

Availability of stage at diagnosis, cancer treatment delay and compliance with cancer guidelines as cancer registry indicators for cancer care in Europe: Results of EUROCHIP-3 Survey

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EUROCHIP (European Cancer Health Indicators Project) focuses on understanding inequalities in the cancer burden, care and survival by the indicators "stage at diagnosis," "cancer treatment delay" and "compliance with cancer guidelines" as the most important indicators. Our study aims at providing insight in whether cancer registries collect well-defined variables to determine these indicators in a comparative way. Eighty-six general European population-based cancer registries (PBCR) from 32 countries responded to the questionnaire, which was developed by EUROCHIP in collaboration with ENCR (European Network of Cancer Registries) and EUROCOURSE. Only 15% of all the PBCR in EU had all three indicators available. The indicator "stage at diagnosis" was gathered for at least one cancer site by 81% (using TNM in 39%). Variables for the indicator "cancer treatment delay" were collected by 37%. Availability of type of treatment (30%), surgery date (36%), starting date of radiotherapy (26%) and starting date of chemotherapy (23%) resulted in 15% of the PBCRs to be able to gather the indicator "compliance to guidelines". Lack of data source access and qualified staff were the major reasons for not collecting all the variables. In conclusion, based on self-reporting, a few of the participating PBCRs had data available which could be used for clinical audits, evaluation of cancer care projects, survival and for monitoring national cancer control strategies. Extra efforts should be made to improve this very efficient tool to compare cancer burden and the effects of the national cancer plans over Europe and to learn from each other.

Cancer registries have provided population-based, comparative cancer survival statistics since 1950s. Since 1978, EURO-CARE (a co-operative, cancer registry-based project), underlined large differences in cancer survival across Europe.¹⁻⁴ The recurrent question is: what factors are responsible for these differences?

The EUROCHIP projects (European Cancer Health Indicators Project) focused on addressing and measuring inequalities in the cancer burden (<http://www.tumori.net/eurochip>). The EUROCHIP-1 project identified a network of cancer scientists and professionals working in the European Member and Candidate States and proposed a list of population-based health indicators on cancer burden, risk factors, management and outcome of cancer.⁵ Some of these were included in European Community Health Indicators list (ECHI [<http://ec.europa.eu/health/>

http://www.tumori.net/eurochip/material/Report/EUROCHIP-2_Final_report/Annex_03_EUROCHIP_Pilot_Studies.pdf). Among these, three indicators were identified as closely associated with the observed wide intercountry variation in cancer survival: "stage at diagnosis," "cancer treatment delay" and "compliance with cancer guidelines." In some of these countries, indicators were not available for the period 2003–2005, but their collection was possible on a sample of cancer patients against high costs of this collection (http://www.tumori.net/eurochip/material/Report/EUROCHIP-2_Final_report/Annex_03_EUROCHIP_Pilot_Studies.pdf).

This EUROCHIP-3 project focused on the availability of the three main indicators: a comparative way to identify inequalities in cancer risk, care and survival which are "stage at diagnosis," "cancer treatment delay" and "compliance with cancer guidelines" in the European population-based cancer registries (PBCRs) to get insight in the availability of these indicators and in the factors limiting the collection of these.

Methods

Design and data retrieval

A questionnaire was developed by members of EUROCHIP-3 Work Package 5 (WP-5) taking into account the results from

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What's new?

Cancer registries have provided population-based, comparative cancer-survival statistics since the 1950's, and have identified significant differences across Europe. An important question has been: what factors are responsible for these differences? This study, called EUROCHIP-3, found that only 15% of all population-based cancer registries actually collect the three most important indicators for determining inequality in cancer care and survival in Europe. The authors recommend that extra resources be made available to improve this very efficient tool for comparing cancer burden and the effects of national cancer plans.

the previous EUROCHIP (http://www.tumori.net/eurochip/material/Report/EUROCHIP-2_Final_report/Annex_16_EUROCHIP-UK.pdf) and ENCR questionnaires (<http://www.encl.com.fr/>, <http://www.ci5.iarc.fr/>) and in collaboration with the EURO COURSE project (<http://www.eurocourse.org/>).

The questionnaire was emailed on May 3, 2010 to all the European PBCRs ($N = 206$, WHO-Europe) by the European Network of Cancer Registries (ENCR), and was filled out through the web-based "gateway" developed at the International Agency for Research on Cancer (IARC). The administrative data were already partly filled by the ENCR/IARC in the questionnaire and could be rectified when necessary. The registry staff (one or more persons depending on the choice of the PBCR) answered the questions. Although the EUROCHIP-3 project aimed to take all PBCRs into consideration, we excluded the specialized PBCRs for this publication owing to small numbers ($n = 17$).

The questionnaire *OVERVIEW OF CANCER REGISTRATION PRACTICES ENCR Questionnaire* (<http://www.tumori.net/eurochip/material/WP5/Questionnaire.pdf>) consisted of 15 parts: contact details, registry description, conditions of cancer registration, funding of cancer registration, data sources, registration criteria, screening, diagnosis, topography and morphology, tumor variables, treatment variables, follow-up variables, guidelines, registry output and finally permission for sharing data. EUROCHIP-3 WP-5 used a selected data set to identify whether the PBCRs collected the variables necessary for the three indicators "stage at diagnosis," "delay of cancer treatment" and "compliance with guidelines." In addition, we looked at the reasons why PBCRs did not collect data for these indicators (classified as: a lack of interest, lack of finance, lack of qualified staff and lack of access to data sources). In case the PBCR collected the indicators, detailed information was asked about what they were used for.

For the indicator "stage at diagnosis" questions referred to whether stage was collected at diagnosis, which classifications were used (a measure of validity and comparability) and whether staging was registered for all cancers or a group of cancers. The "most valid basis of diagnosis" was required, defined according to the ENCR rules for which date of first event should be chosen in chronological order (histological/cytological confirmation; admission to the hospital because of this malignancy; date of first consultation at the outpatient clinic because of this malignancy, other date of diagnosis,

date of death and date of death at autopsy) (<http://www.encl.com.fr/>). In case an event of higher priority occurs within 3 months of the date initially chosen, the date of the higher priority event should take precedence. PBCRs which collected the variable stage (clinical and/or pathological) for at least one tumor site and registered basis of diagnosis according to the ENCR rules were considered to be able to provide data for the indicator "stage at diagnosis."

The indicator "cancer treatment delay" was defined as the time between the date of incidence (according to "ENCR rules") and the date of first treatment. PBCRs which registered date of incidence and collected the first treatment date for at least one tumor site were considered to be able to provide data for the indicator "cancer treatment delay."

In EUROCHIP, proxy indicators (stage, type of treatment and [starting] dates of treatments) for breast and colorectal cancers were identified to determine the availability of "compliance with cancer guidelines" (<http://www.tumori.net/eurochip/actions.php?page=ps>). The availability within the cancer registration of all these indicators for at least one tumor site, for which national or regional cancer guidelines for diagnosis and treatment are available, was considered to be able to provide data for the indicator "compliance with cancer guidelines."

Data analysis

As the availability of the variables for the indicators might depend on the access to different sources for data collection, we asked the total number of different sources available for cancer registrations and whether they were systematically or occasionally used. Furthermore, the proportion of electronic data sources and the proportion of passive supplied data sources (data are received without any requests by the registry) were determined and put in relation with the available registration budget and the number of collected indicators. Moreover, it was taken into consideration whether population-based screening programs were ongoing in the PBCR region, which could favorably influence the availability of the indicator "stage at diagnosis."

In the questionnaire, factors which might influence the collection of the three indicators, questions about budget, sources for data collection, screening activities, contribution in cancer control evaluation, starting year of PBCR and starting year for the collection of different variables *per* indicator were asked. To make the available budget (in €) comparable

Table 1. Details of respondent general population-based cancer registries 2010

	National N 21	Regional N 65	Total N 86
Total			
Most common sources used	N (%)	N (%)	N (%)
Pathology laboratories	21 (100)	65 (100)	86 (100)
Hospital oncology records	18 (86)	62 (95)	80 (93)
Other hospital records	19 (90)	64 (98)	83 (97)
Radiotherapy departments	17 (81)	54 (83)	71 (83)
Hematology laboratories	18 (86)	51 (78)	69 (80)
Death certificates	15 (71)	52 (80)	67 (78)
Starting year registry	N (%)	N (%)	N (%)
<1990	14 (67)	36 (56)	50 (59)
1990–2000	5 (23)	21 (33)	26 (31)
2001–2010	2 (10)	7 (11)	9 (10)
Unknown	0	1	1
% of NHE <i>per capita</i> available for cancer registration <i>per</i> cancer case	N (%)	N (%)	N (%)
<1%	3 (27)	16 (43)	19 (40)
1–3%	7 (64)	17 (46)	24 (50)
>3%	1 (9)	4 (11)	5 (10)
Unknown	10	28	38

between the EU countries, the available budget of the cancer registrations was defined as the available budget for data collection (office, personnel and equipment) plus the available budget for data processing and hosting, divided by the number of cancer cases in the PBCR region. To adjust for the purchasing power, the available total budget *per* cancer case is expressed as a percentage of the total National Health Expenditure *per capita* (National Health Expenditure [NHE]/*capita*).

$$\frac{\text{Budget(€) for data collection and processing per cancer case}}{\text{National Health Expenditure (NHE) (€) per capita}} \times 100$$

Subsequently, we categorized this percentage into four groups: <1, 1–3, >3% and unknown of the NHE/*capita per* cancer case.

Results

General results

Eighty-six general PBCRs from 32 countries responded (50% of all contacted). This covered about 28% of the EU population. Among respondents, there were 21 national and 65 regional PBCRs (in ten countries, see **Acknowledgements**). The mean number of different data sources used by both the national and the regional PBCRs was 11 (ranging from 3 to 21 sources, SD = 3.5) of which eight sources were used routinely.

Most PBCRs started between 1975 and 2000 (Table 1). Basis of diagnosis was collected in 92% according to the

Table 2. Availability of the indicator “stage at diagnosis,” “cancer treatment delay” and “compliance with cancer guidelines” for 86 general population-based CR, 2010

	National N 21	Regional N 65	Total N 86
Availability of indicator items			
Incidence date according ENCR	N (%)	N (%)	N (%)
Yes	19 (90)	60 (92)	79 (92)
No	1 (5)	1 (2)	2 (2)
Other	1 (5)	4 (6)	5 (6)
Basis of diagnosis according ENCR	N (%)	N (%)	N (%)
Yes	21 (100)	58 (89)	79 (92)
Modified/other rules	0	5 (8)	5 (6)
No	0	1 (2)	1 (1)
Unknown	0	1 (2)	1 (1)
Collection of stage at diagnosis	N (%)	N (%)	N (%)
No	1 (5)	8 (12)	9 (10)
Yes for all tumour types	13 (62)	25 (38)	38 (44)
Yes for at least one tumor type	7 (33)	32 (50)	39 (45)
First treatment date	N (%)	N (%)	N (%)
Yes	15 (71)	22 (34)	37 (43)
Treatment date	N (%)	N (%)	N (%)
Date of surgery	12 (57)	19 (29)	31 (36)
Starting date radiotherapy	11 (52)	11 (17)	22 (26)
Starting date chemotherapy	10 (48)	10 (15)	20 (23)
Treatment type	N (%)	N (%)	N (%)
Type of surgery	9 (43)	17 (26)	26 (30)
Guidelines available	N (%)	N (%)	N (%)
For all tumor sites	5 (24)	20 (31)	25 (29)
For at least one tumor site	6 (29)	14 (22)	20 (23)
None/unknown	10 (48)	31 (48)	41 (48)

Availability of indicators

	N (%)	N (%)	N (%)
“Stage at diagnosis”	20 (95)	50 (77)	70 (81)
“Cancer treatment delay”	13 (62)	19 (29)	32 (37)
“Compliance with cancer guidelines”	7 (33)	6 (9)	13 (15)

ENCR rules (100% in the national PBCRs and 89% in the regional PBCRs).

In Table 2, the availability of the separate items and the availability of the indicators according to the strict definitions are summarized.

Indicator “Stage at diagnosis”

Stage at diagnosis was gathered by 89% of the general PBCRs for at least one tumor site (44% of the PBCRs collected stage for all tumor sites). TNM classification was most frequently

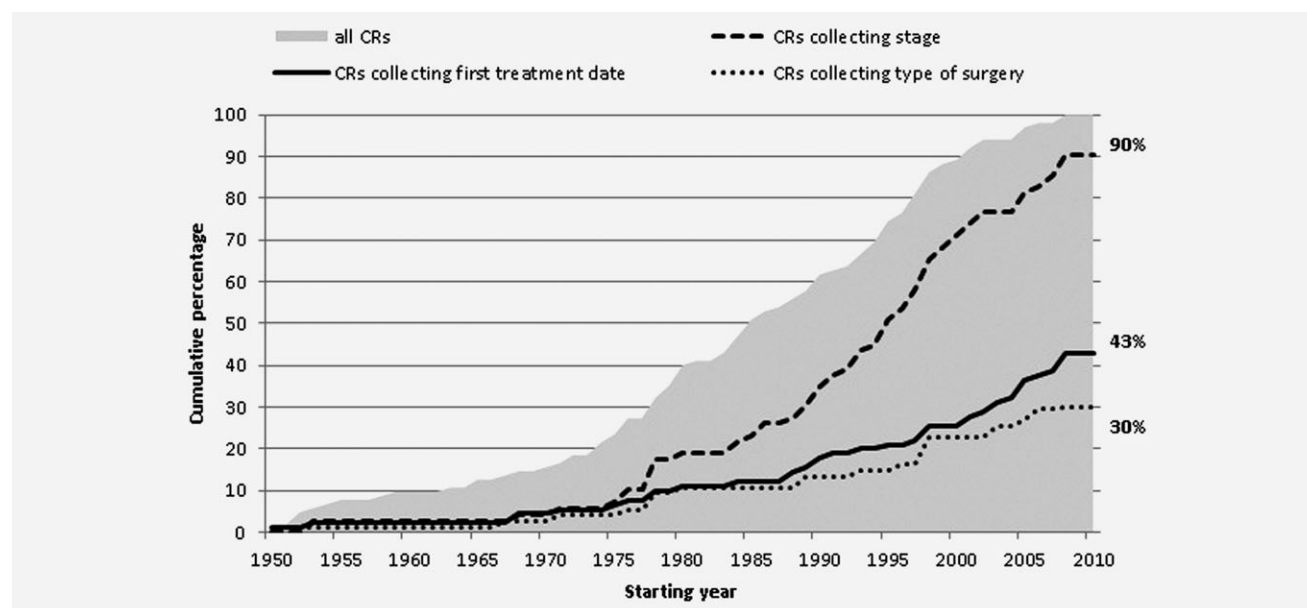


Figure 1. The cumulative percentage of general population based CRs over time and the cumulative percentage of CRs collecting the indicator items stage, first treatment date and type of surgery.

used (39%). In 56% of PBCRs, both clinical and pathological stages were gathered and only in 23% pathology stage was collected. Of the PBCRs, 81% gathered the indicator “stage at diagnosis” according to the definition for at least one cancer site (Table 2).

PBCRs, which did not collect this indicator, had access to fewer information sources than PBCRs which did collect stage. No differences in available budget were found between the PBCRs collecting stage at diagnosis and those which did not.

Indicator “Cancer treatment delay”. The necessary variables to calculate the indicator “cancer treatment delay” were collected by 37% of the responding general PBCRs (Table 2). Limited access to data sources was mentioned as the most important reason for not collecting the first treatment date. However, we did not find a difference in the mean number of data sources used between PBCRs, which did collect all the necessary data variables and those which did not. Those PBCRs, particularly the national CRs, with a high budget *per* cancer case (more than 3% of NHE/capita) collected variables for “cancer treatment delay” more often than PBCRs with a lower budget. No relationship was found between budget and passive data collection. Most PBCRs started collecting first treatment date, after the year 2000.

Indicator “Compliance with cancer guidelines”. To determine the availability of this indicator, we first determined the availability of type of treatment to the PBCR. This was available in 30% of the PBCRs. For the compliance to clinical guidelines, we defined that information should be available on surgery date, starting date of radiotherapy or starting date of chemotherapy. This was gathered by a minority of the gen-

eral PBCRs: 36, 26 and 23%, respectively. About half of the general PBCRs indicated that national or regional cancer guidelines on diagnosis and treatment were available in the areas they covered at least for one tumor site. Only 15% of the PBCRs collected all data for the indicator “compliance with cancer guidelines” (Table 2). Almost all PBCRs with a lower budget did not collect the variables for compliance to cancer guidelines. Lack of qualified staff and access to data sources were the most important reasons why these variables were not collected (Table 2).

All three indicators. In total a minority, 15% of the general PBCRs was able to collect all three indicators. Fourteen PBCRs (16%) were not able to collect the necessary variables for any indicator. Figure 1 shows an overview of the starting year of data collection for three different indicator items. The national PBCRs collected more variables than the regional PBCRs. Even the number of collected indicators varies between regional PBCRs within one country (Fig. 2). Almost a quarter of the PBCRs ($N = 19$) indicated that they were not interested in the variables they did not collect. The others indicated that a lack of source access and qualified staff were the major reasons for not collecting all the variables. No relationship was found between the proportion of electronic data sources and the proportion of passive data sources and the availability of the indicators. For the national PBCR, the higher the available registration budget *per* cancer case is, the more often the three indicators were available. However, this relationship did not exist for the regional PBCRs.

Budget and data sources

Only 56% of the responding general PBCRs indicated the available budget for registration. The national PBCRs had, on

average, more money to spend on cancer registration than the regional PBCRs (respectively 1–3% of the NEH/capita; 64 vs. 45%). Northern European countries had a relative higher available budget for cancer registration than countries from the Eastern part of Europe.

PBCRs used 11 different data sources on average. Overall, 30% of the sources were electronically provided, another 30% on paper, but most sources (40%) were mixed available (electronically and paper). No relationship was found between the use of electronic data sources and the costs for data registration. However, the higher the proportion of passive supplied data sources is (data received without any requests by the registry), the lower the available registration budget. Sources from pathology laboratories and hospital (oncology) records were most commonly used.

Discussion

Only 50% of the invited PBCRs sent back the completed questionnaire. Not all regional registries did respond owing to various reasons such as unknown email address, merges between PBCRs or PBCRs stopped. This problem with the accuracy of the list of cancer registry subsequently emerged as some registries had merged, indicating a higher recorded response rate. Results concerning one region may not represent the situation of the country as a whole, which should be taken into account in generalizing the results of a survey as we used it. The population covered by the general PBCRs which responded was about 221 million (about 28% of EU), and we considered our data as credible. Despite these limitations, this study provided for, the first time, an overview of the available variables for the three indicators (“stage at diagnosis,” “cancer treatment delay” and “compliance with cancer guidelines”) requested for getting insight in the cancer care situation of EU.

There is a relationship between the available budget *per* cancer case and the available number of indicators collected by the national PBCRs. Remarkably, the regional PBCRs which collected all indicators did not report having a higher budget *per* cancer case than those which collected less indicators. Neither, did we find a relationship between the available proportion of electronic data sources or passive supplied data sources and the number of collected indicators.

Although stage at diagnosis is needed to evaluate the effect of early detection and a screening program over time, we were very surprised that 14 out of 86 general PBCRs (covering area with active organized screening programs) did not registry stage, neither had any intention to do so in the near future. Whether data exchange between the PBCR and the screening registry (for these 14 PBCRs) do exist is not known. However, an optimal collaboration between both would enhance an efficient use of skills and budget, improve the quality of the data and in consequence the quality of the early detection and screening programs as well as of the clinical outcomes.

The variables for the indicator “stage at diagnosis” were available in a majority (81%) of the PBCRs. Stage at diagnosis gives an indication of delay before diagnosis, reflecting factors such as percentage of population informed on signs of cancer, accessibility to diagnostic centers or hospitals and capacity of professionals. Comparability of stage at diagnosis between the EU countries will provide important information for each country. The nonregistration of stage at diagnosis reflects the lack of registration and access to information by the PBCR and could, to a lesser extent, reflect the reality and documentation in clinical practice. Still, the percentage of TNM coding was only 39%, which implies a need for enforcing better utilization and documentation of TNM staging to improve delivery of care to patients in all hospital and clinic practice settings.

The necessary variables to calculate “cancer treatment delay” were collected by 37% of the PBCRs, which was mainly owing to the lack of information on dates of treatment. This means that only one-third of the PBCRs can give insight in the patients journey delays and accessibility to treatments, which could impact patient's outcome. To improve patient's outcome “a situation analysis” on delay and answers about causes of lengthy delays, whether it is resources, patient education, the routine of referral patterns and long waits for appointments with specialists, diagnostic imaging appointments or surgery dates or chemotherapy dates or radiation therapy dates, should be given in almost every country and at every center.

The indicator “cancer treatment delay” was defined as the time between the date of incidence (according to “ENCR rules”) and the date of first treatment. PBCRs which registered date of incidence and collected the first treatment date for at least one tumor site were considered to be able to provide data for the indicator “cancer treatment delay.”

For the third indicator “compliance with cancer guidelines,” we combined the results of the proxy indicators (the type of surgical treatment and the starting date of different treatments) and availability of guidelines for at least one tumor site. In only 15% of the general PBCRs, variables for the indicator “compliance with cancer guidelines” were available. We revealed that many PBCRs are not used to support any policy decision making for investment in treatment equipment and required professionals; neither are they to get insight in the treatments available for cancer at regional or national level nor to evaluate the relevance of having guidelines for diagnosis and treatment. PBCRs who are able to compare the given treatment to the recommendations stated in the guideline, to monitor the quality of care and to evaluate the implementation of the guideline should discuss these results with the clinicians.

Information on the three indicators could give explanations and increase understanding of the differences in survival within Europe, which is now possible only by doing high-resolution studies like those within the EUROCARE project.^{6–15}

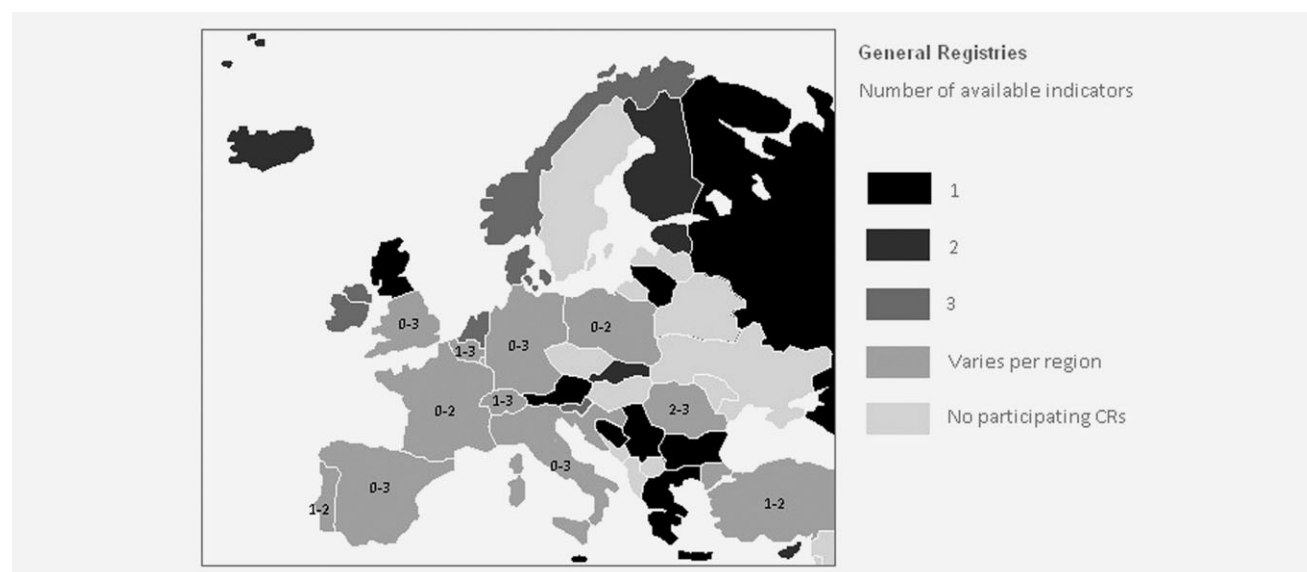


Figure 2. Number of available indicators by country for general population based CRs (partly regional coverage, self-reported), 2010.

Interesting is that 19 out of 86 PBCRs indicated that the reason for not collecting variables was a lack of interest. This suggests that the benefits of collecting data should be made prominently clear for those who should use PBCR results, that is directors, policy makers, politicians and funders. Others indicated that the main reasons were a lack of access to data sources or qualified staff. The United Kingdom pilot studies for EUROCHIP-2 (http://www.tumori.net/eurochip/material/Report/EUROCHIP-2_Final_report/Annex_16_EUROCHIP-UK.pdf) estimated how long it would take to collect data from new sources. Recruitment of new staff and training them, procurement of new hardware and obtaining permission from data owners have to be taken into consideration and will be different for each country, each source and each data. This will influence the time needed to collect data from a new source. The overall average time was estimated to be around 16 months.

Overall, 16% of the PBCRs were not able to provide any indicator and only 15% were able to provide all three indicators with the available variables collected. To ensure comparability, we used strict rules for the definition of the different indicators. We realized that PBCRs could collect parts of the indicators and therefore produce output for their country even if we considered that they did not. However, one important aim of a PBCR is comparability within EU and this requests uniform data definitions.

This study evaluated whether indicators were available according to the declarations of the various PBCRs; however, completeness and quality of the indicators were not yet checked. Past experiences on quantitative collection of these indicators, by the EUROCARE high-resolution studies, underlined that in many general PBCRs these data are collectable with *ad hoc* studies on cancer patient samples.^{6–15} The EUROCHIP-2 pilot studies underlined that the indicator “stage at diagnosis” for breast and colorectal cancers in 2003–2005 were

available in six (out of 11) countries and collectable (but not available) in other three countries, whereas the indicators “compliance with cancer guidelines” for breast cancer were available in five countries and collectable in the other six countries and for colorectal cancer were available in the countries and collectable in other five countries (http://www.tumori.net/eurochip/material/Report/EUROCHIP-2_Final_report/Annex_03_EUROCHIP_Pilot_Studies.pdf).

Our survey showed that only a few of the participating PBCRs had data available which could be used for clinical audits, evaluation of cancer care projects, survival and for monitoring national cancer control strategies. General PBCRs are the most important and reliable source for cancer incidence, prevalence and survival data; therefore, nowadays additional relevant indicators for a National Cancer Control Programme should be requested. Given the skills in high-quality registration, knowledge and organization, the PBCR should be used more efficiently to realize a systematic output of cancer care indicators. These give actual and reliable information on the cancer care situation of the country, compared to the past and to other EU countries and should form the most truthful basis for clinicians, patients, policy makers and politicians. Moreover, differences in survival between countries could be better interpreted having information on the three indicators. Detailed information could pinpoint the underlying problem and give clues for targeted cancer care improvement projects. PBCRs should be stimulated to collect and use data inclusive the three indicators, because of the relevance for optimizing cancer care.

To conclude, population-based cancer registries are a reliable resource to describe the cancer burden, evaluate early detection and screening programs, evaluate guidelines, treatment delay and cancer care. They have an important role in improving the quality of cancer care and should be used as a resource for strategic planning and monitoring cancer control

plans. They require access and resources to collect the relevant variables to enable them to fulfill these roles. Moreover, as the survey addresses issues and indicators that are epidemiologically and clinically relevant not only in Europe, but also worldwide, the results are also important to be picked up by new registries being established worldwide, especially in Low- and Middle-Income countries.

We suggested the following recommendations to promote the collection of variables for the three indicators in cancer registries:

1. To further study the registries in reporting collection of these variables, to determine their practice and to encourage other registries to follow the best practices and help PBCR to overcome obstacles in doing so.
2. To make “stage at diagnosis” a “mandatory” item for screened cancers in the Cancer Registry regions where screening activities are ongoing to provide data to evaluate the effect of the screening programs. There should be no organized cancer screening program without a PBCR.
3. To demonstrate, for those who influence population-based cancer registries (*i.e.*, directors, policy makers, politicians and funders), the benefits of collecting data items generating cancer care indicators for national cancer control strategies, development and evaluation, cancer care programs, and so on.
4. To enhance collection of data items according to the ENCR rules and definitions to make comparisons over years between EU countries useful and relevant.

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List of participating general population-based cancer registries:

Austria: Dr. Richard Greil (Tumorregister des Landes Salzburg); **Belgium:** Prof. Joost Weyler (Antwerp Cancer Registry); Dr. Elizabeth Van Eycken

(Stichting Kankerregister); **Bosnia-Herzegovina:** Dr. Z. Gavric (Cancer Registry of Republic of Srpska); **Bulgaria:** Dr. Nadya Dimitrova (Bulgarian National Cancer Registry); **Croatia:** Dr. Ariana Znaor (HRVATSKI ZAVOD ZA JAVNO ZDRAVSTVO); **Cyprus:** Dr. Pavlos Pavlou (Cyprus Cancer Registry); **Denmark:** Jakob Lyng Sandegaard (Danish Cancer Registry); **Estonia:** Dr. Margit Mägi (Estonian Cancer Registry); **Finland:** Prof. Timo Hakulinen (Suomen Syöpärekisteri); **France:** Dr. Pascale Grosclaude (Registre des Cancers du Tarn); Dr. Marc Colonna (Registre des Cancers de l’Isère); Prof. Michel Velten (Registre Bas-Rhinois des Cancers); Dr. Brigitte Tretarre (Registre des Tumeurs de l’Hérault); Dr. Nathalie Leone (Registre général des Cancers en région Limousin); Dr. Anne-Valérie Guizard (Registre général des Tumeurs du Calvados); Dr. Anne-Sophie Woronoff (Registre des Tumeurs du Doubs); Roger Salamon (Registre général des Cancers de la Gironde); Dr. Francoise Weingertner (Registre général des Cancers du Nord); **Germany:** Dr. Martin Meyer (Bevölkerungsbezogenes Krebsregister Bayern); Prof. J. Engel (Tumorregister München); Prof. Blettner (Krebsregister Rheinland-Pfalz); Dr. Emrich (Krebsregister Rheinland-Pfalz); Dr. Zeifig (Krebsregister Rheinland-Pfalz); Dr. Stefan Hentschel (Hamburgisches Krebsregister); Prof. Alexander Katalinic (Registerstelle des Krebsregisters Schleswig-Holstein); Dr. Sabine Luttmann (Bremen Krebsregister); Mrs Christa Stegmaier (Epidemiologisches Krebsregister Saarland); Dr. Roland Stabenow (Gemeinsames Krebsregister der neuen Bundesländer und Berlin); **Gibraltar:** Dr. Vijay Kumar (Gibraltar Cancer Registry); **Greece:** Prof. Georgios Saroglou (Greek Cancer Registry); **Iceland:** Prof. Laufey Tryggvadóttir (Krabbameinsskrá Íslands); **Ireland:** Dr. Harry Comber (National Cancer Registry Ireland); **Italy:** Dr. Susanna Vitarelli (Registro Tumori della Provincia di Macerata); Dr. Stefano Ferretti (Registro Tumori della provincia di Ferrara); Dr. Roberto Zanetti (Registro Tumori Piemonte Città di Torino); Prof. Marina Vercelli (Registro Tumori Regione Liguria); Dr. Rosario Tumino (Registro Tumori della Provincia di Ragusa); Dr. Paola Zambon (Registro Tumori del Veneto); Maria Lia Contrino (Registro Tumori della Provincia di Siracusa); Dr. Roberto Tessandori (Registro Tumori della Provincia di Sondrio); Dr. Luigi Bisanti (Registro dei Tumori di Milano); Dr. Diego Serraino (North East Italy Cancer Surveillance Network (NEICSN)); Dr. Emanuele Crocetti (Registro Tumori della Regione Toscana (RTRT)); Prof. Massimo Federico (Registro Tumori della provincia di Modena); MD Fabio Falcini (Registro Tumori della Romagna); Prof. Francesco Donato (Registro Tumori della Provincia di Brescia); Dr. Adriano Giacomini (Registro Tumori del Piemonte, Provincia di Biella); Dr. Silvano Piffer (North East of Italy Cancer Surveillance Network—Trento); **Lithuania:** Dr. Giedre Smalyte (Lithuanian Cancer Registry); **Malta:** Dr. Rita Micallef (Malta National Cancer Registry); **Netherlands:** M. Vos (Nederlandse Kankerregistratie); **Norway:** Dr. Frøydis Langmark (Kreftregisteret); **Poland:** Dr. Beata Koscińska (Lublin Regional Cancer Registry); Dr. Maria Zwierko (Warsaw Cancer Registry); Dr. Dariusz Tracz (Rzeszow Regional Cancer Registry); Dr. Stanislaw Gozdz (Kielce Regional Cancer Registry); Mr. Jerzy Blaszczyk (Lower Silesian Cancer Registry); Dr. Agnieszka Dyzmann-Sroka (Greater Poland Cancer Registry); **Portugal:** Dr. Laranja Pontes (Portugal North Region Cancer Registry); Gonçalo Forjaz de Lacerda (Registro Oncologico Regional dos Azores); **Romania:** Dr. Camelia Nicoleta Claiici (Timisoara Regional Cancer Registry); Dr. Daniela Coza (Cluj Regional Cancer Registry); **Russia:** Prof. V.M. Merabishvili (St. Petersburg Population-Based Cancer Registry); **Serbia:** Dr. Dragan Miljus (Central Serbia Cancer Registry); **Slovakia:** Dr. Chakameh Safaei Diba (Slovakia National Cancer Registry); Dr. Maja Primic Zakelj (Slovenia Cancer Registry); **Spain:** Dr. José M^a Díaz García (Registro de Cáncer de Cuenca); Dr. Josep Maria Borrás (Girona Cancer Registry); Dr. Isabel Izarzugaza (Basque Country Cancer Registry); Dr. Maria Jose Sanchez-Perez (Granada Cancer Registry); Dr. Dolores Rojas Martín (Canary Islands Cancer Registry); Dr. Jaume Galceran (Tarragona Cancer Registry); Dr. Maria Ramos (Balearic Islands Cancer Registry); Dr. E. Ardanaz (Navarra Cancer Registry and CIBERESP); Dr. Enrique Almar Marqués (Albacete Cancer Registry); Dr. Laudina Rodríguez Suárez (Registro de Tumores del Principado de Asturias); **Switzerland:** Dr. Bertrand Camey (Registre Fribourgeois des Tumeurs); Prof. Fabio Levi (Registre neuchâtelois des tumeurs); Dr. Silvia

Dehler (Krebsregister des Kantons Zürich); Dr. Andrea Bordoni (Registro Tumori del Canton Ticino); Prof. F. Levi (Registre Vaudois des Tumeurs); **Turkey:** Hülya Karakiliç (Antalya Cancer Registry); Okan Karaoglanoglu (Samsun Kanser Kayit Merkezi); **UK England:** Prof. John Wilkinson (Northern & Yorkshire Cancer Registry and Intelligence Service); Mr. David Meechan (Trent Cancer Registry); **UK Northern Ireland:** Dr. Anna T. Gavin (Northern Ireland Cancer Registry); **UK Scotland:** Dr. David Brewster (Cancer Registry of Scotland in Edinburgh).

References

- Verdecchia A, Francisci S, Brenner H, et al.; EUROCARE-4 Working Group. Recent cancer survival in Europe: a 2000–02 period analysis of EUROCARE-4 data. *Lancet Oncol* 2007;8:784–96.
- Sant M, Allemani C, Santaquilani M, et al.; the EUROCARE Working Group. EUROCARE-4. Survival of cancer patients diagnosed in 1995–1999. Results and commentary. *Eur J Cancer* 2009;45:931–91.
- Brenner H, Francisci S, Angelis RD, et al.; the EUROCARE-4 Working Group. Long-term survival expectations of cancer patients in Europe in 2000–2002. *Eur J Cancer* 2009;45:1028–41.
- Verdecchia A, Guzzinati S, Francisci S, et al.; The EUROCARE Working Group. Survival trends in European cancer patients diagnosed from 1988 to 1999. *Eur J Cancer* 2009;45:1042–66.
- Micheli A, Capocaccia R, Martinez C, et al. Cancer control in Europe: a proposed set of European cancer health indicators. *Eur J Public Health* 2003;13:116–8.
- Sant M; The EUROCARE Working Group. Differences in stage and therapy for breast cancer across Europe. *Int J Cancer* 2001;93:894–90.
- Sant M, Allemani C, Capocaccia R, et al.; the EUROCARE Working Group. Stage at diagnosis is a key explanation of differences in breast cancer survival across Europe. *Int J Cancer* 2003;106:416–22.
- Sant M, Allemani C, Berrino F, et al.; The EUROCARE Working Group. Breast carcinoma survival in Europe and the United States: a population-based study. *Cancer* 2004;100:715–22.
- Allemani C, Sant M, Berrino F, et al. Prognostic value of morphology and hormone receptor status in breast cancer—a population-based study. *Br J Cancer* 2004;91:1263–8.
- Gatta G, Capocaccia R, Sant M, et al. Understanding variation in survival for colorectal cancer in Europe: a EUROCARE high resolution study. *Gut* 2000;47:533–8.
- Ciccolallo L, Capocaccia R, Coleman MP, et al. Survival differences between European and US patients with colorectal cancer: role of stage at diagnosis and surgery. *Gut* 2005;54:268–73.
- Sant M, Aareleid T, Artioli ME, et al. Ten-year survival and risk of relapse for testicular cancer: a EUROCARE high resolution study. *Eur J Cancer* 2007;43:585–92.
- Gatta G, Zigon G, Buemi A, et al. Prostate cancer treatment in Europe at the end of 1990s. *Acta Oncol* 2009;48:867–73.
- Allemani C, Storm H, Voogd A, et al. Variation in “standard care” for breast cancer across Europe: a EUROCARE-3 high resolution study. *Eur J Cancer* 2010;46:1528–36.
- Gatta G, Zigon G, Aareleid T, et al. Patterns of care for European colorectal cancer patients diagnosed 1996–1998: a EUROCARE High Resolution Study. *Acta Oncol* 2010;49:776–83.