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EUROCHIP-II

European Cancer Health Indicator Project-II

The action

INTERIM REPORT

ON THE SECOND PHASE OF EUROCHIP-II

21/06/2006

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1. SUMMARY

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 international group of experts engaged by EUROCHIP-2 is liaising with networks, international agencies, institutions, ministries of health and medical association to thus promote actions, with the aim to improve data collection, data analysis, and results dissemination.

In the first of year of the project (see 1st Interim Report) EUROCHIP-2:

(a) Has activated contacts in each of 30 member states
(b) Has organized or participated in 13 international meetings to promote the network
(c) Started to organize multidisciplinary national groups in most of the participating countries
(d) Defined examples on possible actions to improve the cancer information system
(e) Started the discussion on actions in 14 countries
(f) Reorganized the EUROCHIP web-site (www.tumori.net/eurochip)
(g) Participated in the "1st International Cancer Control Congress" (Vancouver, 23-26 Oct 2005) as invited reporter of cancer control in Europe

In the second year of the project EUROCHIP-2 (related to the present report):

(a) Enlarged the network to 285 participants (See Annex 1-List of Participants)
(b) Has organized or participated in 32 international meetings to promote the network (See § 4)
(c) Promoted discussions on actions in 25 countries and defined actions in 23 (See § 5)
(d) Started the iter to subsidize actions in 22 countries (See § 5)
(e) Prepared the protocol for EUROCHIP Pilot Studies (See § 6)
(f) Prepared the protocol for EUROCHIP screening assessment studies (See § 7)
(g) Prepared recommendations to Network of Competent Authorities to support Cancer Registries (See § 8)
(h) Prepared a reply to the European Commission Green Paper: "Promoting healthy diets and physical activity " (See § 9)
(i) Sponsored educational activity of 9 researchers from Eastern Europe to the course "Cancer survival: principles, methods and applications" (London, 3-7 April 2006)

Results already obtained indicate that the project is overall well accepted and may support our proposal to improve the relationship between research and political decisions on health.

2. INTRODUCTION TO EUROCHIP-2

2.1 INTRODUCTION

EUROCHIP-2 is a Europe-wide multidisciplinary three-annual (2004-2007) project 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 by allowing comparison with Europe as a whole and forming a basis for political action on health. The starting point of the project is the network established by EUROCHIP-1; but the aim is to improve and enlarge this network, and in doing so involve the other networks on cancer.

2.2 BACKGROUND: EUROCHIP-1

The EUROCHIP-1 project under the large-scale Health Monitoring Program (HMP), funded by the European Commission, has provided an important boost to the Europe-wide surveillance system on cancer. EUROCHIP-1 identified a list of indicators describing cancer in terms of burden, prevention activity, standards of care and cure rates. Indicators were selected according to the criteria of ease of collection and comparability. Standardised methods of validating and collecting data were also been proposed. The final list was one of maximum consensus between all interested parties.

More than 130 experts in various fields pertinent to cancer (physicians, economists, sociologists, epidemiologists, planners, etc.) from all Europen Union (EU) member countries (15 countries) participated in drawing up the list and a final report containing the proposed list of indicators and appending detailed information regarding them was produced.

To reduce inequalities across Europe, some countries have to prioritise action on prevention, others on care, others on surveillance, etc. Other countries lack basic epidemiological information and need to establish population-based cancer registries. However, it is vital for each countries' success in the fight against cancer, that the trans-national European nature of the study is maintained at all levels of data collection, data analysis, problem evaluation, and action. Cancer control must develop where different tasks are evaluated and implemented as part of the whole process.

2.3 EUROCHIP-2: AIMS

EUROCHIP-2 aims to improve access to and organisation and integration of information and knowledge on cancer for in all EU countries (25 countries) in order to more take more effective action.

The specific aims of EUROCHIP-2 are:

- to maintain and extend the system of cancer networks created for 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. Cancer Registries (CR) networks, the EUROCARE-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
- to encourage the setting-up of data collection in areas where information is unavailable
- to check the quality and standardisation of available cancer data and that 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 identify deficiencies in European health systems
- to encourage action based on EUROCHIP-2 findings to reduce inequalities in cancer surveillance and control

EUROCHIP-2 is:

- producing results at two levels: for European Union as a whole and for individual countries
- focusing on the problems and inadequacies of individual countries in order to suggest policy changes at the country level
- organising activity as a continuous process, i.e. taking a global view of the information system, involving on one hand the promotion of data collection, on the other analysis of already available data, on the other evaluation promoting political action on established inequalities; all as a continuously re-evaluated process.

2.4 EUROCHIP-2: THE ORGANIZATION

The organisation created for EUROCHIP-1 is maintained and expanded. EUROCHIP-2 has or will be: (a) an International Steering Committee with a co-ordinating role, (b) a Working Group to organize the work, perform analyses and prepare reports; (c) a National Specialist Group in each country concerned with national themes and including professionals involved in cancer (medical oncologists, radiotherapists, surgeons, epidemiologists, economists, sociologists, health planners etc.); (d) Five Domain Specialist Groups operating at the European level on different aspects of cancer (prevention, registration and epidemiology, screening, treatment, and social and economic determinants); (e) a Methodology Group to examine problems relating to the collection, standardisation, and validation of data; and (f) a Panel of Experts to elaborate the International strategy of EUROCHIP-2 and take operational decisions. The Panel of Experts will include delegates from each National Specialist Group, the Domain Specialist Groups, the Methodology Group, and all major networks and institutions directly or indirectly involved in cancer (e.g. International Agency of Research on cancer - IARC, OECD, EUROCARE, EUROPREVAL, European Breast Cancer Network – EBCN).

2.5 EUROCHIP-2: THE EXECUTION

The results of EUROCHIP-1 form the basis for the execution of EUROCHIP-2. The following phases constitute the various aspects of the continuing process for a given indicator:

1. Knowledge: finding data sources, improvement / standardisation of data collection
2. Choice: analyse data, compare data, find relations, find major deficiencies
3. Promotion: design, validate and finance initiatives to reduces cancer disparities

EUROCHIP defines "action" as the activation of one of these phases related to a given indicator. Table 1 shows examples of possible actions finalised to reach the phase for a specific indicator.

The execution of EUROCHIP-2 can be described from by "modular" and "process" approaches which can be represented on three axes. The first axis contains the various cancer health indicators, the second axis is the countries involved in the study, and the third axis is the phase of execution. For a given health indicator, the 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 to execute a given phase.

Consider, for example, the indicator incidence, where the phase may vary markedly from one country to another. We may have the situation (a) where the population is fully covered by cancer registration and cancer incidence is available; in that case the phase "Promotion" would be promoted. For a situation (b) where only a limited portion of the population is covered by cancer registration, then steps to implement national registration would be encouraged – so that phases "Knowledge" and "Choice" would be promoted. For a country (c) with no cancer registration and incidence data are not available (or may only be imprecisely estimated), phase "Knowledge" would be activated.

This apparently complex execution procedure reflects the great variation in stage of implementation of cancer control structures among the various European countries. It also permits us to add value to each country and to all countries together.

What we refer to as the "process" is the simultaneous vision of all phases. Only by a simultaneous consideration of all phases can one obtain assessments of the validity of the indicators and modify them for application to other countries. All participating countries will be therefore able to benefit both from the data comparison and experience of other countries.

Table 1: Examples of actions finalised to reach the phase (in column) for a specific indicator (in row)

INDICATOR	KNOWLEDGE	CHOICE	PROMOTION
Consumption of fruit and vegetables	1) Promotion of Health surveys 2) Update of Health surveys with new questions	Standardization of Health survey from an European prospective (similar questions in all countries)	1) Promotion campaigns on diet 2) Fruits at school
Consumption of alcohol			Alcohol prohibition for under 18s
BMI distribution in population			Advertising
Physical activity			
Tobacco smokers among adults			
Tobacco smokers among 10-14 years			Smoking prohibition for under 18s
Prevalence of ets (environmental tabacco smoke)			Smoking prohibition in public exercises
Prevalence of occupational exposure to carcinogens	Promotion of CAREX project	Presentation of a project to the European Commission for CAREX-2	Law for abolition of an occupational carcinogen
Population covered by high quality Cancer Registries	1) Creation of new Cancer Registries 2) Studies on the use of hospital records	Estimates in areas that are not covered by Cancer registries	Promotion of cancer registration
Cancer incidence rates			
Cancer relative survival rates	Courses and software		Participation in European projects
Cancer prevalence proportions	Courses and software		
Stage at diagnosis: % of cases with early diagnosis, % of cases with a metastatic test	Diffusion of routinary collection of stage in Cancer Registries	EUROCHIP Pilot Studies based on EUROCARE High Resolution studies	Promotion of early diagnosis
% of women that have undergone a mammography	1) Promotion of Health surveys 2) Update of Health surveys with new questions.	Studies on the relation between screening programmes and reduction of cancer site mortality (for which a systematic screening is implemented)	1) Diffusion of European guidelines 2) TV advertising
% of women that have undergone a cervical citology			
% person that have undergone a colo-rectal cancer test			
Organised screening coverage	Merge of databases of subregional organised screening programmes	Studies on sub-national differences in screening programmes	Promotion of new organised screening programmes
Delay of cancer treatment	Diffusion of routinary collection in Cancer registries	EUROCHIP Pilot Studies based on EUROCARE High Resolution studies	Introduction of specific recommended waiting times in oncological plans
% of radiation systems in population	Survey on equipment diffusion	Study on the geographical distribution of equipments in the national area	Promotion of the acquisitions of new equipments
% of Computed Tomography Scanners in population			
Compliance with best oncology practice	Diffusion of routinary collection in Cancer registries	EUROCHIP Pilot Studies based on EUROCARE High Resolution studies	Introduction of specific recommended guidelines in oncological plans
Proportion of patients treated with palliative radiotherapy	Survey on palliative care	Comparison of palliative care law in various European countries	European guidelines on palliative care

2.6 EUROCHIP-2: SUMMARY OF WORK

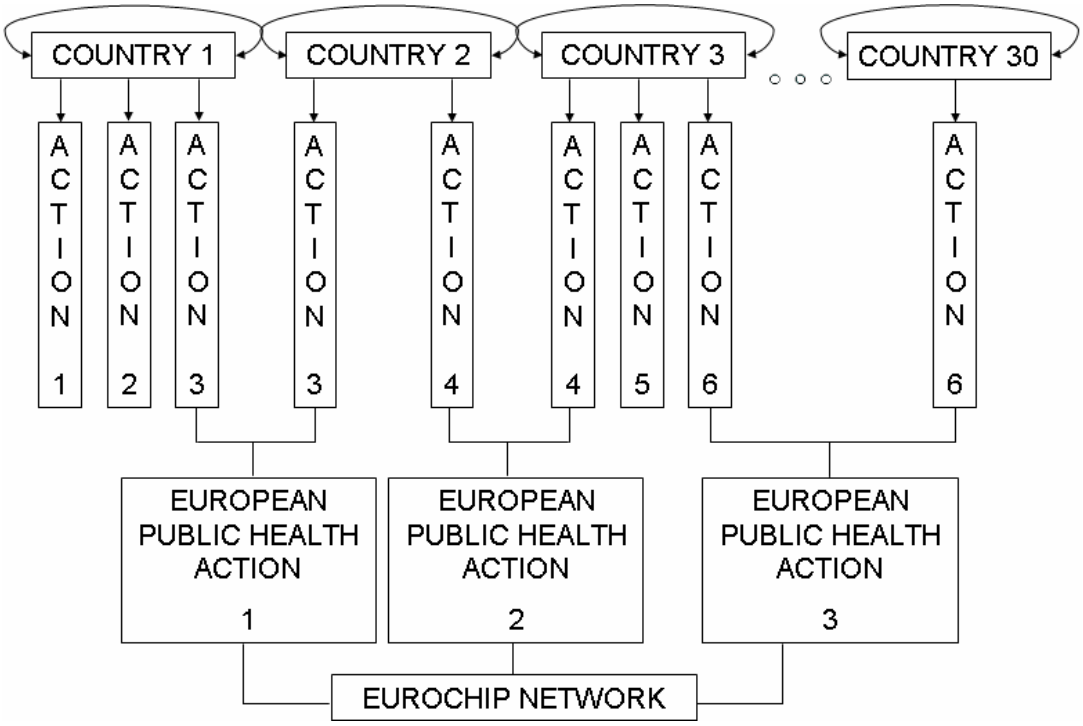
In the first phase of the project (2004-2006) EUROCHIP-2 has in principle:

(a) Has activated contacts in each of 30 member states
(b) Enlarged the network to 285 participants (See Annex 1-List of Participants)
(c) Organized multidisciplinary national groups in most of the participating countries
(d) Defined examples on possible actions to improve the cancer information system
(e) Reorganized the EUROCHIP web-site (www.tumori.net/eurochip)
(f) Participated in the "1st International Cancer Control Congress" (Vancouver, 23-26 Oct 2005)
(g) Has organized or participated in 49 international meetings to promote the network (See § 4)
(h) Promoted discussions on actions in 28 countries (See § 5)
(i) Started the iter to subsidize actions in 22 countries (See § 5)
(j) Prepared the protocol for EUROCHIP Pilot Studies (See § 6)
(k) Prepared the protocol for EUROCHIP screening assessment studies (See § 7)
(l) Prepared recommendations to Network of Competent Authorities to support Cancer Registries (See § 8)
(m) Prepared a reply to the European Commission Green Paper: "Promoting healthy diets and physical activity " (See § 9)
(n) Sponsored educational activity of 10 researchers from Eastern Europe to the course "Cancer survival: principles, methods and applications" (London, 3-7 April 2006)

Starting from the discussions and the material that came out from various national groups (all the material is available at the web-site), EUROCHIP-2 produced a first list of different desirable actions in various oncological fields.

The activity performed by the project follows the scheme in Figure 1: national groups discuss on the major problems in their national cancer control programmes and propose, reaching the maximum consensus possible, specific action/s against these problems. As some general trends can be singled out and it seems really important for EUROCHIP-2 to act in three main intervention areas in Europe (called in figure 1 "EUROCHIP Public Health Action").

Figure 1: Scheme of the discussion in the EUROCHIP-2 network

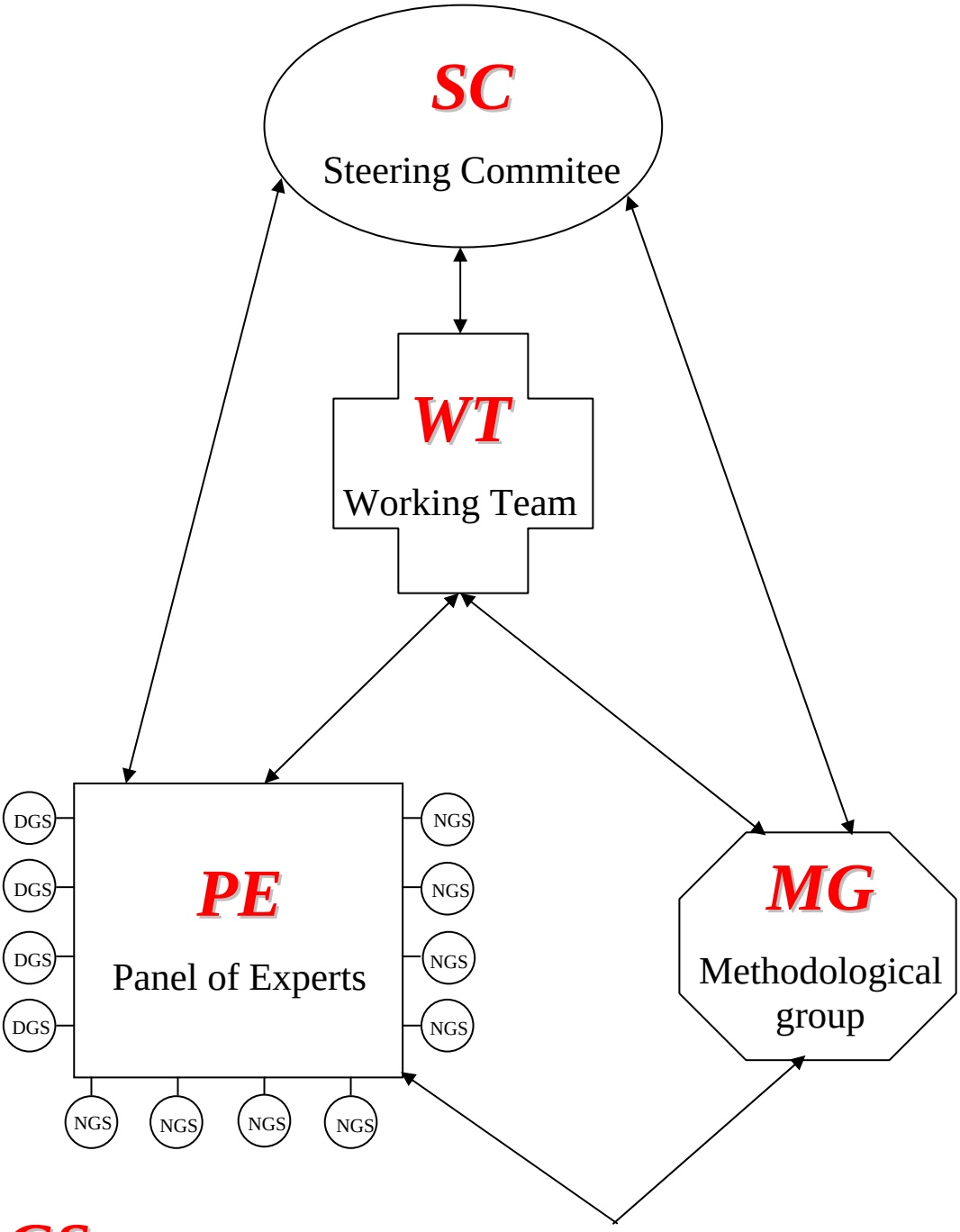


These three main intervention areas are:

1. Early diagnosis (See § 7): the National Group of Lithuania, Bulgaria, Romania, and Latvia underlined an increase trend in cervical cancer mortality rates in discordance with all other European Countries. We estimate that about 2000-2500 avoidable deaths amongst women occur in Eastern Europe every year. The EUROCHIP-2 proposal should focus on the possibility of re-activating cervical cancer screening programmes in the interested countries, as investing resources in this area would represent a very important result for Europe.
2. Cancer treatment delay (See § 6): EUROCARE showed big differences in cancer survival among European countries. EUROCHIP-2 could come into support to identify the causes of these differences, promoting specific studies (EUROCHIP Pilot Studies already mentioned in Table 1) with the collaboration of Cancer Registries (CR), in order to provide information at population level. EUROCHIP Pilot Studies will be organised for two cancer sites: breast and colon. Countries interested to organise these studies are Czech Republic, Cyprus, Finland, France, Ireland, Netherlands, Poland, Portugal, Slovakia, Slovenia, Spain, and UK.
3. Dietary prevention (See § 9): in the fight against the risk of cancer it is important to identify a communal priority aspect. EUROCHIP-2 is discussing on the possibility to reach this objective organizing a large intervention in Europe aimed to set an improved strategy based on Mediterranean diet. Italy is the first country that is going to work on this topic at national level.

3. RESULT 1: FRAMEWORK OF THE PROJECT

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



GS: Groups of specialists at national level (NGS) or international level (by domain: DGS)

3.1 ROLES OF GROUPS

SC: STEERING COMMITTEE

1. Select members of other groups;
2. Guide the work of the PE and MG;
3. Give comments on PE, MG and WT suggestions;
4. Take main strategical decisions.

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, country's discussions, list of actions;
6. Integrate the results produced with those of other projects;
7. Update the web-site
8. Prepare reports.

PE: PANEL OF EXPERTS

1. Refer national decisions;
2. Define and compare various interventions in each country.

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;

NGS: NATIONAL GROUP OF SPECIALISTS

1. Check availability of the indicators in own country
2. Promote the collection of the indicators in own country
3. Promotion of the pilot studies in own country
4. Individuate major actions

DGS: DOMAIN GROUP OF SPECIALISTS

1. Discuss about actions related to the indicators according to the domain
2. Promote the collection of the indicators according to the domain
3. Definition of the pilot studies protocols for indicators of own domain
4. Reply to eventual question coming from NGS

4. RESULT 2: SCHEDULE OF THE MEETINGS

Table 1 presents the schedule of the meetings carried out during the first part of the project.

Table 1. Meetings hold during the first due years

	Date	Group	Place
1	18-21/05/2004	STEERING COMMITTEE	Montpellier
2	24-25/09/2004	PANEL OF EXPERT	Ragusa
3	12-13/10/2004	MM WP MEETING	Luxembourg
4	24/11/2004	CAMON MEETING	Rome
5	13-15/12/2004	CONCORD MEETING	Rome
6	03-04/03/2005	RAPPORTO OSSERVASALUTE (Italy)	Rome
7	09/03/2005	CAMON MEETING	Genoa
8	22-24/03/2005	AIRT CONGRESS (Italian Association of Cancer Registries)	Marsala
9	16-17/3/2005	EUROCHIP-SWITZERLAND	Berna
10	11/04/2005	CARE AND TREATMENT DOMAIN MEETING	Milan
11	02/05/2005	ORGANIZATIONAL MEETING	Milan
12	4-6/05/2005	GRELL AND EUROCHIP LATIN GROUP MEETING	Lisboa
13	13/05/2005	MULTINATIONAL INFORMATION MEETING	Milan
14	27-28/05/2005	OECI MEETING	Athens
15	10/06/2005	NORTH-WESTERN EUROPE GROUP MEETING	London
16	19-22/06/2005	RARE DISEASE MEETING	Luxembourg
17	20-21/06/2005	PUBLIC HEALTH LESSONS	Rome
18	22-24/06/2005	EASTERN EUROPE GROUP MEETING	Bucarest
19	26/06-03/07/2005	ITACARE-EUROCARE-CONCORD	Lozzo di Cadore
20	08/07/2005	ITALIAN GROUP MEETING	Milan
21	13-15/07/2005	SCANDINAVIAN GROUP MEETING	Vilnius
22	20-22/07/2005	CENTRAL EUROPE GROUP MEETING	Prague
23	06-09/09/2005	AIE CONGRESS (Italian Association of Cancer Registries)	Pisa
24	14-16/09/2005	AIRT MEETING (Italian Association of Epidemiology)	Camerino
25	19/09/2005	MULTINATIONAL INFORMATION MEETING	Milan
26	26-27/09/2005	RAPPORTO OSSERVASALUTE (Italy)	Formia
27	14/10/2005	STEERING COMMITTEE	Milan
28	23-26/10/2005	INTERNATIONAL CANCER CONTROL CONGRESS	Vancouver
29	07/11/2005	ORGANIZATIONAL PREVENTION MEETING	Milan
30	10-11/11/2005	PREVENTION DOMAIN MEETING	Basel
31	21/11/2005	TASK FORCE ON DIET	Rome
32	29/11/2005	CAMON MEETING	Genoa
33	06/12/2005	ITALIAN GROUP MEETING	Rome
34	01/02/2006	ORGANIZATIONAL SCREENING MEETING	Turin
35	06-08/02/2006	CONCORD – EUROCARE 4 MEETING	Rome
36	15/02/2006	PILOT STUDIES MEETING	Brighton
37	17/02/2006	BULGARIAN MEETING	Sofia
38	23-25/02/2006	ECN MEETING (European Cancer Network)	Budapest
39	02-03/03/2006	AIRT MEETING (Italian Association of Cancer Registries)	Florence
40	15/03/2006	RAPPORTO OSSERVASALUTE (Italy)	Rome
41	03-07/04/2006	COURSE ON CANCER SURVIVAL	London
42	05-07/04/2006	AIRT CONGRESS (Italian Association of Cancer Registries)	Reggio Emilia
43	28/04/2006	ITALIAN GROUP MEETING	Rome
44	22/5/2006	SCREENING TASK FORCE MEETING	Sofia
45	24-26/5/2006	GRELL	Palma Mallorca
46	6-8/6/2006	MM WP MEETINGS	Luxembourg
47	15-16/6/2006	PANEL OF EXPERTS	Maiori
48	19-20/6/2006	EUROCAN PLUS MEETING	Lione
49	26-30/6/2006	FUTURE PLAN MEETING	Lozzo Cadore

5. RESULT 3: SUMMARY OF THE EUROCHIP-2 RESULTS BY COUNTRY

This table synthesizes all results produced by EUROCHIP-2 in each European country:

		Involvement in the EUROCHIP network	Field of the action	Action subsidized
1	Austria	X	Centralisation of therapy for gynaecological cancers	Within July, 30th
2	Belgium	X	PROCARE-Pilot studies	X
3	Bulgaria	X	Cervical cancer screening	Within August, 15th
4	Cyprus	X	Pilot Studies (See § 6)	Within July, 30th
5	Czech Republic	X	Pilot studies (See § 6)	X
6	Denmark	X	Breast cancer screening	X
7	Estonia	X	Cervical cancer screening	X
8	Finland	X	PERFECT-Pilot studies	X
9	France	X	Pilot studies (See § 6)	X
10	Germany	NO	-	-
11	Greece	X	Cancer registration promotion	X
12	Hungary	~	IN DISCUSSION	
13	Iceland	~	NO ACTION	N.A.
14	Ireland	X	Pilot studies (See § 6)	X
15	Israel	Some Contacts	-	
16	Italy	X	Task force on diet	N.A.
17	Latvia	X	Cervical cancer screening	Within August, 15th
18	Lithuania	X	Cervical cancer screening	Within July, 30th
			Breast cancer delay	X
19	Luxembourg	X	IN DISCUSSION	
20	Malta	X	Screening activity	X
21	Netherlands	X	Pilot studies (See § 6)	X
22	Norway	~	IN DISCUSSION	N.A.
23	Poland	X	Pilot studies (See § 6)	Within July, 30th
24	Portugal	X	Pilot studies (See § 6)	X
25	Romania	X	Cervical cancer screening	Within August, 15th
26	Slovakia	X	Pilot studies (See § 6)	Within July, 30th
27	Slovenia	X	Pilot studies (See § 6)	Within July, 30th
28	Spain	X	Pilot studies (See § 6)	Within July, 30th
29	Sweden	~	IN DISCUSSION	
30	Switzerland	X	IN DISCUSSION	N.A.
31	United Kingdom	X	Pilot studies (See § 6)	X

X: Yes

~: With difficulties

N.A.: Not applicable

All the actions projects are available in internet at the web-site page:

www.tumori.net/eurochip/actions.php .

6. RESULT 4: PILOT STUDY PROTOCOL

BACKGROUND and RATIONALE

Cancer registries have provided population-based, comparative survival statistics for cancer patients since 1960. Moreover, the EUROCARE project - a co-operative, cancer registry-based study - compares cancer patient survival since 1978.

EUROCARE underlined big differences in cancer survival across Europe.

EUROCHIP focuses on fighting inequalities in cancer. Its aim is to improve information and knowledge on cancer. The EUROCHIP-1 project funded by the European Commission under the large-scale Health Monitoring Program (HMP), identified a list of indicators for cancer including those on treatment and clinical aspects related with cancer survival.

Among them, the indicators "***Delay of cancer treatment***" and "***Compliance with guidelines***" were supposed to be strictly associated with the wide inter-country variation in cancer survival. Treatment delay in particular, could be related to:

a) individual condition of the patient
b) biological condition of the patient
c) health system deficiencies

The study here proposed is a feasibility study to collect data on health system delays (point c) adjusting for individual and biological conditions (points a and b).

The EUROCHIP feasibility study represent a key determinant with respect to the inclusion of "Delay of cancer treatment" and "Compliance with guidelines" in the European Commission indicators list on cancer. Up to now, comparisons of these indicators across Europe have never been performed at population level.

INTRODUCTION

EUROCHIP-2 is a European project to define an organisational and logical model that will effectively fight inequalities in cancer in Europe. It aims to improve access and organisation of information and knowledge on cancer in all European countries. By protocol, EUROCHIP-2 works on pilot studies on "Delay of cancer treatment" and "Compliance with guidelines" for three sites: breast, colon, and rectal cancers.

The pilot studies are feasibility studies aimed to assess data collection and availability of these indicators. Sources of these data are Cancer Registries.

Female breast and colorectal cancers are chosen for the present feasibility studies as they are common tumours, with high public health priority, and treated in general hospitals, rather than in specialized structures. Thus the study results will reflect the general clinical practice.

INDICATORS

The EUROCHIP Pilot Studies refer to the following indicators:

1) "*Delay of cancer treatment*"
   - For *breast cancer* (female): the dates to collect are
     - First contact to general practitioner
     - First hospital clinic visit (first hospital contact)
     - Date of first positive mammography
     - Date of first microscopical diagnosis (cytology, biopsy)
     - Date of first treatment (surgery, systemic therapy or radiotherapy)
   - For *colon and rectal cancers*: the dates to collect are
     - First contact to general practitioner
     - First hospital clinic visit (first hospital contact)
     - Date of first positive colonoscopy-sigmoidoscopy or barium enema
     - Date of first microscopical diagnosis (cytology, biopsies)
     - Date of first treatment (surgery, systemic therapy or radiotherapy)
     - Information on elective or emergency surgery
2) "*Compliance with guidelines*"
   - For *breast cancer* (female):
     - Proportion of post-operative breast radiotherapy after breast conserving surgery
     - Proportion of breast conservation surgery in pT1 cases (multiple cancers excluded)
   - For *colon cancer*:
     - Proportion of patients with Dukes C (or TNM Stage 3) receiving adjuvant chemotherapy
     - Proportion of patients with Dukes B (or TNM Stage 2) not receiving adjuvant chemotherapy
   - For *rectal cancer*:
     - Proportion of patients with Dukes B or C receiving pre-operative radiotherapy

AIMS

EUROCHIP Pilot Studies are feasibility studies to identify relevant data systems. They will be performed by cancer registries to address the following questions:

- is it possible, in terms of data accessibility, to collect data on delay of cancer treatment and compliance with guidelines at population level?
- is the information already available?

And to provide solutions to the following issues:

- Sources: from which sources can (or could) the data be obtained
- Limits: describe any shortcomings in the data e.g. lack of geographic comparability, incomplete coverage

CANCER REGISTRY PATIENT SAMPLES AND STUDY PERIOD

EUROCHIP Pilot Studies will be performed by CRs across Europe.

Participating CRs will apply to the following definitions:

a. CR covers the entire country
b. CR covers a local area of the country
c. CR is the central collector of Cancer Registry data (e.g. FRANCIM in France)

For each cancer site the target population is formed by all incident cases diagnosed in 2005 (or in the last available incidence year)

In each of the three cases a sample of the cancer patients will be selected randomly.

The sample numbers will be at least 100 patients for female breast cancer, 100 patients for colon and 100 patients rectal cancers. In the case of participation of more cancer registries from one single country, the sample will be stratified by CR population.

INCLUSION CRITERIA

The patient sample includes:

- patient with first primary tumour: to control individual condition possibly related with delays (persons with past cancer experience have higher attention on own health and have to be excluded)
- patients with age between 15 and 74: to control individual condition possibly related with delays (old persons are not considered in the study in order to eliminate possible confounding due to old patient behaviour)
- female for breast cancer

EUROCHIP PILOT STUDIES ON BREAST CANCER (ICD-9 174)

1

BASIC INFORMATION

A Registry _____ Country _____

B Other malignant tumours (previous or synchronous) Yes ☐ 1 No ☐ 2 Unknown ☐ 9

C Year of birth |_|_|_|_|

D Date of diagnosis as recorded in the Cancer Registry |_|_|_|_|_|_|_|_| D M Y

E Marital status: Single ☐ 1 Married ☐ 2 Widow/er ☐ 3 Separated-Divorced ☐ 4 Unknown ☐ 9

F Number of years of education _____ Unknown ☐ 9

G Site _____ ICD-9 Code |_|_|_|_| ICD-10 Code |_|_|_|_|

Morphology _____ ICD-O__ |_|_|_|_|_| Unknown ☐ 9

Histological confirmation Yes ☐ 1 No ☐ 2 Unknown ☐ 9 Date |_|_|_|_|_|_|_|_| D M Y

H Stage: Indicated ☐ 1 Reconstructed ☐ 2 Unknown ☐ 9 Date of indicated stage: |_|_|_|_|_|_|_|_| D M Y

Pathological TNM (pTNM) pT ____ pN ____ M ____ Size of T in mm |_|_|

Clinical TNM (if pTNM not available or incomplete) T ____ N ____ M ____ Size of T in mm |_|_|

SOURCE			
1-Hospital or out patient discharge	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
2-Screening files	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
3-Multidisciplinary team records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
4-Clinical notes	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
5-Pathological reports	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
6-Questions to GP	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
7-Social insurance records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
8-Other	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4

FIRST CONTACT

I Date of first contact with general practitioner |_|_|_|_|_|_|_|_| D M Y Unknown ☐ 9

SOURCE			
1-Hospital or out patient discharge	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
2-Screening files	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
3-Multidisciplinary team records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
4-Clinical notes	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
5-Pathological reports	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
6-Questions to GP	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
7-Social insurance records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
8-Other	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4

J Date of first contact by (from) general practitioner |_|_|_|_|_|_|_|_| D M Y Unknown ☐ 9

SOURCE			
1-Hospital or out patient discharge	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
2-Screening files	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
3-Multidisciplinary team records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
4-Clinical notes	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
5-Pathological reports	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
6-Questions to GP	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
7-Social insurance records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
8-Other	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4

L

Date of first hospital contact D M Y Unknown ☐9 **2**

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4

FIRST DIAGNOSTIC EXAMINATION

M

Mammography Yes ☐1 No ☐2 NA ☐9 Date: D M Y

If No, not Done because: Refusal or Death ☐1 Medical indication ☐2 Other ☐3 Not Specified ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4

N

Biopsy or needle aspiration Yes ☐1 No ☐2 NA ☐9 Date: D M Y

If No, not Done because: Refusal or Death ☐1 Medical indication ☐2 Other ☐3 Not Specified ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4

O

Skeleton X-Ray or Scintigraphy Yes ☐1 No ☐2 NA ☐9 Date: D M Y

If No, not Done because: Refusal or Death ☐1 Medical indication ☐2 Other ☐3 Not Specified ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4

3

TREATMENT

Q

Surgery Yes ☐1 No ☐2 NA ☐9 Date: D M Y

If No, not Done because: Refusal or Death ☐1 Medical indication ☐2 Other ☐3 Not Specified ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4

TYPE OF SURGERY (if surgery performed)

R

Type of surgery	Any conservative surgery (including quadrantectomy, tumour excision, lumpectomy) ☐1
	Simple mastectomy ☐2
	Any modified radical mastectomy ☐3
	Halmsted mastectomy ☐4
	Surgery not otherwise specified ☐5

S

Axillary Lymphadenectomy Yes ☐1 No ☐2 NA ☐9 Date: D M Y

If No, not Done because: Refusal or Death ☐1 Medical indication ☐2 Other ☐3 Not Specified ☐9

Done with sampling purpose ☐1
Done with clearling purpose ☐2
Done, unspecified reason ☐3
Sentinel lymphonode ☐4
Sentinel lymphonode+lymphadenectomy ☐5
Not done ☐6
Unknown ☐7
No surgery ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4

RECEPTORS

T

Oestrogen receptors Yes ☐1 No ☐2 NA ☐9 Date: D M Y

If Yes: Positive ☐1 Negative ☐2 Not Specified ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2 NA ☐9	If Yes: Active ☐3 Passive ☐4

U

Progesterone receptors Yes ☐1 No ☐2 NA ☐9 Date: D M Y 4

If Yes: Positive ☐1 Negative ☐2 Not Specified ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4

OTHER TREATMENT

V

Chemiotherapy Yes ☐1 No ☐2 NA ☐9 Date: D M Y

If No, not Done because: Refusal or Death ☐1 Medical indication ☐2 Other ☐3 Not Specified ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4

W

Radiotherapy Yes ☐1 No ☐2 NA ☐9 Date: D M Y

If No, not Done because: Refusal or Death ☐1 Medical indication ☐2 Other ☐3 Not Specified ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4

Z

Endocrine treatment Yes ☐1 No ☐2 NA ☐9 Date: D M Y

If No, not Done because: Refusal or Death ☐1 Medical indication ☐2 Other ☐3 Not Specified ☐9

SOURCE

1-Hospital or out patient discharge	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes ☐1	No ☐2	NA ☐9	If Yes: Active ☐3 Passive ☐4

EUROCHIP PILOT STUDIES ON COLON AND RECTAL CANCERS (ICD-9 153-154) 1

BASIC INFORMATION

A Registry _____ Country _____

B Other malignant tumours (previous or synchronous) Yes ☐1 No ☐2 Unknown ☐9

C Year of birth Sex: Male ☐1 Female ☐2 Unknown/Ambiguos ☐9

D Date of diagnosis as recorded in the Cancer Registry |_|_|_|_|_|_|_|_| D M Y

E Marital status: Single ☐1 Married ☐2 Widow/er ☐3 Separated-Divorced ☐4 Unknown ☐9

F Number of years of education _____ Unknown ☐9

G Site _____ ICD-9 Code |_|_|_| ICD-10 Code |_|_|_|

Morphology _____ ICD-O__ |_|_|_|_| Unknown ☐9

Histological confirmation Yes ☐1 No ☐2 Unknown ☐9 Date |_|_|_|_|_|_|_|_| D M Y

H Stage: Indicated ☐1 Reconstructed ☐2 Unknown ☐9 Date of indicated stage: |_|_|_|_|_|_|_|_| D M Y

TNM: Pathological ☐1 Clinical ☐2 T ____ N ____ M ____

Duke's stage _____

SOURCE

1-Hospital or out patient discharge	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4

FIRST CONTACT

I Date of first contact with general practitioner |_|_|_|_|_|_|_|_| D M Y Unknown ☐9

SOURCE

1-Hospital or out patient discharge	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4

J Date of first contact by (from) general practitioner |_|_|_|_|_|_|_|_| D M Y Unknown ☐9

SOURCE

1-Hospital or out patient discharge	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
2-Screening files	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
3-Multidisciplinary team records	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
4-Clinical notes	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
5-Pathological reports	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
6-Questions to GP	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
7-Social insurance records	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4
8-Other	Yes	☐1	No	☐2	NA	☐9	If Yes: Active ☐3 Passive ☐4

2

L

Date of first hospital contact D M Y Unknown ☐ 9

SOURCE

1-Hospital or out patient discharge	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
2-Screening files	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
3-Multidisciplinary team records	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
4-Clinical notes	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
5-Pathological reports	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
6-Questions to GP	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
7-Social insurance records	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
8-Other	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4

FIRST DIAGNOSTIC EXAMINATION

M

Colonoscopy or Sigmoidoscopy Yes ☐ 1 No ☐ 2 NA ☐ 9 Date: D M Y

If No, not Done because: Refusal or Death ☐ 1 Medical indication ☐ 2 Other ☐ 3 Not Specified ☐ 9

SOURCE

1-Hospital or out patient discharge	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
2-Screening files	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
3-Multidisciplinary team records	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
4-Clinical notes	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
5-Pathological reports	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
6-Questions to GP	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
7-Social insurance records	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
8-Other	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4

N

Barium enema Yes ☐ 1 No ☐ 2 NA ☐ 9 Date: D M Y

If No, not Done because: Refusal or Death ☐ 1 Medical indication ☐ 2 Other ☐ 3 Not Specified ☐ 9

SOURCE

1-Hospital or out patient discharge	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
2-Screening files	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
3-Multidisciplinary team records	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
4-Clinical notes	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
5-Pathological reports	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
6-Questions to GP	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
7-Social insurance records	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
8-Other	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4

O

Liver Ultrasound or C.T. Yes ☐ 1 No ☐ 2 NA ☐ 9 Date: D M Y

If No, not Done because: Refusal or Death ☐ 1 Medical indication ☐ 2 Other ☐ 3 Not Specified ☐ 9

SOURCE

1-Hospital or out patient discharge	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
2-Screening files	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
3-Multidisciplinary team records	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
4-Clinical notes	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
5-Pathological reports	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
6-Questions to GP	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
7-Social insurance records	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
8-Other	Yes ☐ 1	No ☐ 2	NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4

3

P

Surgical exploration Yes ☐ 1 No ☐ 2 NA ☐ 9 Date: D M Y

If No, not Done because: Refusal or Death ☐ 1 Medical indication ☐ 2 Other ☐ 3 Not Specified ☐ 9

SOURCE			
1-Hospital or out patient discharge	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
2-Screening files	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
3-Multidisciplinary team records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
4-Clinical notes	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
5-Pathological reports	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
6-Questions to GP	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
7-Social insurance records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
8-Other	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4

TREATMENT

Q

Surgery Yes ☐ 1 No ☐ 2 NA ☐ 9 Date: D M Y

If No, not Done because: Refusal or Death ☐ 1 Medical indication ☐ 2 Other ☐ 3 Not Specified ☐ 9

SOURCE			
1-Hospital or out patient discharge	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
2-Screening files	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
3-Multidisciplinary team records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
4-Clinical notes	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
5-Pathological reports	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
6-Questions to GP	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
7-Social insurance records	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4
8-Other	Yes ☐ 1	No ☐ 2 NA ☐ 9	If Yes: Active ☐ 3 Passive ☐ 4

Was surgery: Planned ☐ 1 Unplanned (e.g. emergency) ☐ 2 Unknown ☐ 9

TYPE OF SURGERY (if surgery performed)

R

Colon Cancers	Rectal Cancers	Colorectal Cancers
Right hemicolectomy ☐ 1	Anterior resection ☐ 1	Endoscopy Polipectomy ☐ 4
Segmental colectomy or left hemicolectomy ☐ 2	Abdomino-perineal resetion ☐ 2	Other specified resections ☐ 5
Total colectomy ☐ 3		Resection not otherwise specified ☐ 6
		Palliative surgery without tumour resection ☐ 7

4

OTHER TREATMENT

V

Chemiotherapy Yes ☐ 1 No ☐ 2 NA ☐ 9 Date: D M Y

If No, not Done because: Refusal or Death ☐ 1 Medical indication ☐ 2 Other ☐ 3 Not Specified ☐ 9

SOURCE								
1-Hospital or out patient discharge	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
2-Screening files	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
3-Multidisciplinary team records	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
4-Clinical notes	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
5-Pathological reports	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
6-Questions to GP	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
7-Social insurance records	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
8-Other	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4

W

Radiotherapy Yes ☐ 1 No ☐ 2 NA ☐ 9 Date: D M Y

If No, not Done because: Refusal or Death ☐ 1 Medical indication ☐ 2 Other ☐ 3 Not Specified ☐ 9

SOURCE								
1-Hospital or out patient discharge	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
2-Screening files	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
3-Multidisciplinary team records	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
4-Clinical notes	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
5-Pathological reports	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
6-Questions to GP	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
7-Social insurance records	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4
8-Other	Yes	☐ 1	No	☐ 2	NA	☐ 9	If Yes: Active ☐ 3	Passive ☐ 4

DATA COLLECTION: TEMPLATE

	Object	Site [1]	Reason	Notes
A	Name of registry and state	B-C-R	Identification of the registry if more registries of one country participate	
B	Other malignant tumours	B-C-R	Control variable for inclusion criteria	Only first primary tumour accepted
C	Year of birth and sex	B-C-R	Individual condition to consider for delays	
D	Date of diagnoses	B-C-R	Date to consider for studying delays	
E	Marital status	B-C-R	Individual condition to consider for delays	
F	Educational status	B-C-R	Individual condition to consider for delays	
G1	Site	B-C-R	Biological condition to consider for delays	
G2	Morphology	B-C-R	Biological condition to consider for delays	
G3	Histological confirmation	B-C-R	Biological condition to consider for delays	The date of the event could be considered in the indicator on delay
H	Stage	B-C-R	To consider for “compliance with guidelines”	
I	First contact by GP	B-C-R	Date to consider for studying delays	
L	First hospital contact	B-C-R	Date to consider for studying delays	
M-P	First diagnostic examinations: date of the event	B-C-R	Date to consider for studying delays	We need to collect the date of any type of diagnostic examination. During the analysis the first date will be chosen
M-P	First diagnostic examinations: source of the date	B-C-R	Useful information for feasibility studies	
M-P	First diagnostic examinations: Not done because	B-C-R	Useful information for studying delays	
Q-Z	First treatment: Date of the event	B-C-R	Date to consider for studying delays	We need to collect the first date of any type of treatment. During the analysis the first date will be chosen
Q-Z	First treatment: source of the date	B-C-R	Useful information for feasibility studies	
Q-Z	First treatment: Not done because	B-C-R	Useful information for studying delays	
R	Type of surgery	B-C-R	To consider for “compliance with guidelines”	
STU	Lymphanedectomy-receptors	B	To consider for “compliance with guidelines”	

[1] B: Breast cancer C: Colon cancer R: rectal cancer

INSTRUCTIONS FOR COMPLETING THE FORMS

A REGISTRY and COUNTRY. Registry and country name

B OTHER MALIGNANT TUMOUR. Distinction whether a previous (or synchronous) malignant tumour was diagnosed. The case is a patient with first primary tumour

C YEAR OF BIRTH. It must be registered using a four digit variable, e.g. |1|9|4|5|

SEX. Only for colon and rectal cancers

D DATE OF DIAGNOSIS (recorded in the CR as incidence date). The date is requested in order to help standardizing the definition of date of diagnosis.

E MARITAL STATUS. Mark the relevant box. **OPTIONALE**

F NUMBER OF YEARS OF EDUCATION. A standardized socio-economic indicator for cancer registries does not exist. This information could be taken from the "educational level" reported in the clinical notes. The transformation in number of years of education is task of the cancer registrar. **OPTIONALE**

G PRIMARY TUMOUR SITE. Site will be written in detail. ICD-9 or ICD-10 code will be reported.

MORPHOLOGY. Morphology must be written out. ICD-Ox code will be reported.

HISTOLOGICAL CONFIRMATION. Enter date of possible histological confirmation.

H STAGE: Stage is to be indicated as recorded in the clinical notes or as reconstructed by the registrar according to TNM classification (TNM Atlas). Available pathological stage (pTNM) should be reported. If pTNM is not available, clinical stage is to be reported. If stage is indicated also the date of indication should to be entered. The source of the date will also be reported distinguishing whether it was hospital or outpatient discharge, screening files, multidisciplinary team records, clinical notes, pathological records, question to GP, social insurance records or other. Boxes to mark are:

- Yes: the information is found
- No: the information could be found but is not found
- NA: the information can never be found in that type of source
- If Yes, Active: the investigator finds the information or receive it after asking for it
- If Yes, Passive: the information is found by the investigator in a file transmitted routinely to the registry

- BREAST cancer. When available, tumour size in millimetres will be recorded. Size is that measured by the pathologist or, in absence, by radiologist/clinician.

- COLORECTAL cancers. DUKES classification is envisaged.

I DATE OF FIRST CONTACT WITH GENERAL PRACTITIONER. This is the date of first contact with GP. The source of this information will be reported (see options in point H). **OPTIONALE**

J DATE OF FIRST CONTACT BY (or FROM) GENERAL PRACTITIONER. This is the date on which the GP requested an hospital or a specialist appointment. The source of this information will be reported (see options in point H).

L DATE OF FIRST HOSPITAL CONTACT. Date of first hospital admission or first visit as outpatient during which the tumour was diagnosed. The source of this information will be reported (see options in point H)

M-P DIAGNOSTIC EXAM. Basic diagnostic examinations are listed in the form.
It is also requested to distinguish whether the examination has been performed or not, and, if not, why. The date of the first positive diagnostic examinations will be reported. The source of this information will be reported (see options in point H)

Q SURGERY. Distinction whether surgery has been performed. The date of surgery will be collected (see options in point H). It is also requested to distinguish whether the surgery was performed or not, and, if not, why.
- COLORECTAL cancers. It is intended to investigate whether surgery was planned or the patient was operated in emergency.

R TYPE OF SURGERY.
- BREAST cancer: common surgical procedures are listed
- COLORECTAL cancers: three lists of surgical procedures are listed, one for colon cancers, one for rectal cancers and one for both these localizations.

S AXILLARY LYMPHADENECTOMY (BREAST cancer). Must report if performed, including purpose (i.e. clearing or sampling nodes). Date of lymphadenectomy will be collected. Data source will be reported (see options in point H)

T-U HORMONAL RECEPTORS (BREAST cancer). Their determination will be recorded, and results will be specified when available. Exam date will be collected. The source of this information will be reported (see options in point H)

V-Z CHEMOTHERAPY, RADIOTHERAPY, and ENDOCRINE TREATMENT. First therapy against the relevant cancer is to be recorded. Treatments for relapses and for subsequent metastasis are not to be considered in these blocks.
The type of therapy (e.g. chemotherapy regimen, dose of radiation) will not be considered in the study. Cases for which one therapy, e.g. chemotherapy was started but interrupted for any reason will be considered as “Chemotherapy Yes”, to record the ‘intention to treat’, rather than the completeness of the therapeutic cycle. The date of treatment will be collected. The source of this information will be reported (see options in point H).
Hormonal therapy (BREAST cancer). Includes sex hormons, tamoxifen, other SERM GnRH, aromatase inhibitors and others.

QUESTIONNAIRE TEST

The forms presented in this protocol collect part of information collected in the EUROCARE High Resolution Studies (HR). Even if in several parts the forms are different it is reasonable to use the HR experience for the validation of the questionnaire.

DATA MANAGEMENT

The Co-ordinating Centre, and the Data Analysis Centre for the EUROCHIP Pilot Studies will be based at the Istituto Nazionale dei Tumori (INT) in Milan.

All the data collected will be implemented in an ACCESS database.

The data entry will be performed in Milan.

CONFIDENTIALITY AND DATA SECURITY

The legal conditions under which data are collected and under which they may be accessed for research vary from country to country. Data requested for the EUROCHIP Pilot Studies relate to individuals diagnosed with cancer but no data or codes allowing the identification of patients are requested. The day and the month of birth are omitted.

IDENTIFYING INFORMATION

No direct identifying information, such as name, address or any public identification code, will be sent to INT.

DATA STORAGE

The following actions will be taken to keep data files safe with respect to potential breaches of confidentiality. Individual data records will be stored only on a computer that is never physically or electronically connected to any external network or the internet. Access to the data will be protected by passwords and specific software.

ANALYSIS

Basic statistical analysis of the data will consist of descriptive measures and comparisons among participant CR areas. Only descriptive statistics will be carried out, including data analysis of missing frequencies.

OUTPUT

A report for the European Commission will be prepared including results of the feasibility studies. As first goal, a couple of articles (one on breast cancer and one on colorectal cancers) will be prepared to show the differences across Europe of the indicators “Delay of cancer treatment” and “Compliance with guidelines” calculated by these studies.

The articles will be prepared during the EUROCHIP activity period.

PUBLICATION POLICY

001 EUROCHIP Pilot Studies (EPS) are research collaborations among European population-based cancer registries, designed to understand the feasibility to collect data on the indicators “Delay of cancer treatment” and “Compliance with guidelines”.

002 The Co-ordinating Centre is in the Istituto Nazionale Tumori, Milan, Italy. The Co-ordinating centre group and the European population-based cancer registries participating in the EPS formed the EUROCHIP Pilot Studies group.

003 Basic analyses are carried out at the Co-ordinating Centre in Milan, but further analyses may also be carried out at the participating cancer registries.

004 The data are collected only for feasibility objectives.

005 The data remain the property of the contributing registries. Any analysis carried out with these data, other than the analyses specified in the protocol themselves, will require the written consent of the contributing registries.

006 Two first publications will be prepared by a member of the EPS group in Milan (material of these two papers will be used for EUROCHIP-2 project reports)

007 The EPS group agrees that future developments of the project should be consistent with the spirit of collaboration that has resulted in the success of previous joint undertakings in which cancer registry data have been combined for analysis.

008 Before submission for publication, draft manuscripts will circulate to the EPS group. Approval will not be unreasonably withheld, and will usually be given within four weeks. Any concerns expressed by the EUROCHIP Pilot Studies group members will be promptly relayed to the authors of the manuscript, for discussion and resolution.

009 The EUROCHIP Pilot Studies Group will be a corporate author in all publications deriving from analyses of the EUROCHIP Pilot Studies data. All publications based on pooled data must include the EUROCHIP Pilot Studies Group amongst the authors (or as author), a suitable authorship formula being: «Authors A, B, C, ... and the EUROCHIP Pilot Studies Group», and all members of the EUROCHIP Pilot Studies must be identified in an annex or footnote in each such publication. Participating registries may choose one/two representatives for each publication: this person may be different for different publications.

010 In general, the researcher(s) who performed the analysis and wrote the paper will be first authors of such publications.

011 To avoid duplicate publication or the publication of inconsistent results without suitable interpretation, cancer registries participating in the EUROCHIP Pilot Studies are expected to inform the Co-ordinating Centre if they publish articles involving the data that have also been submitted to the EUROCHIP Pilot Studies.

7. RESULT 5: SCREENING ASSESSMENT PROTOCOL

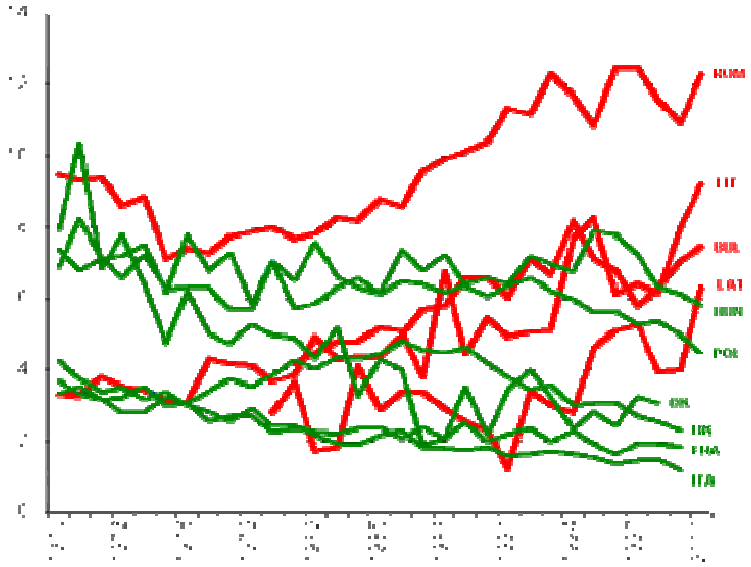
BACKGROUND and RATIONALE

In Western European countries was noticed a substantial decrease in cervical cancer mortality rates. Among Eastern European countries a decrease of mortality was observed in Poland, while rising trends were noticed in Bulgaria, Latvia, Lithuania, and Romania. In these countries it has been assessed about 2500 avoidable deaths in 2000.

This situation is evident in the following figure where uterus cancer mortality trends in age 20-44 are represented. In these ages uterus cancer deaths are mostly due to cervical cancer and so for young ages here considered, overall uterus cancer mortality is a proxy for cervical cancer mortality.

Age standardized mortality rates for uterus cancer. Age: 20-44.

European Standard Population. Per 100.000



INTRODUCTION

EUROCHIP-1 was implemented in Europe to set indicators for all health aspects as part of the European Commission Health Monitoring Programme (HMP). Main aim of EUROCHIP-1 was to promote an established surveillance system on cancer in Europe.

EUROCHIP-2 is an European multidisciplinary three-annual (2004-2007) project to define an organisational and logical model that will effectively fight inequalities in cancer in Europe. The starting point is the EUROCHIP-1 network and it is proceeding by improving and enlarging this network of networks on cancer to include all Member States.

The international group of experts engaged by EUROCHIP-2 is liaising with networks, international agencies, institutions, ministries of health and medical association to thus promote actions, with the aim to improve data collection, data analysis, results dissemination and health system modifications

The EUROCHIP-2 main aim is discussing on promoting important initiatives (ACTIONS) in each country to improve the cancer information system and reduce disparities in health.

AIMS

The EUROCHIP-2 proposal described in this study protocol should focus on the possibility of re-activating cervical cancer screening programmes in the interested countries (Bulgaria, Romania, Latvia, Lithuania, ecc), as investing money in this area would represent a very important result for Europe.

The study described in this protocol aims to:

a) analyze the European cervical cancer screening guidelines to implement in countries with increasing mortality trends;
b) assess the possibility to (re-)organize cervical cancer screening programmes in Romania, Lithuania, Bulgaria and Latvia;
c) promote an European action against increasing trends in cervical cancer mortality for the European Parliament

REFERENCE BOOK

The main activity performed in this study refers to cervical cancer screening programme assessment. The reference book for this activity is the Chapter 4 of the book "Planning and Implementing Cervical Cancer Prevention and Control Programs" prepared by Alliance for Cervical Cancer Prevention in 2004. This book is downloadable at:
http://www.tumori.net/eurochip/material/Screening/ACCP_screening.pdf

IDENTIFYING INFORMATION

Information to collect has to reply to the following issues:

a) Cervical cancer epidemiology
b) Possible scheme of cervical cancer screening programme (see example in annex A) to implement, including proposals of
    a. National or regional organization
    b. Target population
    c. Recruitment interval
c) List of institutions to involve in the screening programme
d) Major interventions needed to start the programme in terms of educational activity, health service facilities, laboratory equipments, information system, ecc
e) Estimation of the costs for implementation of a cervical cancer screening programme

The present study have to give realistic indications to politicians.

CONFIDENTIALITY AND DATA SECURITY

No individual data will be collected and consequently confidentiality issues are not present.

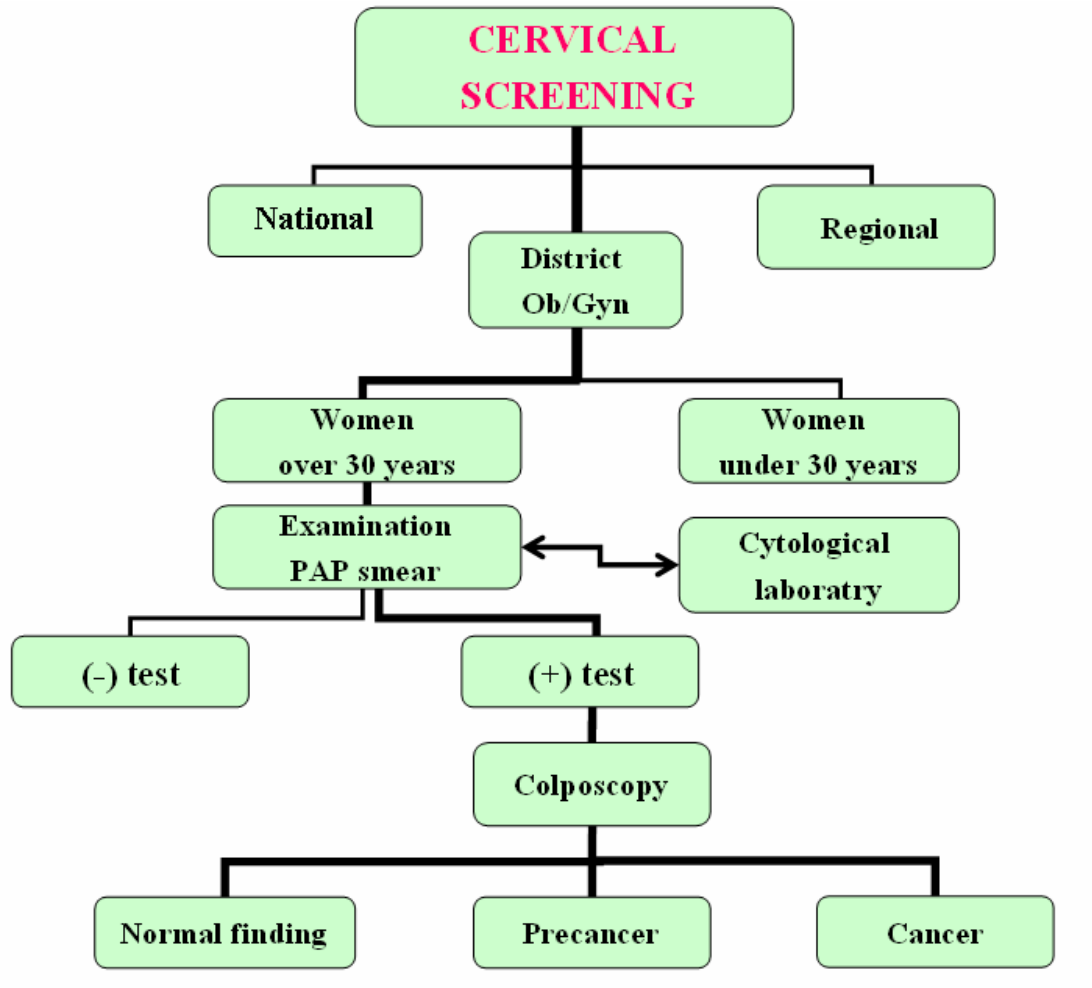
OUTPUT

The main results of the work in each country should be:

a) a report for Health Ministry in order to underline which are the national problems for the evaluation of a cervical cancer screening programme

b) participation in the report that the EUROCHIP Working Team in collaboration with the EUROCHIP Task Force on Cervical Cancer Screening will prepare for the European Parliament

ANNEX A: EXAMPLE OF CERVICAL CANCER SCREENING PROGRAMME SCHEME



8. RESULT 6: RECOMMENDATIONS ON CANCER REGISTRY ACTIVITY

EUROCHIP-2

RECOMMENDATIONS TO THE NETWORK OF COMPETENT AUTHORITIES TO SUPPORT CANCER REGISTRIES

2nd May 2006

EUROCHIP-2 The action
Grant Agreement: n° 2003115
European Commission - Directorate C
Public Health and Risk Assessment
Health & Consumer Protection Directorate general

Project leader:
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INTRODUCTION

This paper would like to underline the important role of the *population-based cancer registries* for the European Public Health system.

On 23 September 2002, the European Parliament and the Council adopted a new Community action programme for Public Health. This programme runs for a 6 year period (2003-2008).
This programme is based on three general objectives: health information, rapid reaction to health threats and health promotion through addressing health determinants.
About the first objective, the purpose of the European Union Health Information System is to provide quality, relevant and timely data, information and knowledge in order to support public health decision-making at European, national, sub-national and local level. Within each geographical area, the Health Information System is a tool necessary to make decisions at strategic, control and operational level, to set directions, to monitor their implementation and to evaluate their impact. The Community Public Health Programme aims to produce comparable indicators on health and health-related behaviour of the population (e.g. data on life styles and other health determinants); on diseases (e.g. incidence and ways to monitor chronic, major and rare diseases); and on health systems (e.g. indicators on access to care for everyone, on quality of care provided, on health human resources, and on financial viability of health care systems).
One of the European Commission Public Health Structures is the Network of Competent Authorities. Its main task is to provide advice on an implementation strategy in regard to the health information and knowledge strand of the Public Health Programme.

About cancer, the EUROCHIP project identified a list of indicators describing cancer in terms of burden, prevention activity, standards of care and cure rates. Various indicators on cancer burden (incidence, survival and prevalence) are collected by *population-based cancer registries*, that is bodies organised at local or at national level in the majority of the European countries. These bodies allow to have comparable cancer data across Europe. Comparisons of cancer registry data across Europe were already performed by IARC (International Agency of Research on Cancer), EUROCARE (for cancer survival), EUROPREVAL (for cancer prevalence), ecc.

Population-based cancer registries **are necessary to reach the objectives of the European Union Health Information System. Each European country has to facilitate the activity of cancer registries both in terms of funding and in terms of availability of cancer patient data (privacy law restrictions sometimes did not allow a cancer registry to work).**

This document, produced by EUROCHIP, aims to underline to the Network of Competent Authorities the importance of *population-based cancer registries* for the European Union Health Information System and the main problems highlighted by them in Eastern European countries.

WHAT IS EUROCHIP?

EUROCHIP-2 is a Europe-wide multidisciplinary three-annual (2004-2007) project 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 by allowing comparison with Europe as a whole and forming a basis for political action on health. The starting point of the project is the network established by EUROCHIP-1.

The EUROCHIP-1 project under the large-scale Health Monitoring Program (HMP), funded by the European Commission, has provided an important boost to the Europe-wide surveillance system on cancer. EUROCHIP-1 identified a list of indicators describing cancer in terms of burden, prevention activity, standards of care and cure rates. Indicators were selected according to the criteria of ease of collection and comparability. Standardised methods of validating and collecting data were also been proposed. The final list was one of maximum consensus between all interested parties.

More than 130 experts in various fields pertinent to cancer (physicians, economists, sociologists, epidemiologists, planners, etc.) from all Europen Union (EU) member countries (15 countries) participated in drawing up the list and a final report containing the proposed list of indicators and appending detailed information regarding them was produced.

To reduce inequalities across Europe, some countries have to prioritise action on prevention, others on care, others on surveillance, etc. Other countries for basic epidemiological information need to establish or to maintain population-based cancer registries. However, it is vital for each countries' success in the fight against cancer, that the trans-national European nature of the study is maintained at all levels of data collection, data analysis, problem evaluation, and action. Cancer control must develop where different tasks are evaluated and implemented as part of the whole process.

EUROCHIP-2 (www.tumori.net/eurochip) is:

- **producing results at two levels: for European Union as a whole and for individual countries**
- **focusing on the problems and inadequacies of individual countries in order to suggest policy changes at the country level**
- **organising activity as a continuous process, i.e. taking a global view of the information system, involving on one hand the promotion of data collection, on the other analysis of already available data, on the other evaluation promoting political action on established inequalities; all as a continuously re-evaluated process**
- **organising actions to reduce cancer health information problems.**

WHY A CANCER REGISTRY?

Cancer is a major burden in each European country. Reducing the nation's cancer burden is a great cause that involves many people, including physicians, researchers, epidemiologists, public health planners, legislators, medical students, and others. All of these people appreciate and rely on cancer data in their effort to win the "War against Cancer". To do this population based cancer registries (CR) are fundamental.

Unlike the system for certain communicable diseases, the registration process for cancer is not usually based on notifications from individual clinicians. Instead, cancer registries receive routine (when possible electronic) notifications from a variety of sources. These sources include district general hospitals, cancer centres, hospices, private hospitals, cancer screening programmes, other cancer registers, primary care, nursing homes and death certificates. Data are frequently received from several sources within an individual institution (e.g. pathology departments, medical records and radiotherapy databases) and refer to entire population covered by the CR.

Cancer registry data are necessary for those interested in the aetiology, diffusion of various diagnosis and treatment procedures. Cancer patient data at population level collected by cancer registries are becoming useful for several reasons.

There are five main reasons why it is necessary to collect information that identifies patients.

- Patients often attend more than one hospital. It is important to know that a cancer reported from a number of different hospitals relates, in fact, to the same person, otherwise registrations would be duplicated and cancer incidence rates would appear to be misleadingly high.
- An important indicator of the effectiveness of cancer services is the percentage of patients who survive their cancer. It would not be possible to link a patient's date of death to their cancer records without identifying information.
- People are often concerned that there might be a high risk of cancer in their locality. These risks cannot be investigated properly without knowing where patients with cancer live (based on postcode of residence).
- People are often worried that their family history may put them at high risk of cancer. An accurate family history is crucial if these individuals are to be offered appropriate advice. The CR is often asked by clinical geneticists to confirm the details of a cancer diagnosis in a relative of someone attending their clinic. In the case of living relatives, this information is only released with the written informed consent of the relative concerned. Often, especially when medical records have been destroyed, the CR is the only available source of such information.
- Occasionally, a previously unforeseen, significant late effect of therapy comes to light many years or even decades after that treatment was in widespread use. In these circumstances, it will be necessary, using all available information sources including the cancer registry, to try and trace all patients who might be at risk, so that they can be informed and counselled about possible interventions to reduce their risk.

WHAT IS A CANCER REGISTRY USEFUL FOR?

Cancer registries undertake a range of public health surveillance and health protection functions. The main functions of cancer registries are:

- monitoring trends in cancer incidence, prevalence and survival (and mortality) over time and between different areas and social groups
- evaluating the impact of environmental and social factors on cancer risk
- supporting investigations into the causes of cancer
- evaluating the effectiveness of cancer prevention and screening programmes. For example, population based data are required to monitor the effectiveness of the existing national screening programmes for breast and cervical cancer and to inform the design of new programmes, e.g. screening for colorectal and ovarian cancer
- evaluating the quality and outcomes of cancer care by providing comparative data about treatment patterns and outcomes
- investigating differences in cancer incidence, survival and access to treatment between social classes and thus contributing to programmes aimed at reducing health inequalities
- providing information in support of cancer genetic counselling services for individuals and families at higher risk of developing cancer.

For example, what we know as a result of information obtained from cancer registration:

- mesothelioma is caused by exposure to asbestos
- skin melanoma rates have been increasing year on year
- lymphoma and oral cancer rates are higher in ethnic minorities
- there is wide variation in how cancer is treated around the country and across countries
- cancer survival for patients living in poor areas is lower than for those living in rich areas
- cancer survival in children has improved dramatically over the last 30 years.

What we may not know in future if cancer registration becomes unreliable:

- how many cancers occur each year, and which are the most common
- whether cancer rates are increasing or decreasing
- if cancer incidence rates in a country are higher or lower than in other countries
- if cancer survival rates in a country have caught up with other European countries
- if inequalities in cancer treatment or survival between rich and poor have been reduced
- if cancer screening programmes are effective
- if people living near landfill sites or power lines have an increased cancer risk
- whether some late deaths in childhood cancer survivors are related to earlier treatments
- if the risk of developing certain cancers is higher in some occupational groups.

CURRENT SITUATION IN EASTERN EUROPE

In Eastern European countries there was be a transition from a centralised, government funded system of health care into one in which the funding is based mainly on a new national health insurance scheme. In these circumstances, there is a need to be vigilant in maintaining those health care information systems which provide data on the health profile of the nation, and which can be used to evaluate the effectiveness of the health care programmes. Health insurance-based statistics are very often related to the use of resources, and have proved of little value in monitoring effectiveness of cancer control activities (prevention and treatment). On the other hand, it is well recognised that cancer registries are particularly useful tool for this purpose.

Even if Slovakia, Estonia and Bulgaria are in the fortunate situation of already possessing a national cancer registry, in these three countries cancer registries have a set of problems in terms of funding and in terms of availability of cancer patient data.

For example Estonia made a huge public health error by legislation to make it impossible for the Estonian cancer registry to obtain access to death certificates. Legislation to facilitate such access in the interests of public health would be a wiser course of action.
Without access to death certificates, as an example, the registry cannot produce reliable estimates of cancer survival for the whole population. As a result:

- we will not know in future if cancer survival rates in Estonia are improving
- we will not know if national or regional investment in earlier diagnosis, screening or treatment services has improved cancer survival for all Estonians
- we will not know if cancer survival in Estonia is approaching the level in other European countries
- we will not even know the true cancer risks of the Estonian population, or how they change with time, because death certificates are crucial to ensuring complete cancer registration

The specific problem for the Bulgarian Cancer Registry is the budget and the support of cancer registration. At present, all health establishments in Bulgaria received their budget from the National Health Insurance Fund via clinical pathways. The National Cancer registry and the 13th regional registries in Bulgaria are parts of health establishments - National oncological hospital and 13th dispensaries. In that case, there is no resources provided for activities like cancer registration, and no national legislation regularizes the statute of that oncological system in Bulgaria.

Poland has the lowest cancer survival in Europe. In order to compare Polish cancer control strategies with other European countries it is necessary that Polish cancer registries participate to international projects aimed to compare cancer strategies and cancer outcomes.

CONCLUSIONS

EUROCHIP-2 is an European project 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.

At this purpose, the main providers of cancer data at population level are cancer registries.

For the European Union Health Information System, cancer registries should have to be considered as the National Institutes of Statistics as they are the only providers of cancer data necessary to estimate cancer incidence, survival and prevalence indicators at population level.

EUROCHIP-2 would like to bring the following points to the attention of the Network of Competent Authorities and the European Commission:

- cancer registries are necessary for cancer control and epidemiological research, public health program planning, and patient care improvement
- cancer registry provide standardized data comparable across Europe
- cancer registries are necessary to implement the European Union Health Information System relatively to cancer
- cancer registries are the unique providers of cancer data at population level

National health authorities should note that:

- **cancer registries need to be maintained and supported**
- **cancer registries need ad-hoc national legislations restricting privacy**

European Commission is encouraged to note that:

- **cancer registries should have to be considered with a role comparable to National Institutes of Statistics**
- **European projects connecting cancer registries are the best way to compare cancer burden across Europe**

9. RESULT 7: REPLY TO THE EC GREEN PAPER ON DIET

Italian Task Force for a National Plan of Dietary Prevention and against Sedentariety

1. Background

In the last 40 years important evidences have arisen suggesting that diet significantly affects the onset of chronic–degenerative pathologies, pain of the developed world.

Association between diet and cancer was studied over a long period and research has now reached a critical turning point. Ecological studies of the 60's, many case–control studies started in the 70's, large perspective studies that begun in the 80's with dietary surveys and bio–banks and, finally, the dietary campaigns of the 90's all contribute to the conclusion that over one third of cancers could theoretically be preventable through changes of eating habits.

Other important evidences in the fields of cardiovascular and degenerative diseases led to the implementation, in some areas of the world, of public health plans on dietary prevention.

2. Italian Task Force for a National Plan of Dietary Prevention and against Sedentariety

Italian Epidemiologists and researchers are working to define a general plan for prevention for all chronic–degenerative diseases where dietary prevention is considered a key action.

This plan looks with interest at the Mediterranean diet as a protective dietary style.

The Task Force should not miss to coordinate with other similar events on dietary prevention in Europe in order to help the creation of a European strategy in the fight against Cancer and Chronic–degenerative Pathologies. The European Public Health Projects EUROCISS, on Cardiovascular diseases, and EUROCHIP, on Cancer, offer the expertise of their members and their Networks to centralize the work related to the proposal.

One of the activity performed by the Task Force is to provide an homogeneous reply to the green book prepared by the European Commission. This reply is here presented.

3. Linked Projects

3.1 EUROCHIP and I TUMORI IN ITALIA

The project **EUROCHIP–1**, funded in 2002–2003 by the EC within "Health Monitoring Programme" (HMP), has contributed to the development of a cancer surveillance system in Europe. HMP was implemented to produce an European public Health Data Bank and EUROCHIP–1 has contributed to this by proposing a list of Cancer Indicators for the development of an information system amongst the European Countries.

EUROCHIP–1's results provided the basis for EUROCHIP–2 The action. The project has enlarged the information network, improves access to cancer information and knowledge in all European Countries and promotes actions to improve health control in the fight against inequalities. Through National Consensus Conferences, **EUROCHIP–2** identifies the cancer–control deficient areas in each country where a public health action is desired and promotes actions characterised by a strong European imprimatur. EUROCHIP–2 helps the relationship between the world of knowledge and the world of decisions.

The project "**I Tumori in Italia**" is the Italian link to the project EUROCHIP–2, and it is aimed to develop a cancer information system through a Portal of Cancer Epidemiology (www.tumori.net) The Italian Cancer Research Institutes, the Institute of Health and the major Italian Cancer Networks are involved. The project gives access to data for the epidemiological description of cancer at national and regional level, provides information on control delays and data for health plans on cancer prevention, early diagnosis and care.

"I Tumori in Italia" have provided incidence estimates and projections for all cancer sites. Projections suggest that incidence levels of the Southern Italian regions will reach the levels of Northern Italian Regions. Cancer epidemiology geography will then be completely modified: Southern regions would lose the origin protection in comparison with the rest of the Italian regions.

Estimates of Lombardy (Northern region characterised by the highest cancer mortality level and one of the highest incidence levels) and Campania (Southern region) show that in 2010 incidence rates for males will be higher in Campania than in Lombardy, and for females the risk will be equal.

It is possible to assume that one of the determinants of risk increment in the Southern Italy are the dietary changes that are progressively taking place. The substitution of the Mediterranean diet with a more northern diet, associated to oncological risk, may be amongst the causes of this important phenomenon. The promotion of primary prevention programmes both on national and regional level would be necessary to slow the increasing trend of cancer incidence. I

3.2 EUROCISS and CUORE

The **EUROCISS** project (European Cardiovascular Surveillance Set) was set up in 2000 by a partnership of EU countries and financed by the European Commission as part of the Health Monitoring Programme with the aim of developing health indicators and recommendations for monitoring the distribution and impact of cardiovascular diseases (CVD) in Europe.

The project was structured in two consecutive phases: the first one between 2000 and 2003 and the actual one which will end in 2007.

The main objectives of EUROCISS phase I were:

To identify which CVD are of importance in public health. The choice was based on two criteria: high prevalence of disease in terms of mortality, morbidity and disability and the possibility of prevention, in terms of modifiable risk factors.

Therefore, diseases included in the project were: acute myocardial infarction/acute coronary syndrome, ischaemic heart diseases, heart failure, cerebrovascular accidents and other cardiovascular diseases of atherosclerotic origin.

To realize an inventory of available indicators in partner countries, which has led to the identification of specific indicators available for single specific diseases or for groups of cardiovascular diseases and to compare data collection methods used in the different countries.

To develop recommendations for collection and harmonization of indicators. The specific indicators were divided into: (1) actually available, (2) those obtainable by matching several indicators, which then require further elaboration to be reliable and available in short time. For example, attack rates, which are collected through population-based registers, are obtained by matching mortality and hospital discharge data for acute events; (3) those which need long periods of time and more resources to be implemented and then validated.

The II phase of EUROCISS foresees the following objectives:

To update the inventory of available indicators in Member States (MS)

To prepare the manual of operations for the implementation of population-based registers of acute myocardial infarction/acute coronary syndrome and stroke in countries lacking these surveillance systems starting from the experience of those countries which have them running in order to assess the attack rate/incidence of CVD;

To prepare the manual of operations for the implementation of CVD surveys on the basis of standardized procedures for assessing the prevalence of CVD in MS.

To create a network of Member States with expertise in chronic diseases surveillance to foster the collection of valid, reliable and comparable indicators in order to improve the surveillance and the prevention of CVD.

The **Cuore** Project - epidemiology and prevention of ischaemic heart diseases - launched in 1998, is financed by 1% of the National Health Fund and is coordinated by the Istituto Superiore di Sanità. The aims of the project were to:

1. estimate the impact of cardiovascular diseases in the general population;
2. evaluate the distribution of cardiovascular risk factors in representative samples of the Italian population;
3. evaluate the cardiovascular risk in the Italian population.

The first objective has been achieved through the implementation of the national register of coronary and cerebrovascular events involving individuals ages 35-74 in eight representative areas of the country (Brianza, Caltanissetta, Firenze, Friuli-Venezia Giulia, Modena, Napoli, Roma and Veneto) to estimate the frequency of acute coronary and cerebrovascular events. The registers allows to produce reliable attack, incidence and mortality rates of acute coronary and cerebrovascular events occurring all over the country.

The second objective has been achieved through the setting up of the Osservatorio Epidemiologico Cardiovascolare, resulting from the collaboration between the Istituto Superiore di Sanità (ISS) and the Associazione Nazionale Medici Cardiologi Ospedalieri (ANMCO). The OEC has as its main objectives: the description of the distribution of cardiovascular risk factors in the Italian population; the assessment of the prevalence of high risk conditions, that is hypertension, hypercholesterolemia, smoking habit, physical inactivity, obesity, diabetes; the assessment of the prevalence of cardiovascular diseases of arteriosclerotic origin, such as angina pectoris, myocardial infarction, TIA (Trans Ischaemic Attack), stroke, intermittent claudication and atrial fibrillation.

The third objective has been achieved through the risk chart tables and the calculation of the Italian cardiovascular risk score. The cardiovascular risk chart is a simple and objective way of assessing the likelihood of experiencing a first major cardiovascular event (myocardial infarction or stroke) over the following ten years, when the values of six risk factors - gender, history of diabetes, smoking, age, systolic blood pressure and total serum cholesterol – are known.

The individual risk score takes also into account serum HDL cholesterol and the prescription of anti-hypertensive medications.

The CUORE Project, allowing the identification of cardiovascular risk factors, promotes a targeted action toward those modifiable risk factors: smoking habit, diet and sedentariness. Since high cardiovascular risk is strongly related to these factors, the adoption of an healthy lifestyle, giving up smoking, consuming healthy food and making physical activity, is an extremely effective preventive tool .

Replies to the GREEN PAPER
"Promoting healthy diets and physical activity: a European dimension for the prevention of overweight, obesity and chronic diseases"

Health across EU policies

What are the concrete contributions which Community policies, if any, should make towards the promotion of healthy diets and physical activity, and towards creating environments which make healthy choices easy choices?

Proposed by Dr. A. Micheli – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan

Health is a shared value and must be promoted. Dietary lifestyles are associated with a set of factors: economy, agriculture, education, etc. The European Union could acknowledge that healthy diet and correct lifestyle should be central elements of different health plans in various European countries.

Proposed by Dr. R. Tumino – Ragusa Cancer Registry

Regional healthy dietary cultures (based on local food availability) have to be promoted, in opposition to "food–globalization" trends.

In other words, nutritional and dietary recommendations have to be based also on dietary culture. This way healthy choices could be easy choices.

For example in Sicily (in principle in small provinces as Ragusa) persons (also young people) maintain the use to consume wild vegetables, that are rich of antioxidants.

Two articles are published on this matter:

- Salvatore S, Pellegrini N, Brenna OV, Del Rio D, Frasca G, Brighenti F, Tumino R. Antioxidant Characterization of Some Sicilian Edible Wild Greens. J Agric Food Chem. 2005; 53:9465–71.
- Tumino R, Frasca G, Giurdanella MC, Lauria C, Krogh V. Consumption of wild vegetables in the EPIC cohort of Ragusa (Sicily). IARC Sci Publ. 2002;156:115–6.

From these evidences, restaurants of the province of Ragusa were invited to introduce wild vegetables in their food lists. The initiative was favourably accepted by the restaurants.

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa
Dr. P. Baili – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan

Organization of a European "healthy lifestyle and physical activity day" to promote good nutrition behaviours by arranging events on local food and sport events in order to discuss about the relevance of these topics for human health.

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Messages on good lifestyles have to reach teenagers and schools. Health education and prevention should be mandatory subjects within specific lectures in the European schools.

Which kind of Community or national measures could contribute towards improving the attractiveness, availability, accessibility and affordability of fruits and vegetables?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

After giving a complete information on fruit and vegetables consumption, it is necessary to grant quality control on products and to promote price policies to make products more affordable.

Proposed by Dr. A. Micheli – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan
Dr. C. Amati – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan
Dr. P. Baili – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan

- In Milan, once a year, the council promotes the offer of 5 kg of fruit and vegetable at low cost in the fruit & vegetables district markets.
- National directives to promote "Fruit & Vegetable Saving Days". Every day of the week supermarkets and street shops should apply a 20% reduction on a different item of fruit and vegetables. The list of items should be decided by directive for the entire calendar year.
- Funding of local productions and favourable conditions for local product importation

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Fruit & vegetables marketing and advertising should be regulated. It is vital to reduce prices of fruit & vegetables to avoid that "healthy diet" could be too expensive.

On which areas related to nutrition, physical activity, the development of tools for the analysis of related disorders, and consumer behaviour is more research needed?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

Analysis of consumer behaviour.

Proposed by Dr. A. Micheli – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan

Studies on interventions and their efficacy to modify dietary behaviour

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Research on dietary behaviours in childhood and teenagers.

The Public Health Action Programme

How can the availability and comparability of data on obesity be improved, in particular with a view to determining the precise geographical and socioeconomic distribution of this condition?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

It could be interesting to focus attention on nursery schools as proxy indicating the way families deal with diet and physical activity.

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

School is the best source to obtain comparable data on young-age-obesity.

How can the programme contribute to raising the awareness of the potential which healthy dietary habits and physical activity have for reducing the risk for chronic diseases amongst decision makers, health professionals, the media and the public at large?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

Promote estimates of the number of avoidable deaths that would emerge if a correct dietary behaviour was adopted in the European countries.

Which are the most appropriate dissemination channels for the existing evidence?

Proposed by Dr. P. Baili – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan

Supermarkets. Little book dedicated to consumers (for example with correct definition of portions) to prepare for supermarket diffusion.

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa
Dr. F. Bellù – Alto Adige Cancer Registry

Schools. A structural programme to reach population and families from off-spring early ages.

Consumer information, advertising and marketing

When providing nutrition information to the consumer, what are the major nutrients, and categories of products, to be considered and why?

Proposed by INRAN group – Istituto Nazionale di Ricerca per gli Alimenti e la Nutrizione – Rome

The choice of nutritional information to be delivered to the general public depends on different types of issues: the compliance of dietary intakes with the RDAs for the target population, the knowledge the population have about nutritional facts and the characterisation of foods (food groups and staple foods) in terms of the correlation with healthy dietary styles (food profiling). The most important actions to undertake are linked to the answers to some questions to outline the information background: a) are dietary intake data available?; b) are RDAs estimated?; c) are dietary guidelines published? If yes, are those food-based dietary guidelines (FBDG), which tools are used to be circulated (pyramid, temple, etc.)?; d) are consumers attitudes, beliefs, perceptions, knowledge, trust data available? e) are anthropometric figures currently surveyed?; f) are training programmes currently implemented? To whom? In other terms a monitoring system is the base to build frameworks to act against non-healthy styles, including overweight and obesity. Moreover, it is important to stress the role of investigating the phenomena per population subgroups. An integrated information system to elaborate indicators would be very helpful for food policy actions.

Which kind of education is required in order to enable consumers to fully understand the information given on food labels, and who should provide it?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

Different colouring of the self-regulated area of packaging in order to allow easy understanding of fat (red), minerals (light blue), vitamin (green) content.

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Label should be clearer, with clear characters (magnifying glass should not be needed to read it)

Are voluntary codes (“self–regulation”) an adequate tool for limiting the advertising and marketing of energy–dense and micronutrient–poor foods? What would be the alternatives?

Proposed by Dr. A. Micheli – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan
Dr. F. Bellù – Alto Adige Cancer Registry

Alternatives could include taxation or other economical incentives/disincentives.

How can effectiveness in self–regulation be defined, implemented and monitored? Which measures should be taken towards ensuring that the credulity and lacking media literacy of vulnerable consumers are not exploited by advertising, marketing and promotion activities?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

Surveys to evaluate dietary changes in population

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

The European Union has to approve an ethical code for advertising and marketing.

Consumer education

How can consumers best be enabled to make informed choices and take effective action?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa
Dr. A. Micheli – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan

It is important to standardize as much as possible information that reach consumers.

Promotion of Projects to connect information sources (newspapers, magazines, TV, internet sites)

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Spread correct information in schools at all costs. "Correct information" also means contrast bad habits.

What contributions can public–private partnerships make toward consumer education?

Proposed by INRAN group – Istituto Nazionale di Ricerca per gli Alimenti e la Nutrizione – Rome

Public and private sectors have great opportunities to converge towards common objectives. Private sector can make available tools receiving revenues deriving from the collaboration itself (e.g. non-food enterprises in the cultural field, environmental field, health, mass media, …), but also giving an healthy imprint to foods and food preparations (e.g. appropriate labelling, consumers group in the supermarkets, …) to use for marketing their own products

In the field of nutrition and physical activity, which should be the key messages to give to consumers, how and by whom should they be delivered?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

Mass media communications, public discussions, brochures, etc prepared by public health personnel with scientific knowledge have to underline community advantages (for example less illness means reduction of health expenditure) and personal advantages (for example peaceful elderly age).

Proposed by Dr. P. Baili – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan

1) TV programs promoting physical activity. E.g. in Italy following to the showing of TV program "Ballando con le stelle" ("Dance and with the Stars"), Dancing Schools gained popularity
2) Fruit & vegetable consumption promotion in the episodes of national TV series.
3) Reality shows as "Big brother" to offer free fruit & vegetables for participants and to ban smoking.
4) Supermarkets' Saving Programmes to prise consumers for fruit and vegetables purchase with double (green) points.
5) Supermarkets' Saving Programmes to grant discounts on fruit and vegetables after a given level of (green) points reached by consumers

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

1) Health education and prevention should be mandatory subjects of specific lectures in European schools.
2) Coherent and strong messages could be given by all European Health Ministers

A focus on children and young people

What are good examples for improving the nutritional value of school meals, and how can parents be informed on how to improve the nutritional value of home meals?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

Private Catering Services in Schools to be checked by a multidisciplinary committee (e.g. teachers, parents, nutritionists,) with planning and monitoring tasks to promote healthy diet and adequate physical activity and control meals preparation and conservation.

Proposed by INRAN group – Istituto Nazionale di Ricerca per gli Alimenti e la Nutrizione – Rome

Presently, various municipalities are arranging their own menus and canteen management in schools. Particularly, the administration in Rome has build a system that became a benchmark for European countries and USA, as illustrated in a recent seminar held for the training of an international experts group. Organic food almost in every school, enhancement of applications to manage school canteens and balance meals from a nutritional point of view are the main principles they are referring to. Parents will be informed using ad hoc prepared booklets on top of the usual meetings

What is good practice for the provision of physical activity in schools on a regular basis?

No replies

What is good practice for fostering healthy dietary choices at schools, especially as regards the excessive intake of energy–dense snacks and sugar–sweetened soft drinks?

Proposed by INRAN group – Istituto Nazionale di Ricerca per gli Alimenti e la Nutrizione – Rome

The WHO has indicated the creation of a healthy environment as a priority for increasing the consumption of fruit among school-children. As examples, more healthy products in school vending machines – water rather than soft drinks, fruit rather than packed snacks, etc., distributions of fresh fruit during school time, and so on

How can the media, health services, civil society and relevant sectors of industry support health education efforts made by schools? What role can public–private partnerships play in this regard?

Proposed by Dr. I. Casella – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan

1) A cartoon promoting fruit & vegetables
2) A computer game on “Healthy cooking”

Proposed by Dr. C. Amati – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan

Circulate amongst the youngsters models of superheroes whose power benefits from fruit& vegs consumption (e.g. Popeye).

Food availability, physical activity and health education at the work place

How can employers succeed in offering healthy choices at workplace canteens, and in improving the nutritional value of canteen meals?

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Employers offering healthy choices at workplace canteens to receive incentives.

What measures would encourage and facilitate the practice of physical activity during breaks, and on the way to and from work?

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Employers encouraging and facilitating physical activity at workplace to receive economical incentives .

Building overweight and obesity prevention and treatment into health services

Which measures, and at what level, are needed to ensure a stronger integration aiming at promoting healthy diets and physical activity into health services?

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Each Health service to be prompted to focus the attention on promotion of healthy diets and physical activity.

Addressing the obesogenic environment

In which ways can public policies contribute to ensure that physical activity be "built into" daily routines?

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Public policies to encourage employers with economical incentives to facilitate physical activity at workplace.

Proposed by INRAN group – Istituto Nazionale di Ricerca per gli Alimenti e la Nutrizione – Rome

Policy interventions to enhance physical activity among the population can be studied. First goals could be worktables that involve experts and stakeholders, and promoting co-ordination among governmental organisations to achieve

Which measures are needed to foster the development of environments that are conducive to physical activity?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa
Dr. F. Bellù – Alto Adige Cancer Registry

It is necessary to limit the use of cars increasing number of pedestrian and cycling paths in metropolitan areas.

Socio–economic inequalities

Which measures, and at what level, would promote healthy diets and physical activity towards population groups and households belonging to certain socioeconomic categories, and enable these groups to adopt healthier lifestyles?

No replies

How can the “clustering of unhealthy habits” that has frequently been demonstrated for certain socio–economic groups be addressed?

No replies

Fostering an integrated and comprehensive approach towards the promotion of healthy diets and physical activity

Which are the most important elements of an integrated and comprehensive approach towards the promotion of healthy diets and physical activity?

Proposed by *Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa*
Dr. A. Micheli – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan
Dr. F. Bellù – Alto Adige Cancer Registry

It is really important to take in consideration that healthy diet and adequate physical activity:

- have economic benefits to entire healthcare system
- have direct benefits to people's quality (and duration) of life

It is moreover vital to consider that over-national directives are successful only if :

- they are rational and shared
- they are comprehensible
- they are translated in specific directives for local realities.

Which role at national and at Community level?

Proposed by *Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa*
Dr. A. Micheli – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan
Dr. F. Bellù – Alto Adige Cancer Registry

It is really important to avoid clashes with local dietary traditions.

If these traditions should be abandoned due to unhelthiness, it is essential this is explained clearly

Recommendations for nutrient intakes and for the development of food–based dietary guidelines

In which way could social and cultural variations and different regional and national dietary habits be taken into account in food–based dietary guidelines at a European level?

Proposed by *Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa*
Dr. A. Micheli – Istituto Nazionale per lo Studio e la Cura dei Tumori – Milan
Dr. F. Bellù – Alto Adige Cancer Registry

Promoting specific dietary behaviour of some local areas as examples of healthy diet.

As mentioned above, it is really important to not create clashes with local dietary traditions.

How can the gaps between proposed nutrient targets and actual consumption patterns be overcome?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

To give information about the risks of an hypercaloric diet in absence of a good physical activity. This requires a long period of evidence-based strategy.

How can dietary guidelines be communicated to consumers?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

General practitioners and paediatrician could be the first communicators.

Proposed by INRAN group – Istituto Nazionale di Ricerca per gli Alimenti e la Nutrizione – Rome

The information in question must be dealt with sensitivity. Diet is so related to psychological and cultural sensitivity, some messages can be rejected if not well structured. Some attempts have been made in Italy, see as an example the proceeding of the conference held in Rome 10-11-12 settembre 2002. National Institute of Statistics (ISTAT), “Informazione statistica e politiche per la promozione della salute” (tr. Statistical information and health promotions policy)

In which way could nutrient profile scoring systems such as developed recently in UK contribute to such developments?

No replies

Cooperation beyond the European Union

Under which conditions should the Community engage in exchanging experience and identifying best practice between the EU and non–EU countries? If so, through which means?

No replies

Other issues

Which of the issues addressed in the present Green paper should receive first priority, and which may be considered less pressing?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

Physical and dietary education in schools

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

All aspects considered in the green paper have similar priority.

Are there issues not addressed in the present Green paper which need consideration when looking at the European dimension of the promotion of diet, physical activity and health?

Proposed by Dr. E. Stagnaro – Istituto Ricerca sul Cancro – Genoa

To discuss about the risk of overweight and not only about obesity.

Focus on the quality of physical activity and not only on the quantity.

Proposed by Dr. F. Bellù – Alto Adige Cancer Registry

Focus on alcohol abuse as cause of eating disorders.

Proposed by Sergio Mariotti, Istituto Superiore di Sanità
Claudio Paretti, Andrea Fidanza, Ente per Nuove tecnologie, Energia e Ambiente

It is felt by the writers of the present short report, that two main issues are not adequately dealt with in the Green Paper.

The first issue concerns the problem of **evaluating the dimension of prevention as an issue** promoted by the Green paper. In facing a difficult prevention problem, the first task should be to highlight how big the problem is, especially since there are striking differences in the distribution of health in the EU, more so now that the EU includes 25 member states. The Green Paper, quoting paragraph II.2, states: "*An analysis made by the Swedish Institute of Public Health concludes that in the EU, 4.5% of disability–adjusted life years (DALYs) are lost due to poor nutrition, with an additional 3.7% and 1.4% due to obesity and physical inactivity – a total of 9.6%, compared with 9% due to smoking ….*". It is dubious if these estimates for the whole of EU should be trusted, when the Green Paper declares in other parts that the available measures of obesity are not well enough defined to be reliable and certainly they are not uniform across all 25 members states. If this is true for obesity, an even bigger problem arises for the measures of daily physical activity, both at work place and at home, which are recognised to involve several difficulties.

The situation is still worse for data relative to dietary habits, which differ widely among the 25 member states, while no dietary surveys in a representative sample of the whole population exist in most states. In spite of the warnings above, an approximate evaluation for the whole of EU can be still attempted, basing the estimates on few countries with more available data, and with the acknowledged risk of large possible errors, building on the philosophy that an approximate estimate is still better than no estimate at all. But what about the internal variance of an estimate of this type inside EU member states?

No evaluations exist of the DALYs lost in the individual member states, and no reliable quantitative assessment of the magnitude of the problem posed to the 25 states by obesity and physical inactivity has ever been undertaken.

For all reasons outlined above, it is clear that a quantitative assessment of the differences in dietary habits, physical activity and obesity among the 25 member states, with differences in risk factors leading to different potential DALYs lost, must be attempted, acknowledging that this is not an easy task. At least, a clear understanding of the order of magnitude of these differences is mandatory: if we want to start a large effort for the prevention of overweight, obesity, lack of sufficient physical activity and chronic diseases that derive from these, it is necessary to know to some extent in which one of the member states the problem is larger in order to differentiate and concentrate the preventive effort.

To this purpose, we propose that one of the tasks to be undertaken should be a large effort to collect the most reliable available measures and indicators related to the quantities of interest addressed by the Green Paper, basing these effort on the previous work carried on in the EU in such projects as ECHI and ECHIM. Once suitable measures or proxies or estimates are available, an accurate evaluation of the DALYs lost due to obesity, other nutrition–related risk factors and physical inactivity should be undertaken possibly for each of the 25 member states. Among the factors related to nutrition, special concerns should be reserved to the effects of bad nutritional habits on high blood pressure and high cholesterol, and to the unfavourable effects of low fruit and vegetable consumption.

Such analysis should follow the methods outlined in the recent WHO publication: “Comparative Quantification of Health Risks”.

A second issue concerns the recommendation of the Green Paper to focus prevention efforts on children and young people (paragraph V.3), since “*lifestyle choices pre–determining health risks at adult age are made during childhood and adolescence*”.

We certainly agree with this recommendation. However, we feel that a second category of people deserves special attention, because of their relative frailty, i.e. of their higher mortality risk: **the over 60, including the oldest–old, up to 85 years of age**.

It is now commonly recognised by most gerontologists that there is no age limit to an effective prevention action. Quoting a famous cardiologist, William B Kannel, the Head of the Framingham Heart Study: " *declines in coronary mortality rates in the US have included the elderly, justifying optimism about the efficacy of preventive measures. Most of the elderly have sufficient remaining life expectancy to warrant vigorous preventive management. Trials of risk factor modification in the elderly indicate that decades of exposure to modifiable risk factors can be countered by measures implemented late in life……*" [2]. Another well–known scientist, James W Vaupel, remarks that, following unification of East and West Germany, mortality in the East declined toward prevailing levels in the West, especially among the elderly, providing strong evidence that, although conditions early in life do significantly influence human health and survival late in life, such effects are of less importance than changes in current conditions [3].

After recent research on aging has challenged the inevitability of the linkage of severe impairment with age, the fact that functional loss is no more considered as a necessary and nearly universal correlate of the aging process is demonstrated by the innumerable initiatives to promote physical activity among the elderly in the USA, Canada, UK and Australia.

In the US the governmental Agency for Healthcare Research and Quality (AHRQ) reports about all the activities to promote physical activity among the elderly on their site[4].

Three important statements that can be found in the reports of the AHRQ are:

1. It's never too late to become physically active. No one is too old to enjoy the benefits of regular physical activity.
2. Investing a small amount of time in becoming more active can produce big dividends in better health. Spending at least 30 minutes in moderate activity, such as a brisk walk or raking leaves, on all or most days of the week has remarkable health benefits for older adults.
3. Research has identified a number of key strategies for what we can do, as individuals and in our communities, to help older people become more active.

A major national planning document for aging and physical activity was released in the US in 2001, to serve as a guide for multiple organizations, associations and agencies, to inform and support their planning work related to increasing physical activity among America's aging population: *The National Blueprint: Increasing Physical Activity Among Adults Aged 50 and Older* [5].

The document concludes that there is a substantial body of scientific evidence which indicates that regular physical activity can bring dramatic health benefits to people of all ages and abilities, and that this benefit extends over the entire life–course.

As a result of the Blueprint, the Active Aging Toolkit was developed by researchers to help healthcare providers prescribe physical activity programs for their older patients: *The First Step to Active Health* [6] provides an evidence–based, progressive activity program. The goal of the program is to improve health and functional ability, to promote independence, and to help prevent chronic disease and disability in adults over age 50. The program includes a step–by–step

approach to improve physical abilities with a variety of simple activities, including cardio/aerobic, flexibility, strength, and balance activities.

Another instruction manual with similar purposes has been developed by the Center for Healthy Aging of the US National Council On The Aging [7], and a guide to physical exercise which includes a DVD or VHS video by the National Institute on Aging [8].

In Australia, the UPLIFT study successfully used physical activity in the management of depressed old people, by means of a progressive resistance training program, while the University of Western Australia started in 2003 a three–year community–based physical activity program focused on people between 60 and 80 years old.

The WHO released in 1996 the Heidelberg guidelines for promoting physical activity among older persons [9], and the scientific committee in charge of developing these guidelines selected those people aged 50 and above as the most appropriate target, i.e. the group of people for which "*the benefits of regular physical activity can be most relevant from the point of view of avoiding or minimizing many of the physical, psychological and social problems which often accompany advancing age*". The WHO also prepared a report aimed at old people's physicians to recommend the prescription of physical activity to their patients: "*Growing older, staying well*" [10].

By contrast to all the initiatives cited above, little is known about systematic promotion of physical activity among the elderly in Italy and in many EU member states.

We suggest that a promotion of physical activity among people aged 60 and above should be undertaken by means of initiatives similar to those described above that proved to be successful in the US and Australia.

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10. LIST OF THE ANNEXES

Annex 01. List of participants