

European Commission
Directorate C
Public Health and Risk Assessment
Health & Consumer Protection Directorate general

GRANT AGREEMENT

n° 2007121

EUROCHIP-III

European Cancer Health Indicator Project-III
Common Action

DELIVERABLE D04

Report on cancer rehabilitation programs in EU Member States and proposal for cancer patient rehabilitation indicators

EUROCHIP-3 WP-6 Leader

Piret Veerus
Department of Epidemiology and Biostatistics
National Institute for Health Development
Hiiu 42 - 11619 Tallinn - Estonia
Phone: +372-6593946
Fax: +372-6593901
E_mail: piret.veerus@tai.ee

ACKNOWLEDGEMENTS

We would like to thank all members of the working group on cancer patient rehabilitation in Europe, all those who were involved in compiling the questionnaires and all those who responded to them.



This publication arises from the project EUROCHIP-3 which has received funding from the European Union in the framework of the Health Programme

TABLE OF CONTENTS

INTRODUCTION	3
HISTORY OF THE DISCUSSION ON THE INDICATOR LIST	4
Initial meeting in November 2009	4
First survey	5
Second meeting in June 2010	5
Second survey	6
Final meetings in June and September 2011	6
RESULTS I: CANCER REHABILITATION STATUS ACROSS EUROPE	10
Cancer rehabilitation definitions	10
Cancer rehabilitation role in political and clinical agendas	10
Cancer rehabilitation capacity (structures, services and funding)	10
Resources	10
Information about resources	11
Funding	11
Conclusions	11
RESULTS II: INDICATORS FOR THE FINAL LIST	14
Burden of cancer rehabilitation needs	14
Indicators measuring the success of rehabilitation	16
Cancer patients' quality of life	16
Cancer patients' rehabilitation needs (and their satisfaction)	17
Return to work	18
Overall conclusion	20
REFERENCES	24
APPENDIX 1 – LIST OF WP-6 EXPERTS	27
APPENDIX 2 – FIRST SURVEY	28
APPENDIX 3 – SECOND SURVEY	41

INTRODUCTION

As a result of constant advances in medicine and other sciences, and in medical technology, cancer survival rates are increasing in Europe¹ and prevalent cases represent a growing proportion of the population: according to RARECARE estimates, based on cancer registry data, there were nearly 17,8 million of all cancer prevalent cases in the European Union (3,566 cases per 100,000) at 1st January 2003.² Trends in population ageing, cancer incidence and survival rates allow to project a huge increase in the number of cancer prevalent cases in the future.³ The EURO CARE project, applying cure models to cancer registry data, estimated the proportion of patients considered to be cured in European countries: for all cancers combined proportion of cured patients among countries varied between 21% and 47% in men, and 38% and 59% in women.⁴

The related burden of disease and cost of medical and psychosocial care are consequently substantial.⁵⁻⁶ In fact, cancer is a chronic illness with patients enduring physical and psychological symptoms years after treatment. Commonly experienced difficulties are physical symptoms such as pain, fatigue, cognitive impairment as well as psychological problems such as health anxiety, irritable mood, demoralization, depression, interpersonal problems or abnormal illness behaviour affecting patients' quality of life.⁷

European recommendations for reducing the burden of cancer in Europe have recognized the value of an integrated approach "to attain optimal results patient-centered comprehensive interdisciplinary approach and optimal psycho-social care should be implemented in routine cancer care, rehabilitation, post-treatment and follow-up".⁸⁻⁹ It has been suggested that "adequate management of patient's quality of life and provision of psychosocial care services" should be included in national cancer control plans. However, at population level little is known on the need for rehabilitation, short- or long-term care and palliative care, or on survivorship issues. Also, little is known on the availability, accessibility or uptake of such care by patients needing services.

The Work package nr 6 of the EUROCHIP-3 project (WP-6)¹⁰ organised an European group of experts in cancer rehabilitation with the aim to provide comparable information on the European level about the number of cancer patients, about rehabilitation programmes, and about the indicators already being used for the evaluation of social aid, psychological and nutritional counselling and palliative care for cancer patients in different Member States; the objective was to define suitable indicators to be used in the future in order to fight with inequalities and to guarantee an evidence-based use of resources and to check availability of comparable data in different countries.

HISTORY OF THE DISCUSSION ON THE INDICATOR LIST

The EUROCHIP-3 WP-6 on cancer patient rehabilitation was started in 2008 and during the first steering group meeting in the same year the specific objectives and possible methods for data collection were defined.

Several conditions were set for cancer patient rehabilitation indicators:

- must be at a population level as in future they could be collected and included in an European Commission database where all the indicators must refer to a country (or region) population
- do not necessarily have to be already available
- can be a proxy
- can be subdivided in low and high priority indicators
- at the end of the project the list must be concise

After the initial meeting, potential partners in all EU Member States were identified and contacted to ask for their interest in collaboration.

The final working group consisted of 35 experts from 27 EU Member States (Appendix 1).

Here below we synthesize the various phases followed to reach consensus on the final list of cancer rehabilitation indicators to propose to the European Commission.

Initial meeting in November 2009

In November 2009, a preliminary list of cancer rehabilitation indicators (http://www.tumori.net/eurochip/material/WP6/Reh_list_nov09.pdf) was discussed during the first working group meeting which took place simultaneously with the 3rd International Cancer Control meeting in Cernobbio, Italy. The desirable indicators were categorized according to their purpose:

- to collect information about cancer burden in Europe
- to map available financial resources for cancer rehabilitation
- to map available human resources for cancer rehabilitation
- to measure the rate of return to work of cancer patients.

The indicators were discussed according to their methodology, data availability, costs related to data acquisition and priority. In addition, it was suggested to collect information which would describe the organisation of cancer rehabilitation in each country.

First survey

The first survey (Appendix 2) was compiled according to the consensus reached during the meeting and collated among the working group members. It collected information about methodology, data sources, data availability and inclusion of the following indicators:

- cancer prevalence by cancer site, by gender and in different age groups;
- proportion of cancer patients with/without relapse;
- amount of funding per cancer rehabilitation per patient per year;
- existence of national strategy for cancer rehabilitation;
- availability of guidelines for cancer rehabilitation;
- availability of follow-up programmes for cancer patients;
- number of NGOs and other organisations involved in cancer rehabilitation;
- availability of social care workers at home;
- training courses for persons involved in rehabilitation programmes;
- availability of social counselling, psychological support, nutritional counselling for cancer patients and their family members;
- proportion of persons with cancer diagnosis returned to work;
- quality of life of cancer patients.

The survey was mailed in April 2010 and by June 2010, 19 respondents from 17 countries (63%) had replied.

Second meeting in June 2010

In June 2010, the information collected after having circulated the first list of indicators was discussed among working group members during the meeting in Warsaw. At the end of this meeting the following consensus was reached:

- indicators on cancer prevalence can be included in the list
- indicators on rehabilitation capacity (organisational resources and data availability about the) and quality of life should need a second survey
- Yes/No indicators (on political strategy, guidelines, homecare availability and training courses) can be considered for a report on cancer rehabilitation status across Europe but not included in the final list of indicators
- indicators on funding and counselling should be dropped from the list for lack of possibility to have comparable information across Europe

Second survey

According to the decisions taken during the Warsaw meeting, the second survey (Appendix 3) was mailed in January 2011 and followed by a reminder in May 2011, and was responded by 25 (93%) EU country representatives by January 2012 (England and Scotland responded separately due to the differences in health care systems, Austria and Sweden responded to the first survey, but not to the second).

The second survey included a questionnaire about data availability regarding two suggested indicators:

- resources available for cancer rehabilitation from public sources (capacity)
- quality of life measurements among cancer patients.

Besides, a short summary describing the cancer rehabilitation situation in the country was asked for. The description had subsections on:

- how is cancer rehabilitation defined
- whether cancer rehabilitation is included in the national cancer control plan
- whether the country has specific guidelines for cancer rehabilitation
- whether there are specific training courses for persons involved in cancer rehabilitation
- whether cancer patient counselling is available (social, psychological, nutritional, etc)
- which are the structures performing cancer rehabilitation in the country
- whether home assistance for patients is available.

In addition, continuous discussions via e-mail and phone were held and literature and web-searches performed. Experts in various countries were consulted.

Final meetings in June and September 2011

The final list of indicators was subsequently discussed during two meetings: in June 2011 in Madrid and in September 2011 in Brussels. At the end, the history of the discussed indicators was synthesized in Table 1 subdividing them in four domains:

- Burden of cancer rehabilitation needs
- Cancer rehabilitation role in political and clinical agendas
- Cancer rehabilitation capacity (in terms of structures, services and funding)
- Indicators measuring the success of rehabilitation

The indicators of these four domains were used for two different WP-6 results:

- the group of yes/no indicators on cancer rehabilitation role in political and clinical agendas and cancer rehabilitation capacity (in terms of structures, services and funding) to be presented as a report on cancer rehabilitation status across Europe
- the other group of indicators (on burden of cancer rehabilitation needs and measuring the success of rehabilitation) to be included in the final list of indicators to suggest to the European Commission.

A literature research strategy was designed to find available examples of population-based methods and sources able to collect data on these indicators. Table 2 shows literature research strategy performed in February 2012 using PubMed for the indicators defined in the final list.

Literature research strategy followed three phases:

- 1) research strategy definition. All the research strategies included the keywords “population-based” or “cancer registry”. The reason of this inclusion is that the indicators to suggest for collection (and for inclusion in a European database) must be at population level while the majority of studies performed in the field of cancer rehabilitation and quality of life are based on clinical/hospital databases that do not follow the above mentioned population level requirement¹.
- 2) reading of all abstracts in order to individuate those articles possibly including the EUROCHIP indicators;
- 3) reading of all “material and methods” sections of the articles defined in point 2. All the articles with a clinical database as data source were excluded from this literature research.

¹ Databases based on all the patients cured in a specific hospital cannot be considered at population level as patients referring to a specific hospital can represent, for example, specific social classes (and not all social classes) while if we randomly extract patients from a population-based cancer registry database we do not perform, by default, any type of selection by social class (or other not known cofounders)

Table 1. History of EUROCHIP-3 cancer rehabilitation indicator list.

Domain	Initial list (Initial meeting Nov 2009)	Intermediate list (First and second survey)	Final list (Final meeting Sep 2011)
Burden of cancer rehabilitation needs	Prevalence (Total and by time) Prop Patients with relapses	→ Prevalence (Total and by time) → Prop Patients with relapses	→ Prevalence (Total and by time) → Cured and Qualified prevalence
Cancer rehabilitation role in political and clinical agendas	Availability of	Availability of - National strategy - Guidelines - Training courses	
Cancer rehabilitation capacity (in terms of structures, services and funding)	- Counselling - Psychological support - Homecare - Psychological support - Nutritional counselling - Social care workers - Exercise programmes Funding for rehabilitation	→ - Counselling - Homecare - FU programs - NGOs → Funding for rehabilitation	
Indicators measuring the success of rehabilitation	Return to work Indicators by cancer site (on rehabilitation needs)	→ Return to work Quality of life →	→ Return to work → Quality of life Indicators by cancer site (on rehabilitation needs): - speech & language therapy for head and neck cancer patients, - physiotherapy for breast cancer patients, - dietician therapy for colorectal cancer patients - psychological support for all cancer patients

Table 2. Pub-Med literature research strategy ^a to find examples of population-based methods and sources able to collect data on cancer rehabilitation indicators included in the final list.

Indicator	Literature research strategy	Nr of articles	Nr of articles found in Europe
Prevalence (Total and by time)	("prevalence"[MeSH Terms] OR ("Survivors/statistics and numerical data"[MAJR]) OR (Survival analysis[MeSH Terms] AND ("cure"[all fields] OR "prevalence"[all fields]))) AND (Cancer[title/abstract] OR neoplasm[title/abstract]) AND ("cancer registry"[all fields] OR "population-based" [all fields] OR "estimate"[all fields] OR "estimating"[all fields] OR "model"[all fields] OR "modelling"[all fields])	1977	40
Cured Prevalence			4
Qualified Prevalence			3
Return to work	("Employment/statistics and numerical data"[MAJR] OR "Sick Leave/statistics and numerical data"[MAJR] OR "Survivors/statistics and numerical data"[MeSH Terms] OR "Workplace"[MeSH Terms] OR "Work Schedule Tolerance"[MeSH Terms] OR "Work Capacity Evaluation" [MeSH Terms] OR "Return to work"[title]) AND (Cancer[title/abstract] OR neoplasm[title/abstract]) AND ("work"[all fields] OR "employment"[all fields] OR "retirement"[all fields])	424	12
Quality of Life	(("Quality of Life"[MAJR] OR "Survivors/psychology"[MAJR] OR "Quality of Life/psychology"[MAJR]) AND (Cancer[title/abstract] OR neoplasm[title/abstract])) OR (("Neoplasms" [MeSH Terms]) AND ("rehabilitation" [all fields] OR "psychological" [all fields])) AND ("cancer registry"[all fields] OR "population-based" [all fields])	438	41
Psychological support for all cancer patients			
Speech & language therapy for head and neck cancer patients	("Head and Neck Neoplasms" [MeSH Terms]) AND ("rehabilitation" [all fields] OR "speech" [all fields] OR "language" [all fields]) AND ("cancer registry"[all fields] OR "population-based" [all fields])	10	
Physiotherapy for breast cancer patients	("Breast Neoplasms" [MeSH Terms]) AND ("rehabilitation" [all fields] OR "physiotherapy" [all fields]) AND ("cancer registry"[all fields] OR "population-based" [all fields])	23	2
Dietician therapy for colorectal cancer patients	("Colorectal Neoplasms" [MeSH Terms] OR "Colonic Neoplasms" [MeSH Terms] OR "Rectal Neoplasms" [MeSH Terms]) AND ("rehabilitation" [all fields] OR "dietician" [all fields]) AND ("cancer registry"[all fields] OR "population-based" [all fields])	13	

^a Literature research strategy followed three phases: 1) research strategy definition; 2) reading of all abstracts in order to individuate those articles possibly including the EUROCHIP indicators; 3) reading of all "material and methods" sections of the articles defined in point 2.

RESULTS I: CANCER REHABILITATION STATUS ACROSS EUROPE

Cancer rehabilitation definitions

Altogether 6 countries (Cyprus, Denmark, Luxemburg, Malta, Poland and Slovenia) did not provide information on cancer rehabilitation definition. The large majority of countries (69%) provided a definition similar to the WHO-definition. More specifically, the vast majority (58%) included physical, psychological and social domains in their definition.

Cancer rehabilitation role in political and clinical agendas

With the help of the survey to European cancer rehabilitation experts, EUROCHIP-3 collected information on a list of proxy yes/no indicators (Table 1) aiming to show the importance of cancer rehabilitation in various EU countries. Cancer rehabilitation was reported to be included in the national cancer plan in 18 European countries. Guidelines for cancer rehabilitation exist in five (6, if Sweden has done it in 2011) EU countries. Training courses for persons involved in rehabilitation (either as general rehabilitation or specialised courses for cancer patients) were reported to be available in 16 countries, being organised mostly by universities, but also by cancer societies or NGOs, and in Greece also by the church. Counselling for cancer patients and their family members is available in 23 EU countries and home care for cancer patients is guaranteed in 22 EU member states (Table 3).

Cancer rehabilitation capacity (structures, services and funding)

Resources

Data about the existing resources for rehabilitation in different EU Member States is scarce and the data sources as well as institutions offering rehabilitation services vary due to differences in health care and social care organisation.

Rehabilitation services for cancer patients (Table 4) are offered in special cancer centres (Bulgaria, Czech Republic, Italy, England, France, Hungary, Netherlands, Poland, Romania, Slovakia, Spain); in general rehabilitation centres (Belgium, Germany, Greece, Netherlands, Poland, Portugal) or in specialized rehabilitation centres for cancer patients (Denmark, Germany, Malta, Netherlands, Spain, Scotland); in general, private, community and university hospitals and health centres (Estonia, Finland, Italy, Ireland, Latvia, Lithuania, Luxembourg, the Netherlands); in hospices (Cyprus, Slovenia) and in health resorts (Slovenia, Slovakia).

In Germany, there are separate specialized centres for inpatient cancer rehabilitation and non-specialised centres for outpatients (the latter also in Poland). In Malta and in Spain, there are

both inpatient and outpatient rehabilitation centres for cancer patients. In Greece, pain and palliative care centres offer rehabilitation services. In Scotland, National Health Service offers general rehabilitation services. In Luxembourg, the services in neighbouring countries are used.

Information about resources

In some countries, information about cancer rehabilitation is available from public health institutes or statistic offices (Slovenia, Czech Republic, Netherlands), in others, from cancer societies (Czech Republic, Hungary, Cyprus), from ministries of health (Belgium – in the future, from the Belgian Cancer Centre, Bulgaria, Poland, Slovakia), or from pension and sickness insurance companies (Germany) and National Health Fund (Poland). In other countries, data about rehabilitation services are available from research organisations (Denmark, France). In many countries, data about rehabilitation could be retrieved from hospitals and organisations offering it (e.g. Greece, Ireland, Slovenia, Italy, France, Portugal, Lithuania, Cyprus, the Netherlands). In Scotland no data are collected on national level whereas cancer charities organise specific rehabilitation for cancer patients and could provide information about their activities. In Malta and in Spain, there are both inpatient and outpatient rehabilitation centres for cancer patients, but no data is available about their activities. No data on rehabilitation services is available from Luxembourg either.

Funding

Data about funding for cancer rehabilitation across Europe turned out to be impossible due to the incomparability of data and also due to difficulties related to their acquisition. The reason for incomparability of funding data lies mostly in differences in health care and social care systems, but also in differences in prices, salaries, etc.

Conclusions

Although most countries agree upon the WHO definition about rehabilitation, the results of the survey indicate that rehabilitation services in most countries are fragmented and that rehabilitation is not a holistic and comprehensive process. There are clearly many barriers to rehabilitation including a weak interface between oncology and rehabilitation healthcare providers, a lack of training for service providers, fragmentation of services and a lack of well-controlled outcome studies. There is a need to collect prospectively data about cancer rehabilitation in Europe in order to guarantee equal rights of citizens. Uniform rehabilitation and quality assurance guidelines might help to increase the quality of rehabilitation.

Table 3. Information about whether rehabilitation is included in the national cancer plan, availability of cancer rehabilitation guidelines, training courses for persons working in the field of rehabilitation, counselling services for patients and family members, and home care in European Union Member States.

Country	Rehabilitation included in the national cancer plan	Cancer rehabilitation guidelines	Training courses for workers in rehabilitation	Counselling services available for cancer patients	Home care available
Austria	Yes, coming	Not yet	Yes	Yes	Yes
Belgium	Yes (since 2008)	No	?	Yes	Yes
Bulgaria	No	No	No	Yes	Yes, but limited
Cyprus	Yes	No	Yes	Yes	Yes
Czech Republic	No	No	Yes, by oncol society	Yes	Yes
Denmark	Yes	Yes	Yes for cancer nurses	Yes	Yes
Estonia	Yes (since 2007)	No	General rehab courses (Not separated for cancer)	Yes	Yes
Finland	?	?	Yes	Yes	Yes
France	Yes	Being prepared	No specific training	Yes	Yes
Germany	No	?	?	Yes	?
Greece	Yes (in national health plan)	No	Yes	Yes	Yes
Hungary	Yes	No	Yes	Partly	Partly
Ireland	Part of cancer control strategy	No	?	?	?
Italy	Yes (since 2010)	Yes	Yes	Yes	Yes
Latvia	Yes	No	No	Part of general counselling	?
Lithuania	Yes	No	NA	NA	NA
Luxembourg	No (anticipated in 2012)	No	No	Yes	Yes
Malta	Yes	No	No	Yes	Yes
Netherlands	Yes, since 2005	Yes	Yes	Yes	Yes
Poland	Yes	No	Yes	By NGOs	No
Portugal	No (only psychosocial care is mentioned in the 2007-10 plan)	No	Yes (for each profession. Not Nat'l program)	Yes	Yes (palliative care)
Romania	No	No	NA	Partly, not regularly by NGOs	Yes (elderly care), limited
Slovakia	No (anticipated in 2012)	No	Yes	Yes	Yes
Slovenia	Yes	No	No specific trainings	Yes	No
Spain	Yes	Yes	Yes, but not regularly	Yes	Yes (palliative care)
Sweden	Yes (since 2009)	Anticipated in 2011	Yes	Yes	Yes
UK- England	Yes, since 2011	Rehab care pathways	Yes	Yes	Yes
UK - Scotland	Yes	No	Yes	Yes	Yes

NA – information not available

Table 4. Health care institutions providing cancer patient rehabilitation services in different EU countries

Country	Special cancer centres	General rehabilitation centres	Cancer rehabilitation centres	General hospitals	Hospices / Health resorts
Austria					
Belgium	X	X	X		
Bulgaria	X				
Cyprus					X
Czech Republic	X				
Denmark			X		
Estonia				X	
Finland				X	
France	X				
Germany		X	X		
Greece		X			
Hungary	X				
Ireland				X	
Italy		X		X	
Latvia		X		X	
Lithuania				X	
Luxembourg				X	
Malta			X		
Netherlands		X	X		
Poland	X	X			
Portugal	X	X		X	
Romania	X				
Slovakia	X				X
Slovenia	X	X	X	X	X
Spain	X	X		X	
Sweden					
UK-England	X				
UK-Scotland	X	X		X	X

RESULTS II: INDICATORS FOR THE FINAL LIST

Burden of cancer rehabilitation needs

Information about cancer prevalence by cancer site (both five-year and total) was reported to be available in all EU countries. Information about relapses is available only in a few countries for selected cancer sites (breast, colorectal, lung, kidney cancer). From cancer registry data, through cure models of relative survival, the *proportion of cured patients* can be estimated indicating patients with the same mortality as the rest of the population of the same age and gender. At European level this indicator is available by EUROCCARE.¹¹

Desired indicator: cancer prevalence	
Acronym:	PREV
Priority:	High
Generic definition:	Proportion of persons with a cancer diagnosis per 100,000 inhabitants
Classified by:	A Cancer site B Gender C Age (5-year age groups) D By duration: 1-year, 5-year, total
Relevance:	Indicator for health care funding, resource planning
Rationale:	Proxy indicator able to quantify the generic burden of cancer rehabilitation at population level
Caveat:	<ul style="list-style-type: none"> This indicator does not distinguish between cured and non cured patients This indicator includes also those patients without rehabilitation needs This indicator can be the reference denominator for other specific indicators on rehabilitation
Methodological definition:	Prevalence indicates how many alive people at an exact date (ex 31/12/xxxx) in a certain population have been diagnosed with cancer: new incidence cases and still alive incident cases of previous years are included
Cost:	Medium
Data sources:	Data from national and/or regional population-based cancer registries. European projects (combining cancer registry data) allow to have common methodologies to estimate comparable indicators across Europe
Availability:	<ul style="list-style-type: none"> EUROPREVAL [1], RARECARE [2] produced estimates of period and total prevalence GLOBOCAN (IARC) [3] produced estimates of 5-year prevalence
Note:	In a few countries (e.g. UK), possibility to estimate by social class
References:	<ol style="list-style-type: none"> 1. Micheli A, Mugno E, Krogh V, et al. Cancer prevalence in European registry areas. <i>Ann Oncol</i> 2002;13(6):840-65 2. Gatta G, van der Zwan JM, Casali PG, et al. Rare cancers are not so rare: The rare cancer burden in Europe. <i>Eur J Cancer</i> 2011;47(17):2493-511 3. Ferlay J, Shin HR, Bray F, Forman D, Mathers C and Parkin DM. GLOBOCAN 2008 v1.2, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 10. Lyon: International Agency for Research on Cancer; 2010. Available at http://globocan.iarc.fr

While to distinguish the prevalent cases depending on their clinical situation (i.e. patients in the last year of their life due to cancer, patients with high intensity of health services utilizations, etc) it is necessary to combine cancer registry data with data on clinical follow-up (presence of recurrences, metastasis, second tumours) and on cancer treatments (or health services utilization due to cancer). To estimate those, it is necessary to link cancer registry data with hospital data as performed in UK¹² and for colorectal cancer in US¹³ or to perform studies collecting all the data on recurrences, metastasis and treatments of a cancer registry patient sample as performed for colon cancer in Italy¹⁴ and for colorectal cancer in France.¹⁵ Such information can be synthesized under the indicator named *qualified prevalence*.

Desired indicator: qualified prevalence	
Acronym:	QUAL.PREV
Priority:	High
Generic definition:	It indicates how many prevalent patients at an exact date (ex 31/12/xxxx) have had recurrence, metastasis, other tumours OR totally recovered
Classified by:	A Cancer site B Gender C Age (5-year age groups)
Relevance:	More precise indicator for funding, resource planning
Rationale:	Proxy indicator able to quantify some specific burden of cancer rehabilitation at population level
Caveat:	Requires long-term (at least 10 years) data on a cohort of cancer patients
Methodological definition:	Qualified prevalence is prevalence proportions subdivision among: <ul style="list-style-type: none"> • Those expected to die in a year • Those expected to die for cancer in more than a year • Those expected to survive with relapses • Those expected to survive without relapses
Cost:	High
Data sources:	Data from national and/or regional population-based cancer registries linked with clinical databases and clinical records. European projects (combining cancer registry data) allow to have common methodologies to estimate comparable indicators across Europe
Availability:	<ul style="list-style-type: none"> • High-resolution studies, based on data from cancer registries (ad hoc collection of clinical data on cancer patient samples) [1] • Data in cancer registry databases linked with clinical data in hospital discharge registers or similar clinical databases [2]
Note:	
References:	<ol style="list-style-type: none"> 1. Gatta G, Capocaccia R, Berrino F, Ruzza MR, Contiero P; EUROPREVAL Working Group. Colon cancer prevalence and estimation of differing care needs of colon cancer patients. <i>Ann Oncol</i> 2004;15(7):1136-42. 2. Maddams J, Utley M, Møller H. Levels of acute health service use among cancer survivors in the United Kingdom. <i>Eur J Cancer</i> 2011;47(14):2211-20.

Indicators measuring the success of rehabilitation

Cancer patients' quality of life

Table 5 underlined the WP-6 experts feedback and knowledge on this indicator. Quality of life (QoL) among cancer patients is measured most often by EORTC QLQ-30,¹⁶ although only for research purposes and not routinely. Other questionnaires in use for quality of life measurements among cancer patients are SF-36, FACT, IRES, WHODAS II, distress thermometer. All respondents except Polish experts agreed that quality of life of cancer patients should be measured on a routine basis.

Table 6 presents a summary of literature research results for European population-based studies on QoL. This type of studies is performed in few areas of Europe: mainly in the Netherlands, Germany, Sweden, Iceland and France.

These studies are at population level as they interview samples of cancer patient extracted from cancer registry databases or use cross-sectional surveys from general population which are linked to cancer registry databases. Various type of quality of life questionnaires were used, the most frequently used are EORTC QLQ-C30¹⁶, SF-36¹⁷ and HADS¹⁸. Survey participation rate varies from 32% to 94%. In the studies identified by our literature research the average participation rate was 72%.

Since its recognition of distress as the sixth vital sign, distress screening has been promoted worldwide. Implementation of screening for psychosocial distress, although difficult to accomplish, using an instrument such as the Distress Thermometer and Problem List (DT/PL)¹⁹⁻²⁰, now validated in many European countries, has been undertaken or is in preparation in hospitals in several countries in Europe. Distress screening at regular intervals during the disease trajectory may give insight into the QoL of patients, improve communication, and increase psychosocial referrals for rehabilitation. Additionally, it may be included as variable in a cancer registry. Therefore, an instrument such as the DT/PL may be a good proxy measurement instrument of QoL.

Desired indicator: quality of life of cancer patients	
Acronym:	QOL
Priority:	High
Generic definition:	Perceived quality of life of cancer patients before and after rehabilitation courses, measured at regular intervals
Classified by:	By cancer site and stage
Relevance:	Success of rehabilitation
Rationale:	To evaluate the quality of rehabilitation of cancer patients
Caveat:	The indicator requires interviews to patients: <ul style="list-style-type: none"> • non participation in the survey could false the population level coverage of the indicator • not necessarily patient is aware that he/she is a cancer patient. So it is necessary to contact before his/her GP
Methodological definition:	Quality of life scores. Questionnaire suggested to be used is EORTC QLQ-C30 [1]
Cost:	High
Data sources:	Studies should be at population level interviewing cancer patient samples extracted from cancer registry databases or from general population cross sectional survey linked to cancer registry databases
Availability:	This type of studies is performed in few areas of Europe: mainly in the Netherlands, Germany, Sweden and France [2]
Note:	Cancer registries might have problems in contacting cancer patients directly, due to confidentiality laws
References:	<ol style="list-style-type: none"> 1. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organisation for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. <i>J Natl Cancer Inst</i> 1993;85:365-76 2. See Table 6 of the WP-6 final report

Cancer patients' rehabilitation needs (and their satisfaction)

Regarding the indicators on rehabilitation needs (and their satisfaction) EUROCHIP-3 suggested this list of proxy indicators: *speech & language therapy* for head and neck cancer patients, *physiotherapy* for breast cancer patients, *dietician therapy* for colorectal cancer patients, *psychological support* for all cancer patients. The literature research strategy on these indicators outlined other two interesting articles on studies performed in Nordic countries. A Swedish population-based prostate cancer registry was linked with the National Hospital Discharge Register and the National Prescribed Drug Register in order to find cancer patients with psychiatric hospitalization and use of antidepressant drugs²¹ while in Norway a survey (with a participation rate of 54%) was conducted to cancer patients extracted from the Norwegian Cancer Registry to define the percentage of utilisation of specific rehabilitation services (physical therapy, physical training, psychological counselling, supportive group sessions, admittance to a convalescent home, consultation with social worker, occupational therapy) to satisfy specific needs²².

Rehabilitation needs and their availability for specific cancer sites:	
<ul style="list-style-type: none"> • speech & language therapy for head and neck cancer patients • physiotherapy for breast cancer patients • dietician therapy for colorectal cancer patients • psychological support for all cancer patients 	
Acronym:	MEET.NEEDS
Priority:	High
Generic definition:	The proportion of patients by cancer site who need these services and the actual proportion counseled
Classified by:	By cancer site
Relevance:	Success of rehabilitation
Rationale:	To evaluate the quality of rehabilitation services for cancer patients
Caveat:	<p>The indicator requires interviews to patients:</p> <ul style="list-style-type: none"> • non participation in the survey could false the population level coverage of the indicator • not necessarily patient is aware that he/she is a cancer patient. So it is necessary to contact before his/her GP
Methodological definition:	Questionnaires to patient groups to identify their needs; number of patients counseled among those who would have needed it
Cost:	High
Data sources:	Studies should be at population level interviewing cancer patient samples extracted from cancer registry databases.
Availability:	
Note:	In several countries, data protection problems may restrict data collection and analysis.
References:	

Return to work

Although the rate of return to work (either part-time or full-time work) was regarded to be an important indicator for the success of rehabilitation among patients of working age, difficulties due to data protection issues were stated in most EU countries. Few studies have been performed at population level to estimate the attitude of return to work of cancer survivors. In the Netherlands, the ArboNed Occupational Health Service register was used, containing sickness absence data and medical diagnoses of 1 million Dutch wage earners working in 33,000 companies of different economic sectors representative of the Dutch workforce (with the exception of the primary sector under-represented in the register).²³⁻²⁶ In European Nordic countries, cancer registry data were linked with census data in Finland,^{27, 28} with Directorate of Taxes in Norway²⁹ and with Labour Market Research Database in Denmark.^{30,31} However these types of studies cannot be extended to other countries, so the unique method to perform similar studies in various European countries should be to organize interviews to cancer survivors samples extracted from cancer registry databases as performed in North West England (50% of participation),³² in Ireland (54%),³³ in Netherlands (80%).³⁴

Rate of return to work among cancer patients	
Acronym:	WORK
Priority:	High
Generic definition:	Indicator able to describe the return to work of cancer patients in working age (as it was demonstrated that cancer survivor are more likely to be unemployed than healthy control people)
Classified by:	By cancer site and by stage at diagnosis, by age group and gender
Relevance:	Success of rehabilitation
Rationale:	To evaluate the quality of rehabilitation of cancer patients
Caveat:	The indicator requires interviews to patients: <ul style="list-style-type: none"> • non participation in the survey could false the population level coverage of the indicator • not necessarily patient is aware that he/she is a cancer patient. So it is necessary to contact before his/her GP
Methodological definition:	Number of workers with a cancer diagnosis working full-time or part-time on the total number of cancer workers
Cost:	High
Data sources:	<ul style="list-style-type: none"> • Studies should be at population level interviewing cancer patient samples extracted from cancer registry databases. • There are some experiences in Europe in which the indicator were estimated linking cancer registry data with census data (Finland), Directorate of Taxes (Norway) or Labor Market Research Database (Denmark) but these types of studies cannot be extended to other countries
Availability:	Some studies were performed in North West England [1], Ireland [2] and South Netherlands [3]
Note:	In several countries, data protection problems may restrict data collection and analysis.
References:	<ol style="list-style-type: none"> 1. Amir Z, Moran T, Walsh L, Iddenden R, Luker K. Return to paid work after cancer: a British experience. <i>J Cancer Surviv</i> 2007;1(2):129-36. 2. Sharp L, Timmons A. Social welfare and legal constraints associated with work among breast and prostate cancer survivors: experiences from Ireland. <i>J Cancer Surviv</i> 2011;5(4):382-94. 3. Mols F, Thong MS, Vreugdenhil G, van de Poll-Franse LV. Long-term cancer survivors experience work changes after diagnosis: results of a population-based study. <i>Psychooncology</i> 2009;18(12):1252-60.

Overall conclusion

The final list of indicators suggested by EUROCHIP-3 on cancer rehabilitation includes:

Burden of cancer rehabilitation needs

- cancer prevalence (total and by time since diagnosis)
- cured and qualified prevalence

Indicators measuring the success of rehabilitation

- rate of return to work for cancer patients
- quality of life of cancer patients (in comparison with general population) using EORTC questionnaire or other international questionnaires
- presence of rehabilitation needs and their satisfaction:
 - o speech & language therapy for head and neck cancer patients
 - o physiotherapy for breast cancer patients
 - o dietician therapy for colorectal cancer patients
 - o psychological support for all cancer patients

The first group of prevalence indicators can be estimated through models of data routinely collected by cancer registries or collecting data on clinical follow-up and treatments of cancer registry patients from clinical records or hospital discharge databases.

For the second group some studies used national population based databases (alone or combining them with cancer registry databases). However these types of studies cannot be extended to other countries for the national specificity of the various databases used. Therefore the way to collect data on cancer patients experience after diagnosis in Europe is to interview them with common questionnaires across countries. Information can be collected through general population national health surveys (under the condition that surveys asks if the interviewed had a cancer diagnosis) or performing specific surveys directly addressed to cancer patient groups. To guarantee information at population level these surveys can only be organized interviewing cancer survivors samples extracted from cancer registry databases.

In the organization of these studies three main aspects must be considered: 1) not necessarily patient is aware that he/she is a cancer patient, so it is necessary to contact before his/her general practitioner or clinician; 2) cancer registries might have problems in contacting cancer patients directly due to national confidentiality laws; 3) cancer patient non participation in the survey could false the population level coverage of the indicator. Regarding the last point the involvement of patient organisations in these type of studies could improve the patient participation.

In conclusion we are aware that such type of studies can meet various type of problems and obstacles but the dramatic increase of cancer prevalent cases (estimated in about 18 million of European citizens in 2003) oblige us and researchers in general to start to work on this field: it is strongly necessary to describe cancer patient needs in order to give fundamental and correct information to cancer control planners.

Table 5. Quality of life (QoL) questionnaires used for cancer patients in different EU countries.

Country	Agree upon collection	Type of QoL questionnaire suggested	Type of QoL questionnaire in use/not in use
Austria	NA	NA	NA
Belgium	Yes	EORTC, distress thermometer	In trials and scientific studies
Bulgaria	Yes	EORTC	Used for scientific purposes, not routinely
Cyprus	Yes	None	None
Czech Republic	Yes	SF 36; WHODAS II	
Denmark	Yes, but possible selection bias + costly	EORTC	Yes, same
Estonia	Yes	EORTC	Only in clinical trials
Finland	Yes	FACT-G, EORTC, SF 36, RBDI, GAS	GAS (goal attainment scaling) in use; others in research projects only
France	Yes	Holistic questionnaire	Planned to be implemented
Germany	+/-	IRES-3 (specific rehab quest); EORTC	EORTC plus specific modules; also SF-36
Greece	Yes	SF 36, WHO QoL	Yes, same
Hungary	Yes	None	None
Ireland	Yes, but costly	EORTC	Ad hoc projects
Italy	Yes, but time-consuming	EORTC	Only in research settings
Latvia	Yes	EORTC (both in Latvian and Russian)	Not used for rehabilitation outcomes assessment
Lithuania	Yes	EORTC	Yes, same
Luxembourg	NA	NA	NA
Malta	Yes	EORTC	Yes, same
Netherlands	Yes	Dutch version of the NCCN distress thermometer + problem list „Lastmeter“; EORTC	EORTC, RAND-36, CES-D, HADS, SCL-90, GHQ, all used for research purposes; „Lastmeter“ used in clinical practice NOTE: Quality of care should also be assessed!
Poland	No, too expensive	EORTC	Not in use
Portugal	Yes	EORTC (also EQ5D, SF20)	In use, but not mandatory
Romania	Yes	FACT	Used for research purposes
Slovakia	Yes	EORTC	Not used in clinical practice
Slovenia	NA	NA	NA
Spain	Yes	EORTC	Only in research settings
Sweden	NA	NA	NA
UK –England	Yes	?	?
UK- Scotland	Yes	EORTC or FACT	Only in individual projects

NA – data not available

Table 6. Pub-Med literature research strategy to find examples of population-based surveys devoted to study QoL of cancer patients in Europe.

1 st Author	Journal	Population	Nation	Cancer patient population	Cancer	Yrs after diagnosis	EORTC questionnaire	SF-36	HADS	Lost for external reasons	Questionnaires sent	Participation
Jansen L	J Clin Oncol.2011; 29(24)	Saarland	D	PB-CR Sample	Colon rectum	10 Yrs	Yes	No	No	-	196	69%
Arndt V	Eur J Cancer.2006; 42(12)	Saarland	D	PB-CR Sample	Colon rectum	1-3 Yrs	Yes	No	No	-	379	82%
Arndt V	J Clin Oncol.2004; 22(23)											
Hoyer M	Acta Oncol. 2011; 50(7)	Cent Sweden	S	PB-CR	Breast	1-2 Yrs	Yes	No	Yes	-	1573	69%
Thong MS	Eur J Cancer. 2011; 47(12)	Eindhoven	NL	PB-CR Sample	Colon	1-10 Yrs	Yes	Yes	No	23%	1135	80%
Thong MS	Int J Radiat Oncol Biol Phys. 2011; 81(3)	Eindhoven	NL	PB-CR Sample	Rectum	1-10 Yrs	Yes	Yes	No	26%	547	85%
Aarts MJ	Urology. 2010; 76(5)	Eindhoven	NL	PB-CR	Prostate	5-10 Yrs	No	Yes	No	21%	964	81%
Thong MS	BJU Int. 2010; 105(5)											
Mols F	BJU Int. 2008; 102(11)											
Mols F	Cancer. 2006; 107(9)											
Grov EK	Eur J Oncol Nurs. 2011; 15(3)	Nord-Trøndelag	N	PB cross sectional survey	Various	1-10 Yrs	No	No	Yes	44%	510	94%
Skoogh J	Int J Androl. 2011; 34(2)	Sweden	S	PB-CR	Testis	3-26 Yrs	No	No	Yes	4%	1173	82%
Schlesinger-Raab A	Ann Oncol. 2010; 21(12)	Munich	D	PB-CR	Melanoma	2 Yrs	Yes	No	No	-	1085	72%
Le Corroller-Soriano AG	Eur J Cancer Care. 2011; 20(1)	France	F	PB cross sectional survey	Various	2 Yrs	No	Yes	No	-	6957	64%
Saevarsdottir T	Cancer Nurs. 2010; 33(1)	Iceland	ICE	PB cross sectional survey	various	0.5 Yrs	No	No	Yes	-	177	81%
Agustsdottir S	Br J Health Psychol. 2010 Feb;15(Pt 1):51-61	Iceland	ICE	PB-CR	Prostate	1-6 Yrs	No	No	Yes	-	383	48%
Djarv T	J Clin Oncol. 2009; 27(12)	Sweden	S	PB-CR	Oesophagus	1-5 Yrs	Yes	No	No	14%	399	89%
Rutegard M	Ann Surg Oncol. 2008; 15(9)											
Rutegard M	Br J Surg. 2008 95(5)											
Viklund P	Eur J Cancer. 2006; 42(10)											
Mehnert A	Psychooncology. 2009; 18(12)	Hamburg	D	PB-CR	Breast	1-6 Yrs	No	No	No	18%	1633	66%
Mehnert A	J Psychosom Res. 2008; 64(4)											

1 st Author	Journal	Population	Nation	Cancer patient population	Cancer	Yrs after diagnosis	EORTC questionnaire	SF-36	HADS	Lost for external reasons	Questionnaires sent	Participation
Korfage IJ	Int J Rad Oncol Biol Phys. 2009; 73(5)	Eindhoven	NL	PB-CR	Cervical	2-10 Yrs	Yes	Yes	No	6%	421	69%
Bouvier AM	Cancer. 2008; 113(4)	Burgundy	F	PB-CR	Colon rectum	0-1 Yrs	Yes	No	No	-	209	60%
Arndt V	J Canc Res Clin Onc. 2008; 134(12)	Saarland	D	PB-CR Sample	Breast	1-5 Yrs	Yes	No	No	-	401	78%
Arndt V	Cancer. 2006; 107(10)											
Arndt V	J Clin Oncol. 2005; 23(22)											
Arndt V	Eur J Cancer. 2004; 40(5)											
van de Poll-Franse LV	Int J Rad Oncol Biol Phys. 2007; 69(1)	Eindhoven	NL	PB-CR	Endometrial	5-10 Yrs	No	Yes	No	12%	405	75%
Mols F	Cancer. 2007; 109(8)	Eindhoven	NL	PB-CR	NH lymphoma	5-15 Yrs	No	Yes	No	23%	360	82%
Waldmann A	Qual Life Res. 2007; 16(5)	Schleswig-Holstein	D	PB-CR Sample	Breast	0-3.5 Yrs	Yes	No	No	-	2366	81%
Mols F	Eur J Cancer. 2006; 42(16)	Eindhoven	NL	PB-CR	H lymphoma	5-15 Yrs	No	Yes		31%	164	80%
Matsuda T	Eur J Epidemiol. 2004; 19(4)	Isère and Tarn	F	PB-CR Sample	Bladder	5-10 Yrs	No	No	No	-	201	47%
Matsuda T	Int J Urol. 2003; 10(8)											
Engel J	Breast J. 2004; 10(3)	Munich	D	PB-CR	Breast	0-5 Yrs	Yes	No	No	-	1131	88%
Engel J	Breast Canc Res Treat. 2003; 79(1)											
Kerr J	Ann Oncol. 2003; 14(3):421-7											
Sandblom G	Br J Cancer. 2004; 22 90(6)	Ostergotland	S	PB-CR	Prostate	>1 year	No	No	No	3%	1402	89%
Sandblom G	Br J Cancer. 2001; 85(4)											
Engel J	Ann Surg. 2003; 238(2)	Munich	D	PB-CR	Rectum	0-4 Yrs	Yes	No	No	-	1038	32%
Helgason AR	Scand J Urol Nephrol. 2001 Apr;35(2):97-101	Sweden	S	PB-CR	Prostate	1.5-2 Yrs	No	No	No	-	431	79%
											25640	72%

PB-CR: survey performed on the entire population-based cancer registry database; PB-CR Sample: survey performed on a random sample of the population-based cancer registry database
Lost for external reasons: patients not interviewed for dementia, unavailable address, non agreement of clinician.

REFERENCES

1. Verdecchia A, Guzzinati S, Francisci S, et al. Survival trends in European cancer patients diagnosed from 1988 to 1999. *Eur J Cancer* 2009;**45(6)**:1042-66.
2. Gatta G, van der Zwan JM, Casali PG, et al. Rare cancers are not so rare: The rare cancer burden in Europe. *Eur J Cancer* 2011;**47(17)**:2493-511.
3. De Angelis R, Grande E, Inghelmann R, et al. Cancer prevalence estimates in Italy from 1970 to 2010. *Tumori* 2007;**93(4)**:392-7.
4. Francisci S, Capocaccia R, Grande E, et al. The cure of cancer: a European perspective. *Eur J Cancer* 2009;**45(6)**:1067-79.
5. Sullivan R, Peppercorn J, Sikora K, et al. Delivering affordable cancer care in high-income countries. *Lancet Oncol* 2011;**12(10)**:933-80.
6. Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010-2020. *J Natl Cancer Inst* 2011;**103(2)**:117-28. Erratum in: *J Natl Cancer Inst* 2011;**103(8)**:699.
7. Grassi L, Travado L. The role of psychosocial oncology in cancer care. In Coleman MP, Alexe DM, Albrecht T, McKee M, editors. *Responding to the challenge of cancer in Europe*. Ljubliana: Institute of Public Health of the Republic of Slovenia; 2008: p.209-30. Available at http://www.euro.who.int/__data/assets/pdf_file/0011/97823/E91137.pdf (accessed February 2012)
8. Council of the European Union. Council Conclusions on Reducing the Burden of cancer.: 2876th Council meeting, Luxembourg, June 9-10, 2008. Available at http://www.consilium.europa.eu/ueDocs/cms_Data/docs/pressData/en/lsa/101031.pdf (accessed February 2012)
9. Gouveia J, Coleman MP, Haward R, et al. Improving cancer control in the European Union: conclusions from the Lisbon round-table under the Portuguese EU Presidency, 2007. *Eur J Cancer* 2008;**44(10)**:1457-62.
10. EUROCHIP (European Cancer Health Indicator Project-III). Available at: www.tumori.net/eurochip (accessed February 2012)
11. EURO CARE (EUROpean CANcer REgistry-based study on survival and CARE of cancer patients). Available at: <http://www.eurocare.it/> (accessed March 2012)
12. Maddams J, Utley M, Møller H. Levels of acute health service use among cancer survivors in the United Kingdom. *Eur J Cancer* 2011;**47(14)**:2211-20.
13. Mariotto A, Warren JL, Knopf KB, Feuer EJ. The prevalence of patients with colorectal carcinoma under care in the U.S. *Cancer* 2003;**98(6)**:1253-61.

14. Gatta G, Capocaccia R, Berrino F, Ruzza MR, Contiero P; EUROPREVAL Working Group. Colon cancer prevalence and estimation of differing care needs of colon cancer patients. *Ann Oncol* 2004;**15(7)**:1136-42.
15. Chauvenet M, Lepage C, Jooste V, Cottet V, Faivre J, Bouvier AM. Prevalence of patients with colorectal cancer requiring follow-up or active treatment. *Eur J Cancer* 2009;**45(8)**:1460-5.
16. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organisation for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;**85**:365-76.
17. Ware JE, Sherbourne CD. The MOS 36-item shortform health survey (SF-36). I. Conceptual framework and item selection. *Medical Care* 1992;**30**:473-83.
18. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983;**67**:361-70.
19. Snowden A, White CA, Christie Z, Murray E, McGowan C, Scott R. The clinical utility of the distress thermometer: a review. *Br J Nurs* 2011;**20(4)**:220-7.
20. Carlson LE, Groff SL, Maciejewski O, Bultz BD. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol* 2010;**28(33)**:4884-91.
21. Bill-Axelsson A, Garmo H, Nyberg U, et al. Psychiatric treatment in men with prostate cancer--results from a Nation-wide, population-based cohort study from PCBaSe Sweden. *Eur J Cancer* 2011;**47(14)**:2195-201.
22. Thorsen L, Gjerset GM, Loge JH, et al. Cancer patients' needs for rehabilitation services. *Acta Oncol* 2011;**50(2)**:212-22.
23. Roelen CA, Koopmans PC, Groothoff JW, van der Klink JJ, Bültmann U. Return to work after cancer diagnosed in 2002, 2005 and 2008. *J Occup Rehabil* 2011;**21(3)**:335-41.
24. Roelen CA, Koopmans PC, van Rhenen W, Groothoff JW, van der Klink JJ, Bültmann U. Trends in return to work of breast cancer survivors. *Breast Cancer Res Treat* 2011;**128(1)**:237-42.
25. Roelen CA, Koopmans PC, Groothoff JW, van der Klink JJ, Bültmann U. Sickness absence and full return to work after cancer: 2-year follow-up of register data for different cancer sites. *Psychooncology* 2011;**20(9)**:1001-6.
26. Roelen CA, Koopmans PC, de Graaf JH, Balak F, Groothoff JW. Sickness absence and return to work rates in women with breast cancer. *Int Arch Occup Environ Health* 2009;**82(4)**:543-6.

27. Taskila-Abbrandt T, Martikainen R, Virtanen SV, Pukkala E, Hietanen P, Lindbohm ML. The impact of education and occupation on the employment status of cancer survivors. *Eur J Cancer* 2004 ;**40**:2488-93.
28. Taskila-Abbrandt T, Pukkala E, Martikainen R, Karjalainen A, Hietanen P. Employment status of Finnish cancer patients in 1997. *Psycho-Oncology* 2005;**14**:221-6
29. Syse A, Tretli S, Kravdal Ø. Cancer's impact on employment and earnings-a population-based study from Norway. *J Cancer Surviv* 2008;**2**:149-58.
30. Carlsen K, Oksbjerg Dalton S, Diderichsen F, Johansen C. Risk for unemployment of cancer survivors: A Danish cohort study. *Eur J Cancer* 2008;**44**:1866-74.
31. Carlsen K, Oksbjerg Dalton S, Frederiksen K, Diderichsen F, Johansen C. Cancer and the risk for taking early retirement pension: A Danish cohort study. *Scandinavian Journal of Public Health* 2008;**36**:117-25.
32. Amir Z, Moran T, Walsh L, Iddenden R, Luker K. Return to paid work after cancer: a British experience. *J Cancer Surviv* 2007;**1(2)**:129-36.
33. Sharp L, Timmons A. Social welfare and legal constraints associated with work among breast and prostate cancer survivors: experiences from Ireland. *J Cancer Surviv* 2011;**5(4)**:382-94.
34. Mols F, Thong MS, Vreugdenhil G, van de Poll-Franse LV. Long-term cancer survivors experience work changes after diagnosis: results of a population-based study. *Psychooncology* 2009;**18(12)**:1252-60.

APPENDIX 1 – LIST OF WP-6 EXPERTS

Country	Name	Email address
Austria	Hubert Denz	hubert.denz@tilak.at
	Elisabeth Andritsch	elisabeth.andritsch@klinikum-graz.at
Bulgaria	Nikolay Yordanov	dr_yordanoff@abv.bg; dr.n.yordanoff@gmail.com
Belgium	Elke Van Hoof	elke.vanhoof@wiv-isp.be
Cyprus	Sophia Nestoros	sophia.nestoros@anticancersociety.org.cy
Czech republic	Olga Svestkova	Olga.svestkova@lf1.cuni.cz
Denmark	Christoffer Johansen	christof@cancer.dk
Estonia	Piret Veerus	piret.veerus@tai.ee
France	Mélanie Samson	msamson@institutcancer.fr
	Jeanne Marie Bréchet	jmbrechet@institutcancer.fr
Finland	Matti Rautalahti	matti.rautalahti@cancer.fi
Hungary	Miklos Garami	miklos.garami@gmail.com
Germany	Hans Bartsch	bartsch@tumorbio.uni-freiburg.de
Greece	Athina Valadouca	athinajv@ath.forthnet.gr
Italy	Luigi Grassi	luigi.grassi@unife.it
Ireland	Deirdre Murray	deirdree.murray@hse.ie
Latvia	Aivars Vetra	aivars_vetra@inbox.lv
Luxembourg	Astrid Scharpantgen	Astrid.Scharpantgen@ms.etat.lu
Lithuania	Nomeda Vaitekunaite	nomedava@yahoo.com
Malta	Rita Micallef	rita.t.micallef@gov.mt
Netherlands	Josette Hoekstra-Weebers	j.hoekstra-weebers@iknl.nl
		j.hoekstra-weebers@umcg.nl
Poland	Rafal Halik	rhalik@pzh.gov.pl
Portugal	Luzia Travado	luziatravado@netcabo.pt
	Cristina Portugal	
Romania	Florian Nicula	nicula@iocn.ro
	Dégi L. Csaba	csabadegi@gmail.com
Spain	Tarsila Ferro	tferro@iconcologia.net
	Xavier Bonfill	xbonfill@santpau.cat
	Roswitha Britz	roswithabritz@web.de
Slovakia	Olga Sadovska	oosadovska@hotmail.com
	Martina Ondrušová	martina.ondrusova@hotmail.com
Slovenia	Marjetka Jelenc	Marjetka.Jelenc@ivz-rs.si
	Branko Zakotnik	
Sweden	Maria Hellbom	maria.hellbom@skane.se
UK	Gill Hubbard	gill.hubbard@stir.ac.uk
	Eva Gail	geva@aix-150.ion.ucl.ac.uk
	Jackie Turpenney	jackie.turnpenney@ncat.nhs.uk
	Sharon Cavanagh	sharon.cavanagh@nhs.net

APPENDIX 2 – FIRST SURVEY

European Cancer Health Indicator Project Eurochip-3 WP-6 Cancer patient rehabilitation indicators

OUR MANDATE

The EUROCHIP-3 “Common Actions” (2008-2011)² Work Package on cancer rehabilitation indicators³(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 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)

² The EUROCHIP Projects focus on cancer health information in the EU and are funded within the Programme 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.

³ 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 b. sex c. age
Main source of data	cancer registry (CR). In some countries CR covers the entire population, in others one or 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: $p(s, sx, g, p, a) = \frac{P(s, sx, g, p, a)}{Pm(sx, g, p, a)}$ <p>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) Pm (sx,g,p,a)= average population specific per sex (sx), geographic area (g), calendar year (p), age (a)</p>
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
<u>Operational definition</u>	
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 [pdf attached]

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:

Source of data:

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
<u>Operational definition</u>	
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 on funding:

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

Follow-up for cancer patients defined as a subsequent examination of a patient for the purpose of monitoring earlier treatment.

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
Possible data sources	to be defined in each country (Health Ministry survey, expert survey, internet ad hoc data collection, patient organisations, cancer society, etc.)

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]
Possible data sources	to be defined in each country (Health Ministry survey, expert survey, internet ad hoc data collection, patient organisations, cancer society, etc.)

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)
Possible data sources	to be defined in each country (Health Ministry survey, expert survey, internet ad hoc data collection, patient organisations, cancer society, etc.)

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, etc for cancer patients and their family members [Y/N]; which of these are available and for whom
Possible data sources	to be defined in each country (Health Ministry survey, expert survey, internet ad hoc data collection, patient organisations, cancer society, etc.)

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
<u>Operational definition</u>	
Numerator	number of persons with a cancer diagnosis working (part-time, full-time)
Denominator	total number of cancer patients

NB! Possible methodology for data collection is open for discussion!

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)
<u>Operational definition</u>	quality of life scores measured by general or specific scales
Source of data	from scientific publications, on-going studies, etc

PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Possibility of collection (at population level):

Methodology:

Source of data:

THANK YOU!

APPENDIX 3 – SECOND SURVEY

CAPACITY

Type of indicator: Resources available for cancer rehabilitation from public sources
Acronym: CAPACITY
Generic definition: number of providers in cancer rehabilitation field
Relevance: for planning, funding, end results
Rationale: proxy measurement of resources for cancer rehabilitation
Methodology: number of rehabilitation centers for cancer patients

DISCUSSION

COUNTRY: _____

Please fill in the following table replying to the following questions:

- 1st column In your country, which types of centers perform cancer rehabilitation?
- 2nd column Are this type of centres dedicated exclusively to cancer patients?
- 3rd column Are this type of centres diffused in the entire country?
- 4th column Is data on diffusion (number) of this type of centres available? If yes, from which source?

Type of center (if necessary add description)	Only for cancer patients?	Diffused in the country?	Data available? From which source?

QoL

Type of indicator: quality of life scores before and after rehabilitation courses
Acronym: QoL
Generic definition: perceived quality of life of cancer patients, measured by quality of life questionnaires
Classification: by cancer site and stage
Rationale: to evaluate the quality of rehabilitation of cancer patients
Methodology: quality of life scores evaluated by means of validated questionnaires

PROPOSAL

QoL questionnaire to cancer patients

DISCUSSION

COUNTRY: _____

Do you agree on this type of data collection?

If yes, which type of QoL questionnaire should be addressed to cancer patients?

Is this questionnaire already used in your country?

Is the questionnaire validated and is it internationally used (in other words are the results comparable among countries?)

Cancer rehabilitation report

We suggest to address in a report to the European Commission all the other indicators previously discussed in the framework of WP6, describing cancer rehabilitation in each European Union country.

We kindly ask you to prepare a **synthesis** on cancer rehabilitation in your country including:

- what is intended by "cancer rehabilitation" (definition according to the health care system in your country)
- whether cancer rehabilitation is included in the national cancer control plan (yes/no; since when)
- whether your country has specific guidelines for cancer rehabilitation (yes/no; since when)
- whether there are specific training courses on cancer rehabilitation (yes/no; which, by whom organized)
- whether cancer patient counselling is available (social, psychological, nutritional, etc)
- which are the structures performing cancer rehabilitation in your country
- whether home assistance (home care) is available
- any other characteristics you consider important for describing cancer rehabilitation in your country

COUNTRY: _____