure						2		D

Table 4	UK+IRE	I+A+F+D	BENELUX	SWEDEN	PORTUGAL	GREECE	SPAIN	PE
1.06. Occupational risks								
1.06.1. Prevalence of exposure to carcinogenic chemicals such as								
1.06.1.1. Exposure to asbestos	2	2	0	1	3	2	2	A
1.06.1.2. Exposure to polycyclic aromatic hydrocarbons	0	0	0	1	1		0	C
1.06.1.3. Exposure to solvents	0	0	0	1	0	1	0	D
1.06.1.4. R47 characterisation of substances responsible for carcinogenic effects						2		D
1.07. Infections								
1.07.1. Seroprevalence of Hepatitis B/C	1-2	2	0	2	2	1	1	A and E
1.07.2. Seroprevalence of HPV	1-2	0	0	2	2	1	0	C and E
1.07.3. Seroprevalence of HIV	1-2		0	2	1	1	0	A and E
1.08. Reproductive factors								
1.08.1. Fertility	0	1	0		0	1	0	D
1.08.2. Age at first pregnancy	1	1	0	2-3	0	1	1	D
1.08.3. Age at menarche	1	0	0	1-2	0	1	1	D
1.08.4. Age at menopause	0	0	0	1-2	0	1	0	D
1.09. 'Preventive' Drugs								
1.09.1. Oral Contraceptive drug	1	1	0	1	1	1	1	E
1.09.2. Hormonal Replacement Treatment drug	1	1	0	1	1	1	1	E
1.09.3. NSAID drug	0	0	0	1	0	1	0	D
1.10. Socio-economic determinants								
1.10.1. Education level attained	2	3	0	3	2	2	3	E
Deprivation indexes		3	0			1		E
Income		3	0			1		E
1.10.2. OECD indexes of health and welfare								
1.10.2.1. Gross Domestic Product	0	3	0	1	2	2	3	E
1.10.2.2. Total Social Expenditure	0	3	0	1	2	2	3	E
1.10.2.3. Total National Expenditure on Health		3	0	2	3	2	3	E
1.10.2.4. Total National Expenditure on Cancer	3	3	0			2	2	A
1.10.2.5. Total Public Expenditure on Health		3	0	2	3	2	3	E
1.10.2.6. Total Public Expenditure on Cancer	3	3	0		3	2	2	A
1.10.3. Demographic determinants								
1.10.3.1. Percentage of elderly in 2010, 2020, 2030	2	3	0	3	3	2	3	E
1.10.3.2. Age distribution of the population			3			2		E
1.10.3.3. Percentage of migrants			3					D

Table 4								PE
	UK+IRE	I+A+F+D	BENELUX	SWEDEN	PORTUGAL	GREECE	SPAIN	
2. Occurrence domain								
2.01. Preclinical phase								
2.01.1. Early detection facilities and activity								
2.01.1.1. Mammography	0		0	3	0	3	0	D
2.01.1.2. Breast cancer screening	3	3	0		3	3	3	A
2.01.1.3. Cervical cancer screening	3	3	0		3	3	3	A
2.01.1.4. Occult blood		1	0		1	2	0	C
2.01.1.5. PSA		1	0		1	2-3	0	C
2.01.1.6. Endoscopy / colonoscopy		1	0		1	3	0	C
2.01.2. Indirect indicators of screening activity (early detection)								
2.01.2.1. Incidence of in situ carcinoma of cervix (for Greece only in organized screening settings)		0	0	2	0	2	0	C
2.01.2.2. Incidence of DCIS and LCIS of breast (for Greece only in organized screening settings)		3	3	2	3	3	2	B
2.01.2.3. Incidence of adenocarcinoma in adenomatous polyp		1	0	2	1	1	0	C
2.01.2.4. Incidence of A stage for prostate (in the AUS classif)		0	0	2		0	0	C
2.01.3. Performance of early detection programs (for Greece specifically per site and per time interval)								
2.01.3.01. Screening volume	3	3	0	2	3	3	2	EUROCHIP SCREENING
2.01.3.02. Screening recall rate		3	0	2	3	3	2	
2.01.3.03. Screening detection rate		3	0	2	3	3	2	
2.01.3.04. Screening localized cancers		3	0	2	3	3	2	
2.01.3.05. Screening positive predictive value		3	0	2	3	3	2	
2.01.3.06. Screening benign/malignant biopsy ratio		3	0	2	3	3	2	
2.01.3.07. Screening conservative vs radical treatment		3	0	2	3	3	2	
2.01.3.08. Screening interval between detection and treatment		3	0	2	3	3	2	
2.01.3.09. Screening 'interval cancers'		3	0	2	3	2	2	
2.01.3.10. Screening sensitivity		3	0	2		3	2	
2.01.3.11. Screening Specificity		3	0	2		3	2	
2.02. Clinical phase								
2.02.1. Incidence								
2.02.1.1. Coverage of cancer registration	3	3	0	3	3	3	3	A
2.02.1.2. Quality of cancer registration								
2.2.1.2.1. DCO	2	3	0	2	2	3	0	E
2.2.1.2.2. Incidence/mortality	1	1	0	3	2	1	0	E
2.2.1.2.3. Percentage of istological cases (for Greece % of laboratory-verified tests)	2		0	2	2	1-2	0	E
2.02.1.3. Standard descriptive indexes								
2.2.1.3.1. Incidence rates	3	3	0	3	3	3	3	A and E
2.2.1.3.2. Incidence trends	3		0		2	3	3	2.02.1.3.1
2.02.2. Symptoms								
2.02.2.1. Interval between first symptoms and diagnosis	3		0	0	3	0	0	A
2.02.2.2. Interval between first symptoms and first definitive treatment	3		0		3	0	0	
2.02.2.3. Interval between first medical attendance and definitive treatment	3		0		3	0	0	
2.02.3. Diagnosis								
2.02.3.1. Interval between diagnosis and treatment	3		0	2	3	3	2	A
2.02.3.2. Diagnostic facilities (CAT, Magnetic Resonance Equipment, colonoscopie, upper GI endoscopies, PET)			0		1	0	3	B – E

Table 4	UK+IRE	I+A+F+D	BENELUX	SWEDEN	PORTUGAL	GREECE	SPAIN	PE
2.02.4. Extent of disease								
2.02.4.1. ENCR 'condensed' TNM	3	3	3	3	3	3	3	A
2.02.4.2. TNM not available (for Greece not necessary as an indicator)	3	3	3	?	3		1	2.02.4.1
2.02.5. Stage determinants								
2.02.5.1. EUROCARE 'condensed' C factor	3	2	3	1	2	2	1	B
2.02.5.2. C factor not available	3	2	3	?		2	1	2.02.5.1
2.02.6. Extent of Biological characterization of tumours								
2.02.6.1. ER				0				
2.02.6.1.1. % available	3	3	3			3	1	B
2.02.6.1.2. % +ve	1	1				3	1	D
2.02.6.2. PR				0				
2.02.6.2.1. % available	3	3	3			3	1	B
2.02.6.2.2. % +ve	1	1				3	1	D
2.02.6.3. HER for breast cancer			3	0			1	D
2.02.6.4. C-kit for GISTs						3		D
2.02.6.5. EGFR Per specific site + %ve						3		D
2.02.6.6. % of patients with biological characterisation of tumour carried out (for Greece + % ve)	3				2	3	1	D
2.02.7. Primary Treatment								
2.02.7.1. Availability of treatment facilities								
2.02.7.1.1. Radiation equipment (LinAcs less than 10 yrs old)	3	3	3	2	3	3	3	A
2.02.7.1.2. % of centres at least 2 radiation LinAcs equipm		3	3		2	3		A
2.02.7.1.3. Patients treated by activity volume of the unit		3	3			?	2	
2.02.7.1.4. N. of bed-days attributable to cancer care	3		1			2	1	C
2.02.7.1.5. % patients receiving multidisc. cancer care	3		3			2	1	
2.02.7.1.6. Transferability of cancer patients from specialised to general hospitals						1-2		
2.02.7.2. Availability of specialists								
2.02.7.2.1. General practitioners (for Greece Internists)	1		0	1	1	1	1	D
2.02.7.2.2. Doctors by specialization (Specialists in radiotherapy, Radiographers, Physicists, Haematologists Radiologists, Psicologists working in oncology, Palliative care nurses, Palliative care phisicians) (For Benelux: graduated after 1980)	3	3	?	1	3	1	2	A and E
2.02.7.2.3. Surgeons with an annual cancer workload more than a certain nr of patients specified in guidelines	3	0	?			0	0	
2.02.7.3. Percentage of patients (with a given cancer) who were seen by consultants with a workload of more than x patients with that cancer per year	3	0	3			0	0	
2.02.7.4. % of patients with access to multidisciplinary care	3	0	3			0	0	
2.02.7.5. % children cured in specialised children cancer centr.			3			?	2	
2.02.7.6. Accepted guideline								
2.02.7.6.1. Guidelines exist (for Greece Protocols exist)	1	1	0	2	1	1	1	D
2.02.7.6.2. Compliance with guidelines	3	3	3	2		1	1	A
2.02.7.6.3. % of people involved in clinical trials			3			1	1	B
2.02.1.7. Proportion of patients treated with								
2.2.1.7.1. Patients treated by surgery (if site-specific)	3	3		2	2	1	2	E
2.2.1.7.2. Patients treated with conservative surgery	3	3		2		1	2	C
2.2.1.7.3. Patients treated with radiotherapy (Separate into primary/other or by intent - curative/palliative)	3	3		2	3	1	2	C
2.2.1.7.4. Patients treated with adjuvant chemotherapy	3	3		2	2	1	2	C
2.2.1.7.5. Patients treated with hormonal treatment	3	3		2	2	1	2	C
2.02.1.8. Reports to official bodies on radiotherap. activ.			3					C

Table 4	UK+IRE	I+A+F+D	BENELUX	SWEDEN	PORTUGAL	GREECE	SPAIN	PE
3. Outcome domain								
3.01. Survival (for Greece Only where a tumour registry exist)								
3.01.1. Observed survival								A and E
3.01.1.1. 1-year observed survival	0	0		3	0	0	0	3.01.1
3.01.1.2. 5-years observed survival	0	0		3	0	0	0	3.01.1
3.01.2. Relative survival								A and E
3.01.2.1. 1-year relative survival	3	3		3	3	2	3	3.01.2
3.01.2.2. 5-years relative survival	3	3		3	3	2	3	3.01.2
3.01.2.3. 10-years relative survival			3					3.01.2
3.01.2.4. Relative survival for all cancers		3			1		3	3.01.2
3.01.2.5. 30-day mortality	3	3			2	0	3	C
3.02. Recurrences								
3.02.1. Proportion of local recurrences	3	3		0	2	0	0	C
3.02.2. Time after progression of distant methastatis		3				0	0	C
3.03. Proportion of cured patients	3			0	3		0	3.01.2
3.04. Average survival of fatal cases	3			2	2		0	3.01.2
3.05. Prevalence								A and E
3.05.1. Total prevalence	1	2		3	1	2	1	3.05
3.05.2. 5-years prevalence	1	2		3	1	2	1	3.05
3.05.3. 2-years prevalence	1	2		3	1	2	1	3.05
3.05.4. 'Morbidity' prevalence	1	2		1	1	2		3.05
3.05.5. 'Pre-morbidity' prevalence	1	0		0	0	0	0	D
3.06. Quality life of cancer patients								
3.06.1. Patients with social and home assistance	0	0		1	0	0	0	C
3.06.2. Quality of life at one year (QLQC30)	3	0				0	0	C
3.06.3. Experience of cancer care	3	0				0	0	C
3.06.4. Functional status at one-year (SF36 or QLQC (EORTC))	3	0				0	0	C
3.06.5. Rehabilitation programs (Y/N)			3					C
3.06.6. Oncology nurses			3					D
3.06.7. Palliative care nurses			3					D
3.07. Indirect indicator for pain treatment								
3.07.1. Use of morfine	3	3			1	3	3	A
3.07.2. Pain units and hospices	3	3		1		3	2	A
3.08. Mortality								
3.08.1. Standard indicators	3	3		3	3	3	3	A and E

6.2 INDICATORS BY RANK

A Rank

Table 5.a. Indicators with only A rank

	Code	Indicator Name	Domain Group that have to discuss the indicator
1	1.01.1	Daily Smokers	EUROCHIP PREVENTION
2	1.06.1.1	Exposure to Asbestos	EUROCHIP PREVENTION
3	1.10.2.4	Total National Expenditure on cancer	EUROCHIP MACRO VAR
4	1.10.2.6	Total public expenditure on cancer	EUROCHIP MACRO VAR
5	2.01.1.2	Breast cancer screening	EUROCHIP SCREENING
6	2.01.1.3	Cervical cancer screening	EUROCHIP SCREENING
7	2.02.1.1	Coverage of comprehensive cancer registration	EUROCHIP CANCER REG.
8	2.02.2.1	Interval between first symptoms and first definitive treatment	EUROCHIP TREATMENT
9	2.02.3.2	Interval between diagnosis and treatment	EUROCHIP TREATMENT
10	2.02.4.1	TNM	EUROCHIP CANCER REG
11	2.02.7.1.1	Radio-therapy equipment	EUROCHIP TREATMENT
12	2.02.7.1.2	Units with at least 2 LinAcc	EUROCHIP CLINICIAN
13	2.02.7.2.2	Doctors by specialization	EUROCHIP AND HMP HOSPITAL DATA
14	2.02.7.6.1	Compliance with guidelines	EUROCHIP TREATMENT
15	3.07.1	Use of morfine	EUROCHIP AND HMP PHARMACEUTICAL DATA
16	3.07.2	Pain units and hospices	EUROCHIP CLINICIAN

Table 5.b. Indicators with A and E rank

	Code	Indicator Name	HMP Group which has already discuss the indicator
1	1.02.1	Fruit & Vegetable daily consumption	HMP FOOD/NUTRITION
2	1.02.5	Alcohol daily consumption	HMP ALCOHOL
3	1.03.1	BMI	HMP PHYSICAL ACTIVITY
4	1.07.1	Seroprevalence of Hepatitis B/C	HMP INFECTIONS
5	1.07.3	AIDS Incidence	HMP INFECTIONS
6	2.02.1.3.1	Incidence rates	HMP IARC
7	3.01.1-2	Observed and survival rates	HMP IARC
8	3.05	Prevalence rates	HMP IARC
9	3.08	Mortality rates	HMP IARC

B Rank

Table 5.c. Indicators only with B rank

	Code	Indicator Name	Domain Group that have to discuss the indicator
1	1.01.3	Tobacco sales	EUROCHIP PREVENTION
2	1.01.4	Tobacco price	EUROCHIP PREVENTION
3	1.01.6	Tobacco legislation	EUROCHIP PREVENTION
4	2.01.2.2	Incidence of DCIS & LCIS of breast	EUROCHIP SCREENING
5	2.02.5.1	Eurocare condensed C factor	EUROCHIP CANCER REG
6	2.02.6.1.1	ER Available	EUROCHIP DIAGNOSIS
7	2.02.6.2.1	PR Available	EUROCHIP DIAGNOSIS
8	2.02.7.6.3	% of people involved in clinical trials	EUROCHIP CLINICIAN

Table 5.d. Indicators with B – E rank

	Code	Indicator Name	HMP Group which has already discuss the indicator
1	1.05.2.1	PM10 emissions	HMP POLLUTION
2	2.02.3.2	Diagnostic facilities	HMP HOSPITAL DATA

C Rank

Table 5.e. Indicators only with C rank

	Code	Indicator Name	Domain Group that have to discuss the indicator
1	1.05.4	Radon exposure in households	EUROCHIP PREVENTION
2	1.06.1.2	Exposure to PAH	EUROCHIP PREVENTION
3	2.01.1.4	Occult blood	EUROCHIP SCREENING
4	2.01.1.5	PSA	EUROCHIP SCREENING
5	2.01.1.6	Endoscopy	EUROCHIP SCREENING
6	2.01.2.1	Incidence of insitu carcinoma of cervix	EUROCHIP SCREENING
7	2.01.2.3	Incidence of Adenocarcinoma polyp	EUROCHIP SCREENING
8	2.01.2.4	Incidence of A stage for prostate	EUROCHIP SCREENING
9	2.02.7.1.4	Number of bed-days attributable to cancer care	EUROCHIP CLINICIAN
10	2.02.7.7.2	Patients treated with conservative surgery	EUROCHIP TREATMENT
11	2.02.7.7.3	Patients treated with radiotherapy	EUROCHIP TREATMENT
12	2.02.7.7.4	Patients treated with chemotherapy	EUROCHIP TREATMENT
13	2.02.7.7.5	Patients treated with hormonal treatment	EUROCHIP TREATMENT
14	2.02.7.8	Reports to official bodies on radiotherapy activ	EUROCHIP TREATMENT
15	3.01.2.5	30-day mortality	EUROCHIP MG
16	3.02.1	Proportion of recurrences	EUROCHIP MG
17	3.02.2	Survival after progression	EUROCHIP MG
18	3.06.1	Patients with social-home assistance	EUROCHIP CLINICIAN
19	3.06.2	Quality of life at one year (QLQC30)	EUROCHIP CLINICIAN
20	3.06.3	Experience of cancer care	EUROCHIP CLINICIAN
21	3.06.4	Functional status at one-year	EUROCHIP CLINICIAN
22	3.06.5	Rehabilitation programs	EUROCHIP BENELUX

Table 5.f. Indicators with C rank and “not for” EUROCHIP

	Code	Indicator Name	HMP Group which has already discuss the indicator
1	1.02.2	Vegetable Fiber daily consumption	HMP FOOD / NUTRITION
2	1.02.3	Meat daily consumption	HMP FOOD / NUTRITION
3	1.02.4	Processed meat daily consumption	HMP FOOD / NUTRITION
4	1.07.2	HPV seroprevalence	HMP INFECTIONS

No Rank**Table 5.g. Indicators with no rank**

	Code	Indicator Name	Domain Group that have to discuss the indicator
1	2.02.2.2	Interval between first symptoms and first definitive treatment	EUROCHIP TREATMENT
2	2.02.2.3	Interval between first medical attendance and definitive treatment	EUROCHIP TREATMENT
3	2.02.7.1.3	Patients treated by volume of activity	EUROCHIP TREATMENT
4	2.02.7.1.5	Multidisciplinary cancer care	EUROCHIP TREATMENT
5	2.02.7.1.6	Transferability	EUROCHIP TREATMENT
6	2.02.7.2.3	Surgeons with an annual cancer workload	EUROCHIP CLINICIAN
7	2.02.7.3	Percentage of patients who were seen by consultants with a workload	EUROCHIP CLINICIAN
8	2.02.7.4	Percentage of patients with access to multidisciplinary care	EUROCHIP CLINICIAN
9	2.02.7.5	Proportion of children cured in specialised cancer centres	EUROCHIP TREATMENT

ANNEX 1. LIST OF THE PARTICIPANTS

In the first column of the participant tables there is the group of the participant. The abbreviations are:

Abbreviations	Group
SC	Steering Committee
PE	Panel of Experts
MG	Methodological Group
WT	Working Team
GS	National Group of Specialists
DS	Domain Group of Specialists

In the third column of the participant tables there is/are the domain/s of the specialist. The domains are:

- 1 = Prevention
- 2 = Cancer registration and epidemiology
- 3 = Screening
- 4 = Treatment and clinical aspects
- 5 = Macro-health variables

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ANNEX 2. REPORT OF THE GROUP OF SPECIALISTS OF THE UK AND IRELAND

EUROCHIP Meeting 2 May 2002

Note for the record

Attendees: Bob Haward, Ian Kunkler, John Steward, Mike Richards, Harry Comber, Pat Doorley, Helen Shirley-Quirk, Michel Coleman

In *Italic* there are the replies provided by Andrea Micheli

General discussion of EUROCHIP

1. Michel Coleman provided a brief overview of the EUROCHIP project. Questions were raised about the background to the project and to the wider Health Monitoring Programme of which it forms part. The European legal framework to carry out communal public health activities was specified, and the absence of legal powers to compel member states to act was noted. Any cancer health indicators agreed by the EUROCHIP project will therefore be voluntarily (not compulsorily), collected by member states.

The question of how any indicators would be used was considered important. Only when that is clear can the indicators could satisfactorily suit the requirements of the Health Monitoring Programme.

2. The Steering Committee was requested to provide clarification on the aims of EUROCHIP:
 - Facilitate comparisons of structures, processes and outcomes?
 - Understand international variations in Europe?
 - Enable member states to devise strategies for progress against cancer?

Yes, EUROCHIP effects comparisons, tries to understand the reason of the variations and, first of all, individuates important aspects on which to start strategies against cancer

3. The group requested the Steering Committee to provide information on other components of the Health Monitoring Programme.
 - Is there any experience of countries using HMP indicators (not yet)?
No, we have not yet information about the use of HMP indicators
 - Is there any experience of creating HMP indicator lists for other disease areas?
Yes, all HMP projects produce interim and final reports. They are published on Internet in a web site called CIRCA. In the next weeks we will circulate the address and the password to access CIRCA (a CD with HMP project reports was circulates in the EUROCHIP group).

Discussion of proposed EUROCHIP indicators

4. The nature of the indicators:

- Are these exclusively those that would be most useful for Europe-wide comparison (eg. 30-day mortality after radical cancer surgery), or could they be indicators for national use, or possibly restricted to a few member states but not all?

In general the indicators would allow a comparison between all 15 member countries. But we can also accept indicators for a group of countries as we know that the variability is for many aspects high and those information useful for some countries may not match the interest of the others

- Should indicators be site-specific or general? (This will vary between indicators).

Yes, in fact a considered classification axis is the cancer site

- How can an indicator be specified - for example what can be measured with available data or what would it be desirable to measure?

We can propose to the Commission indicators not yet available. In these cases the Panel of Experts will decide the indicator and its characteristics.

- Precise and comprehensive definitions of indicators will be required. Examples exist, such as the technical specifications of indicators used by the UK Department of Health for NHS Performance Indicators.

The precise definition is the aim of the “Desired indicator” section of the form. This part is obviously fundamental for indicators not yet available.

5. The group decided to rank each of the 107 draft indicators on a four-point scale:

3 = most important

2 = second priority

1 = low priority

0 = not supported for use as an indicator

This proposal has been accepted as standard

6. All 107 proposed indicators were ranked on this scale, in many cases with a detailed discussion about availability of data, relevance for international comparison, problems of definition etc. An annotated list of proposed indicators, showing this ranking, is attached (Annex A).

7. Several additional indicators were proposed - these are included in Annex A.

Please can you complete the “desired indicator” section for the new indicators that you have proposed?

8. The group agreed that EUROCHIP should propose that the EU fund research to develop methodology or data for indicators that are considered desirable but currently unavailable. Detailed justification of such indicators would also be required. An example would be the proportion of cases of a particular cancer that develop recurrence within a defined period. This was considered a useful measure of the adequacy and appropriateness of primary treatment.

I do agree and I will insert these doubts in the EUROCHIP final report.

For example, other groups found that recurrences are a very important aspect, too.

9. Funding the collection of data to underpin proposed indicators was also considered. If the data are already collected, how is data collection funded - by the state or as a research project - and if the latter, how is that research funded? If the data are not already collected, should they be collected, and if so, how should data collection be funded?

All problems regarding the collection of the data are not pertaining to this project. All decisions are the duty of the European Commission. The final HMP proposal is to produce a European databank and after this first pillar the funds will be used to collect data. Other specifications are not yet possible.

Organisation of EUROCHIP project

10. The group felt that the geographic organisation of Groups of Specialists would limit the degree of expertise that could be brought to bear in developing the indicators. Each group of specialists contains a small number of experts in a range of domains. Each of those specialists is isolated from similar specialists in other countries. The panel of experts is Europe-wide but focused on geographic representation rather than areas of special interest. The group recommended that the Panel of Experts be enlarged and organised around five domains:

Prevention

Epidemiology and cancer registries

Screening

Diagnostic and treatment services (including workforce and facilities)

Quality of service delivery

The Group of Specialists felt that experts in each of these five domains should be invited from each of the geographic areas in the European Union, and possibly one or two from each country. These groups would then be able to provide specialist expertise to define the selected indicators within each of their respective domains and, crucially, to achieve a Europe-wide consensus. The group felt that such a consensus would be essential to ensure that the indicators eventually proposed achieve the broadest possible acceptance by the clinical, public health and policy sectors with which we are dealing. The group suggested that the September 2002 meeting of the Panel of Experts could possibly be amplified in this way, although obviously the meeting scheduled for May 2002 in Arona could not be altered at this short notice.

In general, the Steering Committee approved this proposal. The new organization will concern the Groups of Specialists and not the Panel of Experts. We will organize a meeting of the new Groups of Specialists for each of these 5 domains (I changed the last in “Quality of service delivery, health systems and macrovariables relative to health”) with specialist/s for each country. The national Groups of Specialists will aim to give information on the indicator availability. I thought I would not change the Panel of Experts as it has an important national-political role to develop EUROCHIP in the various countries: Italy and Spain are already asking their ministries for funds to organize their NATIONAL-EUROCHIP.

11. The group suggested that the Steering Committee ensured that other work in Europe or elsewhere on the development of indicators should be examined, to avoid unnecessary duplication of effort.

The US Council of State and Territorial Epidemiologists (CSTE) has developed a series of about 150 indicators, including 50 on cancer - these are available at www.cste.org. A list of the cancer-specific indicators is attached as Annex B. Detailed specifications for these indicators have been developed and an example is included in Annex B, along with background information.

We have already examined the major databanks (OECD, HDI) and we will control other databanks

Recommendations of the UK-Ireland Group of Specialists

- Modify the structure and organisation of the Panel of Experts' meetings so that they become pan-European workshops, including one expert in each of five domains (see para 10) from each country or area. These five groups would provide detailed advice on the content and importance of selected indicators, and crucially, would be likely to enhance the acceptability of the final set of indicators.
- Recommend to the European Union that research be carried out to define the best approach to data collection and the applicability of indicators that are considered desirable but are not currently available.
- The Working Team to circulate the complete list of addresses and emails of all members of Groups of Specialists and Panel of Experts, to facilitate Europe-wide linkage between EUROCHIP participants.

We are contacting each Group of Specialists leader to have all e_mail addresses of meeting participants. Moreover we have the intention to prepare a web site where you will be able to find each type of material about EUROCHIP.

- Anticipate future calls by the EU to fund the development of additional indicators.
- Avoid duplication of work by linking with other projects to define health indicators, particularly those in the Health Monitoring Programme or ESTRO, but also outside Europe, e.g. the USA.
- Propose a model of a detailed technical specification for a cancer indicator (an example from the UK is attached at Annex C; a US example is included in Annex B).

ANNEX 3. REPORT OF GROUP OF SPECIALISTS OF GREECE

May 21st, 2002

Attendees: Dr P. Arapantoni-Dadioti, Prof A. Linos, Dr A. Micheli, Dr E. Riza, Dr Stathaki-Ferderigou, Dr S. Tsiliakos, Dr C. Chatzis

Excused: Prof. I. Garas, Mr Stavrakakis

Dr E. Riza welcomed all participants and initiated the meeting with a self-introduction of all participants. Dr A. Micheli gave a brief presentation of the EUROCHIP project.

General discussion on the project

(this part mainly addresses the EUROCHIP Steering Committee)

It was stressed that data availability affects the ranking of indicators in each country despite the fact that EUROCHIP is mainly an intellectual piece of work and not a data collection activity. Separate desirable from available or measurable.

Differences in data collection methods will probably affect comparability of many indicators at the European level. Similar experience already exists from the operation of the two European cancer screening networks (breast and cervical cancer).

How should data be collected? Focus on data collection at the national level or at the European level for reasons of comparability?

Funding for data collection? Is it the country's responsibility to collect the data and then share it with other countries or will the EU through programmes or other ways facilitate (i.e. fund) data collection? Which is the exact part of the EU: funding of data collection or guidance on how to collect (or maybe both)?

If the EU relies of nationally collected data, will there be any way of "forcing" the central health administration in each country to collect such data? If not, the project may be unrealistic for most countries in different extent of course depending on data availability.

Greece, as yet, does not have a tumour registry, hence data collection for many indicators in the list is impossible despite their importance for cancer monitoring and surveillance. A Greek oncology commission (2 participants of the GS meeting are members of this Committee) has filed a proposal to the Ministry of Health to set up a cancer registry following an EU approved operation protocol, decision still pending.

Discussion on the list of proposed indicators

(this part mainly addresses the EUROCHIP methodological group).

The group felt the list was very detailed in intellectual terms but impractical in realistic terms. The ranking proposed by the UK+IRL group was used (list attached).

For prevention domain

Tobacco:

- a) there was concern on the accuracy and definition of indicators, especially in childhood smoking where reporting is most certainly biased. A new indicator was proposed (number of routine surveys in childhood tobacco consumption to cross-check accuracy).
- b) proposal to drop anti-tobacco advertising, difficult to measure instead new indicator: Money spent on anti-tobacco advertising.

Dietary factors:

- a) daily consumption was considered as very tricky and difficult to measure accurately (portions, pieces, times per day, week, month?), proposal to modify into *sales of..* Define exact source of data, e.g. also include published epidemiological studies, not just EPIC. Caution to cover all Member States and since we are talking long term, consider the fact that new countries may enter the EU very shortly and they are NOT covered by EPIC.
- b) Increasing availability of organic produce in the market may call for an additional indicator. However, a difficulty exists on what is legally defined as organic. To check.

Reproductive factors:

- a) useful mostly for research purposes based on specific study protocols.

Socio-economic determinants:

- a) definitions should be carefully looked at. OECD indices should be separated into public, private and other (perhaps in a special caveat for Greece).
- b) Total national & public expenditure on cancer is very difficult to get in Greece.

*For occurrence domain**Early detection facilities and activity:*

- a) make sure to define that data collection comes from organised screening settings, how is opportunistic going to be handled?

Performance of early detection programmes:

- a) it has to be site-specific and for a given time-period of operation.

Incidence:

- a) Percentage of histological cases to change into laboratory-verified tests as there may be other tests except histology (e.g. pathology, myelogram).

Extent of disease:

- a) some new indicators were proposed like C-kit for Gastro-Intestinal Stroma Tumours (GISTs) which may well be rare but they have specific, targeted and effective treatment.
- b) doctors should be separated by speciality
- c) proportion of children cured in specialised cancer centres: use of this indicator is questionable: where else could children seek treatment?
- d) In Greece as in some other countries (e.g. Italy) cancer-specific hospitals exist, therefore specification of hospitals should be made (indicators 2.02.7.1.3, 7.2 etc.). Perhaps transfer of patients from specialised to general should be considered as an indicator. Studies have shown that 15-20% of beds in cancer hospitals is given to non-cancer patients.
- e) Indicators 2.02.7.6.1-2.02.7.7.5 could be optional, they are particularly useful for insurance providers, for public health?

*For outcome domain**Survival:*

- a) these indicators may be used only where a tumour registry exists and should be measured properly.

Recurrences:

- a) useful only for research purposes, not very useful as a public health indicator.

Conclusions/Recommendations

EUROCHIP is a useful project, perhaps a bit too ambitious in terms of influencing national policies on cancer data collection. Duplication of activities with other projects should be carefully examined to avoid additional workload. Use of existing information should be a priority. Site-specific indicators should be collected whenever possible as they will enhance flexibility and comparability. Find out if the EU is prepared to fund data collection at the national level and in which framework, in order to co-ordinate future activities and continuation of EUROCHIP.

ANNEX 4. REPORT OF GROUP OF SPECIALISTS OF BENELUX

EUROCHIP meeting of the BENELUX –group

16th may 2002, Maastricht (The Netherlands)

A. Prerequisites

Indicators should be relevant for the professionals in oncological care, since they are the data providers and an important target group.

B. Types of sentinel cancers

Etiology: - Kaposi
- mesothelioma
- NHL

Care (early detection, care, quality of life, economics)

- testis
- HD
- ALL Childhood
- Cervix

ADD: - *NHL*
- *myelodysplasia (possibility with ICD-O3)*
- *leukaemia*
- *ovary*
- *rectum*
- *thyroid*

C. “1” Prevention domain

1.01. to 1.09.: see ECHI

1.10.3: demographic determinants

ADD: % < 20 y, 20-39 y, 40-64 y, 65+ y

Arguments :

- increasing numbers of elderly with specific needs and specific care demands (comorbidity)
- care is given by the middle groups and there is already in some countries an insufficient number of care providers

- in the future care will be given by youngest group (limited numbers → penury of care providers ?)

ADD : % of migrants

Arguments:

- shift of pathology (ex. tobacco-related for migrants from Eastern Europe)
- problems of communication → training of health professionals
- problems with access

ADD: Transborder care

Arguments:

- increasing problem within Benelux and in the future within Europe
- indicator ?
- better tool for exploration are scenarios (what if ...)

ADD: Genetic testing and counselling

Arguments:

- future developments in oncology
- monitoring of at risk populations

D. “2” Occurrence domain

2.02 Preclinical phase: these indicators need an incredible infrastructure for being measured accurately and correctly. Only instituted projects may generate good data on screening parameters, that appear in published reports. Also, there is little standardisation in the definition of many of these items (eg, what means endoscopy exactly?).

Only the % of DCIS in breast cancer may be obtained routinely.

2.02.1. incidence : use of existing databases should be stimulated

- IARC
- ACCIS (children)
- EUROCIM

2.02.3. diagnosis: use of marketing data of industry

2.02.7. primary treatment

ADD: reports to official bodies (Ministry, Health Boards, etc) on radiotherapeutic activities: Y/N

Arguments: in many countries such reports are mandatory and can provide detailed information on radiotherapeutic infrastructure (personnel and equipment) (2.02.7.1. and other)

ADD: number of subspecialists trained or graduated after 1980

- *Radiotherapists*
- *Paediatric oncologists*
- *Medical oncologists/haematologists*
- *Oncological surgeons*

E. Outcome domain

3.01. Survival

Use data from EURO CARE project

ADD: 10 year survival

3.05. Prevalence: use data of EUROPREVAL

3.06. Quality of life of cancer patients

ADD:

- *rehabilitation programs: Y/N*
- *Number of psycho-oncologists*
- *number of oncology nurses*
- *number of palliative care nurses*

Arguments: quality of life assessment should not be limited to palliative care

Routine monitoring of QoL is unlikely. This is usually done within trials of specific studies.

3.08. Mortality: use existing data (EURO CIM)

ADD:

- *death before age 65 due to cancers, and for main cancers*
- *death before age 75 due to cancers, and for main cancers*

Arguments: indicator for premature death

ANNEX 5. REPORT OF THE GROUP OF SPECIALISTS OF DENMARK

Dear Andrea and EUROCHIP,

I have now had the first contact with the Danish National Health Indicator Project with whom I have shared all the papers so far received from EUROCHIP. I asked their participation and help in the project. The reply was mailed to us in Danish and herewith translated into English:

Dear Dr. Storm,

Thank you for your mail to the National Health Indicator Project regarding the European Cancer Health Indicator Project (EUROCHIP). We read the material with great interest.

The basic idea, developing similar health indicators for the health services in Europe is sensible. It requires, however, that the indicators developed are relevant, well defined and usable. We find the original idea of developing a common European set of indicators very reasonable, inasmuch it is not sound if every single country develops their own. Below follow the comments to the material forwarded by you regarding EUROCHIP. Our comments are especially focused on the area for the health indicators that the National Health Indicator Project deals with, that is clinical indicators for good quality in relation to prevention, diagnostics, treatment, care and rehabilitation.

We totally agree that a large part of the indicators mentioned in the EUROCHIP document, already is available in our well-monitored society at a good and controlled quality compared to what is available elsewhere. In general the proposed indicators are very general and superior which in term means that it will be difficult to interpret the results coming from using them. A large part of the proposed indicators regards structure, and may not necessarily say anything about quality of the services of the health care system in relation to the single patient.

The proposed indicators for the patients passage through the health care system, is mainly in relation to mortality and quality of life. This means that it will be difficult on the basis of these indicators to evaluate the quality of the patient's passage through the health care system. Ideally, a set of indicators should be developed for each disease (process and/or result indicators) for elucidating the clinical situation and the results for the patient and for patient groups in relation to specified cancer diseases. This is the way of thinking in the National Health Indicator Project, where a group of clinicians from various disciplines appointed by scientific societies, give priority to the most important indicators for elucidating the patients way through the system and the results. By doing this it is possible to evaluate central parts of the passage through the health system for patient groups and the effect hereof. I should like to call your attention to the health indicators development regarding lung cancer, as I understand you are aware of the existence of these.

We recommend that a set of specific indicators like the one developed for lung cancer is developed for each of the cancer diseases mentioned. It is a central defect in the EUROCHIP, as described in the material we have received, that prognostic factors are missing. If one should compare health unit's responsibility for treatment, counties or countries it is central that in relation to each of the different indicators, prognostic factors are developed in order to be able to adjust for case mix. We find that this is an important message to the European working group that comparisons without adjustment for case mix are absurd. It is thus not sufficient just to bring up a list over relevant indicators. It must be accompanied by a list of prognostic factors, belonging to these, in order to make qualified comparisons and thus for each an evidence based information. To this adds, that it will be relevant to list some concrete measures of quality in relation to the indicators. In the terminology of quality assessment this is called standards. In the National Indicator Project standards are developed on the basis of the scientific literature, and where this is not available, on the basis of a consensus between the peers in the field.. This means that the reporting units of the data has a possibility to assess whether they adhere to accepted, well motivated standards. Finally, it must be said that if one wishes to measure the quality of the patients passing through the health care system, it may be relevant to add so-called "soft values". These include information and communication, continuity and coordination etc. This type of indicators is by nature difficult to measure, but we wish to mention that these aspects are totally missing in the draft proposal for EUROCHIP standards. At present there is an ongoing project in Denmark, looking into this in collaboration between Aarhus County and The National Board of Health and the Ministry of Health. In conclusion we find it extremely relevant that a European list of relevant indicators on cancer, is developed. In the above we have only dealt with so-called clinical indicators. We propose that for each area a list of specific and valid indicators are developed for each single cancer disease. Such a list will make possible relevant and qualified comparisons on cancer treatment between countries. In addition to this, there is a need for development of prognostic factors enabling the adjustment for case mix. If case mix adjustment is not made, in the comparison between reporting units and countries, it may mean that wrong conclusions are drawn on the data. Finally, we would like to mention the so-called "soft values" which are not included. This goes for areas like communication, information, continuity and coordination. These areas are central, but also difficult to measure and it may be too ambitious to include at present.

Finally, we would like to stress that the National Health Indicator Project is making itself available to the continued work with EUROCHIP if this is of interest. We are looking forward to a positive and constructive collaboration.

Yours sincerely, Jan Mainz.

ANNEX 6. REPORT OF THE GROUP OF SPECIALISTS OF AUSTRIA

**EUROCHIP-Meeting
Austrian Group
April 22nd 2002, Salzburg**

Prof. Thaler, Oncologist

Prof. Vutuc, Epidemiologist

Prim. Hausmaninger, Oncologist

excused: Klimont, Statistician

Oberaigner, Epidemiologist

General points:

- All participants agree that this is a very important project
- There is some scepticism concerning too huge data set with too many variables
- There is scepticism on comparability of data, hence there should be done detailed work in order to define really comparable indicators
- The group has the feeling that there should be an own section of indicators on structure of the health system
- Ranking of of relevance is needed
- The group has the feeling that there should also be a ranking of comparability
- One consequence of this work should also be recommendations on necessary informations to collect for every country and also on detailed procedures how to collect the information

Details on indicators have been directly contributed in the discussions at the Meeting in Maiori and will be reflected by in the next version of the list of indicators.

ANNEX 7. REPORT OF THE GROUP OF SPECIALISTS OF SWEDEN

EUROCHIP 2nd LIST OF INDICATORS - Estimates by the SWEDISH group

	Indicator	Problems (+ = yes, - = no)			Availability (+ = yes, - = no)			Rank
		Data collection	Quality	Standardisation	National level	Regional level	Site specific data only	
1.	Prevention domain: Prevalence of major causes (and attributable risk estimates)							
1.01	Tobacco							
1.01.1.	Daily smokers	+/-	+	?	-	-	+/-	3
1.01.2	Tobacco sales	-	-		+	+		2
1.01.3	Tobacco price	-	-	?	+	+/-		1-2
1.01.4	Anti-tobacco advertising	+	+		+/-	-		1
1.01.5.	Tobacco legislation	-	-		+	+/-		1-2
1.02.	Dietary factors							
1.02.1	Fruit & Vegetables daily consumption	-	-	+	+	-		2
1.02.02	Vegetable Fiber daily consumption	+	+	+	+	-		1
1.02.3	Meat daily consumption	-	-	+	+	-		1
1.02.4	Processed meat daily consumption	+	+	+	+	-		1
1.02.5.	Alcohol daily consumption	+	+/-	+	+	-		2-3
<i>1.02.6.</i>	<i>Indirect indicators</i>							
1.02.6.1.	Diabetes mortality	-	+	-	+	+		2-3
1.02.6.2	Alcoholic cirrhosis mortality	-	+	-	+	+		2-3
1.03.	Weight Profiles							
1.03.1.	Obesity	+	+	?	-	-		2-3
1.04.	Physical activity							
1.04.1.	Active vs sedentary occupations	+	+	+	+	-		1
1.05.	Air pollution							
1.05.1.	Determinants							
1.05.1.1.	Vehicle density	-	-	?	+	+		1
1.05.1.2.	Industrial density	-	-	?	+	+		1

	Indicator	Problems (+ = yes, - = no)			Availability (+ = yes, - = no)			Rank
		Data collection	Quality	Standardisation	National level	Regional level	Site specific data only	
1.05.2.	Actual measurements							
1.05.2.1.	PM10 emissions	-	-	-	+	+		1
1.05.2.2.	NO2 emissions	-	-	-	+	+		1
1.05.2.3.	SO2 emissions	-	-	-	+	+		1
1.05.2.4.	O3 emissions	-	-	-	+	+		1
1.05.3.	<i>Effects</i>							
1.05.3.1.	Prevalence of asthmatic disease	+	-	-	+/-	-		1
1.06.	Occupational risks							
1.06.1.	Prevalence of exposure to carcinogenic chemicals such as							
1.06.1.1.	Exposure to asbestos	+	+	+	-	-	+	1
1.06.1.2.	Exposure to PAH	+	+	+	-		+/-	1
1.06.1.3.	Exposure to solvents	+	+	+	-	-	+	1
1.07.	Infections							
1.07.1.	Non-alcoholic cirrhosis mortality	+	+	+	+	+		2
1.07.2.	Helicobacter mortality	+	+	+	+	+		2
1.07.3.	HPV mortality	+	+	+	+	+		2
1.07.4.	HIV prevalence	+	+	+	+	+		2
1.08.	Reproductive factors							
1.08.1.	Fertility							
1.08.2.	Age first pregnancy	-	-		+	+		2-3
1.08.3.	Age at menarche	-	-		+	+		1-2
1.08.4.	Age at menopause	-	+/-		+	+		1-2
1.09.	“Preventive” Drugs							
1.09.1.	OC drug	+/-	-	+/-	+	+	+	1
1.09.2.	HRT drug	+/-	-	+/-	+	+	+	1
1.09.3.	NSAID drug	+/-	-	+/-	+	+		1

	Indicator	Problems (+ = yes, - = no)			Availability (+ = yes, - = no)			Rank
		Data collection	Quality	Standardisation	National level	Regional level	Site specific data only	
1.10.	Socio-economic determinants							
1.10.1.	Educational level attained	-	-	-	+	+		3
	Deprivation indexes							
	Income							
1.10.2.	OECD indexes of health and welfare							
1.10.2.1.	Gross Domestic Product	-	-		+			1
1.10.2.2.	Total Social Expenditure	-	-		+			1
1.10.2.3.	Total National Expenditure on Health	-	-		+			2
1.10.2.4.	Total Public Expenditure on Health	-	-		+			2
1.10.2.5.	Computed Tomography Scanners	-	-		+	+		2
1.10.3.	Demographic determinants							
1.10.3.1.	Percentage of elderly in 2010	-	-	-	+	+		3
2.	Occurrence domain							
2.01.	Preclinical phase							
2.01.1.	<i>Early detection facilities and activity</i>							
	Cervical smears							
2.01.1.1.	Mammography	-	-	-	+	+	+	3
	Occult blood							
	Endoscopy							
2.01.2.	<i>Indirect indicators of screening activity (early detection)</i>							
2.01.2.1.	“Incidence” of in situ carcinoma of cervix	-	+	-	+	+	+	2
2.01.2.2.	Incidence of DCIS and LCIS of breast	-	+	-	+	+	+	2
2.01.2.3.	Incidence of adenocarcinoma in adenomatous polyp	-	+	-	+	+	+	2
2.01.2.4.	Incidence of A stage for prostate (in the AUS classification of prostate cancer)	+	+	+	-	-	?	2

	Indicator	Problems (+ = yes, - = no)			Availability (+ = yes, - = no)			Rank
		Data collection	Quality	Standardisation	National level	Regional level	Site specific data only	
2.01.4.	<i>Performance of early detections programs</i>							
2.01.4.01.	Screening volume	-	+	+	+	+	+	2
2.01.4.02.	Screening recall rate	-	+	+	+	-	+	2
2.01.4.03.	Screening detection rate	-	+	+	+	+	+	2
2.01.4.04.	Screening localized cancers	-	-	-	+	+	+	2
2.01.4.05.	Screening small cancers	-	-	-	+	+	+	2
2.01.4.06.	Screening positive predictive value	-	-	+	+	+	+	2
2.01.4.07.	Screening benign/malignant biopsy ratio	-	-	-	-	+	+	2
2.01.4.08.	Screening conservative vs radical treatment	-	-	-	+	+	+	2
2.01.4.09.	Screening interval bet. detection and treatment	+	-	-	-	-	+/-	2
2.01.4.10.	Screening “interval cancers”	-	-	+	+/-	+	+	2
2.01.4.11.	Screening sensitivity	-	-	+	+	+	+	2
2.01.4.12.	Screening specificity	-	-	+	+	+	+	2
2.02.	Clinical phase							
2.02.1.	<i>Incidence</i>							
2.02.1.1.	Coverage of cancer registration	-	-	-	+	+	+	3
2.02.1.2.	<i>Quality of cancer registration</i>							
2.02.1.2.1.	DCO	+	+	+	-	-	-	2
2.02.1.2.2.	Incidence/mortality	-	-	-	+	+		3
2.02.1.2.3.	Percentage of histological cases	-	-	-	+	+	+	2
2.02.1.3.	<i>Standard descriptive indexes</i>							
2.02.1.3.1.1	Incidence rates	-	-	-	+	+		3
2.02.1.3.2.	Incidence trends	-	-	-	+	+		3
2.02.2.	<i>Symptoms</i>							
2.02.2.1.	Interval between symptoms and diagnosis	+	+	+	-	-	+/-	0
2.02.3.	<i>Diagnosis</i>							
2.02.3.1.	Interval between diagnosis and treatment	+	+	+	-	-	+/-	2

	Indicator	Problems (+ = yes, - = no)			Availability (+ = yes, - = no)			Rank
		Data collection	Quality	Standardisation	National level	Regional level	Site specific data only	
2.02.3.2.	<i>Diagnostic facilities: availability and use</i>							
2.02.3.2.1.	CAT	-	-	-	+	+		0
2.02.3.2.2.	Magnetic Resonance Equipment	-	-	-	+	+		1
2.02.4.	<i>Extent of disease</i>							
	TNM	+	+	+	-	-	+	3
2.02.4.1.	ENCR “condensed” TNM	+	+	+	(+)	-	+	3
2.02.4.1.1.	Incidence rate of the localized stages	+	+	+	-	-	+	3
2.02.4.1.2.	Incidence rate of the advanced stages	+	+	+	-	-	+	3
2.02.4.1.3.	TNM not available cases							?
2.02.5.	<i>Stage determinants</i>							
2.02.5.1.	EUROCARE “condensed” C factor	+	+	+	-	-	+/-	1
2.02.5.1.1.	Percentage of the C1	+	+	+	-	-	+/-	0
2.02.5.1.2.	Percentage of the C2	+	+	+	-	-	+/-	0
2.02.5.1.3.	C factor not available cases							?
2.02.6	<i>Extent of Biological characterization of tumours (if relevant for treatment)</i>							
2.02.6.1.	ER	+	+	+	-	-	+	0
2.02.6.2.	PR	+	+	+	-	-	+	0
2.02.6.3.	HER for breast cancer	+	+	+	-	-	+/-	0
2.02.7.	<i>Primary Treatment</i>							
2.02.7.1.	<i>Availability of treatment facilities</i>							
2.02.7.1.1.	Radiation equipment	-	-	+	+	+		2
2.02.7.1.2.	Cancer hospitals	-	-	-	+	+		1
2.02.7.1.2.1.	Number of 1 000 000 pop	-	-	-	+	+		2
2.02.7.1.2.2.	Number of beds per 1000 p	-	-	-	+	+		2
2.02.7.1.2.3.	Proportion of patients treated in cancer hosp	-	-	-	+	+		1
2.02.7.2.	<i>Availability of specialists</i>							
2.02.7.2.1.	General practitioners	-	-	-	+	+		1
2.02.7.2.2.	Oncologists	-	-	-	+	+		1
2.02.7.2.3.	Specialists in radio-therapy	-	-	-	+	+		1

	Indicator	Problems (+ = yes, - = no)			Availability (+ = yes, - = no)			Rank
		Data collection	Quality	Standardisation	National level	Regional level	Site specific data only	
2.02.7.3.	Consistency with consensus and guidelines	+	+	+	-	-	+/-	2
2.02.7.4.	<i>Proportion of patients treated with</i>							
2.02.7.4.1.	Patients treated by surgery	+/-	-	-	+	+	+	2
2.02.7.4.2.	Patients treated with conservative surgery	+/-	-	+	+	+	+	2
2.02.7.4.3.	Patients treated with radiotherapy	+/-	+/-	+	-	-	+	2
2.02.7.4.4.	Patients treated with adjuvant chemotherapy	+	+	+	-	-	+	2
2.02.7.4.5.	Patients treated with hormonal treatment	+	+	+	-	-	+	2
3.	Outcome domain							
3.01.	Survival							
3.01.1.	<i>Observed survival</i>							
3.01.1.1.	1-year observed survival	-	-	-	+	+		3
3.01.1.2.	5-years observed survival	-	-	-	+	+		3
3.01.2.	<i>Relative survival</i>							
3.01.2.1.	1-year survival	-	-	-	+	+		3
3.01.2.2.	5-years relative survival	-	-	-	+	+		3
3.02.	Recurrences							
3.02.1.	Proportion of recurrences	+	+	+	-	-	+	0
3.03.	Proportion of cured patients	+	+	+	-	-	+	0
3.04.	Average survival of fatal cases	-	-	+	+	+	+	2
3.05.	Prevalence							
3.05.1.	Total prevalence	-	-	-	+	+		3
3.05.2.	5-years prevalence	-	-	-	+	+		3
3.05.3.	2-years prevalence	-	-	-	+	+		3
3.05.4.	“Morbid” prevalence	+	+	+	-	-		1
3.06.	Quality life of cancer patients							
3.06.1.	Patients with social and home assistance	+	+	+	-	+/-	-	1
3.07.1.	Use of morphine	+	+	+	+/-	-		1
3.08.	Mortality							
3.08.1.	Standard indicators	-	-	-	+	+		3

ANNEX 8. INDIVIDUAL CONTRIBUTE: QUESTIONS AND PRIORITIES BY DR. MIKE RICHARDS (UK)

Introduction

1 Groups of specialists from European countries have been asked to help identify health indicators relevant to cancer, as part of the Health Monitoring Programme. However, the potential uses of the proposed health indicators have not yet been made explicit.

2 This paper attempts to identify the questions that policy makers, epidemiologists and others might wish to address - for which health indicators would provide valuable information. A framework for prioritising the inclusion of individual health indicators is also proposed.

Broad Questions

3 The following broad questions are likely to be of interest to policy makers, epidemiologists, health service researchers, clinicians and patient groups:

- **Q1** : How does the burden of cancer differ between EU member states?
- **Q2** : Why does the burden of cancer vary (e.g. variations in the prevalence of known risk factors; variations in rates of early cancer detection; variations in the quality of treatment)?
- **Q3** : What factors may account for the variations identified in question 2?
- **Q4** : What resources are available and what actions are being taken in different member states to reduce the burden of cancer?

Q1: How does the burden of cancer differ?

4 This is the most fundamental question. Further questions may be relatively pointless unless information is available regarding the incidence, mortality and survival from cancer by age, sex and cancer type. National and regional cancer registries already collect this information and important comparative studies have been undertaken for several years (e.g. the EURO CARE comparison of cancer survival rates). It is essential that this information continues to be updated.

5 Associated with this, it will be essential to be able to assess the validity and reliability of data collected by cancer registries. The various measures of cancer registry coverage and quality should therefore be given high priority.

Q2: Why does the burden of cancer differ?

6 If differences in incidence, mortality and survival are observed, the next obvious question is 'why'? Researchers will wish to know the extent to which

- The problem is exposed to factors which are known to increase or decrease the incidence of cancer. Measure of the following parameters may therefore be valuable:
 - Smoking prevalence
 - Fruit and vegetable consumption
 - Obesity prevalence
 - Physical activity levels
 - Alcohol consumption
 - Asbestos exposure
 - Exposure to infections
 - Exposure to radon
 - Exposure to air pollutants

- Patients with cancer are diagnosed/treated 'early' or 'late' in the course of the disease. The following measures may reflect this
 - Duration of symptoms before treatment
 - Stage of disease at diagnosis
 - One year survival rates

- Patients with cancer receive high quality treatment. A variety of measures of the structure, process and outcome of care may give an indication of the quality of treatment. Examples include:
 - Measures of specialisation and teamwork
 - Development of guidelines
 - Measures of the proportion of patients receiving care which accords with agreed guidelines
 - Outcomes such as 30 day mortality rates after surgery

Q3: What factors may account for variations in the parameters in Q2?

7 Some of the factors which account for variations in the parameters may be measurable. Others will be more intangible. For example, smoking prevalence may be related to price and to levels of advertising of smoking products (both of which can be measured), but may also relate to cultural and attitudinal factors which may be less easily measured (e.g. the influence of smoking by prominent members of society on smoking rates among the population in general).

8 The extent to which patients present with advanced stages of cancer will depend both on the speed with which they seek medical assistance and on the speed with which the medical system responds once the patient has presented. Patient delay may relate both to ignorance of the symptoms of cancer and to cultural factors (e.g. not wanting to bother the doctor). System delay may reflect both capacity restraints and organisational factors.

9 Many of these factors could be measured if considered of sufficient importance. However, in some areas research would be needed to develop robust cross-cultural measures.

Q4: What resources/services are available?

10 The relationship between the provision of cancer control programmes (prevention, screening, diagnosis, treatment and care) and outcomes (e.g. incidence, mortality and survival) is of ever increasing interest to a wide range of stakeholders. It would therefore be useful to compare the 'outputs' across member states (see Q1 above) with the 'inputs' in terms of financial resources, services, workforce, facilities, etc. These might include:

- Prevention services (e.g. smoking cessation services)
- Screening services (and measures of their coverage/quality)
- Diagnostic services and activity levels for symptomatic patients

e.g. CT scanners per million population
 CT scans undertaken per million population p.a.
 MRI scanners per million population
 MRI scans per million population
 Gastroscopies per million population
 Colonoscopies per million population

- Treatment facilities + activity levels

e.g. Major surgical procedures for cancer
 Acute hospital bed days occupied by cancer patients
 Radiotherapy facilities per million population
 No of fractions/courses of radiotherapy
 No of patients receiving chemotherapy

- Workforce

e.g. Surgeons
 Oncologists
 Radiologists
 Pathologists
 Haematologists
 Palliative Care Specialists

Diagnostic radiographers
 Therapy radiographers

Costs of health/cancer care

Prioritisation of Health Indicators

11 Experience at the UK/Ireland specialists' meeting seemed to indicate that judgements on priority were based on the following factors:

- Everyone agreed that indicators which address Q1 above should be given very high priority.
- Items which provide answers to Q2 - Q4 were also given high priority - but with some variation according to the perspective of the individual concerned.
- Higher priority was given to those items which are likely to have the greatest impact on the burden of cancer (e.g. smoking outweighs radon as a cause of lung cancer and was therefore given higher priority).
- Higher priority was given to those items for which there is the strongest research evidence regarding their impact on the burden of cancer (e.g. low priority given to some of the air pollution factors for which strong evidence is lacking).

Panellists were aware of a tendency to downscore items for which reliable indicators may not be routinely available - even though these may be important.