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Cancer rehabilitation indicators for Europe

Paolo Baili [a,*], Josette Hoekstra-Weebers [b], Elke Van Hoof [c], Hans Helge Bartsch [d],
Luzia Travado [e], Miklos Garami [f], Francesca Di Salvo [a], Andrea Micheli [a,g],
Piret Veerus [h], The EUROCHIP-3 Working group on Cancer Rehabilitation

[a] Descriptive Studies and Health Planning Unit, Fondazione IRCCS "Istituto Nazionale dei Tumori", via Venezian 1, 20133 Milan, Italy
[b] Comprehensive Cancer Center Netherlands, Location Groningen, Griffeweg 97, Groningen, The Netherlands
[c] Belgian Cancer Centre, Rue Juliette Wytsmanstraat 14, 1050 Brussels, Belgium
[d] Tumor Biology Centre at Albert-Ludwigs University, Breisacherstr. 117, 79106 Freiburg, Germany
[e] Clinical Psychology Unit, Central Lisbon Hospital Centre, Hospital de S. José, Rua José António Serrano, 1150-199 Lisboa, Portugal
[f] Hungarian Paediatric Oncology Network, Hungarian Paediatric Cancer Registry, Budapest, Hungary
[g] Scientific Committee, Federazione Italiana delle Associazioni di Volontariato in Oncologia (F.A.V.O.), Via Barberini 11, 00187 Rome, Italy
[h] Department of Epidemiology and Biostatistics, National Institute for Health Development, Hiiu 42, 11619 Tallinn, Estonia

Abstract   Little is known of cancer rehabilitation needs in Europe. EUROCHIP-3 organised a group of experts to propose a list of population-based indicators used for describing cancer rehabilitation across Europe. The aim of this study is to present and discuss these indicators. A EUROCHIP-3 expert panel reached agreement on two types of indicators. (a) Cancer prevalence indicators. These were proposed as a means of characterising the burden of cancer rehabilitation needs by time from diagnosis and patient health status. These indicators can be estimated from cancer registry data or by collecting data on follow-up and treatments for samples of cases archived in cancer registries. (b) Indicators of rehabilitation success. These include: return to work, quality of life, and satisfaction of specific rehabilitation needs. Studies can be performed to estimate these indicators in individual countries, but to obtain comparable data across European countries it will be necessary to administer a questionnaire to randomly selected samples of patients from population-based cancer registry databases. However, three factors complicate questionnaire studies: patients may not be aware that they have cancer; incomplete participation in surveys could lead to bias; and national confidentiality laws in some cases prohibit cancer registries from approaching patients. Although these studies are expensive and difficult to perform, but as the number of cancer survivors increases, it is important to document their needs in order to provide information on cancer control.
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* Corresponding author: Tel.: +39 02 23903527; fax: +39 02 23903528.
   E-mail address: lifetable@istitutotumori.mi.it (P. Baili).

1. Introduction

Cancer survival is increasing in Europe as a result of early diagnosis and improved treatment,[1] with the corollary that the proportion of persons in the population with a (past) diagnosis of cancer is growing. According to RARECARE estimates – based on cancer registry data – there were 3566 persons per 100,000 with a diagnosis of any type of cancer in the European Union on 1st January 2003, equivalent to a total prevalence of nearly 17.8 million.[2] The number of prevalent cancer cases is projected to increase as the European population continues to age, as cancer incidence increases, and as survival improves.[3] EUROCARE estimated that the proportion of patients (diagnosed from 1988 to 1999) considered cured of their cancer (all cancers combined) varied between 38% and 59% in women, and 21% and 47% in men, by country.[4]

Cancer is often a chronic condition and patients may endure physical and psychological symptoms for years after their treatment is complete.[5] Such symptoms can worsen the quality of life, and include pain, fatigue, cognitive impairment, worries about health, irritable mood, demoralization, depression and interpersonal problems.[5]

The Council of Europe has recognised that reducing the cancer burden in Europe will require an integrated approach to cancer control and has noted that 'to attain optimal results a patient-centred, comprehensive interdisciplinary approach and optimal psycho-social care should be implemented in routine cancer care, rehabilitation, post-treatment and follow-up'.[6]

To provide data in the area of cancer rehabilitation needs, as part of its work-package 6 (WP-6) initiative, the European Cancer Health Indicator Project (EURO-CHIP-3)[7] recruited a group of unpaid experts to draw up a list of plausible population-based indicators able to describe cancer rehabilitation in Europe. The panel adopted the broad definition of rehabilitation proposed by the WHO: 'a process aimed at enabling patients to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels'.[8] The panel also adopted a broad definition of cancer survivors: the total prevalence of persons in the population with a diagnosis of cancer.

Table 1
List of cancer rehabilitation indicators considered and eventually adopted list.

Domain	Initial list *(before first meeting)*		Intermediate list *(after first questionnaire)*		Final list *(after last meeting)*
(i) Cancer rehabilitation needs	Prevalence (total and by years from diagnosis)	→	Prevalence (total and by years from diagnosis)	→	Prevalence (total and by years from diagnosis)
	Proportion of patients with relapses	→	Proportion of patients with relapses	→	Proportion of cured and differentiated prevalence
(ii) Prominence/presence of cancer rehabilitation on political and clinical agendas			Availability of – National Policy Documents – Guidelines – Training courses		
(iii) Cancer rehabilitation capabilities (structures, services and funding)	Availability of – Counselling – Psychological support – Homecare	→	Availability of – Counselling – Homecare – FU programmes – NGOs		
	– Psychological support – Nutritional counselling – Social care workers – Exercise programmes				
	Funding for rehabilitation	→	Funding for rehabilitation		
(iv) Measures of rehabilitation success	Return to work	→	Return to work	→	Return to work
			Quality of life of cancer patients	→	Quality of life of cancer patients
	Indicators of rehabilitation needs according to cancer site	⟶			Indicators of rehabilitation needs according to cancer site: – Speech and language therapy for head and neck cancer patients – Physiotherapy for breast cancer patients – Dietary advice for colorectal cancer patients – Psychological support for all cancer patients

The aims of the present article are: (a) to describe the candidate indicators evaluated by the expert panel; (b) to present the final list of indicators proposed by the panel and (c) to present the results of a literature survey, undertaken after definition of the final list, to find English language scientific articles concerned with methods for estimating the proposed indicators.

2. Materials and methods

2.1. Work of the panel – production of indicators

Work on cancer rehabilitation indicators started in 2009 and concluded in the early months of 2012. During that time 37 experts on cancer rehabilitation (public health professionals, epidemiologists, palliative care professionals, oncologists, clinical psychologists and other physicians) from the 27 European Union member states were recruited to the WP-6 panel. The work of the panel proceeded by meetings. Five meetings were held.[9] Before the first meeting, the WP-6 coordinator group prepared a list of possible rehabilitation indicators for consideration (Table 1, column 2). Between meetings, panel members carried out their own literature searches to find data on the indicators suggested. Also between meetings two *ad hoc* questionnaires were sent out to panel members soliciting further information and opinions (particularly from members not present at the previous meeting). The questionnaires, available online,[10] were devised by the WP-6 coordinator group typically in response to matters arising or decisions taken during previous meetings. The first questionnaire went out in April–June 2010 and solicited opinions on definitions, methods of determining and sources of data for estimating the indicators being considered. The second questionnaire, sent out in January–September 2011, solicited information for assessing the feasibility of using (estimating) the indicators being considered for adoption.

2.2. Criteria for selecting final list of indicators

It was agreed that any cancer rehabilitation indicator proposed must: (a) be available or estimable for entire populations; (b) describe the same aspect of cancer rehabilitation in all European countries and (c) be collectable by standardised methods in all countries.

Indicators were initially sought in the following domains: (i) cancer rehabilitation needs; (ii) prominence/presence of cancer rehabilitation on political and clinical agendas; (iii) cancer rehabilitation capabilities (structures, services and funding) and (iv) measures of rehabilitation success. Table 1 shows the indicators discussed and eventually adopted by the expert panel. The last column shows the final indicators proposed by the panel.

2.3. Systematic literature search

In order to find articles describing methods for estimating the indicators included in the final list, we carried out a systematic literature search in February 2012 using PubMed.[11] We first decided the search terms (first column, Table 2). We next examined abstracts of articles found, to identify those potential pertaining to indicators. Finally we read the Materials and Methods of articles apparently pertaining to indicators and selected those that were pertinent. Table 2 shows results of the PubMed search.

3. Results

3.1. Indicators on cancer rehabilitation needs

The expert panel found that the indicator best able to quantify patients with rehabilitation needs was *total prevalence*.[12] This indicator can be estimated from cancer registry data[12] or through mathematical modelling of mortality and survival data.[13] The EUROPREVAL[14] and RARECARE[2] projects produced estimates of total prevalence by cancer site in Europe in 1992 and 2003, respectively. Total prevalence comprises recently-diagnosed patients, those undergoing treatment or follow-up and also long-term survivors, some of whom may be considered cured. It is useful to divide total prevalence into subgroups of cancer survivors having particular needs. One subdivision is according *to time elapsed from diagnosis* (e.g. two-year prevalence, five-year prevalence, which refers to survivors with diagnosis, respectively, in the two and five years preceding the prevalence index date).[13,14] Years from diagnosis to reference date identifies (is a useful proxy for) groups of patients with differing healthcare needs. A study on prevalence by years from diagnosis was recently performed in the United Kingdom (UK).[15] GLOBOCAN[16] produced Europe-wide estimates of five-year prevalence for 2008. We found 40 other scientific articles dealing with population-based cancer prevalence in Europe (Table 2).

It is also possible to apply cured models to cancer registry data to estimate the *proportion of cured patients*. This is the fraction of the total prevalence consisting of patients with the same life expectancy as the general population of the same age and sex; the remaining fraction consists of patients who will die of their disease and who may have different healthcare needs from cured patients. The proportion of cured patients indicator has been estimated by EUROCARE for all cancers combined and various cancer sites for several European countries.[4]

It is also useful to identify other sub-groups of prevalent cases according to their clinical situation and likely demands on health care facilities. To do this, cancer

Table 2
Results of PubMed search[a] for articles on population-based methods for collecting data on final list of cancer rehabilitation indicators.

Search terms	No. articles	Indicator	No. articles pertaining to Europe
("prevalence" [MeSH term] OR ("Survivors/statistics and numerical data" [MAJR]) OR ("Survival analysis" [MeSH term] 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	Prevalence (total and by time) Cured prevalence Differentiated prevalence	40 4 3
("Employment/statistics and numerical data" [MAJR] OR "Sick Leave/statistics and numerical data" [MAJR] OR "Survivors/statistics and numerical data" [MeSH term] OR "workplace" [MeSH term] OR "work schedule tolerance" [MeSH term] OR "work capacity evaluation" [MeSH term] 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	Return to work	12
(("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	Quality of life Psychological support for all cancer patients	41 2
("head and neck neoplasms" [MeSH term]) AND ("rehabilitation" [all fields] OR "speech" [all fields] OR "language" [all fields]) AND ("cancer registry" [all fields] OR "population-based" [all fields])	10	Speech and language therapy for head and neck cancer patients	
("breast neoplasms" [MeSH term]) AND ("rehabilitation" [all fields] OR "physiotherapy" [all fields]) AND ("cancer registry" [all fields] OR "population-based" [all fields])	23	Physiotherapy for breast cancer patients	
("colorectal neoplasms" [MeSH term] OR "colon neoplasms" [MeSH term] OR "rectal neoplasms" [MeSH term]) AND ("rehabilitation" [all fields] OR "dietician" [all fields]) AND ("cancer registry" [all fields] OR "population-based" [all fields])	13	Dietary advice for colorectal cancer patients	

[a] Three-phase search strategy: (1) definition of search terms; (2) examination abstracts to identify articles possibly pertaining to indicators; (3) reading of Materials and Methods of articles found in (2).

registry data (incidence and vital status) are combined with information on treatment (or use of health service facilities) and follow-up (to identify recurrences, metastases, second tumours, side-effects of treatment, etc.) in order to produce estimates of what EUROCHIP-3 has designated *differentiated prevalence,* in which patients are divided according to their health status as follows: (a) cases not undergoing cancer treatment and without distant or local relapse; (b) cases expected to die of cancer within a year and probably requiring terminal care and home assistance (c) cases requiring health care or rehabilitation, expected to die of cancer after a year.[17]

This has been shown to be feasible by studies performed in the UK on cancer survivors in general[18] and for colorectal cancer survivors in the US by linking hospital discharge data with cancer registry data.[19] Similar studies have also been performed in Italy[17–20] (colon cancer) and France[21] (colorectal cancer): these studies collected data (recurrences, metastasis and treatments) from clinical records for samples of cases archived in cancer registries.

3.2. Indicators on measures of rehabilitation success

The panel initially sought an indicator of *return to work*, since cancer survivors of working age are likely to be unemployed more often than healthy people.[22] Relatively few population-based studies have been performed on proportions of cancer survivors who return to work: the literature search found 12 articles (Table 2). For example a Dutch study used the ArboNed Occupational Health Service register, containing sickness absence data and medical diagnoses for 1 million Dutch wage earners working in 33,000 companies in various economic sectors, to estimate return to work.[23–26] Cancer registry data were linked to census data in Finland,[27,28] with the Directorate of Taxes database in Norway,[29] and with the Labour Market Research Database in Denmark.[30,31] However, these methods of study cannot be extended to other countries because the occupational databases exploited by these studies do not exist in most other European countries.

A feasible approach applicable to all European countries would be to perform surveys on samples of cancer survivors extracted from cancer registry databases. However, questionnaires would have to be compatible across languages and cultures. Surveys of this type have been performed in North West England (50% participation),[32] Ireland (54% participation)[33] and South Netherlands (80% participation).[34]

The panel extensively examined the feasibility in collecting population-based data on *quality of life* of cancer patients, as this was considered an important indicator of cancer rehabilitation success. Table 3 summarises 41 European population-based studies on the quality of life, found by the literature search. These studies were mainly confined to the Netherlands, Germany, Sweden, Iceland and France; they can be considered population-based as they involved samples of cases extracted from cancer registry databases, or were cross-sectional surveys of the general population linked to cancer registry databases. Various types of questionnaires were used; those used most frequently were EORTC QLQ-C30 (European Organisation for Research and Treatment of Cancer QLQ-C30),[35] SF-36 (36-item short form health survey),[36] and HADS (Hospital Anxiety and Depression Scale).[37] Participation varied from 32% to 94% with an average participation rate equal to 72%.

The panel also drew up a list of proxy indicators of rehabilitation needs and whether those needs are being met. These were: *speech & language therapy* for head and neck cancer patients; *physiotherapy* for breast cancer patients; *dietary advice* for colorectal cancer patients; and *psychological support* for all cancer patients. Our literature search on these indicators found two interesting articles. In one, data from a Swedish population-based prostate cancer registry was linked with the National Hospital Discharge Register and the National Prescribed Drug Register to find prostate cancer patients who had been hospitalised for psychiatric reasons or who used antidepressant drugs.[38] In the other, a survey (participation rate 54%) was carried out on cancer cases extracted from the Norwegian Cancer Registry to identify the proportions using specific rehabilitation services (physical therapy, physical training, psychological counselling, supportive group sessions, admittance to convalescent home, consultation with social worker and occupational therapy) to satisfy specific needs.[39]

3.3. Indicators excluded from the final list

The final list excluded the following indicators originally considered by the panel: (a) list of proxy yes/no (present/absent) indicators to assess the extent to which cancer rehabilitation was present on political and clinical agendas. Such information was considered too unreliable and subject to change to warrant inclusion in our list. (b) Indicators on the presence of rehabilitation structures and services, because the sources of information that were found proved not to be comparable across countries. (c) Indicators on cancer rehabilitation funding. Here replies to the first questionnaire made it clear that data on funding would be difficult to obtain, and also that even if this were possible, it was unlikely that funding data would be comparable across European countries.

4. Discussion

All indicators of cancer rehabilitation discussed by EUROCHIP-3 had two prerequisites: they had to be population-based and had to be collectable by

Table 3
Results of PubMed literature search for population-based surveys on quality of life of European cancer survivors.

First author	Journal	Population	Nation	Cancer patient population	Cancer	Years from diagnosis	EORTC questionnaire	SF-36	HADS	Lost for external reasons[1] (%)	Question-naires sent	Particip-ation (%)
Jansen L	J Clin Oncol 2011; 29(24)	Saarland	D	PB-CR sample	Colon rectum	10	Yes	No	No	–	196	69
Arndt V Arndt V	Eur J Cancer2006; 42(12) J Clin Oncol 2004; 22(23)	Saarland	D	PB-CR sample	Colon rectum	1–3	Yes	No	No	–	379	82
Hoyer M	Acta Oncol 2011; 50(7)	Cent Sweden	S	PB-CR	Breast	1–2	Yes	No	Yes	–	1573	69
Thong MS	Eur J Cancer 2011; 47(12)	Eindhoven	NL	PB-CR sample	Colon	1–10	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	Yes	Yes	No	26	547	85
Aarts MJ Thong MS Mols F Mols F	Urology 2010; 76(5) BJU Int 2010; 105(5) BJU Int 2008; 102(11) Cancer 2006; 107(9)	Eindhoven	NL	PB-CR	Prostate	5–10	No	Yes	No	21	964	81
Grov EK	Eur J Oncol Nurs 2011; 15(3)	Nord-Trøndelag	N	PB cross sectional survey	Various	1–10	No	No	Yes	44	510	94
Skoogh J	Int J Androl 2011; 34(2)	Sweden	S	PB-CR	Testis	3–26	No	No	Yes	4	1173	82
Schlesinger-Raab A	Ann Oncol 2010; 21(12)	Munich	D	PB-CR	Melanoma	2	Yes	No	No	-	1085	72
Le Corroller-Soriano AG	Eur J Cancer Care 2011; 20(1)	France	F	PB cross sectional survey	Various	2	No	Yes	No	-	6957	64
Saevarsdottir T	Cancer Nurs 2010; 33(1)	Iceland	ICE	PB cross sectional survey	various	0.5	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	No	No	Yes	-	383	48
Djarv T Rutegard M Rutegard M Viklund P	J Clin Oncol 2009; 27(12) Ann Surg Oncol 2008; 15(9) Br J Surg 2008 95(5) Eur J Cancer 2006; 42(10)	Sweden	S	PB-CR	Oesophagus	1–5	Yes	No	No	14	399	89
Mehnert A Mehnert A	Psychooncology 2009; 18(12) J Psychosom Res 2008; 64(4)	Hamburg	D	PB-CR	Breast	1–6	No	No	No	18	1633	66
Korfage IJ	Int J Rad Oncol Biol Phys 2009; 73(5)	Eindhoven	NL	PB-CR	Cervical	2–10	Yes	Yes	No	6	421	69
Bouvier AM	Cancer 2008; 113(4)	Burgundy	F	PB-CR	Colon rectum	0–1	Yes	No	No	-	209	60
Arndt V Arndt V Arndt V Arndt V	J Canc Res Clin Onc 2008; 134(12) Cancer 2006; 107(10) J Clin Oncol 2005; 23(22) Eur J Cancer 2004; 40(5)	Saarland	D	PB-CR sample	Breast	1–5	Yes	No	No	-	401	78
van de Poll-Franse LV	Int J Rad Oncol Biol Phys 2007; 69(1)	Eindhoven	NL	PB-CR	Endometrial	5–10	No	Yes	No	12	405	75
Mols F	Cancer 2007; 109(8)	Eindhoven	NL	PB-CR	NH lymphoma	5–15	No	Yes	No	23	360	82

Table 3 (*continued*)

First author	Journal	Population	Nation	Cancer patient population	Cancer	Years from diagnosis	EORTC questionnaire	SF-36	HADS	Lost for external reasons[1] (%)	Question-naires sent	Particip-ation (%)
Waldmann A	Qual Life Res 2007; 16(5)	Schleswig–Holstein	D	PB-CR sample	Breast	0–3.5	Yes	No	No	-	2366	81
Mols F	Eur J Cancer 2006; 42(16)	Eindhoven	NL	PB-CR	H lymphoma	5–15	No	Yes	No	31	164	80
Matsuda T	Eur J Epidemiol 2004; 19(4)	Isère and Tarn	F	PB-CR sample	Bladder	5–10	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	Yes	No	No	-	1131	88
Engel J	Breast Canc Res Treat 2003; 79(1)											
Kerr J	Ann Oncol 2003; 14(3):421–427											
Sandblom G	Br J Cancer 2004; 22 90(6)	Ostergot-land	S	PB-CR	Prostate	>1	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	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	No	No	No	-	431	79
Totals											25640	72

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

standardised methods across all European countries. The implication is that the main source of indicators must be population-based cancer registries. Cancer registries are present in most European countries, although the percentage of national populations covered by cancer registration varies.[40] Two main types of indicators emerged from the deliberations of the panel:

(a) Indicators based on cancer prevalence. These include total prevalence, prevalence by time from diagnosis to prevalence date, and what EURO-CHIP-3 has called differentiated prevalence. These indicators were considered to be very useful proxies of the burden experienced by different groups of cancer survivors, and assumed to have differing cancer rehabilitation needs. Cancer prevalence-based indicators can be estimated by models using data routinely collected by cancer registries[13–15] or – for samples of cases archived by cancer registries – from data on diagnosis, treatment and follow-up obtained from clinical records[20,21] or hospital discharge databases.[17]

(b) Measures of the success of rehabilitation in terms of (i) return to work for patients of working age; (ii) quality of life and (iii) satisfaction of rehabilitation requirements (specifically, the panel chose to investigate speech and language therapy for head and neck cancer survivors, physiotherapy for breast cancer survivors, dietary therapy for colorectal cancer and psychological support for all cancers).

The success of rehabilitation has been estimated by a number of national studies.[23–26,29–31,38] To quantify the rehabilitation services used by cancer survivors, cancer registry databases can be linked with those of the structures providing rehabilitation services. For example, a Danish study combined cancer registry and population-based databases to assess hospitalisation for depression as a measure of the psychological burden experienced by cancer patients.[41] However, this method only investigates rehabilitation needs that are being met; it can say nothing about survivors not present in rehabilitation service databases. Furthermore, these types of studies cannot be performed across the whole of Europe because the necessary databases are not uniformly present in all countries.

One way forward would be to collect data on the cancer experiences of cancer survivors by getting representative samples of them to complete validated questionnaires in all countries.

Information can also be collected through national health surveys of the general population (although such surveys would need to ask specifically whether the respondent had ever been diagnosed with cancer). Surveys can also be performed that are directed specifically at cancer survivors.

Whatever method is used to obtain a picture of rehabilitation needs and facilities across Europe, the surveys must be conducted on population-based samples of survivors (i.e. sampled from cancer registry databases). Samples obtained from hospital databases are not representative of the population as a whole, and are therefore likely to provide biased and inaccurate information.

The Dutch experience with PROFILES (Patient-Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship) is relevant here.[42] All cancer patients archived in the Eindhoven cancer registry were asked to complete questionnaires whose objective was to investigate the physical and psychosocial impact of the cancer, and the involvement of patients' physicians in improving survivorship.[42]

Other aspects need to be considered when organising and conducting surveys: (a) in some countries the survivor may not always be aware that he/she was diagnosed with cancer so in those situations the survivor's general practitioner or clinician must be contacted first; (b) national confidentiality laws may prevent cancer registries from contacting cancer patients; (c) if non-participation levels are high, the survey could provide false (biased) results. The PROFILES studies had 75–80% participation rates,[42] while other important studies in Norway,[39] the UK[32] and Ireland[33] had lower participation rates (50–55%). Getting patient organisations involved might improve participation rates. Although surveys are expensive and have the above-discussed limits, they have the potential to provide important information on cancer rehabilitation.

To conclude, as far as we are able to ascertain no other studies have investigated possible indicators of cancer rehabilitation in Europe. We are aware of the preliminary nature of our proposals, and intend the present the study as a starting point on which we hope other groups will build on and improve. We believe, particularly in view of the dramatic increase in numbers of cancer survivors in Europe (estimated to be 18 million in 2003), that it is important to start collecting information about cancer survivors as soon as possible through pilot studies, to identify their needs and whether they are being met, to obtain information on the availability of rehabilitation services in order to guide European cancer control policies in line with Council of Europe recommendations.

EUROCHIP-3 working group on cancer rehabilitation

Austria: Hubert Denz (National Hospital Tirol), Elisabeth Andritsch (Medical University of Graz); *Belgium*: Elke Van Hoof (Belgian Cancer Centre), Clair Watts (European Oncology Nursing Society); *Bulgaria*: Nikolay Yordanov (Comprehensive Cancer Centre-Vratsa Ltd.); *Cyprus*: Sophia Nestoros (Ministry of Health); *Czech Republic*: Olga Svestkova (Charles University); *Denmark*: Christoffer Johansen (Danish Institute of Public Health); *Estonia*: Piret Veerus (National Institute for Health Development); *France*: Mélanie Samson, Jeanne-Marie Bréchot (Institut National du Cancer); *Finland*: Matti Rautalahti, Liisa Pylkkanen (Cancer Society of Finland); *Hungary*: Miklos Garami (Hungarian Paediatric Oncology Network); *Germany*: Hans Bartsch (Tumour Biology Centre at Albert-Ludwigs University); *Greece*: Athina Vadalouca (University of Athens); *Italy*: Luigi Grassi (University of Ferrara), Camilla Amati, Ilaria Casella, Milena Sant (Fondazione IRCCS 'Istituto Nazionale dei Tumori'); *Ireland*: Deirdre Murray (Irish Cancer Control programme, MoH); *Latvia*: Aivars Vetra (Riga Stradins University); *Lithuania*: Nomeda Vaitekunaite (Ministry of Health); *Luxembourg*: Astrid Scharpantgen (Direction de la Santé); *Malta*: Rita Micallef (Malta Ministry of Health); *The Netherlands*: Josette Hoekstra Weebers (Comprehensive Cancer Center the Netherlands); *Poland*: Magdalena Bielska-Lasota, Rafal Halik (National Institute of Public Health-National Institute of Hygiene); *Portugal*: Luzia Travado (Central Lisbon Hospital Centre), Cristina Portugal (Ministry of Health); *Romania*: Florian Nicula ('Ion Chiricuta' Institute of Oncology), Dégi L. Csaba (University of Babes-Bolyai); *Spain*: Tarsila Ferro (Pla director d'oncologia), Xavier Bonfill (IIB Sant Pau-CIBERESP, Universitat Autònoma de Barcelona), Anita Margulies (European Society Oncology Nurses EONS); *Slovakia*: Olga Sadovska (National Cancer Institute), Martina Ondrušová (Slovak Academy of Sciences); *Slovenia*: Marjetka Jelenc (Slovenian Institute of Public Health), Branko Zakotnik (Ljubliana Institute of Oncology); *Sweden*: Maria Hellbom (Lund University Hospital); *UK*: Gill Hubbard (University of Stirling), Eva Gail (Oxford Brookes University), Jackie Turpenney (National Cancer Action Team), Sharon Cavanagh (North London Cancer Network).

Conflict of interest statement

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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. Grassi L, Travado L. The roen of psychosocial oncology in cancer care. In: Coleman MP, Alexe DM, Albreht T, McKee M, editors. Responding to the challenge of cancer in Europe. Ljubljana: Institute of Public Health of the Republic of Slovenia; 2008. p.209-30. Available from: http://www.euro.who.int/__data/assets/pdf_file/0011/97823/E91137.pdf (accessed on February 2012).

6. Council of the European Union. Council conclusions on reducing the burden of cancer: 2876th Council meeting, Luxembourg, 10 June, 2008. Available from: http://www.eu2008.si/en/News_and_Documents/Council_Conclusions/June/0609_EPSCO-cancer.pdf (accessed on May 2012).

7. EUROCHIP. Available from: www.tumori.net/eurochip (accessed on February 2012).

8. World Health Organization. Health topics. Rehabilitation. Available from: http://www.who.int/topics/rehabilitation/en/ (accessed on October 2012).

9. EUROCHIP-3 WP-6. Available from: http://www.tumori.net/eurochip/wp.php?page=6 (accessed on October 2012).

10. EUROCHIP-3 WP-6 final report to the European Commission. Available from: http://www.tumori.net/eurochip/material/WP6/WP6_report.pdf (accessed on October 2012).

11. PubMed. Available from: http://www.ncbi.nlm.nih.gov/pubmed/ (accessed on February 2012).

12. Capocaccia R, De Angelis R. Estimating the completeness of prevalence based on cancer registry data. *Stat Med* 1997;**16**(4):425–40.

13. De Angelis R, Grande E, Inghelmann R, et al. Cancer prevalence estimates in Italy from 1970 to 2010. *Tumori* 2007;**93**(4):392–7.

14. Micheli A, Mugno E, Krogh V, et al. Cancer prevalence in European registry areas. *Ann Oncol* 2002;**13**(6):840–65.

15. Maher J, McConnell H. New pathways of care for cancer survivors: adding the numbers. *Br J Cancer* 2011;**105**(Suppl):S5–S10.

16. Ferlay J, Shin HR, Bray F, Forman D, Mathers C, Parkin DM. GLOBOCAN 2008 v1.2, Cancer incidence and mortality worldwide: IARC CancerBase No. 10. Lyon: International Agency for Research on Cancer; 2010. Available from: http://globocan.iarc.fr (accessed on February 2012).

17. Baili P, Vicentini M, Tumino R, et al. A method for differentiating cancer prevalence according to health status, exemplified using a population-based sample of Italian colorectal cancer cases. Acta Oncol in press.

18. 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.

19. Mariotto A, Warren JL, Knopf KB, Feuer EJ. The prevalence of patients with colorectal carcinoma under care in the US. *Cancer* 2003;**98**(6):1253–61.

20. Gatta G, Capocaccia R, Berrino F, Ruzza MREUROPREVAL Working Group. Colon cancer prevalence and estimation of differing care needs of colon cancer patients. *Ann Oncol* 2004;**15**(7):1136–42.

21. 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.

22. de Boer AG, Taskila T, Ojajärvi A, van Dijk FJ, Verbeek JH. Cancer survivors and unemployment: a meta-analysis and meta-regression. *JAMA* 2009;**301**(7):753–62.

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-Abrandt 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-Abrandt T, Pukkala E, Martikainen R, Karjalainen A, Hietanen P. Employment status of Finnish cancer patients in 1997. *Psychooncology* 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. *Scand J 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.

35. 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.

36. Ware JE, Sherbourne CD. 36-item shortform health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;**30**:473–83.

37. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67**:361–70.

38. Bill-Axelson 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.

39. Thorsen L, Gjerset GM, Loge JH, et al. Cancer patients' needs for rehabilitation services. *Acta Oncol* 2011;**50**(2):212–22.

40. Curado MP, Edwards B, Shin HR, et al. Cancer incidence in five continents, vol. IX. IARC Scientific Publications No. 160. Lyon: International Agency for Research on Cancer; 2007. Available from: http://ci5.iarc.fr/CI5i-ix/ci5i-ix.htm (accessed on October 2012).

41. Dalton SO, Laursen TM, Ross L, et al. Risk for hospitalization with depression after a cancer diagnosis: a nationwide, population-based study of cancer patients in Denmark from 1973 to 2003. *J Clin Oncol* 2009;**27**(9):1440–5.

42. van de Poll-Franse LV, Horevoorts N, van Eenbergen M, et al. The patient reported outcomes following initial treatment and long term evaluation of survivorship registry: scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. *Eur J Cancer* 2011;**47**(14):2188–94.