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# EUROCHIP-III

## European Cancer Health Indicator Project-II

## Common Action

INTERIM SCIENTIFIC REPORT

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# 1. THE EUROCHIP-3 PROJECT

## 1.1 INTRODUCTION

EUROCHIP-1 made available a comprehensive list of indicators covering key cancer aspects i.e. burden, prevention, standards of care and cure rates. More information is available on cancer than for other diseases, thanks to a long established tradition of cancer registration in the majority of Member States (MSs). The picture of cancer in Europe offered large regional inequalities in incidence, survival and mortality, reflecting the difficulties of European MSs to modify health systems to reduce the risk of cancer, improve control, and bring results research to a benefit for all citizens and patients. Aims of the EUROCHIP-2 were to improve the organization and accessibility of information in Europe and discuss on cancer control priorities at national and European level. With EUROCHIP-2 specific studies were activated in the majority of EU MSs with focus on European cancer health inequalities.

EUROCHIP-3 is a multidisciplinary 3-year common-action project to remedy major inequalities in cancer, and form the pillars of a EU cancer control strategy. The cancer inequalities addressed by EUROCHIP-2 are: 1. Women die due to avoidable causes of death: excess of cervical cancer mortality because of lack of screening. 2. The European cancer information system is quite complete in some Member States and poor in others. 3. The needs of people with a past diagnosis of cancer are often inadequately met. 4. Cancer management costs are increasing faster than resources. To work against these inequalities EUROCHIP-3 was organized into work packages (WP): WP-4 to reduce avoidable cancer deaths in 5 MSs; WP-5 to extend cancer registration to areas where registration is lacking; WP-6 to develop indicators for rehabilitation of cancer survivors; WP-7 to investigate new methods to reduce costs of cancer control.

This interim report is organised with the present introductive chapter to present the project and its organization, followed by a chapter for each work package (WP).

## 1.2 BACKGROUND: EUROCHIP-1 AND -2

The “EUROCHIP-1” project (2001-2003) was subsidized by the EC in the Health Monitoring Programme (HMP) and provided an important boost to the Europe-wide surveillance system on cancer. With the participation of more than 130 multidisciplinary EU cancer experts (i.e. physicians, economists, sociologists, epidemiologists, planners) from all 15 European Union Member States (EU MS), the project produced a list of indicators describing burden, prevention, standards of care and cure rates, for cancer. Indicators were selected by criteria of collectability and comparability. Standardised methods of validating and collecting data were also proposed. The final list was one of maximum consensus between all interested parties, and offers a starting point to plan actions for the reduction of inequalities across Europe, using a Europe-wide approach at all levels. An on-going cancer control system should be encouraged and

different cancer health (e.g. data collection and analysis, problem evaluation and political action) should be evaluated and implemented as part of a whole process.

This concept lead to EUROCHIP-2 Project aimed to encourage action to reduce inequalities in cancer control. The project acted in three main intervention areas in Europe:

1. Early diagnosis: in Estonia, Lithuania, Bulgaria, Romania, and Latvia there is an increase trend in cervical cancer mortality rates in discordance with all other European Countries. The EUROCHIP-2 activity focussed on the possibility of re-activating cervical cancer screening programmes in the interested countries. Specific assessment studies were performed in each country to underline major problems in the organization of screening programmes.
2. Cancer diagnosis and treatment indicators: EUROCHIP-2 promoted specific feasibility studies to evaluate the possibility to collect the indicators "Percentage of cancer cases with early diagnosis", "Cancer treatment delay", "Compliance with best oncology practice" at population level. They were run for two cancer sites: breast and colon, in Czech Republic, Cyprus, Finland, France, Ireland, the Netherlands, Poland, Portugal, Slovakia, Slovenia, Spain, and UK.
3. European coverage of cancer registration: the European Information System requires the adequate coverage of the European Union by cancer registration. Scientific evaluations, political pressure and networking activity were initiated with the objective of stirring the attention of stakeholders to the problem of lacking registration in Greece and Luxembourg.

### 1.3 EUROCHIP-3: WORK PACKAGES

There are 7 WPs in EUROCHIP-3: three horizontal WPs i.e. coordination (WP-1), dissemination (WP-2), evaluation (WP-3), and four vertical WPs focussing respectively on cervical screening (WP-4), cancer regsitry (WP-5), cancer rehabilitation indicators (WP-6) and cancer costs (WP-7).

WP-1 is run by Andrea Micheli and the EUROCHIP-3 Working Team at the Descriptive Studies and Health Planning Unit based at the main partner institute INT in link with the EUROCHIP-3 Steering Committee. The Coordination WP is in charge of the overall networking and bureaucratic activity behind the development of the entire project.

WP-2 is run by Alberto Costa and the Cancer World Team at the European School of Oncology, Milan, Italy. WP-3 makes available ESO's communication expertise and capacity to help the identified target audiences successfully receive the results of the EUROCHIP WPs with the final aim of bridging the way of European cancer information to cancer stakeholders such as cancer patients, health policy makers and health care professionals.

WP-3 is run by Zdravka Valerianova, Director of the National Cancer Hospital in Sofia, Bulgaria in collaboration with the Health Psychology Research Centre (HPRC) in Sofia. The Evaluation WP is responsible for assessing the completion of the project's deliverables by monitoring a number of given indicators linked with the project scheduled timeframe.

WP-4 is run by Ahti Anttila, Mass Screening Registry Director at the Finnish Cancer Registry in Helsinki, Finland. Marc Arbyn, director of Cancer Epidemiology Unit of the Scientific Institute of Public Health in Brussels, collaborates at the WP-4. The work package further develops the specific activities carried out on cancer screening with the project EUROCHIP-2 and investigates the issue of poor adherence to cervical cancer screening programmes in Bulgaria, Romania, Estonia, Latvia and Lithuania as one of the most significant and preventable determinant of high mortality rates for cervical cancer in these EU countries.

WP-5 is run by Renée Otter, Director at the Comprehensive Cancer Centre (IKNO) in Groningen, the Netherlands, and includes two key European cancer-information related objectives: a) to evaluate the status of the collection of EUROCHIP-1 cancer registry indicators in the EU with focus on the EUROCHIP-2 pilot-study indicators on the diagnostic and treatment indicators (stage at diagnosis, compliance with guidelines, delay of cancer treatment); b) to promote the creation of cancer registration in the two EU countries lacking population -based registration i.e. Greece and Luxembourg.

WP-6 is run by Piret Veerus, Epidemiologist at the National Health Development Centre in Tallin, Estonia. It discusses the collectability and relevance of cancer rehabilitation indicators in the EU and will provide the EC with a list recommended for collection in all EC Member States.

WP-7 is run by Andrea Micheli and the EUROCHIP-3 Working Team at INT in Milan, Italy. With this WP a seed is being planted for rethinking cancer cost in the perspective of extending high standard care to the ever-growing number of patients in low-resource countries in the EU, and proposing best practice in high income EU countries with deficient care systems. A list of procedures characterising the care path for breast cancer and child leukaemia is discussed and cost alternatives are examined.

### 1.4 EUROCHIP-3 ORGANIZATION

Some groups which were created in EUROCHIP-2 are maintained in EUROCHIP-3:

- Working Team-WT: coordinating the project;
- Steering Committee-SC: main decision-making body;
- Domain Groups of Specialists-DGS: European specialist groups dedicated to specific domains: cervical screening (WP-4), cancer registry and epidemiology (WP-5), cancer rehabilitation (WP-6), breast and childhood cancer costs (WP-7);
- National Groups of Specialists-NGS: consensus groups active in Lithuania, Latvia, Estonia, Bulgaria, Romania and Poland (WP-4);
- Panel of Experts-PE: composed of one cancer expert per each EU Member State, i.e. experts from cancer institutions and major European cancer networks (International Agency Research on Cancer-IARC, European Cancer Network-ECN, EUROCARE, EUROPREVAL, European Network of Cancer Registries-ENCR, European Coalition Against Cancer-ECPC), and DGS leaders. The PE is engaged in the promotion of EUROCHIP-3 results (end of the project).

## 2. EUROCHIP-3 MAIN RESULTS

The main results of the first period of the EUROCHIP-3 project (detailed described in the following paragraphs and annexes) are:

- co-organization of the 3rd International Cancer Control Congress (see par 3.2). Information on the congress are available at http://www.cancercontrol2009.com/;
- regular updates were circulated to the Network with respect to the constitution of the Joint Action European Partnership for Action Against Cancer in connection with the communication from the Commission to the European Parliament, the Council, the European Economic And Social Committee and the Committee of the regions (http://ec.europa.eu/health/ph_information/dissemination/diseases/docs/com_2009_291_en.pdf);
- submission of five scientific articles on cervical screening situation in Eastern Europe (abstracts in Annexes 1-5);
- the 2nd edition of the EU guidelines for Cervical cancer screening screening were distributed to the EUROCHIP Network (http://annonc.oxfordjournals.org/content/21/3/448.full.pdf);
- preparation of protocols for cervical screening adherence studies in Eastern European countries (par 6.3 and Annexes 7-12);
- participation of Poland in the WP-4 activity (not initially foreseen);
- design of the qualitative questionnaire for cancer registry indicator availability in Europe (par 7.3 and Annexes 13-15);
- agreement with ENCR (European Network of Cancer Registries) and EUROCOURSE project to avoid work duplication in Europe on cancer registry indicators;
- training course for Greek cancer registry operators (see par 7.4 and Annex 16);
- discussion on an initial list of cancer rehabilitation indicators (Annex 17);
- start of activities for WP-7 (see par. 9).

# 3. WP-1 COORDINATION

## 3.1 MEETINGS

WP-1 members participated in the following meetings/conferences:

| Date | Place | Aims | Activity* |
|---|---|---|---|
| 26/09/2008 | Tallinn | EUROCHIP-3 WP-4 and WP-6 activity coordination | Organizer |
| 31/10/2008 | Milan | EUROCHIP-3 Steering Committee meeting | Organizer |
| 20/01/2009 | Sofia | EUROCHIP-3 WP-4 activity discussion | Participation |
| 10/03/2009 | Amsterdam | EUROCHIP-3 WP-5 activity discussion | Participation |
| 19/03/2009 | Bruxelles | Meeting "European Partnership Action Against Cancer" | Invited |
| 29/05/2009 | Costantia | EUROCHIP-3 WP-4 dissemination | Invited |
| 06/08/2009 | Phone call | EUROCHIP-3 WP-2 activity coordination | Participation |
| 29/09/2009 | Bruxelles | Meeting "European Partnership Action Against Cancer" | Invited |
| 26/10/2009 | Phone call | Discussion on Cernobbio's meeting with WP-2 | Participation |
| 08-11/11/2009 | Cernobbio | 3rd International Cancer Control Congress | Co-organizer |
| 08/11/2009 | Cernobbio | EUROCHIP-3 WP-4 and WP-2 coordination | Participation |
| 11/11/2009 | Cernobbio | EUROCHIP-3 WP-6 activity discussion | Participation |
| 08/12/2009 | Bruxelles | Meeting "European Partnership Action Against Cancer" | Invited |
| 28/01/2010 | Luxembourg | Meeting "European Partnership Action Against Cancer" | Invited |
| 16/03/2010 | Rome | EUROCHIP-3 WP-7 activity discussion | Organizer |

* "Organizer": WP-1 members organized (or co-organized) the event; "Participation": WP-1 members participated in the discussion and helped in the organization of the event; "invited": WP-1 member/s was/were invited to participate in the event.

## 3.2 3RD INTERNATIONAL CANCER CONTROL CONGRESS (ICCC-3)

EUROCHIP-3 Working Group co-organized the 3rd International Cancer Control Congress (ICCC-3). The congress was an occasion to share and discuss on cancer control experience across the world focussing on Low-Medium Income country situation. It also aimed to create possible interaction for cancer control projects between European and African Unions. About 400 delegates from 60 countries participated at the congress. These are the main results:

- Scientific monograph published in Tumori Volume 95 (5) in September-October 2009 (http://www.tumorionline.it/index.php?archivio=yes&vol_id=455) with 6 articles on cancer control experience in the world. More than 100 authors from 30 countries participated in the monograph;
- 131 posters, 21 invited speakers and 64 oral presentations in 6 sessions and 33 workshops;
- Availability of meeting spaces for international projects, organizations and bodies: EUROCARE, EUROCHIP, CONCORD, the European School of Oncology (ESO), the International Union Against Cancer (UICC), the Organization of European Cancer Institutes (OECI), Alliance Against Cancer (ACC), the Italian Federation of Oncology Voluntary Associations (FAVO), Terry Fox Foundation, the African Palliative Care Association (APCA), Lance Armstrong Foundation, World Health Organization, International Agency of Atomic Agency (IAEA), Italian Health Ministry, Lombardy Region;
- The *Cernobbio declaration* to sustain cooperation on cancer control between European and African Unions was signed by more than 120 participants and is being endorsed by the EU and AU heads;
- An European parliamentary question was presented after ICCC-3 to sustain the congress request to consider cancer in the international collaboration policies between European and African Unions.

## 3.3 WEB SITE

The EUROCHIP web-site was updated for the interim report presentation at www.tumori.net/eurochip.

# 4. WP-2 DISSEMINATION

## 4.1 MEETINGS

WP-2 members participated in the following meetings/conferences:

| Date | Place | Aims |
|---|---|---|
| 31/10/2008 | Milan | EUROCHIP-3 Steering Committee meeting |
| 21-26/03/2009 | Sintra | Participation of 4 Bulgarian and Romanian doctors to the 3rd ESO Masterclass in Oncology nursing |
| 06/08/2009 | Phone call | EUROCHIP-3 WP-2 activity coordination |
| 26/10/2009 | Phone call | Discussion on Cernobbio's meeting with WP-1 |
| 08/11/2009 | Cernobbio | EUROCHIP-3 WP-4 and WP-2 coordination |

## 4.2 PROJECT PUBLICATIONS

- Micheli A, Baili P, Ciampichini R, Verdecchia A. Evaluating the outcomes of cancer control. In Elwood JM, Sutcliffe AB (Ed) Cancer control. Oxford university press, New York. (2010)
- Arbyn M, Raifu AO, Weiderpass E, Bray F, Anttila A: Trends of cervical cancer mortality in the member states of the European Union. Eur J Cancer, 45(15): 2640-8, 2009;
- Micheli A, Sanz N, Mwangi-Powell F, Coleman MP, et al: International collaborations in cancer control and the Third International Cancer Control Congress. Tumori, 95(5): 579-596, 2009;
- Arbyn M, Antoine J, Valerianova Z, Mägi M, Stengrevics A, Smailyte G, Suteu O, Micheli A: Trends in cervical cancer incidence and mortality in Bulgaria, Estonia, Latvia, Lithuania and Romania. Submitted to Tumori (Abstract in Annex 1);
- Veerus P, Arbyn M, Amati C, Baili P, EUROCHIP Working Group: Impact of implementing a nationwide cervical cancer screening programme on female population coverage by Pap-tests in Estonia. Submitted to Tumori (Abstract in Annex 2);
- Viberga I, Engele L, Baili P, EUROCHIP Working Group: Past, Present and Future of the Cervical Cancer Screening in Latvia. Submitted to Tumori (Abstract in Annex 3);
- Valerianova Z, Panayotova Y, Amati C, Baili P, EUROCHIP Working Group: Cervical Cancer Screening in Bulgaria - Past and Present Experience. Submitted to Tumori (Abstract in Annex 4);
- Apostol I, Băban A, Nicula F, et al: Cervical cancer assessment in Romania under EUROCHIP-2. Submitted to Tumori (Abstract in Annex 5).

## 4.3 FUTURE ACTIVITIES

WP-2 activities up to now have referred to the dissemination of EUROCHIP-2 results and definition of the future dissemination of WP-4 results. The discussions on future activities referred to:

- political pressure linked with results of the WP-4 studies on adherence to cervical screening programs;
- possible cytology training courses in Baltic countries;
- help in the dissemination of cervical cancer screening information linked with the Lithuanian website (www.gimdoskaklelis.lt);
- possible conference with Romanian parliamentary women to lever political attention to the issue of organised cervical cancer screening in Romania.

In the last year of the project specific meetings between WP-1, WP-2 leaders and WP-5, WP-6, WP-7 leaders will be organized in order to define the best way to disseminate the specific results.

# 5. WP-3 EVALUATION

## 5.1 EVALUATION SURVEY

An evaluation survey (Annex 6) was sent to EUROCHIP-3 associated and collaborating partners who are actively involved in the project WPs in order to evaluate the project status (next paragraph).

## 5.2 PROJECT STATUS

An evaluation of the project is described per each Work package:

- WP-1 (Coordination): WP-1 members participated in various specific WP meetings in order to guarantee that EUROCHIP-3 aims were followed. WP-1 also promoted the participation of several members of the EUROCHIP-3 network to the 3rd International Cancer Control Congress (November 2009). In that occasion specific EUROCHIP meetings were organized;
- WP-2 (Dissemination): specific activities were performed on the dissemination of EUROCHIP-2 results. WP-2 members participated in various EUROCHIP-3 meetings to learn of the WP work and propose possible future EUROCHIP-3 results to disseminate. Up to now, the main area connected with WP-2 is the area of cervical screening (WP-4);
- WP-4 (Cervical screening): articles on EUROCHIP-2 results were prepared and submitted. Protocols on the EUROCHIP-3 adherence studies were prepared in 5 countries (Estonia, Lithuania, Latvia, Bulgaria, Romania). Moreover Poland have proposed to organize a similar study within the EUROCHIP-3 umbrella. In some countries (i.e. Lithuania, Latvia, Romania) the protocol definition was delayed and prepared between Month 12 and Month 18;
- WP-5 (Cancer registry activities): the questionnaire on the availability of cancer registry indicators across Europe was designed and agreed with other European organizations (European Network of Cancer Registries) and projects (EUROCOURSE) so to avoid duplication of efforts. WP-5 members organized specific training for Greece cancer registry operators. WP-5 members are in contact with the Ministry of Health in Luxembourg to provide support in the decision making processes necessary for the activation of a National Population based Cancer Registry in Luxembourg. The EUROCHIP Network helped the government intervention in funding a Study for the implementation of a National Cancer Registry which was completed in 2008 by the Public Research Centre for Health (http://www.crp-sante.lu/fr/project/638), and currently, the CRP-Santé is mandated by the Ministry of Health to implement a national network of hospital-based cancer registries (the first step will be focused on breast and lung cancers). CRP-santè is the key partner in EUROCHIP for meeting the deliverables of WP-5 regarding cancer registration Luxembourg;
- WP-6 (Cancer rehabilitation indicators): a group of specialists was created with representatives from 21 member states. An initial list of indicators was prepared in order to start the discussion on European availability and comparability among countries;
- WP-7 (Cancer cost discussion): two groups of specialists were created with representatives from international organization and 12 EU MS covering expertise in pharmaceutics, clinical, radiology, rehabilitation, public health, health technology, health economy, international organizations, patient groups. A list of items was prepared per each one of the studied cancer sites and a meeting was fixed to start a descriptive discussion on possible cancer management alternatives with no impact in outcome.

# 6. WP-4 CERVICAL SCREENING

## 6.1 INTRODUCTION

The EUROCHIP-3 WP-4 studies how to increase adherence to organised cervical screening in 5 MSs (Bulgaria, Romania, Estonia, Lithuania, Latvia). These countries will constitute a base for testing currently available know-how on how to manage effective screening programmes, so as to achieve acceptable coverage and quality standards with medium or low level of health care resources.

## 6.2 MEETINGS

WP-4 members participated in the following meetings/conferences:

| Date | Place | Aims |
|---|---|---|
| 26/09/2008 | Tallinn | EUROCHIP-3 WP-4 and WP-6 activity coordination |
| 31/10/2008 | Milan | EUROCHIP-3 Steering Committee meeting |
| 20/01/2009 | Sofia | EUROCHIP-3 WP-4 activity discussion |
| 29/05/2009 | Costantia | EUROCHIP-3 WP-4 dissemination |
| 08/11/2009 | Cernobbio | EUROCHIP-3 WP-4 and WP-2 coordination |

## 6.3 EUROCHIP-2 RESULTS ARTICLES

Five scientific articles on EUROCHIP-2 results were submitted to Tumori Journal (see abstracts in the Annexes 1-5). Specific analysis on cervical cancer trends were performed for EUROCHIP-3:

- mortality trends in Europe: published in the European Journal of Cancer;
- mortality and incidence trends in the 5 MSs: submitted to Tumori (abstract in Annex 1).

## 6.4 PROTOCOLS AND STATUS OF THE WP-4 STUDIES

Specific studies on adherence to cervical cancer screening programmes were designed in the five member states after in depth discussions at national and local level. Moreover, Poland proposed to organize a similar study within the EUROCHIP-3 umbrella.

In *Estonia,* a questionnaire was designed to find out the reasons for low adherence rates in the cervical cancer screening programme (for details see Annex 7). The initial stratified population sample included 3047 women. After cross-checking of their working status, living place etc from population and insurance registries, 2942 women were left in the final sample (3 died, 39 lost work and health insurance, 63 had an incomplete address). On 9$^{th}$ April 2010 all questionnaires were posted [on 14$^{th}$ April 2010, 205 responses obtained]. All questionnaires were mailed both in Estonian and Russian.

In *Latvia,* WP-4 will perform a survey to identify the existing issues and problems preventing the involvement of medical staff in the cervical screening programme (for details see Annex 8). In this phase the study was designed and the questionnaire was prepared. Partners involved in the project are: Latvian Association of Gynaecologists and Obstetricians; Latvian Association for Family Planning and Sexual Health (LFPSHA); Latvian Association of Rural Family Doctors; Latvian Association of Family Doctors; Latvian Association of Cytologists; WHO, Regional Office; Ministry of

Health of the Republic of Latvia; European Cervical Cancer Association; Department of Ob/Gyn of Riga Stradins University; Medical Faculty of University of Latvia; Health Compulsory Insurance State Agency/ Health Payments Centre; Health Economics Institute.

In *Lithuania,* WP-4 is investigating the differences of the organized invitation component in a screening programme with a decentralized invitation system (for details see Annex 9). In this phase the study was designed and the invitation letter was prepared.

In *Bulgaria*, the aim of WP-4 group is to assess the introduction and implementation of the STOP and GO for a Check-up project (National Campaign for Early Diagnostics of Cancer), aiming to reach one million women by an information campaign for cancer prevention, create and maintain screening registry, create functional screening centres with a national scope, establish guidelines on good practice for cancer screening and a package of documents regulating the operation of the programme, as well as to create and implement a population-based call-recall system (for details see Annex 10). The WP-4 group would assist in testing different invitation packs – the testing packs are currently in discussion with the program managers. WP-4 experts were involved in guidelines and regulation development, that are approved and ready to use.

In *Romania* (for details see Annex 11), WP-4 will perform adherence surveys both on cervical cancer screening and on vaccination. Questionnaires were designed and are included in Annex 11.

In *Poland* a survey will be implemented to evaluate trends of knowledge and health-behaviour of Polish women after three years of the national screening program activity (for details see Annex 12).

### 6.5 FUTURE ACTIVITIES

- Meeting in Poland (May-June 2010) to evaluate the status of various WP4 national studies;
- Evaluation of the results of national adherence studies;
- Presentation of the results to the EUROCHIP network;
- Dissemination of the results through WP-2.

# 7. WP-5 CANCER REGISTRY INDICATORS

## 7.1 INTRODUCTION

WP-5 has a double aim: to continue the Cancer Registry (CR) promotion in countries without CRs (i.e. Greece and Luxembourg) and to identify, through qualitative questionnaires and forum discussion amongst European CRs, where adequate data for the production of cancer indicators is lacking, which kind of data is lacking, and which are major problems reported by the CRs.

## 7.2 MEETINGS

WP-5 members participated in the following meetings/conferences:

| Date | Place | Aims |
|---|---|---|
| 31/10/2008 | Milan | EUROCHIP-3 Steering Committee meeting |
| 27/02/2009 | Lyon | EUROCHIP-3 WP-5 questionnaire discussion |
| 11/03/2009 | Amsterdam | EUROCHIP-3 WP-5 Greece activity discussion |
| 7-8/4/2009 | Lyon | EUROCHIP-3 WP-5 questionnaire discussion |
| 25/8/2009 | Eindhoven | EUROCHIP-3 WP-5 questionnaire discussion |
| 21-25/09/2009 | Groningen | Training course for Greek cancer registry operators |
| 5/11/2009 | Amsterdam | EUROCHIP-3 WP-5 questionnaire discussion |

## 7.3 CANCER REGISTRY QUALITATIVE QUESTIONNAIRE

This work package aims to improve population-based cancer registration of cancer indicators, in particular "stage at diagnosis" (extension of tumour at diagnosis), "cancer treatment delay" and "compliance with cancer guidelines". To promote the collection of these indicators it is necessary to get insight in the present situation in all European cancer registries. WP-5 addressed the following questions:

- Which European cancer registries routinely collect data items for these cancer indicators
- Which European cancer registries do not collect data items for these cancer indicators and what are the reasons for not collecting these items (lack of budget, staff, data sources, legislation)
- What is the contribution of European cancer registries to the description of cancer burden or evaluation of cancer control.

To answer the above mentioned questions a specific for this purpose developed questionnaire will be addressed to all European cancer registries The protocol of the questionnaire is in the Annex 13 while the questionnaire is in the Annex 14. The questionnaire is distributed to the European Cancer Registries. A pilot of the questionnaire has been conducted with 10 Cancer Registries and the ENCR Steering Committee. The questionnaire asks about contact details of the registry (to make it possible to clearify some answers if necessary), registry description, conditions of cancer registration, funding of cancer registration, data sources, registration criteria, screening, diagnosis, coding topography and morphology, tumour items (i.e. stage at diagnosis), treatment items (i.e. date of diagnosis), follow-up items, role in guideline evaluation and registry output. Finally we ask the CR for permission to share the data with the public or only with ENCR members.

The questionnaire is developed for the EUROCHIP-3 project. To prevent duplication of effort, the content of the questionnaire has been discussed with other parties like the ENCR (European Network of Cancer Registries) and the EUROCOURSE project (the invitation letter is in Annex 15). To reduce the workload for the CR some questions already asked for other projects (ENCR CI5 questions) will be filled out by default. The updated answers will also be shared with the ENCR. The EUROCOURSE project expressed interest in some questions. The answers will be shared after permission by the CR.

### 7.4 GREECE AND LUXEMBOURG

The Hellenic Cancer Registry was charged by the Ministry of Health to the Hellenic Centre for Diseases Control and Prevention (KEELPNO) under the law no 3370/2005 but initiated activity on June 13, 2008 within the funding system of the Hellenic Cancer Society. A training programme was formed by Mrs Margery Duin, with specific aim to assist in the development of a Cancer Registry (CR) in Greece. The course took place at IKNO (Groningen) from 21-24 September 2009 and was attended by three members of staff of the Hellenic Cancer Registry at the Hellenic Centre for Diseases Control and Prevention (HCC-KEELPNO). The three participants were Lia Tzala, Elisa Ferekydou and Gerasimos Gerolymatos. The course was tailor-made for the HCC-KEELPNO staff needs and preferences to share the knowledge and experience gained in the Netherlands. During the course, discussions were made with the trainers and speakers on the various difficulties faced by HCC since it started operating in KEELPNO, together with possible solutions. Specifically, the following topics (see agenda in Annex 16) were covered:

- The structure of the cancer reporting system in the Netherlands and the way it started and progressed over the years, including the development and management of clinical networks
- Description of the health system in the Netherlands and the way this aids reporting
- Description of cancer registration in the Netherlands, including electronic database demonstration
- Linkage of cancer registry database with other databases and identification of duplicate records
- Discussions and exercises on coding issues using ICD-O-3
- Discussions and exercises on TNM classifications (cTNM and pTNM)
- Description and discussions on the coding manual used by IKNO
- Brief description of the running screening programmes in the Netherlands
- Guidelines on confidentiality

WP-5 members are in contact with the Ministry of Health in Luxembourg to provide support in the decision making processes necessary for the activation of a National Population based Cancer Registry in Luxembourg. Currently the CRP-Santé is mandated by the Ministry of Health to implement a national network of hospital-based cancer registries (the first step will be focused on breast and lung cancers).

### 7.5 FUTURE ACTIVITIES

- Monitoring of Cancer Registry Pilot in Greece;
- Two meetings to evaluate the cancer registry status in Luxembourg;
- Collection, analysis and dissemination of questionnaire data.

# 8. WP-6 CANCER REHABILITATION INDICATORS

## 8.1 INTRODUCTION

The needs of cancer survivors are an emerging aspect of cancer control. The list of indicators produced by EUROCHIP-1 did not include indicators for cancer rehabilitation. However, it is expected that the need for rehabilitation services for cancer patients will increase as mortality for several cancers tends to decline. WP-6 will therefore be concerned with defining a list of indicators on cancer rehabilitation in collaboration with patient associations.

## 8.2 GROUP

| | | | |
|---|---|---|---|
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## 8.3 MEETINGS

WP-6 members participated in the following meetings/conferences:

| Date | Place | Aims |
|---|---|---|
| 26/09/2008 | Tallinn | EUROCHIP-3 WP-4 and WP-6 activity coordination |
| 31/10/2008 | Milan | EUROCHIP-3 Steering Committee meeting |
| 11/11/2009 | Cernobbio | EUROCHIP-3 WP-6 activity discussion |

### 8.4 PRESENT LIST OF INDICATORS

The present discussion is based on these notes:

- Included indicators must be at population level
- Included indicators do not necessarily have to be already available
- Included indicators can be can be a proxy
- Included indicators can be subdivided in high and low priority
- It is important to discuss of common sources across Europe and on the efforts necessary for collection
- At the end of the project the list must be concise (5-6)

The present list includes the following indicators:

1. Cancer prevalence;
2. Proportion of cancer patients with/without relapse;
3. Amount of funding per cancer rehabilitation per patient per year;
4. Existence of national strategy for cancer rehabilitation;
5. Availability of guidelines for cancer rehabilitation;
6. Availability of follow-up programmes for cancer patients;
7. Number of NGOs and other organisations involved in cancer rehabilitation;
8. Availability of social care workers at home;
9. Training courses for persons involved in rehabilitation programmes;
10. Availability of social counselling, psychological support, nutritional counselling for cancer patients and their family members;
11. Proportion of persons with cancer diagnosis returned to work;
12. Quality of life of cancer patients.

The Annex 17 is the document prepared to promote the online discussion on present indicator list.

### 8.4 FUTURE ACTIVITIES

- Summary of online discussion (April-May 2010);
- Discussion meeting in Poland (May-June 2010);
- Update of the list after meeting discussion;
- Research of data availability in various countries;
- Preparation of methodological description for data collection (for each indicator);
- Presentation and dissemination of the results to the EUROCHIP network.

# 9. WP-7 CANCER COST DISCUSSION

## 9.1 INTRODUCTION

Given the progressive cost increase of cancer care, increasing best practice diffusion and cost-effectiveness in cancer care is to become the most strategic approach to global cancer control in the framework of the fight against inequalities in health care. We rated this approach with high priority following the results of the previous EUROCARE and EUROCHIP projects.

The 3rd International Cancer Control Congress (ICCC-3) held in Cernobbio, Italy, on 8-11 November 2009 (see par. 3.2) focussed on the topic of international cooperation on cancer control and confirmed the necessity for further research to be given to this area in global cancer control. With ICCC-3, ideas for future cancer control international collaborations were shared, and others were newly created. In particular, seeds for European Union (EU) – African Union (AU) future cancer control collaborations were organised and can be also be taken in consideration at the global level to contribute to the discussion on international collaboration in middle and low income countries with the involvement of international research, practice and policies on primary prevention, treatment, early detection and in improving health monitoring (see http://www.tumorionline.it/allegati/00455_2009_05/fulltext/05-Kerner%20(610-622).pdf).

This WP is discussing the economic strategy linked to the procedures characterizing the natural history of breast cancer and Acute Lymphoblastic Leukaemia, suggesting innovations in cancer management that reduce costs, yet promote the wider use of the best available cancer treatment practices.

## 9.2 MEETINGS

| Date | Place | Aims |
|---|---|---|
| 09/11/2009 | Cernobbio | EUROCHIP-3 WP-7 preliminary activity meeting |
| 16/03/2010 | Rome | EUROCHIP-3 WP-7 activity discussion |

## 9.3 GROUP

Discussion is running with the involvement of multidisciplinary experts and is divided in two groups focussing on Breast Cancer (B) and Child Leukaemia (C).

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## 9.4 ACTIVITIES

WP-7 activities in this first period aimed to:

- promote discussion on cancer control priorities in low-medium income countries during the 3rd International Cancer Control Congress. Results of this discussion are published in the monograph available at: http://www.tumorionline.it/index.php?archivio=yes&vol_id=455;
- identify the main databases for health technology assessment (HTA). The database of INAHTA (International Network of Agencies for Health Technology Assessment - http://www.inahta.org/) includes various reports on HTA studies. For breast cancer 33 reports were identified;
- evaluate the available information in the Cochrane Library aimed to provide the best evidence for health care. For breast cancer 35 Cochrane reviews are available;
- identify the main clinical guidelines for breast cancer. The UK National Institute for Health and Clinical Excellence (NICE) provides guidelines for Early and locally advanced breast cancer (http://www.nice.org.uk/nicemedia/pdf/CG80FullGuideline.pdf) and for advanced breast cancer (http://www.nice.org.uk/nicemedia/pdf/CG81FullGuideline.pdf) including in each chapter specific paragraph on available information on Health Economic Evaluation. This material is the main starting point for discussion of WP-7 breast cancer group;
- identify the scientific reviews on Childhood leukaemia current clinical guidelines;
- create groups of experts for breast cancer and childhood leukaemia including experts in various fields: epidemiology, clinic, pharmacology, health technology assessment, economics, rehabilitation. The creation of the groups is yet ongoing;
- define the list of procedures to promote discussion in the two groups. The current list of procedures are in Annex 18 for breast cancer and in Annex 19 for childhood leukaemia. Each procedure here described includes a list of possible items to be evaluated economically. The first meeting of the two groups will evaluate these procedures and identify the items on which the group will reach consensus on assessment studies.

## 9.5 FUTURE ACTIVITIES

- WP-7 meeting in Rome (May-June 2010);
- Literature review on items defined in the meeting;
- Online discussion;
- promotion and dissemination of the results to the EUROCHIP network in collaboration with WP-2.

## LIST OF ANNEXES

ANNEX 1 – Abstract of the article on cervical cancer trends
ANNEX 2 – Abstract of the article on cervical screening in Estonia
ANNEX 3 – Abstract of the article on cervical screening in Latvia
ANNEX 4 – Abstract of the article on cervical screening in Bulgaria
ANNEX 5 – Abstract of the article on cervical screening in Romania
ANNEX 6 – Evaluation survey
ANNEX 7 – WP-4 Cervical screening study protocol for Estonia
ANNEX 8 – WP-4 Cervical screening study protocol for Latvia
ANNEX 9 – WP-4 Cervical screening study protocol for Lithuania
ANNEX 10 – WP-4 Cervical screening study protocol for Bulgaria
ANNEX 11 – WP-4 Cervical screening study protocol for Romania
ANNEX 12 – WP-4 Cervical screening study protocol for Poland
ANNEX 13 – WP-5 Cancer registry qualitative questionnaire protocol
ANNEX 14 – WP-5 Cancer registry qualitative questionnaire
ANNEX 15 – WP-5 Cancer registry qualitative questionnaire Invitation Letter
ANNEX 16 – WP-5 Concept of training program registration staff Greece
ANNEX 17 – WP-6 Cancer rehabilitation indicator lists online discussion
ANNEX 18 – WP-7 List of procedures for breast cancer
ANNEX 19 – WP-7 List of procedures for childhood leukaemia

## ANNEX 1 – ABSTRACT OF THE ARTICLE ON CERVICAL CANCER TRENDS

### TRENDS IN CERVICAL CANCER INCIDENCE AND MORTALITY IN BULGARIA, ESTONIA, LATVIA, LITHUANIA AND ROMANIA

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## ABSTRACT

*Objective*
The burden of cervical cancer varies considerably in the European Union. In this paper, we describe trends in incidence of and mortality from this cancer in the five most affected member states.

*Methods*
Data on number of deaths from uterine cancers and the size of the female population of Estonia, Latvia, Lithuania, Bulgaria and Romania were extracted from the WHO mortality data base. Mortality rates were corrected for inaccuracies in the death certification of not otherwise specified uterine cancer. Incidence data were obtained from the national cancer registries. Joinpoint regression was used to study the annual variation of corrected and standardised incidence and mortality rates. Changes by birth cohort were assessed for specific age groups and subsequently synthesized by computing standardised cohort incidence/mortality ratios.

*Results*
Joinpoint regression revealed rising trends of incidence (in Lithuania, Bulgaria and Romania) and of mortality (in Latvia, Lithuania, Bulgaria and Romania). In Estonia, rates were rather stable. Women born between 1940 and 1960 were at continuously increasing risk of both incidence of and mortality from cervical cancer.

*Conclusions*
Rising trends of cervical cancer in the most affected EU member states reveal a worrying pattern that warrants urgent introduction of effective preventive actions as described in the European guidelines.

## ANNEX 2 – ABSTRACT OF THE ARTICLE ON CERVICAL SCREENING IN ESTONIA

### IMPACT OF IMPLEMENTING A NATIONWIDE CERVICAL CANCER SCREENING PROGRAMME ON FEMALE POPULATION COVERAGE BY PAP-TESTS

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## ABSTRACT

*Background*
The objective of the EUROCHIP project in Estonia was to describe the organised cervical cancer screening programme started in 2006 (after pilot studies in 2003-2005), to compare its performance with opportunistic screening, and to define priorities for improvement of the programme.

*Methods*
Population data was retrieved from Statistics Estonia, data about performed Pap-smear tests within the screening programme from the Estonian Cancer Society and from clinics and labs participating in the programme, data about Pap-smear tests outside the screening programme from the Estonian Health Insurance Fund, and data about cancer incidence and mortality from the Estonian Cancer Registry database.

*Results*
During the first year after implementing the nationwide cervical cancer screening programme in Estonia, the number of tests outside the organised programme remained high. Within the organised programme, the number of Pap-tests in different age groups increased with age except for the oldest age group while population coverage with Pap-tests outside the organised screening programme decreased with age. The number of cervical cancer cases at early stages increased after implementation of organised screening. The time-frame does not permit to draw any definitive conclusions.

*Conclusions*
Implementation of organised cervical cancer screening did not decrease the volume of opportunistic screening. The factors influencing attendance in the organised cervical cancer screening programme in different age groups should be studied further. Moreover, a central cancer screening registry without restrictive data protection legislation would improve data collection and enable to evaluate performance of the programme on a regular basis.

## ANNEX 3 – ABSTRACT OF THE ARTICLE ON CERVICAL SCREENING IN LATVIA

### PAST, PRESENT AND FUTURE OF THE CERVICAL CANCER SCREENING IN LATVIA

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## ABSTRACT

*Objective*
The present descriptive study summarizes the historical activity on cervical cancer screening in Latvia, assesses the current screening situation, and defines the existing and expected obstacles and problems for the implementation of a proper organized population-based cervical cancer screening program in Latvia.

*Material and methods*
Available data on cervical cancer burden were collected from Latvian cancer registry. Availability of trained medical staff and laboratory systems were obtained through the Latvian Association of Cytologists and the Health Compulsory Insurance State Agency of Latvia (HCISA).

*Results*
Cervical cancer incidence in Latvia is increasing since 1989 when the compulsory preventive gynaecologic examinations were stopped.
Cervical opportunistic screening program in Latvia should be performed by GPs. But only 30 out of 1470 GPs provide gynaecological care for their patients while, out of 484 certified gynaecology practitioners, 35 had direct contractual relationship with the HCISA while 398 had only an indirect contractual relationship with the Agency. Moreover, in Latvia, there are about 29 laboratory specialists employed with cytological testing with an average age of 57 years: 13 of them have already passed the retirement limit.

*Conclusions*
Traditionally in Latvia, most women request gynaecological services for preventive and health promotion reasons or in the case of having a gynaecological disease. So the overloaded general practitioners and the lack of involvement of gynaecologists are one of the main obstacles to solve for implementing an organized screening program in Latvia. Moreover insufficient availability of quality-assured services and resources for cytology testing and other services of the programme, and for monitoring and evaluating the whole programme must be considered in the implementation of a comprehensive screening plan.

## ANNEX 4 – ABSTRACT OF THE ARTICLE ON CERVICAL SCREENING IN BULGARIA

### CERVICAL CANCER SCREENING IN BULGARIA - PAST AND PRESENT EXPERIENCE

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## ABSTRACT

*Background*
In Bulgaria the previously (1970-1985) existing population based cervical cancer screening was replaced in the early 1990s with an opportunistic model due to political and socioeconomic reasons. As a result, in the last 20 years, cervical cancer incidence and mortality rates steady increased.
The objective of the EUROCHIP project in Bulgaria was to evaluate the readiness of the health system as well as health providers' attitudes to implementation in the country of a population based screening program for cervical cancer.

*Methods*
Using a structured questionnaire, a convenience sample of medical specialists representing different actors involved in cervical cancer prevention, treatment, financing and policy were interviewed.

*Results*
The majority of interviewed practitioners worried that organization and implementation of an effective population-based cervical cancer screening program is not possible in the current unstable health system. A nostalgic attitude to the cervical cancer screening, performed in the past and pessimistic view on the capability of the current health system to cope are strong. As main barriers to implementation of an effective program were pointed financial and organizational ones. Motivation for gynaecologists to perform smear test should include better information, organization and payment.

*Discussion*
Medical specialists in Bulgaria are aware of the alarming rates of cervical cancer incidence and mortality in the country. However, due to the insufficient communication and interaction between policy makers and front-line health care staff, they do not have enough information on the ongoing programs. Absence of health policy regarding screening is considered as main barrier for implementation of an effective screening program.

## ANNEX 5 – ABSTRACT OF THE ARTICLE ON CERVICAL SCREENING IN ROMANIA

### CERVICAL CANCER ASSESSMENT IN ROMANIA UNDER EUROCHIP-2

Iuliana Apostol[1], Adriana Baban[2], Florian Nicula[3], Ofelia Suteu[3,4], Daniela Coza[3], Camilla Amati[5], Paolo Baili[5] on behalf of the EUROCHIP Working Group[6]

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## ABSTRACT

*Background*
Inside the European project EUROCHIP-2, the Romania team has ruled out an assessment study regarding cervical cancer screening programs (CCS) in Romania, in Nov 2006-March 2007. The general purpose was to be aliened to European Council recommendations that states that an organized cervical screening program should be offered in all member states, in order to reduce the specific incidence and mortality. The aim of the study was to assess cervical cancer burden and current cervical cancer screening status in Romania and in various sub-regions (DR), and also to identify problems and barriers and to propose solutions for implementing an organized cervical cancer screening program at national level.

*Methods*
The study was based on a statistical survey and a comprehensive literature review of the most important European, national and regional papers or studies completed in this field.

*Results*
Over 2000-2006, a total number of 22,830 new cases and 12,763 deaths from cervical cancer was registered in Romania. In 2005, the crude rate of incidence varied largely in the 8 DR between 17.8-31.3 and mortality varied between 12.3-21.5. The proportion of women tested by DRs on total female population varied between 3.2%-0.6%; the highest screening activity was observed in region VI, where run the only organized CCS in Romania. In 2005, there were one GP per 578 female population aged 25-65; regarding the specialists in 2007 per country we had: 3,012 women aged 25-65 per one gynaecologist, 21,195 women per one oncologist and 13,258 women per one histopathologist.

*Discussion and conclusion*
There were no major changes in policy screening over 2000-2006 correlated with no major difference in specific mortality in Romania. Significant differences in incidence and mortality between DRs were observed in 2005, which impose deeper analyzes of local conditions and resources and local strategies to be adopted. The burden of cervical cancer is particularly high in Romania and is related to the absence of an organized CCS program or the ineffectiveness of the opportunistic screening programs. It is needed that European Council recommendations be implemented and quality assurance strategies to be checked and maintained at all screening levels in Romania.

## ANNEX 6 – EVALUATION SURVEY

*by Dr Zradvka Valerianova and Dr Julia Panayotova*

The present questionnaire is addressed to the colleagues involved in the activity of EUROCHIP-3 Work Packages (WPs) with the aim of evaluating the status of the project overall activity.

| | | |
|---|---|---|
| Name and Surname | _____ | |
| Institute | _____ | |
| Involved in WP | nr.4 [ ] | |
| (please tick) | nr.5 [ ] | |
| | nr.6 [ ] | |
| | nr.7 [ ] | |
| Role of involvement in WP | Work Package leader | [ ] |
| (please tick) | member of associated partner institute | [ ] |
| | member of collaborative partner institute | [ ] |
| | private expert | [ ] |
| Date | ___/___/_____ | |

*Please reply only to questions in the section of your WP or WPs*

### WP-4 CERVICAL CANCER SCREENING ACTIVITY

1. If you have prepared a protocol on cervical cancer screening adherence study,

   a) in which month was it submitted? _____

   b) in which month was study activity started? _____

   c) is your health ministry aware of this study? _____

   d) is your health ministry directly involved in this study? _____

   e) if yes, in which way is the health ministry involved in this study?

2. Did you disseminate the aims of EUROCHIP-3 WP4 and the results from EUROCHIP-2 on cervical screening?

   a) If yes, in how many events up to now? _____

   b) Please specify in which events:

   c) Do you have already organised specific future events (if yes please specify)?

## WP-5 CANCER REGISTRY INDICATORS ACTIVITY

1. How many cancer registries received the questionnaire on cancer indicators up to now? _____ representing ____ EU member states

2. How many cancer registries have replied to the questionnaire on cancer indicators up to now? _____ representing ____ member states

3. How many ECHI cancer indicators are included in the questionnaire? _____

4. Which ECHI cancer indicators are included in the questionnaire?

5. How many and which initiatives did you promote with respect the implementation of a cancer registry in Greece?

6. How many and which initiatives did you promote with respect to the implementation of a cancer registry in Luxembourg?

## WP-6 CANCER REHABILITATION INDICATORS ACTIVITY

1. How many specialists have been involved in the WP-6 activity up to now? _____ representing ____ member states

2. How many cancer rehabilitation indicators are now considered in the WP-6 list? _____

3. How many events did you organise for WP-6? _____

## WP-7 CANCER COST ACTIVITY

1. How many specialists have been involved in the WP-7 activity up to now? _____ representing ____ member states

2. How many events did you organise for WP-7? _____

## ANNEX 7 – WP-4 CERVICAL SCREENING STUDY PROTOCOL FOR ESTONIA

*by Dr Piret Veerus*

### ADHERENCE TO CERVICAL CANCER SCREENING IN ESTONIA

***BACKGROUND.*** Organised population-based cervical cancer screening was implemented in Estonia in the year 2006. According to the National Cancer Strategy, personal invitations to the organised cervical cancer screening programme are mailed to all insured women in the age group of 30 to 59 years with a 5-year interval after a negative test. Women diagnosed with cervical cancer, women without health insurance and women having had a Pap-smear in past 12 months are excluded from the list of invitees. The adherence rates to the organised cervical cancer screening programme have remained very low (a mean population-based coverage of 12-13% in all age groups) regardless media campaigns twice a year. The incidence of primarily detected cervical cancer has remained the same since the year 2000 as well as the number of primarily detected cancer cases diagnosed in a localised stage at the time of diagnosis. One of the reasons for no changes in the trend of cervical cancer incidence and stage at diagnosis could be low attendance to cervical cancer screening programme.

***AIMS OF THE STUDY.*** The objective of the present study is to find out the reasons for low adherence rates in the cervical cancer screening programme. The reasons for non-attendance will be studied with the help of a questionnaire mailed together with the invitation to screening. These reasons have not been studied earlier.

***METHODS.*** The target group for the questionnaires will be a sample of women in the target group of the screening programme. The sample will be stratified according to age. The sample size will be calculated according to the attendance rates in different age groups and with the presumption of a 50% response rate. The questionnaire will be mailed together with a covering letter. The covering letter will encourage women to respond regardless their intention to participate in the programme. The questionnaire includes questions for the possible non-attendance linked with the administrative problems within the programme (unsuitable reception hours, wish to register via e-mail or web-page, etc) and questions asking about factors associated with the participant's knowledge and background characteristics (lack of knowledge about the test and its indications, considering the test unnecessary or of no benefit, considering oneself not to be at risk for cervical cancer, low socioeconomic status, age, etc). As Estonia has a minority of Russian-speaking population, the survey questions and the covering letter will be translated into Russian. The covering letter and the questionnaire both in Estonian and Russian will be mailed together with the invitation to screening and a return envelope with a post tax paid. The survey will be carried out with the help of the Estonian Health Insurance Fund and the returned questionnaires will be coded and filed by a person contracted at the Estonian Cancer Society. The analysis will be carried out at the National Institute for Health Development.

***RESULTS EXPECTED***. The results of the analysis will be used in order to map the problems associated with the organisation of the screening programme and in order to identify the reasons associated with the participants' lack of knowledge about the usefulness of screening, fear of the test, etc.

***IMPLEMENTATION OF THE RESULTS.*** According to the results of the analysis, possibly needed changes in the organisation of the programme will be identified, the screening programme will be modified accordingly and the media campaigns to different target groups will be tailored and organised in order to make them more efficient.

***TIMETABLE***

| | |
|---|---|
| Detailed study plan, negotiations with different partners, drafting the questionnaire | Jan – Sept 2009 |
| Drafting covering letter, translation of questionnaires into Russian | Oct – Nov 2009 |
| Pilot study (60 questionnaires to a random sample from different age groups) | Dec 2009 |
| Stratified sample from the population registry, printing of the questionnaires | Jan – Mar 2009 |
| Mailing the questionnaires, data coding and entering from the returned questionnaires, media coverage | April – Dec 2010 |
| Data analysis | Jan – Apr 2011 |
| Report, information dissemination | May – Aug 2011 |

***QUESTIONNAIRE***

*1. Have you heard about the cervical cancer screening programme?*
1 yes
2 no

*2. Do you fully understand the enclosed invitation and leaflet describing the screening programme?*
1 yes
2 no

*3. Do you plan to participate in the cervical cancer screening programme?*
1 yes
2 no

*4. Listed below are some possible reasons for non-attendance, please encircle as many as needed*
1 I have just had a regular check-up at my gynaecologist
2 I do not have time for it
3 the reception hours are not suitable
4 the clinic is too far from my living-place
5 the waiting-time is too long
6 I am afraid to give a test
7 my uterus has been removed
8 I do not think it is necessary

*5. How would you like to register for the screening?*
1 by phone
2 by e-mail
3 via web

*6. Where would you like to have the Pap-smear taken?*
1 at the women's clinic
2 at the family doctor's office

*7. How would you like to be informed about your test result?*
1 by phone
2 by mail
3 by e-mail
4 from a midwife or a doctor

*8. When did you last visit your gynaecologist?*
1 less than a year ago
2 less than five years ago
3 more than five year ago
4 don't remember

*9. If your family doctor would remind you about participation in the screening, how would you feel?*
1 happy that he/she is concerned about my health
2 I don't care
3 I wouldn't like it
4 I don't know

*10. Where would you like to get information about the screening programme?*
1 from TV
2 from women's magazines
3 from family doctor/family nurse
4 together with a personal invitation sent by mail
5 other….
6 I do not need more information

*11. Which of the following factors are risk factors for cervical cancer?*

| | Yes | No | I don't know |
|---|---|---|---|
| Smoking | | | |
| Many sexual partners | | | |
| HPV | | | |
| No regular check-ups | | | |
| STD | | | |

Now we would like to answer some questions about your life and health

*12. Your age…years*

*13. Your nationality…..*

*14. What is your marital status?*
1 married/cohabitant
2 single
3 divorced
4 widowed

*15. Are you currently in paid work?*
1 yes
2 I am retired
3 I am unemployed
4 I study
5 other

*16. Are you a daily smoker?*
1 yes
2 no, I have never smoked
3 no, but I have been a daily smoker earlier

*17. How many times have you given birth? …*

*18. Have you ever had sexually transmitted diseases (gonorhhoea, chlamydiosis, trichomonosis)?*
1 yes
2 no
3 don't know

*19. Have you ever used contraceptive pills?*
1 yes
2 no
3 don't know

*20. How many sexual partners have you had in your lifetime?*

*21. Your place of residence*
1 big town
2 small town
3 countryside

## ANNEX 8 – WP-4 CERVICAL SCREENING STUDY PROTOCOL FOR LATVIA

*by Dr Ilze Viberga*

### THE POSSIBLE INFLUENCE OF THE MEDICAL STAFF INVOLVED IN THE ORGANIZED CERVICAL CANCER SCREENING ON THE RESPONSIVENESS TO THE CENTRALLY INSSUED INVITATIONS.

#### *BACKGROUND*

The organized cervical cancer screening program implemented in Latvia from Jan 2009 is based both on the formation of a comprehensive and optimal target group of residents and on extensive opportunity for medical staff to take part in performing the screening manipulations. Latvia screening program is unique because the medical staff can actually influence the responsiveness to the invitation letters through their professional activities thus ensuring efficient functioning of the screening. The program includes the following:

1. The general practitioners (GP), who have contracts with the HPC (Health Payment Centre), can access the screening module in the HIS (Health Information System) that contains information about the relationship with the screening program of all females registered with the particular practitioner: the sending date of the invitation letter, reference No. of the letter and the screening examination date and findings. Regular monitoring of the HIS Screening module data allows the GP or his/her assistant/nurse to identify persons who have been issued an invitation but who do not display any marks in the module about any examination. By actively contacting those persons, the GP can find out the reasons and encourage the women to respond to the invitations and get involved into the screening program. If in their practices cytological smears can be taken, GPs can perform this manipulation as a part of the program: they must contact the Screening Section of the HPC online and require the invitation letter and the screening examination form electronically (if a woman has visited the GP due to any other reason and cannot produce the screening invitation letter).
2. Gynaecologists can act similarly — contact the Screening Section of the HPC and require the invitation letter and the screening examination form electronically if a woman has visited the doctor due to any other reason such as for advice on the selection of contraception. Private gynaecologists may use the invitation letter and the examination account form to send the smear to the cytological examination as a part of the screening paid by the state and the data from the laboratory are delivered to the Screening module of the HPC.
3. The 19 December 2006 Regulation No. 1046 of the Cabinet of Ministers „The Procedure for Organization and Financing of Health Care" provides that all manipulations performed as a part of the screening, including the taking of cytological smear, testing and the consequent examinations following the algorithm approved by the above regulations are fully compensated to the performer irrespective of any financial quota requirements. Moreover, the taking of cytological smear and testing as a part of the screening program may be also performed to inpatients and the payment for the manipulation is excluded from the payment for the treatment in the hospital.

Regardless of all the above mechanisms integrated in the implementation plan of the screening program, responsiveness to the invitation letters sent out in 2009 does not exceed 15% (30,684 women responded to 208,359 letters). General practitioners actually do not engage in promoting the organized screening; within the screening, private gynaecologists have sent to laboratory for testing about 3% of examinations, though about 40% of all gynaecologists have private practices according to the Latvian Association of Gynaecologists and Obstetricians. The screening examination of inpatients is not performed: may be due to the lack of information both among the public and the medical staff.

#### *AIMS OF THE STUDY*

Taking into consideration the specific features of the organized cancer screening program implemented in Latvia, we propose to survey the awareness, motivation and readiness of medical staff to perform activities aimed at increasing the responsiveness to the organized screening invitation letters and improving the effectiveness and rate of the screening program. The aim of the survey is to identify the existing issues and problems preventing the involvement of medical staff in the screening program so that the issues could be eliminated to significantly increase the responsiveness to the screening and its overall effectiveness.

***METHODS***

The surveys are intended for specific target groups with a common basis part and variable questions part as appropriate for the professional specifics of each target group. The target groups of medical staff might be as follows:

1) General practitioners;
2) Gynaecologists with contracts with the HPC;
3) Private gynaecologists;
4) Management of hospitals.

***RESULTS EXPECTED***

Results will show the professionals groups' knowledge, awareness, understanding tasks of screening program and show ways for new inputs to improve screening program for the second three years round that will be started from 2012.

***TIMETABLE***

| **Task** | **Time** |
|---|---|
| Detailed study plan, negotiations with different partners, drafting the questionnaire | Jan – Dec 2010 |
| Pilot study (a random sample from different target groups of medical staff) | Oct – Dec 2010 |
| Distributing the questionnaires, data coding and entering from the returned questionnaires, media coverage | Jan – Mar 2011 |
| Data analysis | Apr – Aug 2011 |
| Report writing, information dissemination | Sep – Dec 2011 |

## ANNEX 9 – WP-4 CERVICAL SCREENING STUDY PROTOCOL FOR LITHUANIA

*by Dr Ruta Kurtinaitiene*

### STUDY TO INCREASE ATTENDANCE AT SCREENING FOR CERVICAL CANCER

***BACKGROUND***. The Lithuanian Ministry of Health started nationwide organized cervical cancer screening programme in the middle of 2004. The programme represents the first attempt of run a national cancer screening program in Lithuania. The first analysis of the data shows variation of Bethesda categories according pathology departments, creation of data base and ineffective decentralized invitation system. The first three-year programme round shows that more than 50% of target women did not receive a PAP smear examination. The decreasing attendance ratio is observed in the second program period from 43% to 34% of target age group women. Lack of population-based invitation system is seen as the weakness of the program The poor knowledge about the purpose of the screening and risk factors, ineffective decentralized invitation system is the main reason for low attendance ratio.

***AIMS OF THE STUDY***. The objective of the study is to increase attendance ratio for cervical cancer screening programme in county with the highest incidence of cervical cancer through personal invitations. To investigate the differences of organized invitation component in screening programme with the decentralized invitation system. In order to show the importance of the centralized invitation system, the invitation campaign will be organised.

***METHODS***. The county with the highest incidence of cervical cancer was selected for the study. The low invitation ratio was observed during the screening program in one of the largest primary health care centre of this county (2400 invitations of 13 670 registered women). The target age 25-60 group insured women who not-attend cervical cancer screening program (from 2004) will be selected for the study from the primary health care centre registries (PHCCR). The personal registered invitation letter to attend the primary health care centre for Pap smear taking will be send by post (expecting to send about 2000 letters). We will provide information campaign on regional TV, local newspapers, web site and radio to ask women to participate in CC screening programme. Gynaecologists will be responsible for taking conventional Pap smear. All conventional Pap smears and requisition forms will be sent to Diagnostic Pathology laboratory for cytological investigation. The results will be registered to the pathology laboratory data base. Response ratio will be calculated. The statistical analysis of cytological results of attended women will be analysed. The data will be compared to cervical cancer screening data with purpose to show the effectiveness of invitation component in cervical cancer screening program. Proportion of women attending screening after intervention and the cumulative proportion after the interventions as well as the cumulative proportions of cytologic abnormalities will be analysed.

***RESULTS EXPECTED***. The modified invitation increase attendance compared with the standard invitation letter. Reminders by mail and media could drastically increase women's participation in Papanicolaou smear screening and increase the number of detected precursor lesions and thereby save lives. We expect to achieve approximately 60-70% response ratio.

***IMPLEMENTATION OF THE RESULTS*.** In order to achieve the desired results, the attention should be drawn to the issues of informing the society and politicians of Lithuanian Ministry of Health with study results, arousing their motivation to participate in research programmes, creating computerized systems, which could help with registering and controlling the research at different stages of the programme, i.e. invitations to participate, reminding of them, providing research results, foreseeing visits to a gynaecologist. Further research is needed to determine whether sending additional information about cervical screening with reminder letters can increase the uptake of Pap tests, and whether this strategy can be successfully applied to women in harder to reach groups.

***TIMETABLE***

| | |
|---|---|
| Detailed study plan, negotiations with different partners, drafting the invitation letter | Mar 2010 |
| Stratified women from the PHCCR; printing invitation letters | Apr - May 2010 |
| Mailing the invitation letters, data coding and entering | Jun 2010 |
| The obtaining of Pap smear and cytological investigation | Jul - Dec 2010 |
| Data analysis | Jan - Mar 2011 |
| Report, information dissemination | Apr-Aug 2011 |

## ANNEX 10 – WP-4 CERVICAL SCREENING STUDY PROTOCOL FOR BULGARIA

*by Dr Zradvka Valerianova and Dr Julia Panayotova*

***BACKGROUND.*** In the last 20 years, the incidence and mortality from cervical cancer in Bulgaria have risen constantly, which is in sharp contrast to the steady decline in most European countries. Up to the late 1980s mortality rates from cervical cancer in Bulgaria were comparable to the rates of many EU countries. A dramatic increase in mortality rates is observed during the political and socio-economic reforms of the last two decades. Thus in 2006, 1208 new cases of cervical cancer, are registered. Cervical cancer is responsible for 7.7% of all cancer cases in females, after breast cancer, non-melanoma skin cancer and corpus uteri cancer. In 2006, as well as in the last 20 years, approximately 30% of the new cervical cancer cases are in advanced (III + IV) stages.
Incidence and mortality rates have been increasing in years. There is 84% increasing of the new cancer cases of cervix uteri in the age groups of 30-49 in 2004 in comparison to 1984. Incidence rates have increased from 22.7 (1984) to 46.7 (2004) per 100 000 females for the same age groups. Mortality rates increased 2.5 times – from 4.7 (1984) to 11.0 (2004) per 100 000 females. In 2006 standardized mortality rate (European standard) from uterus cancer (C53-55) is 14.4 for Bulgaria, 6.8 for EU 25 and 9.3 for Europe per 100 000 females [Ferlay J. Annals of Oncology, 2007].
In Bulgaria there are enough human and physical resources, but lack of instructions and organization for implementation of organized population based screening programme according to the results of the Bulgarian report under EUROCHIP 2 and other publications. Currently, Bulgaria has no national programme for cancer prevention, however, there are ongoing efforts to develop one. In May 2009 a project, named *National Campaign for Early Diagnostics of Cancer* (NCEDC) has been accepted and signed by the Minister of Health and the Minister of Labour and Social Policy, under the operative program Development of Human Resources of the EC (BG051PO001 -5.3.0). This project will be in act in the period May 2009-September 2010. According to this project, one million women in Bulgaria should be reached by an information campaign for cancer prevention and about 50,000 women should be tested for cervical cancer.

***AIMS OF THE STUDY.*** In fact, the so called National Campaign, with the provision of 50,000 preventive check-ups for cervical cancer, would serve as a pilot program and would provide all the medical experts and decision makers with enough data to prepare and implement a real national wide population based cervical cancer screening program. The aim of the Bulgarian national group in WP-4 under EUROCHIP-3 is to assess the introduction and implementation of the project NCEDC*.* Aiming to follow the objectives and tasks of the above-mentioned program, Bulgarian experts will assess the project through SWOT analysis. According to the results of the SWOT analysis, the Bulgarian group will give recommendations for the future introduction of organized population-based cervical cancer screening in the country. According to the main aim the tasks of the Bulgarian group of experts in the WP-4 of EUROCHIP-3 are as follows:

- To cooperate with experts involved in the NCEDC by:
  - Participation in the mass media awareness campaign and other related events;
  - Participation in the events organized for the starting of the project NCEDC;
  - Giving recommendations for better results in the future;
  - Circulating The EU Guidelines on cervical cancer screening among health authorities;
  - Disseminating information for the already existing CCS Programme Proposal and other relevant documents to the public, medical groups, and decision-makers.
- To have a leading role in the establishment of a screening registry under the project. The National Campaign for Early Diagnostics of Cancer foresees a Screening Registry to be established on the basis of the organized cancer network in the country. This network includes 13 regional cancer centres with cancer registries (named dispensaries) and a National Oncological Hospital, part of which is the Bulgarian National Cancer Registry.
- To focus on the organization of call-recall system. Therefore, a survey would be conducted with women and medical professionals, aiming to assess the organization of the National Campaign for Early Diagnostics of Cancer and especially the invitation process. Data would be analyzed and recommendations will be given.
- To test different invitation packs, in order to propose the most appropriate pack for the future population based screening program.
- To disseminate survey results to the public, medical groups, and decision-makers.

***SURVEY CHARACTERISTICS*** (target group, number of interviews, type of interview, type of survey extraction: i.e. oral/by phone/self-compiled). The proposed survey will cover women (screened and non-attendant) and medical professionals, involved in the screening process Screened women and medical professionals will be studied directly through questionnaires and non-attendant through phone-interviews. We foresee to ask about 300 attendants, 1000 non-attendants and 100 medical professionals.

***TYPE OF QUESTIONS IN THE QUESTIONNAIRE***

- **Specialists - questionnaire 1 (self-compiled)**
  - Evaluation of the screening trainings
  - Evaluation of the provided guidelines
  - Evaluation of the organization for screening
  - Preference for appointment model
  - Evaluation of the attendance rates
  - Main problems
  - Recommendations
- **Women (Attendants) – questionnaire 2 (self-compiled)**
  - Knowledge on cervical cancer
  - Motivation for participation
  - Evaluation of the provided invitation pack
  - Evaluation of the organization for screening
  - Main problems
  - Recommendations
- **Women (Non- attendants) – phone interview**
  - Availability of knowledge and information on cervical cancer
  - Motivation for non-participation
  - Evaluation of the provided invitation pack
  - Preference for appointment model
  - Main problems
  - Factors for future participation
  - Recommendations
- **Evaluation of the effectiveness of the invitation pack –** using different information packs we aim to develop an effective and attractive one in terms of content (readability, suitability, etc.) and design. To propose it for the future population-based program. In partnership with ECCA printed information materials would be evaluated. Women of different age, social and educational status, living in different parts of the country would participate in the evaluation.

***RESULTS EXPECTED*****.** Using different methodological approaches, through questionnaires and phone interviews, we expect to obtain information on:

- Motivations among different target groups for participation in the proposed screening campaign
- Evaluation of the provided invitation pack and options for optimization
- Main problems according to health providers and consumers
- Recommendations from the participants in the screening process
- Changes in the knowledge and attitudes towards screening in the last 5 years (comparison with existing data)

The evaluation of the invitation package would give us opportunity to test different contents and designs in order to propose the best model for the future national cervical cancer screening program. Collaboration with other countries and good practises will be discussed.
On the basis of the obtained data to propose optimized evidence-based screening model for national wide screening program.

***METHODS FOR RESULTS DIVULGATION***

- Public round table for results reporting and recommendations given
- Interviews in the media
- Workshop with policy makers and leading specialists

## ANNEX 11 – WP-4 CERVICAL SCREENING STUDY PROTOCOL FOR ROMANIA

*by Dr Florian Nicula*

### REGIONAL PILOT CERVICAL CANCER PREVENTION PROGRAMME WILL INTEGRATE ORGANISED CERVICAL CANCER SCREENING PROGRAMME BASED ON POPULATIONAL PAP TESTING WITH HPV VACCINATION CAMPAIGN

A Regional Commission representing Institute Management Unit and Cluj County Public Health Authority will implement the *Regional Pilot Cervical Cancer Prevention Programme*. Programme main purpose is to improve epidemiological population-based quality control of both interventions, screening and vaccination, working on cohorts of vaccination, catch-up and Pap testing. Programme database will be population-based, connected to our already functional Regional Cancer Registry, ENCR member since 2003.

Up today coverage is extremely low, 20% for screening and less then 5% vaccination target, explaining our highest mortality rates across Europe.

Programme short term strategy is to increase screening and vaccination coverage, in the meantime we randomise different strategies of screening in rural and urban areas as school-based versus vaccination centres in gynaecologic and family planning units, targeting at least 10% 2010 coverage of both screening and vaccination cohorts. Programme has resources for implementation but also has resources for population information campaign.

Before starting information campaign we will send a questionnaire in each cohort, screening target population 25-64 years old in order to investigate particular compliance aspects in rural and urban areas, as screening policies were and will be completely different: invitations in urban and mobile units un rural, as no gynaecological facilities are in places in most of rural villages a lot of them being totally unassisted as medical human. In the mean time vaccination target population will be investigated, teenagers young women up to 26 years old and especially mothers responsible for vaccination decision which is still in huge debate in our country.

Reasons for women compliance in both programmes are of course different, so different questionnaires for each target cohort will be sent within EUROCHIP Programme.
Questionnaires are to be attached by Romanian Society of Health Psychology, our partner in Programme activities related to interactions with target female population.

***QUESTIONNIARE ON SCREENING***

# Section 1

**Town:**

**DEMOGRAPHIC DATA:**

Age:
Marital Status:
Do you have children:
What is your ethnicity:
What is your religion:
What education do you have:

1. No education
2. Primary education
3. High School
4. Technical/ 2 year college/certificate
5. College/University
6. Post-graduate
7. Don't Know

Would you describe your family background as:

1. Wealthy (Within the highest 25% in your country)
2. Quite well-off (Within the 50-75% range in your country)
3. Not quite well off (Within the 25-50% range in your country)
4. Quite poor (Within the lowest 25% in your country)

# Section 2

**SELF-PERCEIVED HEALTH**

All in all, how would you describe your state of health these days? Would you say it is...

| | |
|---|---|
| 1 | Very good |
| 2 | Good |
| 3 | Fair |
| 4 | Poor |
| 9 | Don't know |

# Section 3

**Screening history**

**[1]** Have you ever had smear test? yes no don't know

(If you think you have never had a smear test please go to question **7**

**[ 2]** If YES is the person who did your last test your GP?
yes no

If NO who was this person?
a. doctor at family planning clinic YES NO
b. gynaecologist YES NO

**[3]** How many smear tests have you had?
none ☐ 1-5 ☐ 6-9 ☐ 10+ ☐

**[4]** When was your last smear test?

| | | | |
|---|---|---|---|
| less than 6 months ago | ☐ | over 3 years but less than 5 years ago | ☐ |
| over 6 months but less than a year ago | ☐ | over 5 years ago | ☐ |
| over a year but less than 3 years ago | ☐ | have not had any | ☐ |

**[5]** Have you ever had an abnormal smear test result? yes no

**[6]** Thinking about your last smear test please circle a number for each part to show how you felt about it.

| | not at all | | | | extremely |
|---|---|---|---|---|---|
| was it simple to get it? | 1 | 2 | 3 | 4 | 5 |
| was it painful? | 1 | 2 | 3 | 4 | 5 |
| was it embarrassing? | 1 | 2 | 3 | 4 | 5 |
| was it quick? | 1 | 2 | 3 | 4 | 5 |
| was it worrying? | 1 | 2 | 3 | 4 | 5 |
| was it reassuring? | 1 | 2 | 3 | 4 | 5 |

**[7A]** Do you intend to go for smear tests in the future?
Definitely yes Probably yes No

**[7B]** If you were invited to have the cervical smear, would you take up the offer?
Definitely yes Probably yes Probably not Definitely not

**[8]** Do most of the female members of your family (e.g. mother, daughter, sister) have regular smear tests?
Yes no don't know not applicable

**[9]** Do most of your friends have regular smear tests?
yes no don't know

**[10]** Does your partner think that it is a good idea to have smear tests?
yes no don't know not applicable

**[11]** How did you first learn about cervical smears?

| | |
|---|---|
| Never heard of them before today | 1 |
| From parent | 2 |
| From friend/ sibling | 3 |
| From Doctor/Nurse | 4 |
| From School personnel | 5 |
| From radio, TV, magazine | 6 |

**[12]** Do you personally know anyone who has had cervical cancer?

yes no

If yes who are they? (please tick all boxes which apply)

sister ☐ mother ☐ other female relative ☐ friend ☐ acquaintance ☐ work colleague ☐ other ☐

## Section 4

### Knowledge about cervical cancer and smears

Please read the following questions and tick the box that is next to the answer that you think is correct.
PLEASE TICK ONLY ONE BOX FOR EACH QUESTION.
Do not worry if you are not sure of the answers, in this case just tick the 'don't know' box.

**[1]** Who should have a cervical smear test?

- ☐ don't know
- ☐ any woman over 20 years old
- ☐ only married women
- ☐ only women over 40 years old

**[2]** How often should a woman have a smear test?

- ☐ don't know
- ☐ once
- ☐ every 3-5 years
- ☐ every 6-9 months

**[3]** How can a woman get a cervical smear test?

- ☐ don't know
- ☐ she can ask her GP for a test
- ☐ she can do one herself at home
- ☐ she must visit a hospital

**[4]** Which of the following describes the purpose of the smear test?

- ☐ don't know
- ☐ it detects abnormal cells
- ☐ it detects cervical cancer
- ☐ it establishes if the woman is a virgin

**[5]** What does the smear test involve?

- ☐ don't know
- ☐ looking at the woman's cervix
- ☐ cutting away a small piece of cervix
- ☐ collecting cells from the cervix

**[6]** When can a smear test <u>not</u> be done?

- ☐ don't know
- ☐ when the woman is overweight
- ☐ when the woman is having her menstrual period
- ☐ when the woman is on antibiotics

**[7]** Which of the following is an early warning signal for cervical cancer?

- ☐ don't know
- ☐ a burning sensation in the vaginal area
- ☐ vaginal bleeding after sexual intercourse
- ☐ vaginal itching

**[8]** Which of the following factors makes a woman more likely to develop cervical cancer?

- ☐ don't know
- ☐ using tampons
- ☐ beginning the menopause before age 40
- ☐ having had unprotected sex with several partners

**[11]** Does a woman smoking have an effect on her chances of developing <u>cervical</u> cancer?

- ☐ don't know
- ☐ yes, her chances are increased
- ☐ yes, her chances are decreased
- ☐ no, smoking has no effect on her chances

# Section 5

**Perceptions of risk, severity, costs and benefits**

The following statements have been made by women about cervical cancer and having smear tests. Please read each statement and then circle the letter(s) according to how true each statement is for you. If you have never had a smear test please answer imagining how you would feel if you did. Please answer every question.

**Key:** strongly agree (1); agree (2); unsure (3); disagree (4); strongly disagree (5).

| | | | | | |
|---|---|---|---|---|---|
| **[1]** My physical health makes it likely that I will get cervical cancer | 1 | 2 | 3 | 4 | 5 |
| **[2]** My lifestyle makes it likely that I will get cervical cancer | 1 | 2 | 3 | 4 | 5 |
| **[3]** My chances of getting cervical cancer are small | 1 | 2 | 3 | 4 | 5 |
| **[4]** I am very afraid of having a smear test | 1 | 2 | 3 | 4 | 5 |
| **[5]** Getting cervical cancer would interfere with my sex life | 1 | 2 | 3 | 4 | 5 |
| **[6]** There is nothing I can do to detect cervical cancer | 1 | 2 | 3 | 4 | 5 |
| **[7]** I believe that a smear test will only find evidence of cervical cancer when it is too late to treat it | 1 | 2 | 3 | 4 | 5 |
| **[8]** I do not see myself getting cervical cancer in the next year | 1 | 2 | 3 | 4 | 5 |
| **[9]** Having a smear test is too inconvenient for me | 1 | 2 | 3 | 4 | 5 |
| **[10]** If I have regular smear tests cervical cancer will be found before it is advanced | 1 | 2 | 3 | 4 | 5 |
| **[11]** I believe that my chances of getting cervical cancer are high | 1 | 2 | 3 | 4 | 5 |
| **[12]** Having a smear test would not give me peace of mind | 1 | 2 | 3 | 4 | 5 |
| **[13]** If I got cervical cancer I would have problems which would last a long time | 1 | 2 | 3 | 4 | 5 |
| **[14]** I am flustered whenever I have a | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| smear test | 1 | 2 | 3 | 4 | 5 |
| **[15]** Having regular smear tests is not a good idea | 1 | 2 | 3 | 4 | 5 |
| **[16]** If I got cervical cancer my whole life would change | 1 | 2 | 3 | 4 | 5 |
| **[17]** My feelings about myself would not change if I got cervical cancer | 1 | 2 | 3 | 4 | 5 |
| **[18]** Getting a smear test does not interfere with my other activities | 1 | 2 | 3 | 4 | 5 |
| **[19]** Getting a smear test is time consuming | 1 | 2 | 3 | 4 | 5 |
| **[20]** With my family history I am unlikely to get cervical cancer | 1 | 2 | 3 | 4 | 5 |
| **[21]** There is a good possibility that I will get cervical cancer | 1 | 2 | 3 | 4 | 5 |
| **[22]** I don't mind giving up my time to have a smear test | 1 | 2 | 3 | 4 | 5 |
| **[23]** I am rarely embarrassed when I have a smear test | 1 | 2 | 3 | 4 | 5 |
| **[24]** Cervical smear tests can detect abnormal changes before I would notice any symptoms | 1 | 2 | 3 | 4 | 5 |
| **[25]** Getting cervical cancer would not be a problem for me | 1 | 2 | 3 | 4 | 5 |
| **[26]** I have a lot to gain by having regular smear tests | 1 | 2 | 3 | 4 | 5 |
| **[27]** I find that smear tests are painful | 1 | 2 | 3 | 4 | 5 |
| **[28]** I worry a lot about getting cervical cancer | 1 | 2 | 3 | 4 | 5 |
| **[29]** I do not think that I am the sort of woman who would get cervical cancer | 1 | 2 | 3 | 4 | 5 |
| **[30]** I would be reassured about cervical cancer if I had smear tests regularly | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| **[31]** The way a smear test is performed causes me distress | 1 | 2 | 3 | 4 | 5 |
| **[32]** Cervical smear tests are no good at detecting cervical cancer in its early stages | 1 | 2 | 3 | 4 | 5 |
| **[33]** I am never made to feel uncomfortable when having a smear test | 1 | 2 | 3 | 4 | 5 |

## Section 6

**1**. I ought to visit the gynecologists and get smears more regularly:

Agree Disagree Don't know

**2.** What are some of the things that prevented you from having smears/ having smears more regularly? (Check all that apply)

1. Lack of time
2. Exhaustion
3. Gynecological visits are unpleasant
4. Difficult communication with physicians
5. The male sex of physicians
6. Fear of bad diagnosis
7. It hurts
8. It is embarrassing
9. Long lines and waiting
10. Don't know whom to consult and how
11. The high cost of services and tests
12. Long travel to clinics
13. I don't think it is important
14. Other _____
15. I already have regular smears 13

B1. If you have ever had a Pap smear, how many times have you had an abnormal Pap smear result?
☐ Never ☐ Once ☐ Twice ☐ Three or more times ☐ Does not apply

B2. Has a doctor or other medical professional ever told you that you had **genital warts**?
☐ No ☐ Yes ☐ Don't know

B3. Has a doctor or other medical professional ever told you that you had **cervical cancer**?
☐ No ☐ Yes ☐ Don't know

B4. Has a doctor or other medical professional ever told you that you have **HPV (human papilloma virus)**?
☐ No ☐ Yes ☐ Don't know

**SUGGESTIONS**
What do you think would improve the situation with prevention and early detection of (cervical) cancer in women?

***QUESTIONNIARE ON VACCINATION***

The next questions are about human papilloma virus, also known as HPV.

D1. Have you ever heard of HPV (human papilloma virus)?
□ No □ Yes □ Don't know

Please read each statement below and mark whether it is true or false. This is *not* a quiz. We just want to know your opinion.

| | True | False | Don't Know |
|---|---|---|---|
| D2. HPV (human papilloma virus) is the virus that causes herpes. | ☐ | ☐ | ☐ |
| D3. Genital warts are caused by some types of HPV. | ☐ | ☐ | ☐ |
| D4. HPV is the virus that can cause cervical cancer. | ☐ | ☐ | ☐ |
| D5. The best way to prevent disease caused by HPV is to have regular Pap smears performed. | ☐ | ☐ | ☐ |
| D6. If a woman's Pap smear is normal she doesn't have HPV. | ☐ | ☐ | ☐ |
| D7. Changes in a Pap smear may indicate that a woman has HPV. | ☐ | ☐ | ☐ |
| D8. Genital warts are caused by the herpes virus. | ☐ | ☐ | ☐ |
| D9. HPV can cause cancer. | ☐ | ☐ | ☐ |
| D10. Pap smears will almost always detect HPV if a woman has it. | ☐ | ☐ | ☐ |
| D11. HPV can be passed from the mother to baby during birth. | ☐ | ☐ | ☐ |

D12. The symptoms of HPV include… (Check ALL that apply)

☐ Warts that sometimes itch or bleed
☐ Sores on the penis or vagina that don't heal
☐ Discharge from genitals (watery, yellow, white discharge)
☐ Warty growths
☐ Burning upon urination
☐ Reduction of urine flow
☐ No visible signs or symptoms
☐ Don't know/never heard of it

D13. If untreated, HPV… (Check ALL that apply)
☐ Can cause cervical cancer
☐ Can cause infertility
☐ Can cause pre-cancer (dysplasia)
☐ Can cause warts
☐ Will usually disappear by itself
☐ Can cause death
☐ Can cause sterility
☐ Don't know

D14. Which of the following increases your risk for HPV infection? (Circle ALL that apply)
☐ If you begin having sex before the age of sixteen
☐ If you have many sexual partners
☐ If your partner has had many sexual partners
☐ Birth control pills
☐ Smoking
☐ Excessive stress
☐ Poor nutrition
☐ Don't know

**In case you have not heard of HPV, it is a sexually transmitted infection. Some common types of HPV lead to cervical cancer.**

D15. Do you think that you have ever been infected with one of the types of HPV that cause cancer?
☐ No ☐ Yes ☐ Don't know

D16. Let's assume you maintain the same lifestyle and health behaviors you currently engage in. What is the chance that you will be infected with a cancer causing type of HPV in the future?
☐ No chance ☐ Low ☐ Moderate ☐ High ☐ Certain

D17. If you became infected with a cancer causing type of HPV, how serious a threat to your health would it be?
☐ No threat ☐ Very low ☐ Low ☐ Moderate ☐ High ☐ Very high

**HPV Vaccine**

There is a new vaccine that prevents HPV infection with two cancer causing types of HPV. 7 out of 10 cervical cancer cases can be prevented if people use this vaccine.

E1. Have you heard of the HPV vaccine before today?
☐ No ☐ Yes ☐ Don't know

E2. How likely would you be to get the HPV vaccine when it becomes available? Assume the vaccine is free.
☐ Very unlikely ☐ Unlikely ☐ Neither unlikely nor likely ☐ Likely ☐ Very likely

E3. How likely would you be to get the HPV vaccine if it prevented **cervical cancer**? Assume the vaccine is free.
☐ Very unlikely ☐ Unlikely ☐ Neither unlikely nor likely ☐ Likely ☐ Very likely

E4. How likely would you be to get the HPV vaccine if it prevented **genital warts**? Assume the vaccine is free.
☐ Very unlikely ☐ Unlikely ☐ Neither unlikely nor likely ☐ Likely ☐ Very likely

E5. How effective do you think the HPV vaccine is in preventing **HPV infection**?
☐ Not at all ☐ Slightly ☐ Moderately ☐ Very ☐ Extremely

E6. How effective do you think the HPV vaccine is in preventing **cervical cancer**?
☐ Not at all ☐ Slightly ☐ Moderately ☐ Very ☐ Extremely

E7. What would be the best age to give a person the HPV vaccine?

☐ 0-2
☐ 3-10
☐ 11-16
☐ 17-25
☐ 25+

**Please tell us how much you agree or disagree with the following statements.**

| | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
|---|---|---|---|---|---|
| E8. The HPV vaccine may have serious side effects. | ☐ | ☐ | ☐ | ☐ | ☐ |
| E9. The HPV vaccine is safe. | ☐ | ☐ | ☐ | ☐ | ☐ |
| E10. The vaccine will prevent children from getting HPV. | ☐ | ☐ | ☐ | ☐ | ☐ |
| E11. The HPV vaccine can prevent cervical cancer. | ☐ | ☐ | ☐ | ☐ | ☐ |
| E12. The vaccine can cure HPV infection. | ☐ | ☐ | ☐ | ☐ | ☐ |
| E13. If an adolescent girl received the HPV vaccine, she may be more likely to have sex. | ☐ | ☐ | ☐ | ☐ | ☐ |
| E14. Adolescent girls should be vaccinated against HPV. | ☐ | ☐ | ☐ | ☐ | ☐ |
| E15. Adolescent boys should be vaccinated against HPV. | ☐ | ☐ | ☐ | ☐ | ☐ |

## Health Information

F1. I would like more information about **HPV**.
☐ Strongly disagree ☐ Disagree ☐ Neither disagree nor agree ☐ Agree ☐ Strongly agree

F2. I would like more information about the **HPV vaccine**.
☐ Strongly disagree ☐ Disagree ☐ Neither disagree nor agree ☐ Agree ☐ Strongly agree

How much attention do you pay to information about health and medical topics…

| | Not at all | A little | Some | A lot | Don't know |
|---|---|---|---|---|---|
| F3. … on the television? | ☐ | ☐ | ☐ | ☐ | ☐ |
| F4. … on the radio? | ☐ | ☐ | ☐ | ☐ | ☐ |
| F5. … in the newspaper? | ☐ | ☐ | ☐ | ☐ | ☐ |
| F6. … in magazines? | ☐ | ☐ | ☐ | ☐ | ☐ |
| F7. …on the Internet? | ☐ | ☐ | ☐ | ☐ | ☐ |

## Your Daughter's Health

The next questions are about adolescent daughters. If you do not have a daughter, please answer these questions as if you do. If she is not an adolescent (11-16), imagine her being this age.
G1. What is the chance that your adolescent daughter will get **cervical cancer** in the future?
☐ No chance ☐ Low ☐ Moderate ☐ High ☐ Certain

G2. If she had **cervical cancer**, how serious a threat to her health would it be?
☐ No threat ☐ Very low ☐ Low ☐ Moderate ☐ High ☐ Very high

G3. What is the chance that your adolescent daughter will be infected with **HPV** in her lifetime?
☐ No chance ☐ Low ☐ Moderate ☐ High ☐ Certain
G4. If your adolescent daughter were infected with **HPV**, how serious a threat to her health would it be?
☐ No threat ☐ Very low ☐ Low ☐ Moderate ☐ High ☐ Very high

### Vaccinating your Daughter

When the new HPV vaccine is approved for public use, it will probably be recommended for adolescent girls between ages 11 and 16.
Please answer the next questions thinking about your adolescent daughter. If you do not have a daughter, please answer these questions as if you do. If she is not an adolescent (11-16), imagine her being this age.

H2. How likely would you be to vaccinate your adolescent daughter against HPV when it becomes available? Assume the vaccine is free.
☐ Very unlikely ☐ Unlikely ☐ Neither unlikely nor likely ☐ Likely ☐ Very likely

H3. Imagine that the vaccine requires three shots. How likely would you be to get your adolescent daughter vaccinated, return **1 month** later for the second shot and then return 6 months later for the third shot?
☐ Very unlikely ☐ Unlikely ☐ Neither unlikely nor likely ☐ Likely ☐ Very likely

H4. Imagine that the vaccine requires three shots. How likely would you be to get your adolescent daughter vaccinated, return **2 months** later for a second shot and then return 6 months later for the third shot?
☐ Very unlikely ☐ Unlikely ☐ Neither unlikely nor likely ☐ Likely ☐ Very likely

H5. How likely would you be to vaccinate your adolescent daughter against HPV if it prevented **cervical cancer**? Assume the vaccine is free.

☐ Very unlikely ☐ Unlikely ☐ Neither unlikely nor likely ☐ Likely ☐ Very likely

H6. How likely would you be to vaccinate your adolescent daughter against HPV if it prevented **genital warts**? Assume the vaccine is free.

☐ Very unlikely ☐ Unlikely ☐ Neither unlikely nor likely ☐ Likely ☐ Very likely

H7. Who is the **best** person to give an HPV vaccination to an adolescent daughter? Please check ONLY one.

☐ Family doctor or general practitioner
☐ Doctor who specializes in children's health (pediatrician)
☐ Doctor who specializes in women's health (OB/GYN)
☐ Nurse or physician assistant
☐ None of the above

H8. Who is the **second** best person to give an HPV vaccination to an adolescent daughter? Please check ONLY one.

☐ Family doctor or general practitioner
☐ Doctor who specializes in children's health (pediatrician)
☐ Doctor who specializes in women's health (OB/GYN)
☐ Nurse or physician assistant
☐ None of the above

**How much would the following things discourage or encourage you to get your adolescent daughter vaccinated against HPV?**

| | Discourage a lot | Discourage a little | No Effect | Encourage a little | Encourage a lot |
|---|---|---|---|---|---|
| H10. Doctor's recommendation | ☐ | ☐ | ☐ | ☐ | ☐ |
| H11. Receiving a reminder (letter, call) | ☐ | ☐ | ☐ | ☐ | ☐ |
| H12. Ease of getting to the place offering the vaccination | ☐ | ☐ | ☐ | ☐ | ☐ |
| H13. Low cost of the vaccine | ☐ | ☐ | ☐ | ☐ | ☐ |
| H14. Free or paid for by insurance | ☐ | ☐ | ☐ | ☐ | ☐ |
| H15. Highly effective in preventing HPV infection | ☐ | ☐ | ☐ | ☐ | ☐ |
| H16. Vaccine has side effects | ☐ | ☐ | ☐ | ☐ | ☐ |

## ANNEX 12 – WP-4 CERVICAL SCREENING STUDY PROTOCOL FOR POLAND

*Justyna Car, Magdalena Bielska-Lasota*

### EVALUATION OF KNOWLEDGE AND HEALTH-BEHAVIOR OF POLISH WOMEN AFTER IMPLEMENTATION OF THE NATIONAL CERVICAL CANCER SCREENING

#### *BACKGROUND*

Poland is still a high risk cervical cancer country, however, a very slow improvement can be seen in the last ten years. A steady increase of women's awareness concerning cervical cancer prevention and participation in opportunistic screening could have influenced this trend.

The previous studies performed on a representative sample of Polish women showed a substantial discrepancy in knowledge and health behaviour, which depends on age group, level of education and place of residence. The source and quality of information concerning benefits of early diagnosis were also evaluated. The same questions were asked in the subsequent studies, therefore trends could be observed [1, 2].

The National Cervical Cancer Screening Program in Poland still resulted in unacceptable low attendance of women invited by individual letters (less than 25% after 3 years of Program) [3]. Regional differences in the country were also visible.

That might suggest the following:

- Inadequate promotion of screening in Poland, which resulted in insufficient knowledge and low attendance in screening,
- Opportunistic screening, carried out in the private sector (which is not under control) may compete with the above organized on the national level.

#### *THE AIM OF THE STUDY*

1. To evaluate trends of knowledge and health-behaviour of Polish women after three years of the national screening program activity,
2. To recognize causes and opinions concerning incapability of national screening program.

#### *MATERIAL AND METHODS*

The questionnaire containing two groups of items will be designed:

- Items corresponding with the previous studies,
- Items concerning opinions about national cervical screening accessibility, psychological determinants, level of satisfaction and women preferences

One part of the questionnaire will contain methods used in the previous studies, which will allow for trends' evaluation.

The Public Opinion Research Centre (CBOS) [http://www.cbos.pl] will conduct interviews on the personal level in the representative sample of population. This approach will assure the high quality of research.

#### *EXPECTED RESULTS*

There is an urgent need to modify the cervical screening program in Poland to make it more efficient. It is expected that the results of the study will bring evidence that special effort should be addressed to the specific segments of population and perhaps the methodological approach used in promoting the program may be modify.

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## ANNEX 13 – WP-5 CANCER REGISTRY QUALITATIVE QUESTIONNAIRE PROTOCOL

*By Renée Otter, Sabine Siesling, Annemiek Kwast, Anna Gavin, Jean-Michel Lutz*

### POPULATION-BASED CANCER REGISTRY INDICATORS: DISSEMINATION AND PROMOTION

#### *BACKGROUND AND RATIONALE*

Since 1960 cancer registries provided population-based, comparative survival statistics for cancer patients. EUROCARE (a co-operative, cancer registry-based project) has collected and analysed survival data on patients diagnosed since 1978. They underlined large differences in cancer survival across Europe. The most recent evaluation on cancer survival among patients diagnosed in 2000-02 (EUROCARE-4 study) showed highest survival rates in the northern European countries and lowest for those in the eastern European countries. Although, patients in eastern Europe had the highest improvement in survival for major cancer sites during 1991-2002.

The EUROCHIP project (European Cancer Health Indicators Project) focuses on fighting inequalities in the burden of and care for cancer. It aims to improve information and knowledge on cancer. It will add value to action on country level as well as European action through data comparison.

EUROCHIP-1 project started to improve and enlarge a network on cancer including all Member and Candidate States. EUROCHIP-1 proposed a list of health indicators to provide comparable information about the burden, risk factors, management and outcome of cancer, in order to facilitate cancer control across Europe. Among them, three indicators were supposed to be strictly associated with the wide inter-country variation in cancer survival: “stage at diagnosis”, “cancer treatment delay” and “compliance with cancer guidelines”. The international group of experts engaged by EUROCHIP-2 lease with networks, international agencies, institutions, ministries of health and medical associations by promoting actions, analyzing data, and disseminating results. In addition EUROCHIP-2 promoted pilot studies in 11 countries to study the feasibility of collecting indicators. In most of the countries where pilot studies have been performed, collection was possible but sometimes very expensive. The ongoing EUROCHIP-3 will consider the most important indicators to identify inequalities. Series of specific actions to address them will be developed, so as to establish the pillars of a EU-wide cancer control strategy.

#### *AIMS*

The Dutch Comprehensive Cancer Centre North East (CCCNE) is leader of work package 5 from the EUROCHIP-3 project. This work package aims to improve population-based cancer registration of cancer indicators, in particular “stage at diagnosis” (extension of tumour at diagnosis), “cancer treatment delay” and “compliance with cancer guidelines”. To promote the collection of these indicators it is necessary to get insight in the present situation in all European cancer registries. Work package 5 addressed the following questions:

- Which European cancer registries routinely collect data items for these 3 cancer indicators
- Which European cancer registries do not collect data items for these cancer indicators and what are their reasons for not collecting these items (lack of budget, staff, data sources, legislation)
- What is the contribution of European cancer registries to the description of cancer burden or evaluation of cancer control.

#### *DESIGN AND DATA RETRIEVAL*

To answer the above mentioned questions a questionnaire will be addressed to all European cancer registries. This questionnaire is based on the results of the pilot studies (on the above mentioned indicators) performed by the EUROCHIP-2 project and the ENCR-Cancer Incidence in Five Continents (CI5) questionnaire.

To prevent duplication of effort, the content of the questionnaire has been discussed with other parties like the ENCR and the EUROCOURSE project. To reduce the workload for the CR some questions already asked for other projects (ENCR CI5 questions) were filled out by default.

The final EUROCHIP-3 questionnaire consist of 15 parts: contact details, registry description, conditions of cancer registration, funding of cancer registration, data sources, registration criteria, screening, diagnosis, coding topography and morphology, tumour items, treatment items, follow-up items, guidelines, registry output and finally permission for sharing data.

The complete questionnaire is added in Annex 1.
The invitation to participate and complete the EUROCHIP-3 questionnaire was send by email to all CR through the ENCR. The email contained an invitational letter (including the webpage and personal code for the CR) and this protocol. The questionnaire was filled out through the web based "gateway", which was been newly developed at the IARC. This gateway is a protected environment therefore each CR will receive their personal code. The questionnaire was completed by registry staff from existing knowledge of current practice. This might be only one person (a registry manager or director or someone equivalent) or a number of staff with different areas of expertise.
A reminder was send to the CR four weeks after the first invitation.

***DATA ANALYSIS AND RESULTS***

Descriptive statistics will be used to summarise.

- registry details
- staff and funding
- data sources
- screening
- the use of the CR data

Analysis of the 3 main indicators: "stage at diagnosis", "cancer treatment delay" and "compliance with cancer guidelines".
Identification of the CRs who routinely collect data items for these indicators.
Identification of the CRs who can not collect data items for these indicators and identification of the underlying problems.

***CONFIDENTIALITY AND DATA SECURITY***

Data requested for the EUROCHIP-3 study relate to the European cancer registries. Data requested for this study do not relate to individuals diagnosed with cancer.
For the collection of the data a web based survey tool will be used. The questionnaire will be send to the Cancer Registries who agreed to collaborate through the web based "gateway", developed at IARC. All CRs receive personal codes to enter the questionnaire. Replies on the questionnaire will be transcribed to a database at the IARC. When the survey is closed the complete database will be send to the CCCNE protected with a password. Analysis will be performed at the CCCNE.

***ACCESS TO THE EUROCHIP-3 DATA***

The EUROCHIP-3 database is held at the Comprehensive Cancer Centre North East in Enschede the Netherlands, with a backup at IARC. At CCCNE the analysis are carried out. Data will be shared with the ENCR and EUROCOURSE project. In the questionnaire the CR can give permission for sharing data with other ENCR members or sharing data unrestricted to the public.

***PUBLICATION POLICY***

The EUROCHIP-3 database will be used by WP5 researchers to carry out descriptive statistics. The final report and article of the deliverable results of this study will be send to all participating CRs to provide an opportunity for review. They can comment within four weeks. Other participating projects may publish after the EUROCHIP-3 report and an article has been published. In general, the researchers who performed the analyses and wrote the paper will be first author in the publication.

***TIME TABLE***

| | | |
|---|---|---|
| April | 2010 | Survey distributed to Cancer Registries |
| June | 2010 | Survey closed |
| June – September | 2010 | Data analyses |
| October | 2010 | Report to Cancer Registries |

## *ANNEX 13.1 DETAILED RATIONAL*

### *1 Registry details*

To improve population based registration it is important to know the current state of the cancer registry in each country and to identify possible problems with the population-based registration. Therefore we ask about the:

- Area covered by de registry: Is the registry national, regional or hospital based. Its population, the surface area, year registry started and area growth in recent years.
  *These items presents a definition of the area covered by the registry and whether the cancer-registry is population-based (for the entire country).*
- Collected tumour types: For which sites are data collected and are besides malignant also benign or in situ cases registered. Most recent complete year and total incidence of this year.
  *These items present the completeness of registration by tumour types.*
- Legislation: Are there specific agreements for cancer registration and is there a legislation limiting the cancer registration.
  *The presence of laws and rules that make cancer registration a reportable disease can ensure completeness of the registry data collection. However legislation on data privacy can limit data collection and use of data.*

### *2 Staff and funding*

Staff and funding are asked to get insight in the possibilities of the CR and the extension of the registration. Therefore we ask about the:

- Staff: Indication of the full-time equivalent (How many working hours a week for 1 FTE). How is the staff distributed.
  *Total staff in comparison to total incidence and other data gives us information on the registries possibilities. Registration staff can declare possible differences in the method of data collection (passive/active) and the number of different data-items collected, between CR's. The number of epidemiologists can give insight in data analysis and research possibilities.*
- Funding: The average annual budget, how the registry is financed and how the budget is distributed.
  *Total budget in comparison to the incidence and additional data gives information on the registry possibilities. Budget for registration can declare possible differences in data collection between CR's. How the registry is financed gives information on the guaranty on continuity of the registries dataset and gives information on possible differences in the method of data collection (passive/active) and the number of different data-items collected, between CR's.*

### *3 Data sources*

This question gives an overview of the availability of different sources for data collection and the effort needed of accessing these sources.
*For the collection of data, particularly for the 3 indicators, access to different sources might be of importance. Passive or active data collection gives information on the time and effort needed for collecting data and completeness of the records.*

### *4 Screening*

This question gives an overview of the population based screening programmes and whether screening outcomes are included in the cancer registry.
*It is important to know whether screening programmes are carried out, because population based screening results in early detection of cancer, is supposed to lower stage at diagnosis and overall survival.*

### *5 Diagnosis*

Are date of diagnosis and basis of diagnosis defined according to the ENCR rules.
*These questions give information on the comparability of incidence dates.*

The possibility of collecting additional dates.
*For the indicator treatment delay it is interesting to know which other dates than incidence date are available for registration or are currently collected.*

Explanation of the dates

- First visit to primary care physician: date on which patient first consulted the GP with symptoms suggestive of the cancer.
- Screening date: screening date where anything suspicious for cancer was found.
- First out-patient visit to hospital: date on which patient first visit the hospital with symptoms suggestive of the cancer.
- First admission to hospital: hospitalization date for the treatment of the cancer.

- First statement in the medical record by a licensed medical practitioner that the patient has cancer.
- Tumour markers report: Date outcome of tumour markers.
- First Imaging (CT, MRI, ultrasound, mammogram, X-ray): Date of first performed diagnostic imaging.
- Cytology report: Date of first cytology report.
- Histology report: Date of first histology report.
- First multidisciplinary team meeting (pre-treatment): Date of first multidisciplinary meeting were the patient with cancer is discussed.

*6 Tumour items*

- These questions present which coding systems are used for topography and histology.
  *These items give information on the comparability of the data between registries.*
- Stage: Is stage collected, if not what is the reason and is there an intention to collect stage. If stage is collected since which year, for which tumour types and what staging system is used.
  *Stage at diagnosis is considered as an important health indicator. If stage is not collected it is important to know the reason why and if there is an intention to collect stage in the near future. If stage is collected it is important to know for which tumour types stage is collected and the what staging system(s) is (are) used, this gives information on the comparability of the data between registries.*

*7 Treatment*

- (Start) date of first treatment, surgical treatment, radiotherapy, chemotherapy and endocrine therapy. If dates are not collected what is the reason and is there an intention to collect treatment dates in the near future. If dates are collected since which year and for which tumour types.
  *For the indicator cancer treatment delay it is necessary to know the (start) date of treatments. If these items are not collected it is important to know the reason why and whether there is an intention to collect dates in the near future.*
- Type of surgical treatment, radiotherapy, chemotherapy and endocrine therapy. If type of treatment is not collected what is the reason and is there an intention to collect these items. If type of treatment is collected since which year and for which tumour types.
  *For the indicator compliance with guidelines it is necessary to know the type of treatment. If these items are not collected it is important to know the reason why and if there is an intention to collect items in the near future.*
- Residue after surgical treatment.
  *Incomplete resection of the tumour has a strong relation with recurrences and survival but also cancer burden activities. Therefore it is interesting to know whether this item is registered by CRs.*

*8 Follow-up*

Follow-up for local/regional recurrence, distant metastasis, vital status, death certificates used to update vital status, active follow-up and cause of death.

*The incidence of recurrences and distant metastasis has a strong relation with cancer survival. Therefore it is important to know whether these items are registered by CRs.*

*9 Guidelines*

This chapter presents which guidelines for what tumour sites exist on national, regional or institutional level.

*For the indicator "compliance with clinical guidelines" it is necessary to know which guidelines are currently used by the clinicians working in the geographical area covered by the registry. This question is a first inventory to get more insight in the availability of guidelines. In later stage we will contact some selected registries.*

*10 Evaluation*

This chapter presents how data from the registry are used.

*To gain insight in the role of the CR in the improvement of health systems. To obtain an overview how CR data are used.*


# OVERVIEW OF CANCER REGISTRATION PRACTICES ENCR Questionnaire

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International Agency for Research on Cancer
World Health Organization

## 1. Contact

1.1. Are you the chief of the cancer registry?
- Yes -> go to 1.3.1.
- No

1.2.1. Please enter your name: ……

1.2.2. Please enter your email address: ……

1.3.1. Name of the director of the cancer registry: ……

1.3.2. Email address of the director of the cancer registry: ……

1.4. You are logged in as XXXXXXXXXX .

The address of your registry is displayed below:
XXXXXXXXXXXXXXXXXXXX

*Please verify this information to ensure that it is correct. If it is incorrect then please update on the CIN portal (click here to open your record in a new window)*

1.5. Is your registry a member of ENCR?
- Yes
- No
- I don't know

## 2. Registry description

*Selected information about your registry is displayed below. Please verify whether this information is correct.*

2.1.1 Registry type:
- □ National
- □ Regional
- □ Non population-based
- □ Network association
- □ Not a registry

2.1.2. Tumour specialisation:
- □ All Tumours
- □ Lip, oral cavity and pharnyx (C00-C14)
- □ Digestive (C15-C26)
- □ Respiratory (C30-C39 & Mesothelioma)
- □ Bone and soft tissue (C40-C41)
- □ Skin (C44)
- □ Breast (C50)
- □ Breast and gynaecologic (C50-C58)
- □ Female reproductive (C51-C58)
- □ Male reproductive (C60-C63)
- □ Urinary system (C64-C68)
- □ Nervous system (C69-C72)
- □ Endocrine (C73-C75)
- □ Haematopoietic (C81-C96)
- □ Solid tumours (Tumours w/ no liquid area)
- □ Not applicable (Mostly for non-registries)

2.1.3. Age specificity:
- □ All ages
- □ Paediatric
- □ Other age range
- □ Not applicable

2.1.4. Area covered (free text): ……

2.2. Please indicate the year that the registry started: -- Please Select Year --

2.3. Please indicate the current or most recent estimation of area covered by the registry (in km2):
……

2.4. Has the area covered changed during the existence of the registry?
- □ Yes
- □ No

2.5. Please enter the current or most recent estimation of the size of the population covered by the registry (in number of inhabitants): ……

2.6. Please enter the year of reference for the number of inhabitants provided: ……

## 3. Conditions of cancer registration: part 1

3.1.1. Does the law (or any subsidiary regulations) on privacy apply to cancer registration?

- □ Yes
- □ No → Please answer the red indicated questions of part 2

## 3. Conditions of cancer registration: part 2

3.1.2. Under this law (regulation), is informed consent required for a doctor or hospital to submit individual patient data to the cancer registry?

- □ Yes
- □ No

3.1.3. Does this law (these regulations) provide exemption from the requirement for informed consent for cancer registration?

- □ Yes
- □ No

3.1.4. Does this law (these regulations) provide exemption from the requirement for informed consent for the purposes of cancer research?

- □ Yes
- □ No

3.1.5. If informed consent is not required for cancer registration, what other data privacy procedure (if any) is being used? …….

3.2. Is it possible to use identifiable patient data (such as name and/or ID number) in your cancer registry?

- □ Yes Please skip Question 3.4.1.
- □ No Please answer Question 3.4.1.

3.3. How is the data for the cancer registry retrieved or submitted:

Via the treating doctors manually (physical notification form)? Yes / No
By data entry by designated professionals in the cancer registry? Yes / No
Via automatic submission from electronic health care records? Yes / No
Via electronic submission from (e.g.) pathology laboratories or hospital records systems? Yes / No

3.4.1. If you cannot use fully identifiable patient data in your cancer registry, can you use pseudonymised[1] patient data?

- □ YesGo to question 3.4.2.b
- □ No 3.4.2.a You stated that you cannot use fully identifiable patient data for cancer registration. Therefore, are you obliged to use fully anonymised data?
  - □ No
  - □ Yes, please explain ……

[1] *Individual patient data in which the full identity of the patient has been disguised by removal of a part or all identification, e.g. the name and address, date of birth, etc., but it remains possible to link the record back to that individual's identity at the source of the data (e.g. the hospital), for purposes such as quality control, by the use of a special key such as the hospital patient number.*

3.4.2.b Is it possible to use that pseudonymisation procedure (or a similar procedure) for other sources of patient data (e.g. occupational data) to link them to the cancer registry data?

- □ Yes
- □ No

3.5.1. Is a specific law regulating cancer registration currently in force?

- □ Yes
- □ No 3.5.2. Is such a law under consideration?
  - □ No
  - □ Yes, please explain

## 3. Conditions of cancer registration: part 3

3.6. Does your cancer registry have a special code of conduct on confidentiality?

- □ Yes
- □ No

3.7. Is cancer registration subject to regulation by laws or by ethical committees?

- □ Yes
- □ No

3.8. Do you have a special code of conduct on ethics for the registry?

- □ Yes
- □ No

3.9.1. Are you allowed to link cancer registry records to death certificates?

- □ Yes
- □ No

3.9.2. Are you allowed to capture the cause(s) of death as well as the date of death?

- □ Yes
- □ No

3.10. Are you allowed to link cancer registry data to external databases (e.g. occupation) using personal identifying information?

- □ Yes
- □ No

3.11. Are you allowed to provide data to research projects with personal identification of data subjects?

- □ No
- □ Yes, unrestricted
- □ Yes, with restrictions (please specify) ……

3.12. Are you allowed to share and publish anonymised data on single individuals?

- □ No
- □ Yes, unrestricted
- □ Yes, with restrictions (please specify) ……

3.13.1. Have you experienced barriers to any of the following due to privacy legislation?

| | |
|---|---|
| Cancer registration | Yes / No |
| Research using cancer registry data | Yes / No |

3.13.2. Please enter a contact email to get further information about privacy legislation affecting the registry. Multiple email addresses should be separated by a comma (,).

……

3.14.1. Have you experienced barriers to any of the following due to ethical issues?

| | |
|---|---|
| Cancer registration | Yes / No |
| Research using cancer registry data | Yes / No |

3.14.2. Please enter a contact email to get further information about ethical issues affecting the registry. Multiple email addresses should be separated by a comma (,).

……

3.15. Are you willing to provide a short description (with examples) of any legal or ethical problems in cancer registration, or in research using cancer registry data, that could be used in anonymous form for a European survey of this issue aimed at scientists, cancer registries and legislators?

- □ Yes
- □ No

*The information you provided in the section "Conditions of cancer registration" will only be used for analyses and reported in aggregated format, using data submitted by all responding registries. Nevertheless, identified information may also be of interest.*

Could you please indicate if the data disclosed on this page could be identified and shared:

| | |
|---|---|
| 3.15.1 Other ENCR members * | Yes / No |
| 3.15.2 Unrestricted public (i.e. online) * | Yes / No |

## 4. Funding of cancer registration

4.1.1. Please indicate the budget available to the cancer registry in 2009 for all activities (data collection, processing, analyses, research, dissemination etc.): -- please select currency -- € ……

4.1.2. Was the amount for 2009 significantly different from the average available in other years?

- □ It was similar
- □ It was much higher
- □ It was much lower

4.2. Please estimate the percentage of the available budget coming from each of the different sources listed below:

| | |
|---|---|
| …… | Government |
| …… | Competitive grants |
| …… | Health insurance companies |
| …… | Cancer society |
| …… | Charities |
| …… | Other, please specify …… |

0% of 100% total

4.3. Please estimate the percentage of the available budget going into the different activities listed below:

| | |
|---|---|
| …… | Data collection |
| …… | Data processing and analysis |
| …… | Management and administration |
| …… | Research |
| …… | Communication |
| …… | Other, please specify …… |

0% of 100% total

4.4.1. Please indicate how many hours a week is considered a full-time work week: ……

4.4.2. Please indicate the average full-time equivalent (FTE) of staff working in the cancer registry.
*Examples:*

*Two half-time registrars would count for 1 FTE.*
*The registry chief might work as an epidemiologist for 0.3 FTE, 0.5 as a clinician and 0.2 as a manager.*

| | |
|---|---|
| …… | Registrar (e.g. collection, registration, checking) FTE |
| …… | Programmer (e.g. database management, automation and output) FTE |
| …… | Statistician/epidemiologist (e.g. methods, analysis, interpretation, communication) |
| …… | Medical (e.g. pathology, coding, communication) FTE |
| …… | Administration (e.g. secretarial support) FTE |
| …… | Management (e.g. direction) FTE |
| …… | Other (please specify) FTE …… |

0 total

*The information you provided in the section "Funding for cancer registration" will only be used for analyses and reported in aggregated format, using data submitted by all responding registries. Nevertheless, identified information may also be of interest.*

Could you please indicate if the data disclosed on this page could be identified and shared:

| | |
|---|---|
| 4.5.1 Other ENCR members * | Yes / No |
| 4.5.2 Unrestricted public (i.e. online) * | Yes / No |

## 5. Data sources

5.1. Which of the listed sources of data are used to capture the incident cancer cases in your registry? For each of the used data sources please indicate the type of inquiry best describing the current practice.

| | Tick all applicable | | Select one of two | | Select one of three | | |
|---|---|---|---|---|---|---|---|
| | Active (1) | Passive (2) | Systematic routine regular | Occasional exceptional adhoc | Paper | Electronic | Mixed |
| Hospital oncology registries | | | | | | | |
| Radiotherapy departments | | | | | | | |
| Other hospital records | | | | | | | |
| Autopsy reports | | | | | | | |
| Outpatient clinics | | | | | | | |
| Hospices | | | | | | | |
| Pathology laboratories | | | | | | | |
| Haematology laboratories | | | | | | | |
| Other laboratories | | | | | | | |
| Tumour banks | | | | | | | |
| Screening programmes | | | | | | | |
| General practitioners | | | | | | | |
| Pharmacists | | | | | | | |
| Health insurance | | | | | | | |
| Regional population/mortality registry | | | | | | | |
| National population/mortality registry | | | | | | | |
| Death certificates (Identifiable) | | | | | | | |
| Research studies | | | | | | | |
| Networks | | | | | | | |
| Notifications | | | | | | | |
| Private hospital/clinical facilities | | | | | | | |

Do you use any other data sources?

*1Active - registry personnel actively ascertain cancer records, possibly during visits to data providers*
*2Passive - data is received without any requests by the registry*

5.2. Please indicate the numbers of the listed data sources operating within the geographical area covered by the cancer registry:

…… Hospitals (incl. university hospitals) and clinics treating cancer patients
…… Radiotherapy departments / centres treating cancer patients
…… Pathology laboratories
…… Positron Emissions Tomography (PET) scans

## 6. Registration criteria

6.1. Which of the following malignant cancer types does the registry collect data on? *If you only collect data on certain types of cancer then enter the ICD-O codes included or excluded in the text field provided.*

- □ All cancers
- □ Most cancers, except the following ……
- □ Only the following cancers ……

6.2. Do you record benign and/or in-situ cases for the following sites?

- □ All sites
- □ Brain and nervous system
- □ Urinary bladder
- □ Cervix
- □ Breast
- □ Other, please specify ……

6.3. Do you record uncertain/borderline behaviour for the following sites?

- □ Urinary bladder
- □ Ovary

## 7. Cancer screening

7.1. Please indicate the modalities of screening programmes for any of the tumour types listed below, if carried out in your registration area:

| | Existence | | Organisation | | Is "method of detection in relation to screening" used in your registry? (1) | | Any access to the screening database (directly or through record linkage)? | |
|---|---|---|---|---|---|---|---|---|
| | Yes | No | Invitations | Opportunistic | Yes | No | Yes | No |
| Breast cancer | | | | | | | | |
| Cervical cancer | | | | | | | | |
| Ovary cancer | | | | | | | | |
| Colorectal cancer | | | | | | | | |
| Prostate cancer | | | | | | | | |
| Melanoma cancer | | | | | | | | |
| Lung cancer | | | | | | | | |
| Mouth cancer | | | | | | | | |

Are there screening programs for other cancer sites in your registration area?

*1According to the ENCR recommendations http://www.encr.com.fr/detection.pdf*

## 8. Cancer diagnosis

8.1. Is the date of incidence defined according to the ENCR rules?

*Rules can be found at http://www.encr.com.fr*

- □ Yes
- □ No, please specify the rules used

8.2. Do you include date of registration for incident cases?

- □ No
- □ Yes

Please select the definition(s) of 'date of registration' applicable in your registry:

- □ Date of the first case notification to the registry
- □ Date of first inclusion of the case in the database
- □ Date of conclusion/validation of case processing

Do you have a different definition or any further comments regarding the date of registration?

……

8.3. Please indicate for all dates listed below if they are collected in your registry:

| | |
|---|---|
| First visit to primary care physician | Yes / No / In preparation |
| Screening date | Yes / No / In preparation |
| First out-patient visit to hospital | Yes / No / In preparation |
| First admission to hospital | Yes / No / In preparation |
| First mention of cancer in a medical record | Yes / No / In preparation |
| First positive tumour markers report | Yes / No / In preparation |
| Imaging (CT, MRI, ultrasound, mammogram, X-ray) | Yes / No / In preparation |
| First positive cytology report | Yes / No / In preparation |
| First positive histology report | Yes / No / In preparation |
| First multidisciplinary team meeting (pre-treatment) | Yes / No / In preparation |

Do you have any other pre-treatment dates to add?

## 9. Coding of topography and morphology

9.1.1. As regards the original coding of **topography** in your registry, please indicate the years of application for each system used:

| | Year From | Year To |
|---|---|---|
| ICD - O Third Edition | | |
| ICD - O Second Edition | | |
| ICD - O First Edition | | |
| ICD - O Field Trial Edition | | |
| ICD-10 | | |
| ICD-9 | | |

Do you want to add other topography coding systems that are used by your registry?

9.1.2. Have you modified any of the above topography coding systems in any way?

- □ Yes
- □ No

9.1.3. Please specify any modifications to the above topography coding systems:

……

9.2.1. As regards the original coding of **morphology** in your registry, please indicate the years of application for each system used:

| | Year From | Year To |
|---|---|---|
| ICD - O Third Edition | | |
| ICD - O Second Edition | | |
| ICD - O First Edition | | |
| ICD - O Field Trial Edition | | |
| ICD-10 | | |
| ICD-9 | | |

Do you want to add other morphology coding systems used by your registry?

9.2.2. Have you modified any of the above morphology coding systems in any way?

- □ Yes
- □ No

9.2.3. Please specify any modifications to the above morphology coding systems:

……

## 10. Additional tumour description: part 1

10.1. Is the basis of diagnosis defined according to the ENCR rules?

*Rules can be found at http://www.encr.com.fr*

- □ Yes
- □ No, please specify the rules used …….

10.2.1. Do you record stage?

- □ Yes → answer part 2a
- □ No → answer part 2b

## 10. Additional tumour description: part 2a

10.2.2. Please indicate below the information on tumour stage at diagnosis that is collected in your registry:

| | Collected | | Collected since | Classification system(s) used |
|---|---|---|---|---|
| | Yes | No | | |
| All sites | | | | |
| Breast cancer | | | | |
| Cervical cancer | | | | |
| Melanoma | | | | |
| Prostate | | | | |
| Colon & rectum | | | | |
| Lung | | | | |

Do you collect the information on tumour stage for other sites?

10.2.3. Which staging items do you collect for any of the indicated tumour sites?

- □ Clinical stage (after diagnosis and before the first treatment)
- □ Pathological stage (after treatment)
- □ Both clinical and pathological stage
- □ Other, please specify

## 10. Additional tumour description: part 2b

10.2.2. You stated that you did **NOT** collect stage, or left the question blank. Please answer the question below about potential use of stage in the future:

| | Is there an intention to collect this item? Yes / No / In preparation | Reason for not collecting | | | |
|---|---|---|---|---|---|
| | | Lack of interest | Lack of finance | Lack of staff | Limited access to data sources |
| Stage | | | | | |

## 11. Treatment information

11.1. Please select whether the following general treatment items are collected by your registry:

| | |
|---|---|
| Initial treatment | Yes / No |
| Surgery | Yes / No |
| Radiotherapy | Yes / No |
| Chemotherapy | Yes / No |
| Hormonal therapy | Yes / No |

11.2. Please describe how the treatment items below are collected in your registry:

| | Collected since | Collected for tumour sites | | | | | | | | Other site(s) |
|---|---|---|---|---|---|---|---|---|---|---|
| | | All | Breast | Cervical | Melanoma | Prostate | Colorectal | Lung | Other | |
| Date of first treatment | | | | | | | | | | |
| Date of surgical treatment | | | | | | | | | | |
| Type of surgical treatment | | | | | | | | | | |
| Tumour residue after surgical treatment | | | | | | | | | | |
| Start-date radiotherapy | | | | | | | | | | |
| End-date radiotherapy | | | | | | | | | | |
| Type of radiotherapy | | | | | | | | | | |
| Start-date chemotherapy | | | | | | | | | | |
| End-date chemotherapy | | | | | | | | | | |
| Type of chemotherapy | | | | | | | | | | |
| Start-date hormonal therapy | | | | | | | | | | |
| Type of hormonal therapy | | | | | | | | | | |

11.3. Please indicate the **reasons for not collecting** so far any item among those listed below:

| | Is there an intention to collect this item? Yes / No / In preparation | Reason for not collecting | | | |
|---|---|---|---|---|---|
| | | Lack of interest | Lack of finance | Lack of staff | Limited access to data sources |
| Date of first treatment | | | | | |
| Date of surgical treatment | | | | | |
| Type of surgical treatment | | | | | |
| Tumour residue after surgical treatment | | | | | |
| Start-date radiotherapy | | | | | |
| End-date radiotherapy | | | | | |
| Type of radiotherapy | | | | | |
| Start-date chemotherapy | | | | | |
| End-date chemotherapy | | | | | |
| Type of chemotherapy | | | | | |
| Start-date hormonal therapy | | | | | |
| Type of hormonal therapy | | | | | |

11.4.1. Does your cancer registry collect data on co-morbidity at time of diagnosis?

- □ No
- □ Yes 11.4.2. Please select the tumour sites where co-morbidity is collected:
  - □ Breast
  - □ Cervical
  - □ Melanoma
  - □ Prostate
  - □ Colon & rectum
  - □ Lung
  - □ Other, please specify ……

11.5. Do you give feedback to the clinical centres covered by your registration area?

- □ No
- □ Yes, please give details ……

## 12. Follow-up of registered patients

12.1. Please describe how the follow-up items below are collected in your registry:

| | Collected since | Collected for tumour sites | | | | | | | | Other site(s) |
|---|---|---|---|---|---|---|---|---|---|---|
| | | All | Breast | Cervical | Melanoma | Prostate | Colorectal | Lung | Other | |
| Vital status | | | | | | | | | | |
| Date of follow-up | | | | | | | | | | |
| Cause of death | | | | | | | | | | |
| Distant metastasis | | | | | | | | | | |
| Recurrence | | | | | | | | | | |

12.2. Please indicate the **reasons for not collecting** so far any item among those listed below:

| | Is there an intention to collect this item? Yes / No / In preparation | Reason for not collecting | | | |
|---|---|---|---|---|---|
| | | Lack of interest | Lack of finance | Lack of staff | Limited access to data sources |
| Vital status | | | | | |
| Date of follow-up | | | | | |
| Cause of death | | | | | |
| Distant metastasis | | | | | |
| Recurrence | | | | | |

12.3. Do you use death certificates to update the vital status of registered cases?

- □ Yes
- □ No

12.4. Do you use sources other than death certificates to follow up the registered patients for vital status?

- □ No
- □ Yes, please specify …….

## 13. Guidelines

13.1.1. Are evidence-based guidelines for diagnosis and/or treatment of cancer available in your country?

- □ Yes
- □ Unknown -> go to 14.1
- □ No -> go to 14.1

13.1.2. Please indicate the level of applicability and source of reference of guidelines for the following cancer sites:

| | Level | | | Reference |
|---|---|---|---|---|
| | National | Regional | Institutional | |
| Head and neck | | | | |
| Digestive system | | | | |
| Respiratory system | | | | |
| Bone & soft tissues | | | | |
| Skin | | | | |
| Breast | | | | |
| Female genital organs | | | | |
| Male genital organs | | | | |
| Urinary tract | | | | |
| Central nervous system | | | | |
| Blood, bone marrow & lymph nodes | | | | |

Are there guidelines available for any other tumour sites?

## 14. Registry output

14.1. Please indicate the most recent year which is currently considered complete for cancer counts:

…… Year

…… Total number of cases registered in the most recent complete year

14.2. Please describe the contribution of your registry to the description of cancer burden or evaluation of cancer control by selecting the applicable answer below:

| | Production | |
|---|---|---|
| | Routine, regular, frequent | Occasional, ad-hoc, project-based |
| Cancer incidence rates | | |
| Cancer survival | | |
| Cancer mortality rates | | |
| Development of national cancer control strategies | | |
| Evaluation of national cancer control strategies | | |
| Clinical audits on diagnosis/staging | | |
| Clinical audits on treatment | | |
| Clinical audits on waiting times | | |
| Clinical audits on multidisciplinary care | | |
| Evaluation of adherence to clinical guidelines for diagnosis | | |
| Evaluation of impact of clinical guidelines for diagnosis | | |
| Evaluation of adherence to clinical guidelines for treatment | | |
| Evaluation of impact of clinical guidelines for treatment | | |
| Improvement of cancer care projects | | |
| Cancer screening evaluation | | |
| Evaluation of radiation systems use | | |
| Evaluation of usage of Computed Axial Tomography (CT) | | |
| Evaluation of usage of Positron Emission Tomography (PET) | | |
| Evaluation of usage of magnetic resonance technique | | |

Are there other topics that your registry contributes to?

14.3. Does your registry have a web page?

- □ No
- □ Yes, please give the address of the web page ……

## 15. Permissions

*In two specific sections of this questionnaire you have indicated your preferences for sharing the information provided. Protection of the confidentiality of these answers was considered of particular importance. Your selection is reprinted below as a reminder:*

Section on confidentiality, legal and ethical issues:

| | Yes, I will share | No, I will not share |
|---|---|---|
| 3.15.1 Other ENCR members * | | |
| 3.15.2 Unrestricted public (i.e. online) * | | |

Section 'cancer registration funding':

| | Yes, I will share | No, I will not share |
|---|---|---|
| 4.5.1 Other ENCR members * | | |
| 4.5.2 Unrestricted public (i.e. online) * | | |

Below, please select the level of sharing of identified answers to the other questions contained in this questionnaire.

Your preferences will be strictly respected.

15.1.1. Other ENCR members * Yes / No
15.1.2. Unrestricted public * Yes / No

15.2. Do you have any comments to add before the submission of this questionnaire?
……

## 16. Submission

16.1. A confirmation email with a summary of your answers will be sent to the address(es) specified below.
*If you would like to send the confirmation to a different address please enter it here. Multiple email addresses should be separated by a comma (,).*

……

## ANNEX 15 – WP-5 CANCER REGISTRY QUALITATIVE QUESTIONNAIRE INVITATION LETTER

To Directors of Cancer Registries in Europe

Dear colleague, April 2010

We would like to invite you to participate in a survey "Overview of Cancer Registration Practices", conducted jointly by the EUROCHIP-3 (workpackage 5) and EUROCOURSE projects and supported by the ENCR that provided your address.

All European Cancer Registries will be asked to complete this questionnaire which updates information collected in an earlier survey carried out in 2007.To keep your workload to a minimum, relevant answers from previous questionnaires (including those provided for Cancer Incidence in Five Continents) will be preloaded into the new survey and can be updated where necessary.

The questionnaire has been built using a web based system, developed at IARC, and is hosted on a server in a secure environment. Future questionnaires and data requests for projects such as EUROCOURSE, EUROCIM and Eurocan will also be conducted through this web based gateway. You will have the option to place relevant into the public domain (though the ENCR website) or provide these only to other ENCR members (or neither)..

To complete the survey, please go to the URL below or copy and paste the address into your Internet browser address window. Enter the personal code, which is a unique code for each cancer registry and is printed at the bottom of this letter. You will need the personal code to complete the survey, which will take you about 30 minutes. This survey will go through registry details, data sources, items collected in your registry database, guidelines and the role of care evaluation within the registry.

We would greatly appreciate it if you could complete the questionnaire within four weeks (before the 21st of May).

The final report, expected in October 2010, will be sent to each participating registry who will have an opportunity to provide comments. All participating registries will be listed in the acknowledgement section..

**Web address: www.iarc/eurochip3survey.com**

**Respondent key: << res key >>**
Password:

Thank you in advance for your participation in this important project. The questions have been designed to be self-explanatory, but can be commented upon to Annemiek Kwast (a.kwast@ikno.nl). Any questions on the technical aspects of the questionnaire (navigation, return e-mail, etc.) would also be welcomed and should be sent to Mark O'Callaghan (ocallaghanm@fellows.iarc.fr).

Yours sincerely,

**Max Parkin, MD PhD**
Chair of the ENCR
Signature:

**Renée Otter, MD PhD**
Leader of WP-5 of EUROCHIP-3
Signature:

**Jan Willem Coebergh, MD PhD**
Coordinator of EUROCOURSE

Signature:

**David Forman**
Head, Section of Cancer Information
IARC
Signature:

Information on the projects:

EUROCHIP (European Cancer Health Indicators Project: www.tumori.net/eurochip) focuses on fighting inequalities in cancer. Its aim is to improve information and knowledge on cancer. It will add value to each countries action as well as Europe's action through data comparison.
The Dutch Comprehensive Cancer Centre North East is leader of work package 5 from the EUROCHIP-3 project. This work package aims to improve population-based cancer registration of cancer indicators, in particular "stage at diagnosis" (extension of tumour at diagnosis), "cancer treatment delay" and "compliance with cancer guidelines". We therefore developed a questionnaire to identify which indicators cancer registries collect routinely and if not, the reason why and the major problems in collecting these indicators. If you are interested in the study protocol you can contact Annemiek Kwast, EUROCHIP WP5/researcher at the Comprehensive Cancer Centre North East, Enschede/Groningen, the Netherlands: a.kwast@ikno.nl.

EUROCOURSE (EUROpe against Cancer: Optimisation of the Use of Registries for Scientific Excellence in research: www.eurocourse.org) is initiated by the European Network of Cancer Registries (ENCR) and 'their' programme owners and managers: Cancer Societies, regional and national cancer registries and public service organizations, including ministries of Health and Science, charities and cancer centres. The project aims to root cancer registration in cancer control across Europe, through their role of independent and valid transnational information provider on cancer occurrence and outcome, thereby also facilitating translational research. Furthermore, EUROCOURSE should offer a perspective for regional and national funding bodies to contribute to cancer control at European level. If you are interested in the study protocol you can contact Corina van den Hurk, Executive Board EUROCOURSE/ researcher at the Comprehensive Cancer Centre South, Eindhoven, the Netherlands: C.vd.Hurk@ikz.nl

## ANNEX 16 – WP-5 CONCEPT OF TRAINING PROGRAM REGISTRATION STAFF GREECE

**Day 1: September 21st, 2009**

The main points at this first day will be:

- Welcome and introduction
- Training outline this upcoming week.
- The organization of cancer centers in the Netherlands
- IKNO, more than registration alone (presentation)
- Organization of the cancer registration in our region (presentation)
- The development of the cancer registration in Greece (presentation by one of the students)
- Sharing experiences

**Day 2: September 22nd, 2009**

The use of the database

- Collecting information: Which items will be collected and why?
- Developing a database
- Uniformity and quality: How can you make rules regarding encodings to achieve uniformity and quality
- Quality controls in the database

**Day 3: September 23rd, 2009**

The development of a training program for registration staff

- Training of registration staff in the IKNO region (presentation)
- How to develop a training for registration staff in Greece?

**Day 4: September 24th, 2009**

Coding exercises.

- ICD-O book and TNM classification
- Differences in interpretation of encoding
- ICD-O and TNM exercises
- Coding exercises and discussion

**Day 5: September 25th, 2009**

The future

- Evaluation
- Future: How can IKNO support development of the cancer registration in Greece?

## ANNEX 17 – WP-6 CANCER REHABILITATION INDICATOR LISTS ONLINE DISCUSSION

*by Dr Piret Veerus, Camilla Amati, Paolo Baili*

**EUROPEAN CANCER HEALTH INDICATOR PROJECT EUROCHIP-3**
**WP-6 CANCER PATIENT REHABILITATION INDICATORS**

### OUR MANDATE

The EUROCHIP-3 "Common Actions" (2008-2011)[1] Work Package on cancer rehabilitation indicators[2] (WP-6) will list the health indicators for rehabilitation needs of cancer patients (including psychological, clinical, psychiatric, nutritional and social services) necessary for a structured collection of comparable data in the EU to guarantee equal care to all EU citizens. No data collection is envisaged.

### THE LIST

1. Cancer prevalence
   - 1a. Prevalence by cancer site
   - 1b. Cancer prevalence by gender
   - 1c. Cancer prevalence in different age groups
2. Proportion of cancer patients with/without relapse
3. Amount of funding per cancer rehabilitation per patient per year
4. Existence of national strategy for cancer rehabilitation
5. Availability of guidelines for cancer rehabilitation
6. Availability of follow-up programmes for cancer patients
7. Number of NGOs and other organisations involved in cancer rehabilitation
8. Availability of social care workers at home
9. Training courses for persons involved in rehabilitation programmes
10. Availability of social counselling, psychological support, nutritional counselling for cancer patients and their family members
11. Proportion of persons with cancer diagnosis returned to work
12. Quality of life of cancer patients

### DISCUSSION

In the following pages the indicators are briefly described and specific items of discussion are proposed (i.e. collection, methodology and/or availability in various countries). Please note:

- Included indicators must be at population level
- Included indicators do not necessarily have to be already available
- Included indicators can be can be a proxy
- Included indicators can be subdivided in high and low priority
- It is really important to discuss of common sources across Europe and on the efforts necessary for collection
- At the end of the project the list must be concise (5-6)

[1] The EUROCHIP Projects focus on cancer health information in the EU and are funded within the Program of Community Action in the Field of Public Health, Health Information strand.

EUROCHIP-1 (2001-2003) has produced the List of Cancer Health Indicators in the areas of cancer treatment, prevention, screening and epidemiology for the EC ECHIM list (European Community Health Indicators Monitoring).

EUROCHIP-2 "the Action" (2003-2007) has developed actions for the improvement of Cancer Health Information in 24 Member States. Actions included studies on Preventive Diet and Lifestyles, Treatment Best Practices, Cervical Cancer Screening Programmes and on Cancer registration inequalities in the EU.

The EUROCHIP-3 "Common Actions" (2008-2011) sets towards a common EU policy of cancer control for prevention, treatment and care for the improvement of survival and quality of life for cancer patients.

[2] WHO Definition of rehabilitation: " process aimed at enabling patients to reach and maintain optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination."

| **CANCER PREVALENCE** (TOTAL PREVALENCE AND/OR 5-YEAR PREVALENCE) | |
|---|---|
| Acronym | PREV |
| Priority | high |
| Category | cancer burden |
| Rationale | to estimate the number of persons with a cancer diagnosis. Prevalence indicates how many people in an exact date (ex 31/12/xxxx) show potential medical, physical, psychological or social problems as a consequence of cancer. The indicator is useful for health planning, resources allocation. |
| Unit of measurement | proportion of persons with a cancer diagnosis per 100,000 |
| Classified by | a. cancer site<br>b. sex<br>c. age |
| Main source of data | cancer registry (CR). In some countries CR covers the entire population, in others one ore more CRs cover a fraction of population |
| Operational definition | Prevalent cases are people from a population, alive up to a given date, and who had previously been diagnosed cancer. New incidence cases and still alive incident cases of previous years are included in the prevalence. Prevalent proportion shows the proportion of prevalent cases on a total resident population in a given area. It is calculated as follows:<br>$p(s,sx,g,p,a) = \frac{P(s,sx,g,p,a)}{Pm(sx,g,p,a)}$<br>P (s,sx,g,p,a) = estimated number of survivors who had been diagnosed cancer, specific per cancer site (s), sex (sx), geographic area (g), calendar year (p), age (a)<br>Pm (sx,g,p,a)= average population specific per sex (sx), geographic area (g), calendar year (p), age (a) |
| Centralization of data | Five year cancer prevalence estimates are produced by GLOBOCAN; total prevalence estimates are produced by EUROPREVAL [Micheli A et al.. Ann Onc 2002;132(6):840-865 published data in Europe at 31/12/1992]. |
| Cooperation | Methodology used by EUROPREVAL (Capocaccia R et al, Ann Onc 2002;132(6)) is used also by the SEER Program of the NCI in US. The SEER*Stat (the US CR database) implemented the EUROPREVAL methodology to estimate prevalence in US. |

**DISCUSSION**

Prevalence can be used as an indicator of the cancer rehabilitation burden. Prevalence is estimated with data collected by cancer registries.

Discussion referred to the use of 5-year prevalence (number of persons alive at a certain date with a cancer diagnosis in the previous 5 years) or total prevalence (number of persons alive at a certain date with a cancer diagnosis in their past).
5-year prevalence is routinely estimated by IARC and published in the GLOBOCAN database (last available year: 2002). Total prevalence in Europe was estimated for various countries by the EUROPREVAL project (last available year: 1992). In Italy a project recently published estimates of total prevalence using specific methodology (MIAMOD/PIAMOD models) starting from cancer mortality data (available at national level by national Statistic Offices) and cancer survival data (available from EUROCARE project in the majority of European countries). This methodology can be used also in other EU countries. In US total prevalence is estimated starting from SEER Stat data.

The group was favourable about including prevalence in the list of indicators. No agreement was yet reached on the inclusion of 5-year prevalence or total prevalence.

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Type of indicator (5 year and/or total prevalence):

Methodology:

Availability in your country:

**PROPORTION OF CANCER PATIENTS WITH/WITHOUT RELAPSE**

| | |
|---|---|
| Acronym | RELAPSE |
| Priority | high |
| Category | cancer burden |
| Rationale | to estimate the number of persons who have had a relapse after primary cancer diagnosis and treatment |
| Unit of measurement | proportion of patients with/without relapse among total number of persons diagnosed with cancer |
| Operational definition | |
| Numerator | number of cancer patients with/without relapse x 100,000 |
| Denominator | total number of cancer patients |
| Main source of data | Ad-hoc studies on cancer registry data. For methodology see: Gatta G et al, Annals of Oncology 15: 1136–42, 2004 |

**FIRST DISCUSSION**

This indicator should be used as a proxy to estimate how many prevalent cases need "clinical help".

Discussion referred to the way to collect this indicator.

- Data on relapses are not routinely collected by cancer registries in the majority of European countries. Ad hoc collection (with ad-hoc protocols and standard definition of relapses) should be implemented on cancer registry database samples for specific cancer sites. These studies are expensive.
- Information on relapse percentages could be obtained from clinical trials and clinical databases and combined to total prevalence estimates for specific cancer sites.

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Methodology:

For which cancer site/s:

| **FUNDING FOR CANCER REHABILITATION** | |
|---|---|
| Acronym | FUNDING |
| Priority | high |
| Category | financial resources for rehabilitation |
| Rationale | to estimate the financial resources for cancer rehabilitation |
| Unit of measurement | amount of funding per cancer rehabilitation per patient per year |
| Operational definition | |
| Numerator | total amount of funding for cancer rehabilitation per year in EUR (both public and private resources) |
| Denominator | mean number of cancer person with a cancer diagnosis per year |

**FIRST DISCUSSION**

This indicator should be used as a proxy to political attention to cancer rehabilitation issue.

Discussion referred to the possibility of collection and comparison among countries. Similar indicators were also discussed during the EUROCHIP-1 project for other cancer fields (e.g.: cancer registry funds, cancer screening funds, etc) yet no solution was reached to find comparable indicators. It is really difficult and quite impossible to extrapolate funds for cancer rehabilitation from the total public/private funds devoted to cancer or to health in general.
An alternative way can be a cost analysis of cancer rehabilitation experience of a cancer registry patient sample. These studies are expensive.

The majority of colleagues in the group seem to be aware on the impossibility to include this indicator in the list. A possible proxy indicator of political attention to the cancer rehabilitation issue can be a YES/NO indicator on presence of cancer rehabilitation in national cancer control plans *[see next page]*

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at national level):

Methodology:

Possible other indicators:

| **NATIONAL STRATEGY FOR CANCER REHABILITATION** | |
|---|---|
| Acronym | STRATEGY |
| Priority | high |
| Category | rehabilitation strategy |
| Rationale | to guarantee existence of national strategy for cancer rehabilitation |
| a. Unit of measurement | existence of national cancer plan [Y/N] |
| b. Unit of measurement | cancer patient rehabilitation included in the national cancer plan [Y/N] |
| Main source of data | Health ministry survey; expert survey; internet ad hoc collection |

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

## NATIONAL GUIDELINES FOR CANCER REHABILITATION

| | |
|---|---|
| Acronym | GUIDELINES |
| Priority | high |
| Category | rehabilitation strategy |
| Rationale | to guarantee existence of national guidelines for cancer rehabilitation |
| Unit of measurement | existence of national guidelines for cancer rehabilitation [Y/N] |
| Classified by | cancer site |
| Main source of data | Health ministry survey; expert survey; internet ad hoc collection |

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

Do you have some example of guidelines?

## FOLLOW-UP PROGRAMMES FOR CANCER PATIENTS

| | |
|---|---|
| Acronym | FOLLOW-UP |
| Priority | medium |
| Category | rehabilitation strategy |
| Rationale | to guarantee follow-up programmes for cancer patients |
| Unit of measurement | existence of follow-up programmes for cancer patients [Y/N] |
| Main source of data | Health ministry survey; expert survey; internet ad hoc collection |

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

**ORGANISATIONS INVOLVED IN CANCER REHABILITATION**

| | |
|---|---|
| Acronym | NGO |
| Priority | high |
| Category | human resources |
| Rationale | to estimate the human resources for cancer rehabilitation |
| Operational definition | number of organisations and number of members in these organisations |

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

| **AVAILABILITY OF SOCIAL CARE WORKERS AT HOME** | |
|---|---|
| Acronym | HOME_CARE |
| Priority | medium |
| Category | human resources |
| Rationale | to evaluate the availability of social care workers at home |
| Unit of measurement | existence of system offering social aid for cancer patients at home [Y/N] |

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

## TRAINING COURSES FOR PERSONS INVOLVED IN REHABILITATION PROGRAMMES

| | |
|---|---|
| Acronym | TRAINING |
| Priority | high |
| Category | human resources |
| Rationale | to check the availability of training courses for persons involved in rehabilitation programmes |
| Unit of measurement | existence of training courses for persons involved in rehabilitation programmes [Y/N - if possible description of courses; who organises them; whether accreditation exists) |

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at national level):

Type of training courses:

Source of data:

| **COUNSELLING FOR CANCER PATIENTS AND THEIR FAMILY MEMBERS** | |
|---|---|
| Acronym | COUNSELLING |
| Priority | high |
| Category | counselling for cancer patients and their family members |
| Rationale | to check the availability of systems for social counselling, psychological support, nutritional counselling for cancer patients and their family members. |
| Unit of measurement | existence of systems offering social counselling, psychological support, nutritional counselling for cancer patients and their family members [Y/N] |

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at national level):

Type of counselling:

Source of data:

**PROPORTION OF PERSONS WITH A CANCER DIAGNOSIS RETURNED TO WORK**

| | |
|---|---|
| Acronym | RETURN_WORK |
| Priority | high |
| Category | success of cancer treatment and rehabilitation |
| Rationale | to estimate the number of persons with a cancer diagnosis returned to work |
| Unit of measurement | proportion of persons with a cancer diagnosis returned to work |
| Operational definition | |
| Numerator | number of persons with a cancer diagnosis working (part-time, full-time) |
| Denominator | total number of cancer patients |

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at population level):

Methodology:

Source of data:

## QUALITY OF LIFE OF CANCER PATIENTS

| | |
|---|---|
| Acronym | QL |
| Priority | high |
| Category | success of cancer treatment and rehabilitation |
| Rationale | to evaluate the quality of life of cancer patients |
| Unit of measurement | quality of life scores (by cancer site and stage) |
| Operational definition | quality of life scores measured by general or specific scales |

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at population level):

Methodology:

Source of data:

## ANNEX 18 – WP-7 LIST OF PROCEDURES FOR BREAST CANCER

1. ASSESSMENT
   - Screening
   - Mammographic assessment
   - Biopsy
   - Staging Test
   - Routine assessment by Immunohistochemistry of oestrogen receptor (ER) status–progesterone receptor status
   - test human epidermal growth receptor 2 (HER2)

2. TREATMENT - SURGERY
   - Excision and pathological examination
   - Conservative surgery
   - mastectomy
   - reconstruction

   - Lymph nodes (Sentinel lymph node -Axillary lymph node dissection )

3. ADJUVANT TREATMENT

   a) ENDOCRINE THERAPY
      - Ovarian suppression/ablation
      - Aromatase inhibitors (exemestane or anastrozole)
      - letrozole

   b) CHEMOTERAPY
      - tamoxifen after breast conserving surgery to patients with DCIS
      - Docetaxel
      - Paclitaxel
      - Trastuzumab

   c) RADIOTHERAPY
      - Post mastectomy radiotherapy
      - Radiotherapy to nodal areas

4. FOLLOW-UP IMAGING
   - annual mammography (5 years)
   - ultrasound or MRI for routine post-treatment surveillance

5. CLINICAL FOLLOW-UP
   - primary, secondary, shared care
   - BONE LOSS TREATMENT
     - baseline dual energy X-ray absorptiometry (DEXA) scan
     - Bisphosphonates

## ANNEX 19 – WP-7 LIST OF PROCEDURES FOR CHILDHOOD LEUKAEMIA

1. ASSESSMENT
   - cytomorphological and cytochemical examination of a bone marrow aspiration smears
   - Jamshidi needle biopsy
   - cross-sectional radiological imaging
   - Molecular-genetic techniques and/or flow cytometry
   - DNA–polymerase chain reaction (PCR)-based detection

2. TREATMENT
   - an induction period aiming at an initial remission within approximately 4 to 6 weeks by use of multiple cancer chemotherapeutic drugs;
   - consolidation/intensification and re-induction segments to eradicate residual leukemic blasts in patients who are in remission bymorphologic criteria
   - extra compartment therapy such as CNS preventive therapy
   - a maintenance period to further stabilize remission by suppressing re-emergence of drug-resistant clones through continuingreduction of residual leukemic cells

3. FOLLOW-UP AND LONG TERM FOLLOW-UP