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## GLOSSARY

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CR	Cancer Registry
EOD	Extent of Disease
ENCR	European Network of Cancer Registries ( <a href="http://www.encl.com.fr/">http://www.encl.com.fr/</a> )
EUROCARE	EUROpean CAnCER REgistry-based study on survival and CARE of cancer patients ( <a href="http://www.eurocare.it/Home/tabid/36/Default.aspx">http://www.eurocare.it/Home/tabid/36/Default.aspx</a> )
EUROCHIP	European Cancer Health Indicators Project ( <a href="http://www.tumori.net/eurochip/">http://www.tumori.net/eurochip/</a> )
EUROCOURSE	EUROpe against Cancer: Optimisation of the Use of Registries for Scientific Excellence in research ( <a href="http://www.eurocourse.org/">http://www.eurocourse.org/</a> )
IACR	International Association of Cancer Registries ( <a href="http://www.iacr.com.fr/">http://www.iacr.com.fr/</a> )
ICDO	International Classification of Diseases for Oncology
NHE	National Health Expenditure
SEER	Surveillance Epidemiology and End Results ( <a href="http://seer.cancer.gov/">http://seer.cancer.gov/</a> )
TNM	Classification of Malignant Tumours (Tumour, Lymph nodes, Metastasis)
UKACR	United Kingdom Association of Cancer Registration ( <a href="http://www.ukacr.org/">http://www.ukacr.org/</a> )

## TABLE OF CONTENTS

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1: INTRODUCTION .....	5
Objectives and Cancer Indicators .....	6
2: METHODOLOGY .....	7
2.1: Design and data retrieval.....	7
2.2: Data analysis.....	8
3: RESULTS .....	10
3.1: Registry details.....	10
3.2: Indicators.....	14
Stage at diagnosis .....	14
Cancer treatment delay.....	18
Compliance with cancer guidelines.....	22
Indicators and registry output.....	28
4: DISCUSSION.....	33
5: RECOMMENDATIONS.....	35
ANNEX TABLES.....	36
Annex 1: OVERVIEW OF CANCER REGISTRATION PRACTICES ENCR Questionnaire.....	36
Annex 2: Invitation letter.....	57
Annex 3: Participating Cancer Registries.....	59

## 1: INTRODUCTION

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Since the fifties cancer registries have provided population-based, comparative survival statistics for cancer patients. EURO CARE (a co-operative, cancer registry-based project) has collected and analysed survival data on patients diagnosed since 1978. Its reports underlined large differences in cancer survival across Europe. The most recent evaluation on cancer survival among patients diagnosed in 2000-2002 (EURO CARE-4 study) showed highest survival rates in the northern European countries and lowest for those in the eastern European countries. Patients in Eastern Europe had the highest improvement in survival for major cancer sites during 1991-2002<sup>1</sup>.

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

The EUROCHIP-1 project started by identifying a network of cancer scientists and professionals working in the European Member and Candidate States. EUROCHIP-1 proposed a list of well defined health indicators to achieve information about the burden, risk factors, management and outcome of cancer, in order to compare and facilitate cancer control across Europe. Among them, three indicators were identified as closely associated with the observed wide inter-country variation in cancer survival: These were “stage at diagnosis”, “cancer treatment delay” and “compliance with cancer guidelines”.

In Eurochip 2 the international group of experts engaged by EUROCHIP-1 liaised with networks, international agencies, institutions, ministries of health and medical associations promoting actions through analyzing data and disseminating results. In addition EUROCHIP-2 promoted quantitative pilot studies in 11 countries to study the feasibility of collecting the three key indicators identified by Eurochip 1. In most of the countries where pilot studies have been performed, collection was possible but high costs were an issue.

The ongoing EUROCHIP-3 considers the most important indicators to identify inequalities in cancer risk, care and survival. Series of specific actions to address such indicators will be developed, to establish the pillars of an EU-wide cancer control strategy.

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<sup>1</sup> Verdecchia A, Francisci S, Brenner H, et al. Recent cancer survival in Europe: a 2000-02 period analysis of EURO CARE-4 data. *Lancet Oncol* 2007; 8: 784-96

### *Objectives and Cancer Indicators*

Comprehensive Cancer Centre the Netherlands: location Groningen/Enschede, is leader of work package 5 (WP5) of the EUROCHIP-3 project. This WP aims to improve population-based registration of cancer indicators, in particular:

#### *“Stage at diagnosis”:*

Early diagnosis is an important indicator for having a possibility for longer survival from cancer if appropriate treatment is available. For the indicator “stage at diagnosis” we asked whether stage was routinely collected, which classifications were used and whether staging was registered for all cancers or a group of cancers. However, for comparison between registries, and as a measure of validity, only the “most valid basis of diagnosis” is required. Therefore we asked whether CRs registered basis of diagnosis according the ENCR rules. CRs who routinely collected the variable stage (clinical and/or pathological) for at least one tumour site and registered basis of diagnosis according the ENCR rules were considered to be able to provide data for the indicator “stage at diagnosis” . (Questions 10.1, 10.2.1, 10.2.3 Annex 1)

#### *“Cancer treatment delay”:*

The indicator “cancer treatment delay” can be calculated as the time between the date of incidence and the date of first treatment<sup>2</sup>. It is necessary to be informed on the definition of date of incidence (e.g. according to “ENCR rules”). Besides it is interesting to know how many CRs routinely collected pre-diagnostic dates. CRs who routinely registered date of incidence according the ENCR rules and collected the first treatment date for at least one tumour site were considered to be able to provide data for the indicator “cancer treatment delay” . (Questions 8.1, 8.3, 11.2 and 11.3 Annex 1)

#### *“Compliance with cancer guidelines”:*

The availability of the most important variables necessary to define the indicator “compliance with cancer guidelines” was evaluated. Type of surgery, post/preoperative radiotherapy and/or chemotherapy depending on stage can be assessed when stage, type of surgery, date of surgery, starting date of radiotherapy and starting date of chemotherapy were routinely collected for at least one tumour site. Furthermore, cancer guidelines for diagnosis and treatment should be available for at least one tumour site. (Question 10.2.2, 10.2.3, 11.2, 11.3 and 13.1.2 Annex 1)

To promote the collection of these indicators it is necessary to get insight in the present situation in all European cancer registries. WP 5 addressed the following questions:

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

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<sup>2</sup> <http://www.tumori.net/eurochip/indicators.php>

## 2: METHODOLOGY

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### 2.1: *Design and data retrieval*

To answer the questions above a qualitative questionnaire was sent to all European cancer registries (N=206). The questionnaire was developed by members of WP5 and was based on the results of the pilot studies (on the above mentioned indicators) performed by the EUROCHIP-2 project and the ENCR-Cancer Incidence in Five Continents (CI5) questionnaire. However, the current study is not focused on a random sample of cancer patients, but concentrates on a description of the European cancer registries and the available variables for the three indicators. To prevent duplication of effort and to be more efficient, the content of the questionnaire has been discussed with other parties intending to send also a questionnaire to the European CRs, like the ENCR and EURO COURSE. They added additional questions for their projects.

The final questionnaire "*OVERVIEW OF CANCER REGISTRATION PRACTICES ENCR Questionnaire*" 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, tumour variables, treatment variables, follow-up variables, guidelines, registry output and finally permission for sharing data.

For the purpose of WP5 we used the data necessary to identify whether the CRs collected variables for the three indicators "stage at diagnosis", "delay of cancer treatment" and "compliance with guidelines", the reasons why they did not collect data for these indicators and if the data were collected how the data were used.

The complete questionnaire is included in Annex 1.

The invitation to participate and complete the questionnaire was sent by email to all CRs through the ENCR. The email contained the invitational letter including the webpage and personal code for the CR (Annex 2). The questionnaire was filled out through the web based "gateway", which had been newly developed at the IARC. This gateway is a protected environment, each CR received their personal code. The questionnaire was completed by registry staff from existing knowledge of current practice. This could have been only one person (a registry manager or director or someone equivalent) or a number of staff with different areas of expertise. To reduce the workload for the CR some questions already asked for in other projects (ENCR CI5 questions) were filled out by default. A reminder was sent to the CR four weeks after the first invitation.

## 2.2: Data analysis

All European cancer registries were invited to participate in the EUROCHIP-3 project. For the analysis of the results we stratified the CRs in two main groups and four subgroups:

- Population based cancer registries:
  - National cancer registries collecting variables for all cancer patients
  - Regional cancer registries collecting variables for all cancer patients
- Specialised cancer registries:
  - Population based paediatric cancer registries
  - Tumour specific cancer registries collecting variables for all ages

To determine possible factors which could influence the collection of indicators, questions about budget, sources for data collection, screening activities, starting year of CR and starting year for the collection of different variables per indicator were requested.

### *Budget:*

The available budget (€) for cancer registration was calculated by the available budget for data collection plus the available budget for data processing, divided by the number of cancer cases in the CR 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 (NHE/capita).

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

per cancer case

Subsequently we categorised this percentage in four groups: <1%, 1-3% and >3% of the NHE/capita per cancer case or unknown.

### *Data Sources:*

The availability of the variables for the indicators depends on access to different information sources. We assessed the total number of different sources of information available for cancer registration and whether they were systematically used or occasionally used. The total number of different sources and the systematically sources used for cancer registration per CR was used to identify whether there are differences in the number of available data sources between CRs. Furthermore we assessed the relation between proportion of electronic data sources and the proportion passive supplied data sources (data is received without any requests by the registry) with available registration budget and the number of collected indicators.

### *Screening activities:*

The availability of screening activities influences the stage at diagnosis, therefore we identified whether population based screening activities were ongoing in the CR region.



*Starting year:*

The year of establishing the CR and the year when different variables were first collected are important to identify how long it takes for a CR to extend their data set so that they are able to provide variables for 1 or more indicators and whether comparison of indicator outcomes is possible between CRs and countries.

For each registry type we described the availability of the necessary variables for each indicator. Afterwards we were able to describe how many CRs collected all the necessary variables for the three indicators. For the CRs not collecting these variables we described the factors who might influence the collection of these indicators and the indicated reasons from the CRs why they did not collect these variables and whether they have the intention to collect these variables in future. Possible reasons for not collecting were classified as: a lack of interest, finance, qualified staff, or access to data sources

Finally we described the contribution of CRs to the description of cancer burden or evaluation of cancer control and whether the contribution was associated with the number of available indicators.

### 3: RESULTS

#### 3.1: Registry details

This section gives an overview of the participating CRs. In total 206 CRs in 41 different countries were invited to participate. Questionnaires were completed by 103 CRs (50%) from 35 different countries (Annex 4). The population covered (by population based CRs) was about 221,000,000, corresponding to 28% of the population covered by the countries where CRs were invited to participate. For several European countries cancer registration does not cover the national population. Moreover, not all regional registrations responded on the questionnaire. Results for these countries may not therefore represent the situation in the country as a whole (Figure 1). Nevertheless, these results reflect the situation for CRs between countries and within a country.

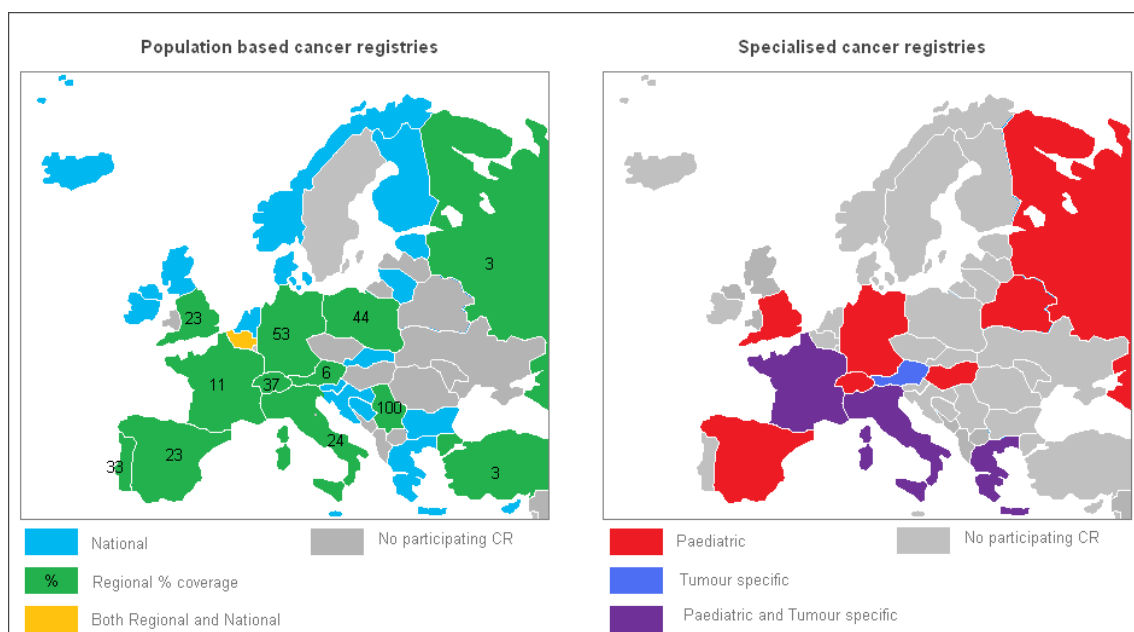


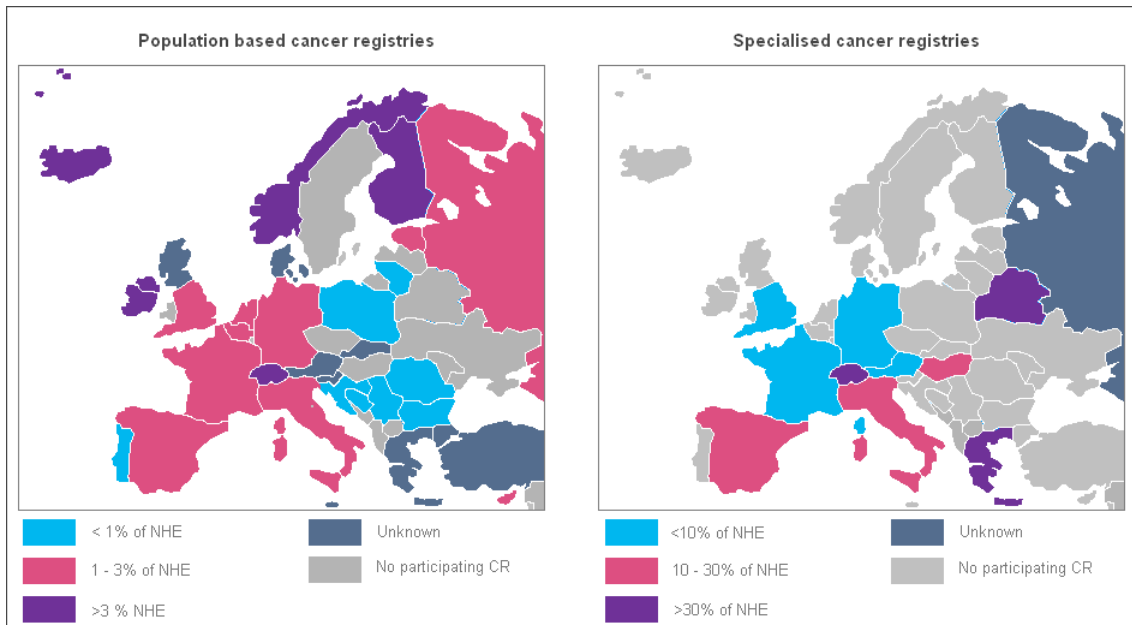
Figure 1: Participating cancer registries

Table 1 shows the CR details. In total 21 national and 65 regional population based registries responded on the questionnaire. Seventeen registries collected data on paediatric or for specific tumour sites. Expressed as percentage of the National Expenditure on Health per capita (NEH/capita), the available registration budget for specialised CRs is higher than the available registration budget for population based CRs (76% of the specialised CRs can spend per cancer case more than 3% of the NEH/capita and 14% of the population based CRs can spend more than 3% of the NEH/capita). Unfortunately not all cancer registries indicated the available budget (overall 41% unknown). Figure 2 shows the differences in available registration budget between countries. Northern European countries have a higher available budget for cancer registration than countries from the eastern part of Europe.

Population based CRs used on average 11 different sources for data collection of which 8 were systematically used, specialised CRs used on average 9 different data sources of which 5 were systematically used.. Sources from pathology laboratories and hospital (oncology) records are frequently used. Specialised CRs seem to have limited access to radio therapeutic institutions or radio therapeutic departments and haematology laboratories. Overall 30% of the sources were electronically, another 30% were on paper, but most sources (40%) were mixed available (electronically and on paper). No relation was found between the use of electronic data sources and lower costs for data registration. However we found a relation between the proportion passive supplied data sources (data is received without any requests by the registry) and a lower available registration budget.

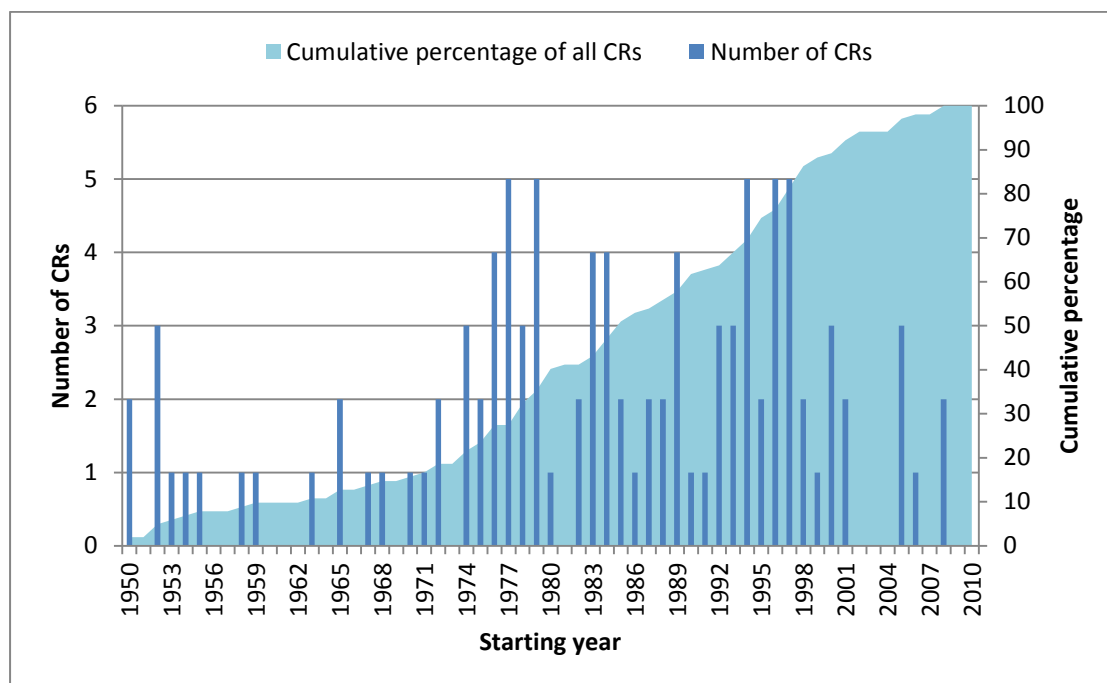
**Table 1 : Cancer registry details**

	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
	N	N	N	N	N	N
Total	21	65	86	10	7	17
% of NHE per capita available for cancer registration per cancer case	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
<1%	3 (14)	16 (25)	19 (22)	0	1 (14)	1 (6)
1-3%	7 (33)	17 (26)	24 (28)	1 (10)	0	1 (6)
>3%	1 (5)	4 (6)	5 (6)	7 (70)	4 (57)	11 (65)
Unknown	10 (48)	28 (43)	38 (44)	2 (20)	2 (29)	4 (24)
	<b>Mean (SD) range</b>	<b>Mean (SD) range</b>	<b>Mean (SD) range</b>	<b>Mean (SD) range</b>	<b>Mean (SD) range</b>	<b>Mean (SD) range</b>
Number of different sources used for data collection (systematic / occasional)	11(3.5) 3 - 21	11(3.3) 4-21	11(3.3) 3-21	9(7) 0-21	9(5.3) 0-15	9(6.2) 0-21
Number of different systematically sources used for data collection	8 (3.7) 0-14	8 (3.8) 0-20	8 (3.7) 0-20	5 (5.1) 0-16	5 (4.6) 0-11	5 (4.8) 0-16
Most common sources used	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Pathology Laboratories	21 (100)	65 (100)	86 (100)	6 (60)	6 (86)	12 (71)
Hospital oncology records	18 (86)	62 (95)	80 (93)	8 (80)	6 (86)	14 (82)
Other hospital records	19 (90)	64 (98)	83 (97)	6 (60)	5 (71)	11 (65)
Radiotherapy departments	17 (81)	54 (83)	71 (83)	4 (40)	4 (57)	8 (47)
Haematology laboratories	18 (86)	51 (78)	69 (80)	6 (60)	2 (29)	8 (47)
Death certificates	15 (71)	52 (80)	67 (78)	6 (60)	4 (57)	10 (59)
Starting year registry	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
<1990	14 (67)	36 (55)	50 (58)	6 (60)	3 (43)	9 (53)
1990-2000	5 (23)	21 (32)	26 (30)	3 (30)	2 (29)	5 (29)
2001-2010	2 (10)	7 (11)	9 (10)	1 (10)	2 (29)	3 (18)
Unknown	0	1 (1)	1 (1)	0	0	0



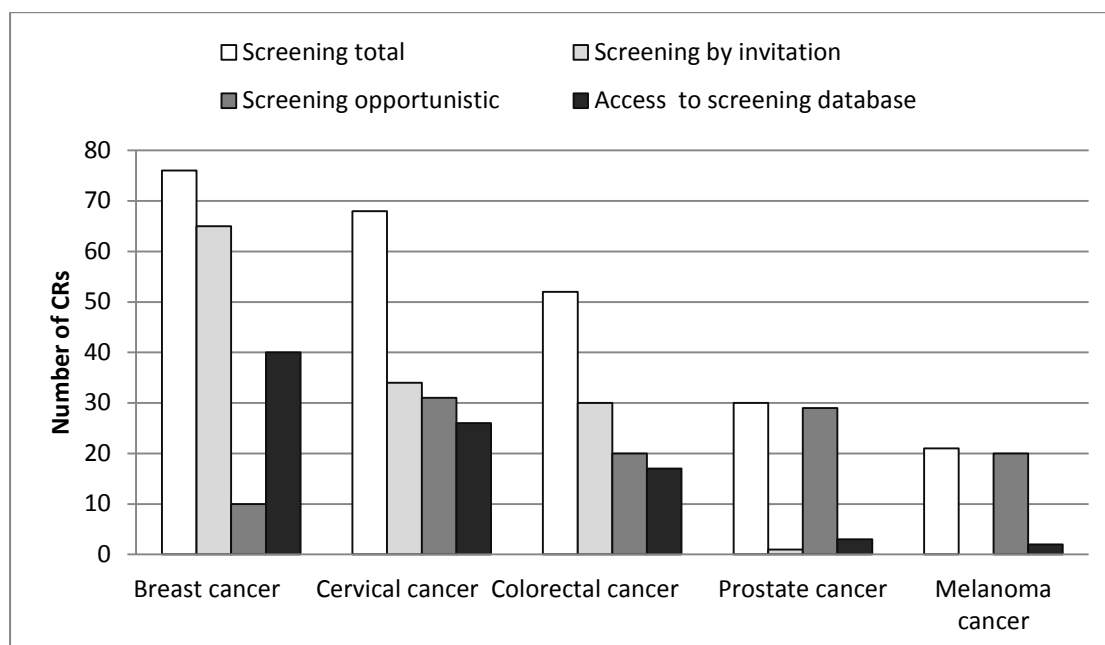
**Figure 2:** Available relative budget for CRs expressed as percentage of the NHE per capita per cancer case.

Figure 3 shows the starting year for all CRs (both population based and specialised). The first CR started in 1950 and the last CR started in 2008. Most CRs started between 1975 and 2000.



**Figure 3:** Number of CRs starting over time and the cumulative percentage of the CRs over time.

Figure 4 shows the screening activities ongoing in the population based CR regions. Breast cancer, cervical cancer and colorectal cancer screening were most common, respectively in 76 CRs, 68 CRs and 52 CRs. In most CRs breast cancer screening was organised by systematic invitation. For the cervical and colorectal screening half of the CRs indicated that screening occurred in the population covered by systematic invitation. Few CRs had access to the screening database. Early detection of prostate and melanoma occurred almost always opportunistic.



**Figure 4:** Screening activities for areas covered by population based CRs (N=86)

**Conclusion:** Cancer registries from 35 different countries responded to the questionnaire, with a population coverage of 28%. Most CRs started between the year 1975 and 2000. The available budget for cancer registration was highest among the specialised CRs. Population based CRs used more different data sources than specialised CRs. CRs with a higher proportion of passive supplied data sources had a lower budget for cancer registration. Sources from pathology laboratories and hospital (oncology) records were most commonly used. Breast cancer, cervical cancer and colorectal cancer screening were most common, although less than half of the CRs had access to the screening database.

### 3.2: Indicators

#### *Stage at diagnosis*

Population based cancer registries:

Table 2 shows the variables necessary to define the indicator “stage at diagnosis”. Basis of diagnosis was routinely collected according the ENCR rules by 92% of the population based CRs. The other CRs slightly adapted the ENCR rules, used ICDO-2 or ICDO-3, used the UKACR rules or used international standards. Most CRs routinely collected stage, 44% of the population based CRs collected stage for all tumour sites and 45% for a selection of tumour sites. TNM classification with or without tumour specific classification was most frequently used by population based CRs, respectively 39% and 42%. Both clinical and pathological or only pathological stage was most often collected, respectively 56% and 23% in population based CRs. The indicator “stage at diagnosis”; can be routinely collected by a majority of the population based CRs (81%). Figure 5 shows the availability of the indicator “stage at diagnosis” in European countries.

Table 3 shows the different factors which might influence the availability of variables for the indicator “stage at diagnosis”. In general no differences in available budget were found between the CRs routinely collecting stage at diagnosis and those who do not. The population based CRs collecting stage at diagnosis had access to more different information sources than CRs who did not collect stage at diagnosis. Interestingly 14 population based regional registries covered areas with screening activities, however, did not collect stage. The majority of the population based CRs started stage collection after 1990 (Figure 6) and started stage collection by the establishing of the CR or after a period of 10 years since establishment.

Table 4 shows the reasons reported by CRs for not collecting stage A lack of qualified staff and access to data sources were the most mentioned reasons for not collecting stage for the population based CRs, the other main reason was a lack of finance. However 4 of the 9 population based CRs did not have the intention to collect stage in the future.

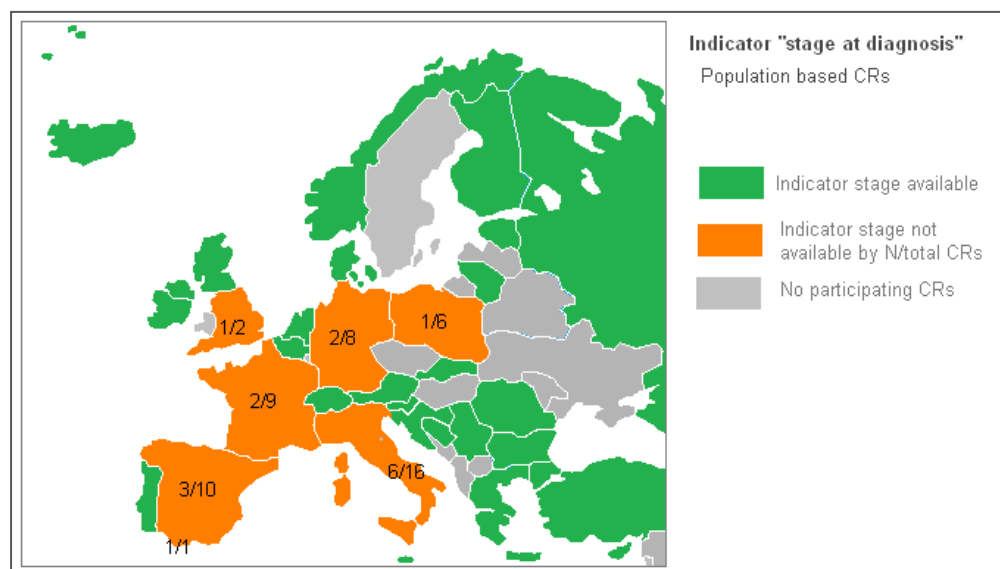
Specialised cancer registries:

Only 2 specialised CRs did not collect the basis of diagnosis according the ENCR rules (Table 3). Specialised CRs often collected only clinical stage 47%. The indicator stage at diagnosis was reported as routinely collectable by a majority of the CRs (76%). Specialised CRs who did not collect the variables for the indicator “stage at diagnosis” reported to have limited access to data sources (Table 4). However none of the CRs who did not collect stage had the intention to collect stage in the future (Table 5).

**Conclusion:** A majority of the population based and specialised CRs collected all the variables necessary to define the indicator “stage at diagnosis”. CRs which did not collect all the variables had access to fewer information sources than CRs who did collect stage. Interestingly 14 population based CRs covered areas with screening activities, however, did not collect stage. This makes evaluation of screening activities by CRs impossible. Another important issue is that 4 of the 9 population based CRs which did not collect stage indicated to have no intention to collect stage in the future. Particularly regional population based CRs indicated that the most important reason for not collecting stage was a lack of access to data sources.

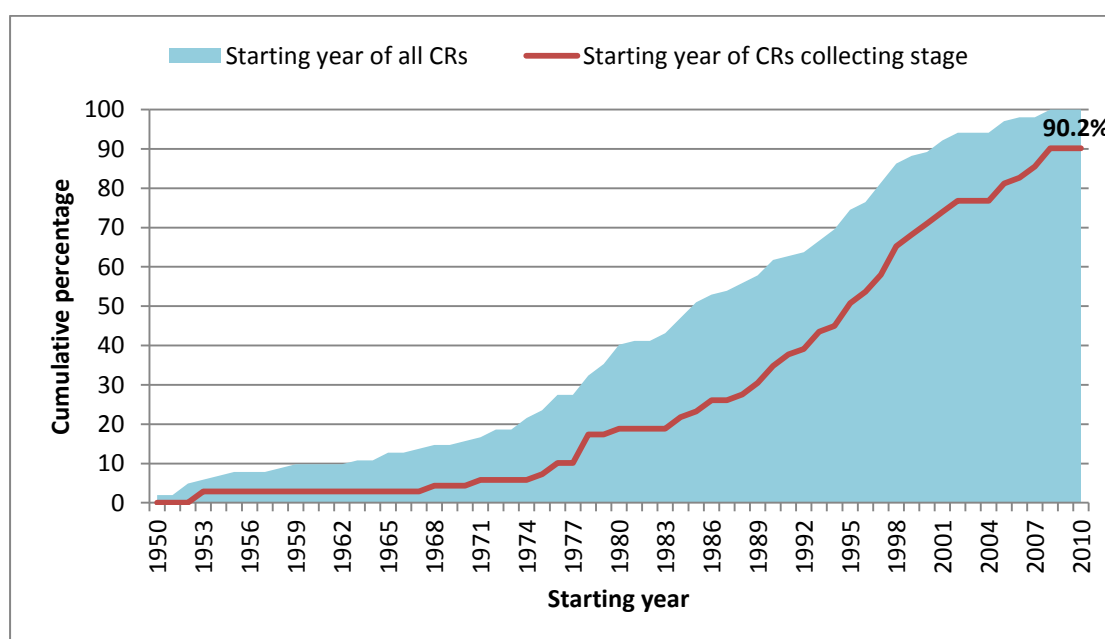
**Table 2:** Indicator “Stage at diagnosis”

	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
	N	N	N	N	N	N
<b>Total</b>	21	65	86	10	7	17
<b>Basis of diagnosis according ENCR</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Yes	21 (100)	58 (89)	79 (92)	9 (90)	6 (86)	15 (88)
Modified / Other rules	0	5 (8)	5 (6)	1 (10)	0	1 (6)
No	0	1 (2)	1 (1)	0	1 (14)	1 (6)
Unknown	0	1 (2)	1 (1)	0	0	0
<b>Stage</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
No	1 (5)	8 (12)	9 (10)	1 (10)	1 (14)	2 (12)
Yes for all tumour types	13 (62)	25 (38)	38 (44)	7 (70)	0	7 (41)
Yes for at least 1 tumour type	7 (33)	32 (50)	39 (45)	2 (20)	6 (86)	8 (47)
<i>If Yes</i>						
<b>Classification system used</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
TNM	6 (30)	24 (42)	30 (39)	4 (44)	3 (50)	7 (47)
SEER	1 (5)	3 (5)	4 (5)	0	0	0
Tumour specific	0	1 (2)	1 (1)	2 (22)	1 (17)	3 (20)
TNM + Tumour specific	9 (45)	23 (40)	32 (42)	2 (22)	0	2 (13)
SEER + Tumour specific	1 (5)	0	1 (1)	0	0	0
EOD	1 (5)	0	1 (1)	0	0	0
Unknown	2 (10)	6 (11)	8 (10)	1 (11)	2 (33)	3 (20)
<b>Stage items collected</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Both, clinical and pathological	15 (75)	28 (49)	43 (56)	3 (33)	2 (33)	5 (33)
Clinical stage	1 (5)	5 (9)	6 (8)	6 (67)	1 (17)	7 (47)
Pathological stage	3 (15)	15 (26)	18 (23)	0	1 (17)	1 (7)
Other	1 (5)	0	1 (1)	0	1 (17)	1 (7)
Unknown	0	9 (16)	9 (12)	0	1 (17)	1 (7)
	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
<b>Indicator “stage at diagnosis”</b>	20 (95)	50 (77)	70 (81)	8 (80)	5 (71)	13 (76)

**Figure 5:** Availability of the indicator “stage at diagnosis”

**Table3** :Factors influencing “stage at diagnosis”

	Population based CRs						Specialised CRs					
	National		Regional		Total		Paediatric		Tumour specific		Total	
Collecting “stage at diagnosis”	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes
Total	1	20	15	50	16	70	2	8	2	5	4	13
% of NHE per capita available for cancer registration per cancer case	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
<1%	0	3(15)	3(20)	13(26)	3(19)	16(23)	0	0	1(50)	0	1(25)	0
1-3%	0	7(35)	4(27)	13(26)	4(25)	20(29)	0	1(13)	0	0	0	1(8)
>3%	0	1(5)	0	4(8)	0	5(7)	2(100)	5(63)	0	4(80)	2(50)	9(69)
Unknown	1(100)	9(45)	8(53)	20(40)	9(56)	29(41)	0	2(25)	1(50)	1(20)	1(25)	3(23)
	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>
Number of different sources used for data collection	2(-)	8(3.5)	6(3.3)	8(3.7)	5(3.3)	8(3.6)	4(3.5)	6(5.5)	2(2.1)	7(4.5)	3(2.6)	6(5.0)
Starting year stage collection	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
<1990	-	4(20)	-	5(10)	-	9(13)	-	5(63)	-	1(20)	-	6(46)
1990-1999	-	6(30)	-	12(24)	-	18(26)	-	1(13)	-	0	-	1(8)
2000-2010	-	7(35)	-	11(22)	-	18(26)	-	1(13)	-	0	-	1(8)
Unknown	-	3(15)	-	22(44)	-	25(36)	-	1(13)	-	4(80)	-	5(38)
Time since starting year CR	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
From the beginning	-	5(25)	-	14(28)	-	19(27)	-	6(75)	-	1(20)	-	7(54)
In recent 10 years	-	3(15)	-	5(10)	-	8(11)	-	0	-	0	-	0
Longer than 10 years	-	9(40)	-	9(18)	-	18(26)	-	1(13)	-	0	-	1(8)
Unknown	-	3(15)	-	22(44)	-	25(36)	-	1(13)	-	4(80)	-	5(38)
Screening activities	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
By invitation	0	15(75)	14(93)	37(74)	14(88)	52(74)	0	2(25)	0	2(40)	0	4(31)



**Figure 6:** The cumulative percentage of CRs over time and the cumulative percentage of CRs collecting stage over time.



**Table 4: Reasons for not collecting the variable stage**

	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
Not collecting the variable stage	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>
Total	1	8	9	1	1	2
Reason for not collecting stage	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Only lack of interest	0	0	0	0	1(100)	1(50)
Only lack of finance	0	0	0	0	0	0
Only lack of staff	0	0	0	0	0	0
Only lack of access	0	3 (38)	3 (33)	0	0	0
All reasons	1(100)	0	1 (11)	0	0	0
Lack of access and staff	0	2 (25)	2 (22)	0	0	0
Lack of finance and staff	0	3 (38)	3 (33)	1(100)	0	1(50)
Intention to collect stage	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
In preparation	0	1 (13)	1(11)	0	0	0
Yes	0	4 (50)	4(44)	0	0	0
No	1 (100)	3 (38)	4(44)	1 (100)	1 (100)	2 (100)

### *Cancer treatment delay*

Population based cancer registries:

Table 5 shows the variables necessary to define the indicator “cancer treatment delay”. The incidence date was routinely collected according the ENCR rules by 92% of the population based CRs. The other CRs used the IACR rules, the UKACR rules, the first date out of three sources (Hospital discharges, death certificates, pathology records), or the date of diagnosis recorded in the clinical record. Besides the date of incidence we asked whether the CRs routinely collected other pre diagnostic dates. Most often “First admission to the hospital” or the “first mention of cancer in a medical record” was registered by population based CRs, respectively 35% and 38%. “First visit to a primary care physician” was registered by only 10% of the population based CRs. First treatment date was collected by less than half of the population based CRs (43%) The variables necessary to calculate the indicator “cancer treatment delay” were routinely collected by 37% of the population based CRs (incidence date). Figure 7 shows the availability of the indicator “cancer treatment delay” in European countries.

Table 6 shows the different factors which might influence the availability of variables for the indicator “cancer treatment delay”. Population based CRs, 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 CRs with a lower budget. The number of available sources did not influence the registration of variables for the indicator “cancer treatment delay” in population based CRs. Most CRs started collecting first treatment date recently, after the year 2000 (Figure 8).

Table 7 shows the reasons why CRs do not collect first treatment date. Limited access to data sources was the most mentioned reason for not collecting date of the first treatment for regional population based CRs.

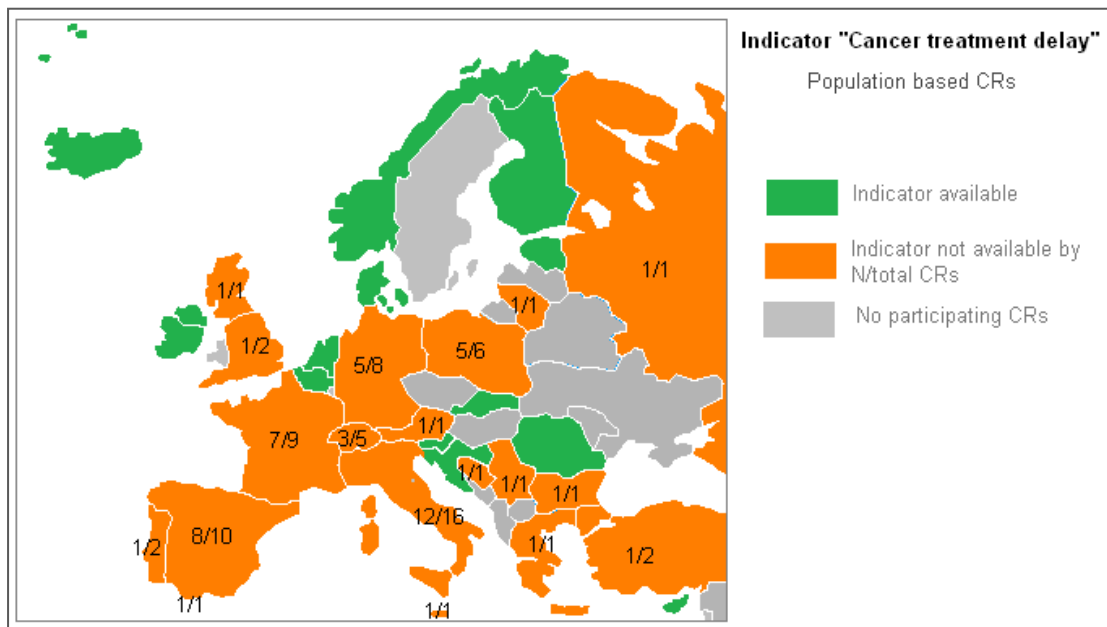
Specialised cancer registries:

Only 2 specialised CRs used other rules for incidence date registration (Table 5). The pre diagnostic date “First admission to hospital” was most frequent collected by specialised CRs (41%), where the “screening date” was least collected (12%). First treatment date was routinely collected by 65% of the specialised CRs. Of the specialised CRs 59% were able to routinely collect the indicator “cancer treatment delay” with the first treatment date. CRs which did not collect all the variables for the indicator had limited access to data sources compared to those who could collect all the variables (Table 6). A lack of qualified staff was the most mentioned reason for specialised CRs (Table 7).

**Conclusion:** The necessary variables to calculate “cancer treatment delay” were collected by 37% of the responding population based CRs. 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 population based CRs who did collect all the necessary data variables and those who did not.

**Table 5:** Indicator “Cancer treatment delay”

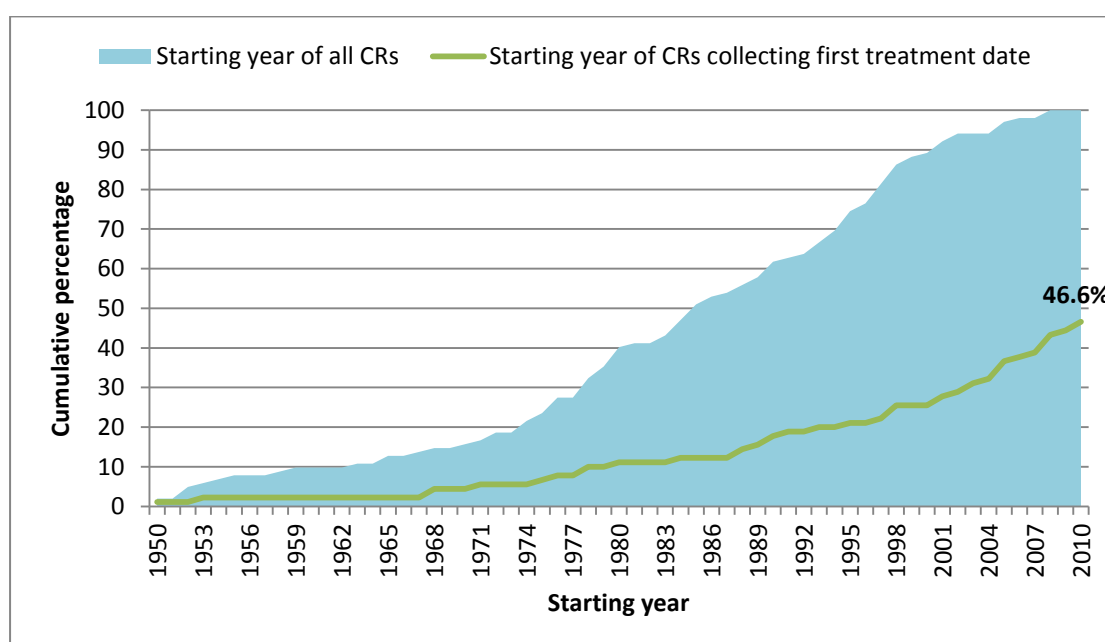
	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
	N	N	N	N	N	N
<b>Total</b>	21	65	86	10	7	17
<b>Incidence date according ENCR</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Yes	19 (90)	60 (92)	79 (92)	8 (20)	7 (100)	15 (88)
No	1 (5)	1 (2)	2 (2)	0	0	0
Other	1 (5)	4 (6)	5 (6)	2 (20)	0	2 (2)
<b>First treatment date</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Yes	15 (71)	22 (34)	37 (43)	6 (60)	5 (71)	11 (65)
<b>Pre diagnostic date</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
First visit to primary care physician	5 (24)	4 (6)	9 (10)	2 (20)	1 (14)	3 (18)
Screening date	5 (24)	13 (20)	18 (21)	1 (10)	1 (14)	2 (12)
First out-patient visit to hospital	5 (24)	9 (14)	14 (16)	3 (30)	1 (14)	4 (24)
First admission to hospital	9 (42)	21 (32)	30 (35)	5 (50)	2 (29)	7 (41)
First mention of cancer in a medical record	7 (33)	26 (40)	33 (38)	2 (20)	1 (14)	3 (18)
<b>Indicator “cancer treatment delay”</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Incidence date - first treatment date	13 (62)	19 (29)	32 (37)	5 (50)	5 (71)	10 (59)



**Figure 7:** Availability of the indicator “cancer treatment delay”

**Table6** : Factors influencing “cancer treatment delay”

	Population based CRs						Specialised CRs					
	National		Regional		Total		Paediatric		Tumour specific		Total	
	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes
Collecting “stage at diagnosis”												
Total	8	13	46	19	54	32	5	5	2	5	7	10
% of NHE per capita available for cancer registration per cancer case	N (%)	N (%)	N(%)	N (%)	N (%)	N (%)	N (%)	N (%)	N(%)	N (%)	N (%)	N (%)
<1%	1(13)	2(15)	11(24)	5(26)	12(22)	7(22)	0	0	0	1(20)	0	1(10)
1-3%	1(13)	6(46)	11(24)	6(32)	12(22)	12(38)	1(20)	0	0	0	1(14)	0
>3%	0	1(8)	2(4)	2(11)	2(4)	3(9)	3(60)	4(80)	0	4(80)	3(43)	8(80)
Unknown	6(75)	4(31)	22(48)	6(32)	28(52)	10(31)	1(20)	1(20)	2(100)	0	3(43)	1(10)
	Mean (SD)		Mean (SD)		Mean (SD)		Mean (SD)		Mean (SD)		Mean (SD)	
Number of different sources used for data collection	8(5.2)	8(2.7)	7(3.9)	8(3.4)	8(4.1)	8(3.1)	3(3.9)	7(5.9)	0	8(3.4)	2(3.6)	7(4.6)
Starting year stage collection	N (%)	N (%)	N(%)	N (%)	N (%)	N (%)	N (%)	N (%)	N(%)	N (%)	N (%)	N (%)
<1990	-	5(38)	-	5(26)	-	10(31)	-	3(60)	-	1(20)	-	4(40)
1990-1999	-	3(23)	-	4(21)	-	7(22)	-	1(20)	-	0	-	1(10)
2000-2010	-	3(23)	-	8(42)	-	11(34)	-	1(20)	-	4(80)	-	5(50)
Unknown	-	2(15)	-	2(11)	-	4(13)	-	0	-	0	-	0
Time since starting year CR	N (%)	N (%)	N(%)	N (%)	N (%)	N (%)	N (%)	N (%)	N(%)	N (%)	N (%)	N (%)
From the beginning	-	3(23)	-	11(58)	-	14(44)	-	4(80)	-	3(60)	-	7(70)
In recent 10 years	-	6(46)	-	2(11)	-	8(25)	-	1(20)	-	1(20)	-	2(20)
Longer than 10 years	-	2(15)	-	4(21)	-	6(19)	-	0	-	1(20)	-	1(10)
Unknown	-	2(15)	-	2(11)	-	4(13)	-	0	-	0	-	0



**Figure 8:** The cumulative percentage of CRs over time and the cumulative percentage of CRs collecting first treatment date over time.

**Table 7: Reasons for not collecting the variable first treatment date**

	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
CRs not collecting first treatment date	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>
Total	6	43	49	4	2	7
Reason for not collecting first treatment date	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Lack of interest	1 (17)	2 (5)	3 (6)	1 (25)	0	1 (17)
Lack of finance	1 (17)	2 (5)	3 (6)	0	0	1 (17)
Lack of staff	0	4 (9)	4 (8)	0	0	0
Lack of access	1 (17)	10 (23)	11 (22)	0	0	0
Lack of staff and access	1 (17)	4 (9)	5 (10)	1 (25)	0	1 (17)
Lack of staff and finance	0	4 (9)	4 (8)	1 (25)	0	1 (17)
Lack of interest and finance	0	2 (5)	2 (4)	0	0	0
Lack of finance, staff and access	1 (17)	4 (9)	5 (10)	0	0	0
All reasons	0	0	0	0	0	0
Reason unknown	1 (17)	11 (26)	12 (24)	1 (25)	2 (100)	3 (50)
Intention to collect first treatment date	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
In preparation	1 (17)	5 (12)	6(12)	0	1 (50)	1 (17)

### *Compliance with cancer guidelines*

#### Population based cancer registries:

Table 8 shows the variables necessary to define the indicator “compliance with cancer guidelines”. In the countries/ areas covered by 48% of the population based CRs guidelines were not available. A minority of the population based CRs routinely collected surgery date, starting date of radiotherapy or starting date of chemotherapy, respectively 36%, 26% and 23%. Type of treatment was routinely collected by 30% of the CRs. In only 15% of the population based CRs were the variables available to estimate compliance with cancer guidelines. Figure 9 shows the availability of the indicator “cancer treatment delay” in European countries.

Table 9 shows the different factors which might influence the availability of variables for the indicator “compliance with cancer guidelines”. Almost all population based CRs with a lower budget did not collect the variables for cancer guidelines. The number of available sources did not influence the registration of variables for the indicator “compliance with cancer guidelines” in population based CRs.

Tables 10a-d show the reasons for not collecting variables for the indicator “compliance with cancer guidelines”. Most mentioned reasons were a lack of access to data sources and a lack of staff, particularly for the regional CRs. A lack of interest was most mentioned for type of surgery (by 12 of the 20 CRs).

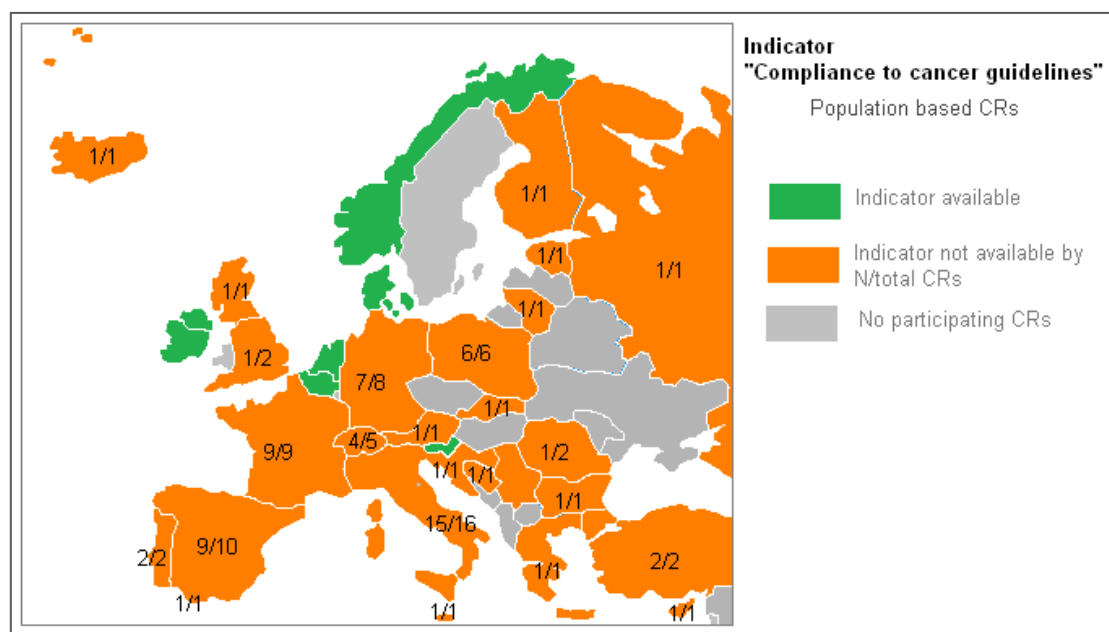
#### Specialised cancer registries:

In 41% of the specialised CR regions guidelines were not available relating to the cancers registered (Table 8). A minority of the specialised CRs routinely collected surgery date, starting date of radiotherapy or starting date of chemotherapy, respectively 41%, 29% and 35%. Type of surgical treatment was routinely collected by 35% of CRs. Only 2 specialised CRs were able to collect all the necessary variables for the indicator “compliance with cancer guidelines”. The number of available sources did not influence the registration of variables for the indicator “compliance with cancer guidelines” in specialised CRs (Table 9). A lack of staff was the most mentioned reason for not collecting the necessary variables for the indicator “compliance with cancer guidelines” (Table 10).

**Conclusion:** 52% of the population based CRs indicated that cancer guidelines were available in the areas they covered for all or at least one tumour site. A minority of the population based CRs collected all data for the indicator “compliance with cancer guidelines” (15%). Particularly the starting date of radiotherapy and chemotherapy were not collected. Lack of qualified staff and access to data sources were the most important reasons why these variables were not collected. A lack of interest was most mentioned for non collection of the variable type of surgery.

	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
<b>Total</b>	21	65	86	10	7	17
Indicator stage at diagnosis (table2)	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
Indicator available	20 (95)	50 (77)	70 (81)	8 (80)	5 (71)	13 (76)
Treatment date	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
Date of surgery	12 (57)	19 (29)	31 (36)	3 (30)	4 (57)	7(41)
Starting date radiotherapy	11 (52)	11 (17)	22 (26)	3 (30)	2 (29)	5(29)
Starting date chemotherapy	10 (48)	10 (15)	20 (23)	4 (40)	2 (29)	6(35)
Treatment type	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
Type of surgery	9 (43)	17 (26)	26 (30)	3 (30)	3 (43)	6(35)
Guidelines available	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
For all tumour sites	5 (24)	20 (31)	25 (29)	2 (20)	0	2 (12)
For at least 1 tumour site	6 (29)	14 (22)	20 (23)	2 (20)	6 (86)	8 (47)
None/unknown	10 (48)	31 (48)	41 (48)	6 (60)	1 (14)	7 (41)
<b>Indicator "Compliance with cancer guidelines"</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
	7 (33)	6 (9)	13 (15)	1 (10)	1 (14)	2 (12)

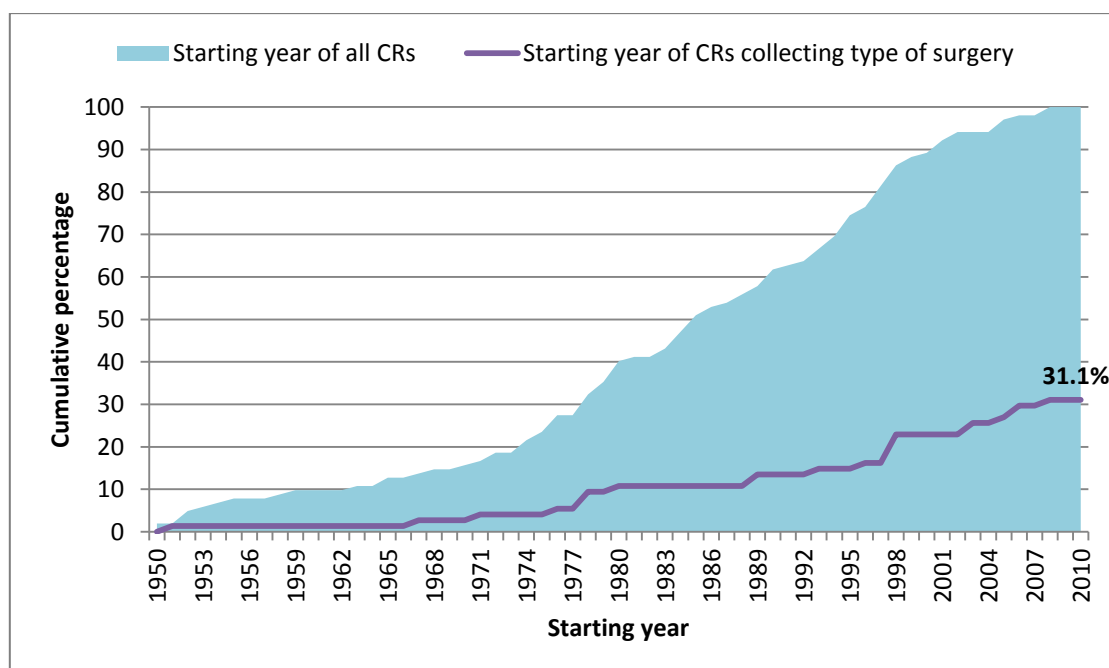
**Table 8 :** Indicator "compliance with cancer guidelines"



**Figure 9:** Availability of the indicator "compliance to cancer guidelines"

**Table 9:** Factors influencing “compliance with guidelines”

	Population based CRs						Specialised CRs					
	National		Regional		Total		Paediatric		Tumour specific		Total	
	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes
Collecting “stage at diagnosis”												
Total	14	7	59	6	53	13	9	1	6	1	15	2
% of NHE per capita available for cancer registration per cancer case	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
<1%	3(21)	0	14(24)	2(33)	17(23)	2(15)	0	0	1(17)	0	1(7)	0
1-3%	4(29)	3(43)	15(25)	2(33)	19(26)	5(38)	1(11)	0	0	0	1(7)	0
>3%	0	1(14)	4(7)	0	4(5)	1(8)	6(67)	1(100)	3(50)	1(100)	9(60)	2(100)
Unknown	7(50)	3(43)	26(44)	2(33)	33(45)	5(38)	2(22)	0	2(33)	0	4(27)	0
	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>
Number of different sources used for data collection	8(4.1)	8(3.0)	8(3.7)	9(5.0)	8(3.7)	8(3.9)	5(5.4)	5(-)	5(5.0)	7(-)	5(5.1)	6(1.4)
Starting year stage collection	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
<1990	-	2(29)	-	2(33)	-	4(31)	-	1(100)	-	1(100)	-	2(100)
1990-1999	-	2(29)	-	1(17)	-	3(23)	-	0	-	0	-	0
2000-2010	-	1(14)	-	2(33)	-	3(23)	-	0	-	0	-	0
Unknown	-	2(29)	-	1(17)	-	3(23)	-	0	-	0	-	0
Time since starting year CR	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
From the beginning	-	2(29)	-	3(50)	-	5(38)	-	1(100)	-	1(100)	-	2(100)
In recent 10 years	-	3(43)	-	2(33)	-	5(38)	-	0	-	0	-	0
Longer than 10 years	-	0	-	0	-	0	-	0	-	0	-	0
Unknown	-	2(29)	-	1(17)	-	3(23)	-	0	-	0	-	0





**Figure 10:** The cumulative percentage of CRs over time and the cumulative percentage of CRs collecting type of surgery.

**Table 10a:** Reasons for not collecting the variables type of surgery

	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
CRs not collecting type of surgery	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>
Total	12	48	40	7	4	11
Reason for not collecting type of surgery	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Lack of interest	1 (8)	4 (8)	5 (8)	1 (14)	0	1 (9)
Lack of finance	1 (8)	1 (2)	2 (3)	0	0	0
Lack of staff	2 (17)	3 (6)	5 (8)	0	0	0
Lack of access	1 (8)	11 (77)	12 (20)	0	0	0
Lack of staff and access	1 (8)	5 (10)	6 (10)	1 (14)	0	1 (9)
Lack of staff and finance	1 (8)	4 (8)	5 (8)	1 (14)	1 (25)	2 (18)
Lack of interest and finance	0	2 (4)	2 (3)	0	0	0
Lack of finance, staff and access	1 (8)	2 (4)	3 (5)	0	0	0
All reasons	1 (8)	0	1 (2)	0	0	0
Reason unknown	3 (25)	14 (29)	17 (28)	4 (57)	3 (75)	7 (64)
Intention to collect type of surgery						
In preparation	2 (17)	7 (15)	9 (15)	1 (14)	0	1 (9)

**Table 10b:** Reasons for not collecting the variables date of surgery

	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
CRs not collecting date of surgery	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>
Total	9	46	55	7	3	10
Reason for not collecting date of surgery	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Lack of interest	1 (11)	2 (4)	3 (5)	1 (14)	1 (33)	2 (20)
Lack of finance	1 (11)	2 (4)	3 (5)	0	0	0
Lack of staff	0	4 (9)	4 (7)	1 (14)	0	1 (10)
Lack of access	0	10 (22)	10 (18)	0	0	0
Lack of staff and access	1 (11)	3 (7)	4 (7)	1 (14)	0	1 (10)
Lack of staff and finance	2 (22)	5 (11)	7 (13)	1 (14)	0	1 (10)
Lack of interest and finance	0	2 (4)	2 (4)	0	0	0
Lack of finance, staff and access	1 (11)	4 (9)	5 (9)	0	0	0
Reason unknown	3 (33)	14 (30)	17 (31)	3 (43)	2 (67)	5 (50)
Intention to collect date of surgery	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
In preparation	2 (22)	7(15)	9(16)	0	0	0



	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
CRs not collecting starting date of radiotherapy	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>
Total	10	54	64	7	5	12
Reason for not collecting starting date of radiotherapy	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Lack of interest	1 (10)	3 (6)	4 (6)	0	1 (20)	1 (8)
Lack of finance	1 (10)	2 (4)	3 (5)	1 (14)	0	1 (8)
Lack of staff	0	4 (7)	4 (6)	0	0	0
Lack of access	0	10 (19)	10 (16)	1 (14)	0	1 (8)
Lack of staff and access	1 (10)	4 (7)	5 (8)	1 (14)	0	1 (8)
Lack of staff and finance	4 (40)	5 (9)	9 (14)	1 (14)	0	1 (8)
Lack of interest and finance	0	2 (4)	2 (3)	0	0	0
Lack of finance, staff and access	1 (10)	6 (11)	7 (11)	0	0	0
Reason unknown	2 (20)	16 (30)	18 (28)	3 (43)	4 (80)	7 (58)
Intention to collect starting date of radiotherapy	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
In preparation	2 (20)	8 (15)	10 (16)	2 (29)	2 (40)	4 (33)

**Table 10c:** Reasons for not collecting the variables starting date of radiotherapy

**Table 10d:** Reasons for not collecting the variables starting date of chemotherapy

	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
CRs not collecting starting date of chemotherapy	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>
Total	11	55	66	6	5	11
Reason for not collecting starting date of chemotherapy	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Lack of interest	1 (9)	3 (5)	4 (6)	0	1 (20)	1 (9)
Lack of finance	1 (9)	2 (4)	3 (5)	0	0	0
Lack of staff	0	4 (7)	4 (6)	0	0	0
Lack of access	0	11 (20)	11 (17)	1 (17)	0	1 (9)
Lack of staff and access	1 (9)	4 (7)	5 (8)	1 (17)	0	1 (9)
Lack of staff and finance	4 (36)	5 (9)	9 (14)	1 (17)	0	1 (9)
Lack of interest and finance	0	2 (4)	2 (3)	0	0	0
Lack of finance, staff and access	1 (9)	6 (11)	7 (11)	0	0	0
Reason unknown	3 (27)	16 (29)	19 (29)	3 (50)	4 (80)	7 (64)
Intention to collect starting date of chemotherapy	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
In preparation	2 (18)	8 (15)	10 (15)	0	2 (40)	2 (18)

### Indicators and registry output

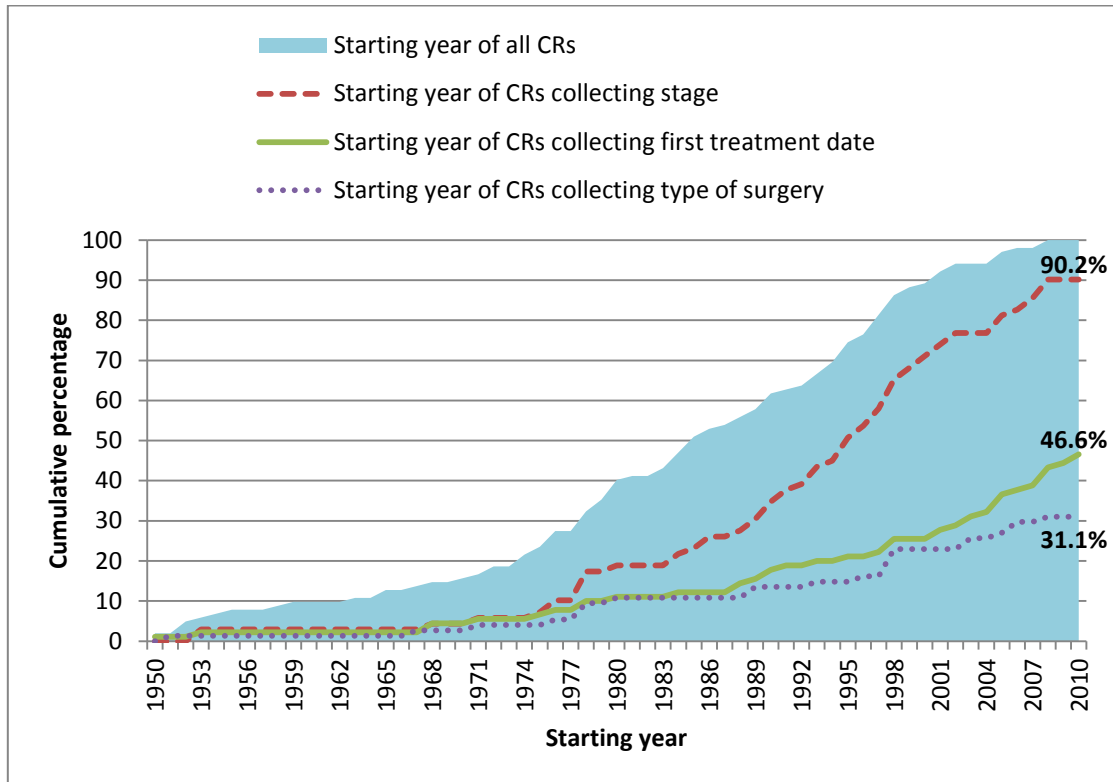
Table 11 shows an overview of the number of available indicators. In total 14 population based CRs (16%) and 3 specialised CRs (18%) were not able to routinely collect the necessary variables for any indicator. A minority was able to routinely collect all three indicators, 15% of the population based CRs and 12% of the specialised CRs. Figure 11 gives an overview of the starting year of data collection for the 3 different indicators. Most CRs started with data collection for the indicators “cancer treatment delay” and “compliance with cancer guidelines” after the year 1990. The national population based CRs seem to collect more variables than the regional CRs. The number of collected indicators varies between regional CRs within a country (Figure 12). Almost a quarter of the CRs (N=24, both population based and specialised) indicated that they were not interested in the variables they did not collect. The others indicated that a lack of access and qualified staff were the major reasons for not collecting all the variables. No relation was found between the proportion of electronic data sources and available indicators nor for the proportion of passive supplied data sources and the number of available indicators (Figures 13 and 14). Figure 15 shows that there is a relation between the available registration budget per cancer case and the available number of indicators for the national population based CRs, however no relation was shown for the regional population based CRs.

Table 12 shows the registry output by number of available indicators for all population based CRs. The CRs collecting data for all three indicators used their data more often for registry output, particularly clinical audits, evaluation of national cancer control strategies and improvement of cancer care projects, than those who did not collect data for all three indicators. However, a large number of CRs did not use their data for registry output.

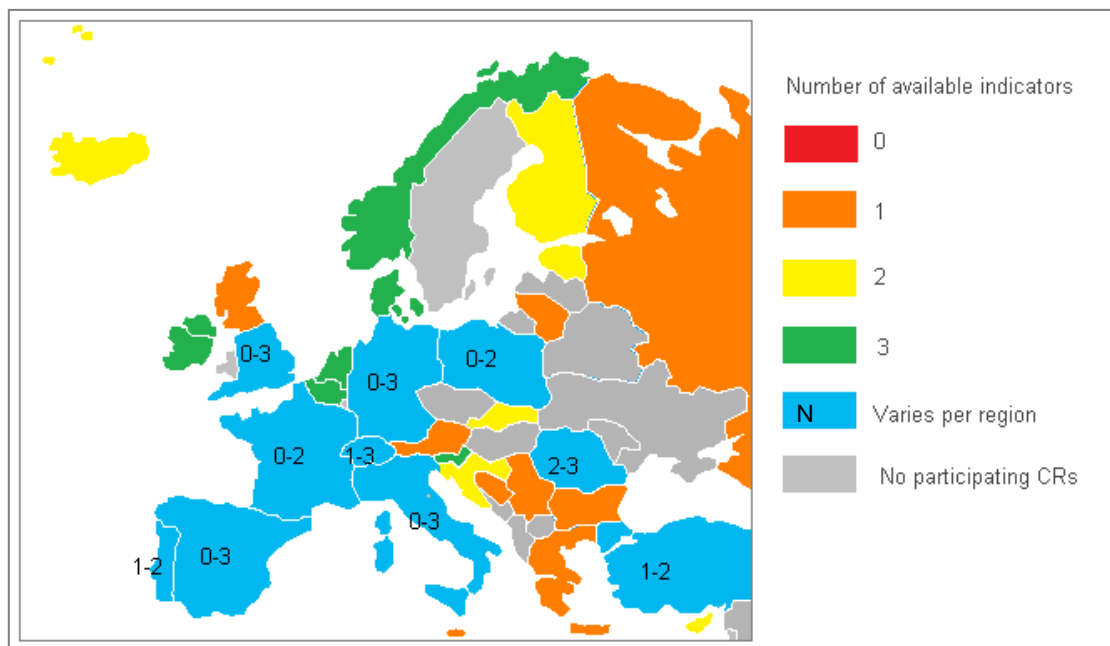
**Conclusion:** Only 15% of the population based CRs were able to collect variables for all 3 indicators. Almost a quarter of the CRs indicated that they were not interested in the variables they did not collect, others indicated to have limited access to data sources and a lack of qualified staff. Given the budget distribution of the CRs collecting variables for 0 to 3 indicators it seems that CRs can enhance the data they collect through more efficient working. On the other hand the data collected by the CRs are not adequately exploited.

**Table 11:** Overview available indicators

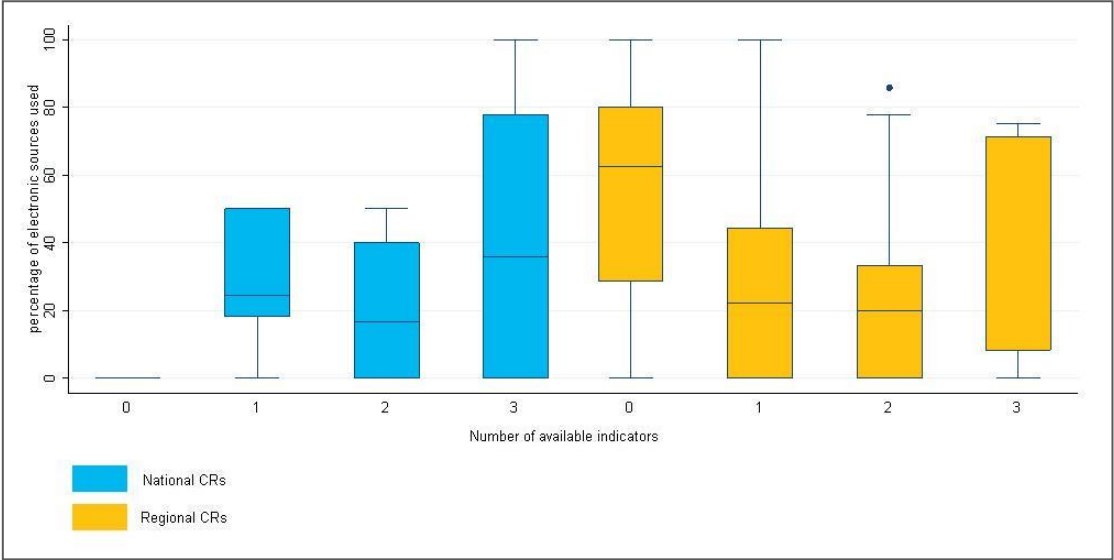
	Population based CRs			Specialised CRs		
	National	Regional	Total	Paediatric	Tumour specific	Total
	N	N	N	N	N	N
Total	20	66	86	10	7	17
Necessary variables available for:	N (%)	N(%)	N (%)	N(%)	N (%)	N (%)
No indicator	1 (5)	13 (20)	14 (16)	2 (20)	1 (14)	3 (18)
1 indicator	7 (33)	35 (54)	42 (49)	3 (30)	2 (29)	5 (29)
2 indicators	6 (29)	11 (17)	17 (20)	4 (40)	3 (43)	7 (41)



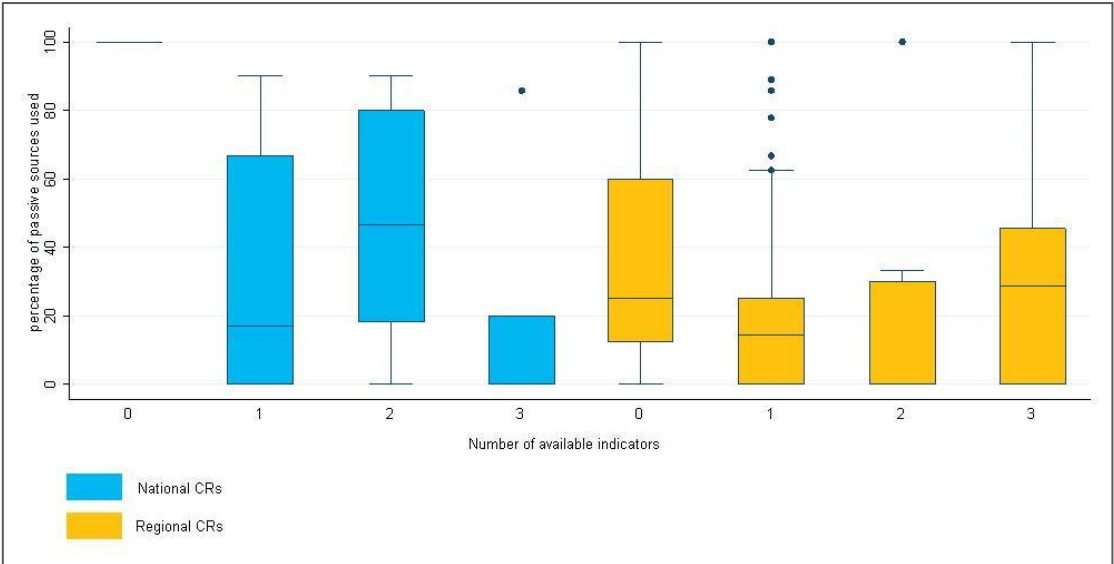
**Figure 11:** The cumulative percentage of CRs over time and the cumulative percentage of CRs collecting stage, first treatment date of type of surgery.



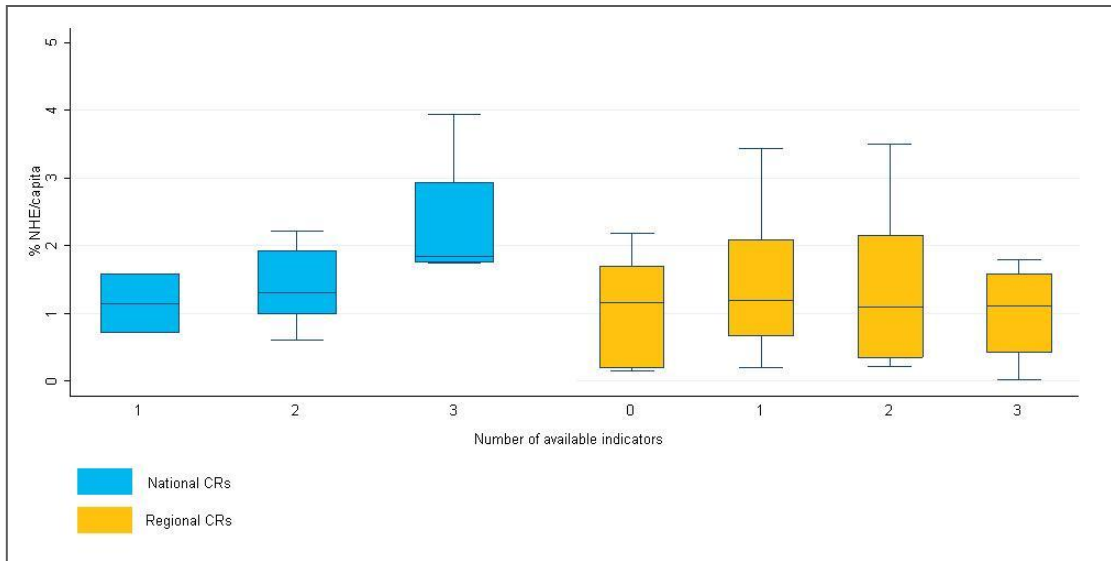
**Figure 12:** Number of available indicators by country for population based CRs



**Figure 13:** Box plot: percentage of electronic data sources used by the number of available indicators



**Figure 14:** Box plot: percentage of passive data sources used by the number of available indicators



**Figure 15:** Box plot: available registration budget per cancer case expressed as percentage of the NHE/capita by the number of available indicators

**Table 12:** Registry output by available indicators for population based CRs

	Number of indicators collected			
	0	1	2	3
	<b>N</b>	<b>N</b>	<b>N</b>	<b>N</b>
<b>Total population based CRs</b>	14	42	17	13
<b>Cancer incidence rates</b>	<b>N (%)</b>	<b>N(%)</b>	<b>N (%)</b>	<b>N (%)</b>
Occasional	2(14)	3(7)	1(6)	0
Routine	11(79)	38(90)	15(88)	12(92)
Not applicable / unknown	1(7)	1(2)	1(6)	1(8)
<b>Cancer survival</b>				
Occasional	4(29)	20(48)	7(41)	3(23)
Routine	7(50)	17(40)	8(47)	8(62)
Not applicable / unknown	3(21)	5(12)	2(12)	2(15)
<b>Cancer mortality rates</b>				
Occasional	1(7)	3(7)	2(12)	2(15)
Routine	12(86)	30(71)	10(59)	9(69)
Not applicable / unknown	1(7)	9(22)	5(29)	2(15)
<b>Evaluation of national cancer control strategies</b>				
Occasional	5(36)	23(55)	9(53)	7(54)
Routine	4(29)	3(7)	2(12)	5(38)
Not applicable / unknown	5(36)	16(38)	6(35)	1(7)
<b>Clinical audits on diagnosis/staging</b>				
Occasional	5(36)	12(29)	5(29)	5(38)
Routine	0	3(7)	0	4(31)
Not applicable / unknown	9(64)	27(64)	12(70)	4(31)
<b>Clinical audits on treatment</b>				
Occasional	5(36)	10(24)	6(35)	7(54)
Routine	0	1(2)	0	2(15)
Not applicable / unknown	9(64)	31(74)	11(65)	4(31)
<b>Clinical audits on waiting times</b>				
Occasional	4(29)	7(17)	2(12)	3(23)
Routine	0	1(2)	0	4(31)
Not applicable / unknown	10(71)	33(81)	15(88)	6(46)
<b>Improvement of cancer care projects</b>				
Occasional	7(50)	15(36)	4(24)	7(54)
Routine	0	0	0	4(31)
Not applicable / unknown	7(50)	27(64)	13(76)	2(15)
<b>Evaluation of cancer screening</b>				
Occasional	5(36)	13(31)	7(41)	5(38)
Routine	6(43)	17(40)	6(35)	6(46)
Not applicable / unknown	3(21)	12(29)	4(24)	2(15)



#### 4: DISCUSSION

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Although questionnaires were completed by 103 Cancer Registries from 35 different countries, this represented a response rate of only 50% which is disappointing from organisations which collect data routinely for epidemiological purposes. There are however some issues regarding the mailing lists used for identification of registries and the need to update these which is being actively pursued by the European network of Cancer registries, (ENCR). The response rate may therefore be higher than reported. The population covered however was about 221,000,000 and so the data are credible. As not all regional registries responded results may not therefore represent the situation in the country as a whole.

Despite these limitations, this study provided for the first time an overview of the routinely available variables for the three indicators, “stage at diagnosis”, “cancer treatment delay” and “compliance with cancer guidelines”, among CRs from all over Europe. The variables for the indicator “stage at diagnosis” were available to a majority of the population based CRs, 81%. For this indicator CRs should collect stage for at least one tumour site. For future evaluations (EUROCHIP-4), the percentage of various tumours with an achieved stage could be a better marker for this. The necessary variables to calculate “cancer treatment delay” were routinely collected by 37% of the population based CRs. For the third indicator “compliance with cancer guidelines” we additionally asked whether guidelines were available for at least one tumour site, the type of surgical treatment and the starting date of different treatments. Only 15% routinely collected variables for the indicator “compliance with cancer guidelines”. Overall, 16% of the CRs were not able to define any indicator and only 15% were able to define all three indicators with the available variables collected. We used strict rules for the definition of the indicators. For the indicators “stage at diagnosis” and “cancer treatment delay” the ENCR rules should be strictly followed regarding the basis of diagnosis and date of incidence, to ensure comparability between the registries. We realized that CRs could collect parts of the indicators and therefore produce output even if we considered that they didn’t collect complete data for any indicator. To ensure comparability between the registries for the indicators “stage at diagnosis” and “cancer treatment delay” we decided that the ENCR rules should be strictly followed (for basis of diagnosis and date of incidence). We realized that CRs could register without strict ENCR rules and thus collect parts of the indicators and therefore produce output on these indicators, which are less comparable to the other CR.

There is a relation between the available budget per cancer case and the available number of indicators for the national population based CRs. Remarkably, the regional population based CRs who collected all indicators did not report having a higher budget per cancer case than those who collected less indicators. Neither did we find a relation between the available proportion of electronic data sources/passive supplied data sources and the number of collected indicators.

Interestingly 24 CRs indicated that the reason for not collecting variables (could be some or all) was a lack of interest. This suggests that the benefits of collecting data need to be made clear for those who set cancer registry direction, ie funders and directors. Others indicated that the main reasons were a lack

of access to data sources or qualified staff. The UK pilot studies<sup>3</sup> for Eurochip 2 estimated how long it would take to collect data from new sources. Considerations in this estimate would be recruitment of new staff and training, procurement of new hardware, obtaining permission from data owners. The time needed to collect a new source will be different for each CR and each country. The overall average time was estimated to be around 16 months.

This study evaluated whether variables were available within the various CRs, however completeness and quality of the indicators were not defined. The UK pilot study reported that more coding effort and quality control will be needed for indicators of “compliance with treatment guidelines” than “delay treatment delay” because dates are easier to work with than data variables such as staging and type of treatment. The EUROCHIP-2 pilot studies concluded that the three indicators were available, although in some countries extra work and funds are needed especially for the indicator “compliance with cancer guidelines”.

Our results showed that only a proportion of the participating CRs used their data for clinical audits, cancer care projects and national cancer control strategies. Population based CRs are the most important source of cancer incidence, prevalence and survival data. However, CRs should be stimulated to collect and use data for the three indicators, because of the relevance for optimizing cancer care.

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<sup>3</sup> [http://www.tumori.net/eurochip/report\\_2.php](http://www.tumori.net/eurochip/report_2.php)  
EUROCHIP-3 WP5 Deliverable D3

## 5: RECOMMENDATIONS

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We suggested the following recommendations to promote the collection of variables for the three indicators in Cancer Registries.

1. To further study the registries reporting collection of these variables to determine and document their practice in order to promote the utility of the CRs for many different purposes in a much more efficient way.
2. To consider making '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 screening programs.
3. To stimulate further exploration for potential data sources for cancer registration
4. To improve communication between the CRs, clinicians, European networks and the government on the value of collecting these variables
5. To optimize the usage of the data collected by Cancer Registries. The CRs must be for the indication of cancer burden, for national cancer control strategies development and evaluation and cancer care projects.
6. Fund holder to promote development and evaluation of cancer guidelines.

**Annex 1: OVERVIEW OF CANCER REGISTRATION PRACTICES ENCR Questionnaire**



## OVERVIEW OF CANCER REGISTRATION PRACTICES

### ENCR Questionnaire

***Eurochip-3 WP5***

Head:

Renée Otter (Enschede/Groningen, the Netherlands)

Members:

Sabine Siesling (Enschede/Groningen, the Netherlands)

Annemiek Kwast (Enschede/Groningen, the Netherlands)

Anna Gavin (Belfast, Ireland)

Jean-Michel Lutz (Geneva, Switzerland)

International Agency for Research on Cancer



**1. Contact**

1.1. Are you the chief of the cancer registry?

Yes -> go to 1.3.1.

No

1.2.1. Please enter your name: .....

1.2.2. Please enter your email address: .....

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

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

.....

1.4. You are logged in as XXXXXXXXXXXX .

The address of your registry is displayed below:

XXXXXXXXXXXXXXXXXXXXXXX

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

1.5. Is your registry a member of ENCR?

Yes

No

I don't know

## 2. Registry description

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

### 2.1.1 Registry type:

- National
- Regional
- Non population-based
- Network association
- Not a registry

### 2.1.2. Tumour specialisation:

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

### 2.1.3. Age specificity:

- All ages
- Paediatric
- Other age range
- Not applicable

2.1.4. Area covered (free text): .....

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

2.3. Please indicate the current or most recent estimation of area covered by the registry (in km<sup>2</sup>):

.....

2.4. Has the area covered changed during the existence of the registry?

- Yes
- No

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

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

**3. Conditions of cancer registration: part 1**

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

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

**3. Conditions of cancer registration: part 2**

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

- Yes
- No

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

- Yes
- No

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

- Yes
- No

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

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

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

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

Via the treating doctors manually (physical notification form)?

Yes / No

By data entry by designated professionals in the cancer registry?

Yes / No

Via automatic submission from electronic health care records?

Yes / No

Via electronic submission from (e.g.) pathology laboratories or hospital records systems?

Yes / No

**3.4.1.** If you cannot use fully identifiable patient data in your cancer registry, can you use pseudonymised<sup>1</sup> patient data?

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

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

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

- Yes
- No

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

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

### 3. Conditions of cancer registration: part 3

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

- Yes
- No

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

- Yes
- No

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

- Yes
- No



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

- Yes
- No

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

- Yes
- No

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

- Yes
- No

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

- No
- Yes, unrestricted
- Yes, with restrictions (please specify) .....

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

- No
- Yes, unrestricted
- Yes, with restrictions (please specify) .....

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

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

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

.....

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

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

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

.....

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

- Yes
- No

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

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

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

**4. Funding of cancer registration**

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

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

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

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

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

0% of 100% total

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

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

0% of 100% total

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

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

Examples:

*Two half-time registrars would count for 1 FTE.*

*The registry chief might work as an epidemiologist for 0.3 FTE, 0.5 as a clinician and 0.2 as a manager.*

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

0 total

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

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

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

## 5. Data sources

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

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

Do you use any other data sources?

*1Active - registry personnel actively ascertain cancer records, possibly during visits to data providers*

*2Passive - data is received without any requests by the registry*

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

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

## 6. Registration criteria

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

- All cancers
- Most cancers, except the following .....
- Only the following cancers .....

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

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

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

- Urinary bladder
- Ovary

## 7. Cancer screening

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

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

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

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

## 8. Cancer diagnosis

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

*Rules can be found at <http://www.enccr.com.fr>*

- Yes
- No, please specify the rules used

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

- No
- Yes Please select the definition(s) of 'date of registration' applicable in your registry:
  - Date of the first case notification to the registry
  - Date of first inclusion of the case in the database
  - Date of conclusion/validation of case processing

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

.....

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

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

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

**9. Coding of topography and morphology**

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

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

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

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

- Yes
- No

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

.....

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

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

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

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

- Yes
- No

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

.....



### 10. Additional tumour description: part 1

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

*Rules can be found at <http://www.enccr.com.fr>*

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

10.2.1. Do you record stage?

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

### 10. Additional tumour description: part 2a

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

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

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

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

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

### 10. Additional tumour description: part 2b

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

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

## 11. Treatment information

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

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

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

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

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

	In preparation	Lack of interest	Lack of finance	Lack of staff	Limited access to data sources
Date of first treatment					
Date of surgical treatment					
Type of surgical treatment					
Tumour residue after surgical treatment					
Start-date radiotherapy					
End-date radiotherapy					
Type of radiotherapy					
Start-date chemotherapy					
End-date chemotherapy					
Type of chemotherapy					
Start-date endocrine therapy					
Type of endocrine therapy					

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

- No
- Yes

11.4.2. Please select the tumour sites where co-morbidity is collected:

- Breast
- Cervical
- Melanoma
- Prostate
- Colon & rectum
- Lung
- Other, please specify .....

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

- No
- Yes, please give details .....

## 12. Follow-up of registered patients

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

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

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

	In preparation	Lack of interest	Lack of finance	Lack of staff	Limited access to data sources
Vital status					
Date of follow-up					
Cause of death					
Distant metastasis					
Recurrence					

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

- Yes
- No

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

- No
- Yes, please specify .....

### 13. Guidelines

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

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

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

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

Are there guidelines available for any other tumour sites?

**14. Registry output**

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

..... Year  
 ..... Total number of cases registered in the most recent complete year

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

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

Are there other topics that your registry contributes to?

14.3. Does your registry have a web page?

- No
- Yes, please give the address of the web page  
 .....

**15. Permissions**

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

Section on confidentiality, legal and ethical issues:

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

Section 'cancer registration funding':

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

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

Your preferences will be strictly respected.

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

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

.....

**16. Submission**

16.1. A confirmation email with a summary of your answers will be sent to the address(es) specified below.

*If you would like to send the confirmation to a different address please enter it here. Multiple email addresses should be separated by a comma (,).*

.....



**Annex 2: Invitation letter**



EUROPEAN NETWORK OF CANCER REGISTRIES

ENCR Secretariat  
International Agency for Research on Cancer  
150 cours Albert Thomas 69372 Lyon Cedex 08 - France  
Tel.: +33 (0)472 73 84 66 – Fax: +33 (0)472 73 86 96  
<http://www.enccr.com.fr>

International Agency for Research on Cancer



In reply, please refer to: DE/92/29-4  
Prière de rappeler la référence: DEP/f1  
By e-mail attachment

3 May 2010

**First ENCR on-line survey**

Dear colleague,

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

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

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

To complete the survey, please go to the URL <http://cinportal.iarc.fr> or copy and paste the address into your Internet browser address window. Enter the username, (which is a unique code for each cancer registry) and the password, both sent to you separately from ENCR Secretariat. You will need the registry to complete the survey, which will take you about 30 minutes. This survey will go through registry details, data sources, items collected in your registry database, guidelines and the role of care evaluation within the registry.

We would greatly appreciate it if you could complete the questionnaire within four weeks (before the 28<sup>th</sup> of May).

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

Thank you in advance for your participation in this important project. The questions have been designed to be self-explanatory, but can be commented upon to Annemiek Kwast ([a.kwast@ikno.nl](mailto:a.kwast@ikno.nl)). Any questions on the technical aspects of the questionnaire (navigation,

return e-mail, etc) would also be welcomed and should be sent to Mark O'Callaghan (ocallaghanm@fellows.iarc.fr).

Yours sincerely,

**Jan Willem Coebergh**  
Coordinator of EUROCOURSE  
Comprehensive Cancer Centre South  
Eindhoven Cancer Registry  
Signature:




**Max Parkin**  
Chair of the ENCR  
University of Oxford  
Signature:



**Renée Otter**  
Leader of WP-5 of EUROCHIP-3  
Comprehensive Cancer Centre North East  
North East Netherlands Cancer Registry  
Signature:



**David Forman**  
Head, Section of Cancer Information  
International Agency for Research on Cancer  
Signature:



**Annex 3: Participating Cancer Registries**

Country	Registry	Registry details			
		Type*	Tumour <sup>‡</sup>	Age <sup>‡</sup>	
<b>AUSTRIA</b>	Austria	N	S	A	
	Salzburg	R	A	A	
<b>BELARUS</b>	Belarus	N	A	P	
<b>BELGIUM</b>	Antwerp	R	A	A	
	Belgium	N	A	A	
<b>BOSNIA_HERZEGOVINA</b>	Bosnia-Herzegovina	N	A	A	
<b>BULGARIA</b>	Bulgaria	N	A	A	
<b>CROATIA</b>	Croatia	N	A	A	
<b>CYPRUS</b>	Cyprus	N	A	A	
<b>DENMARK</b>	Denmark	N	A	A	
<b>ESTONIA</b>	Estionia	N	A	A	
<b>FINLAND</b>	Finland	N	A	A	
	<b>FRANCE</b>	Auvergne-Limousin	R	A	A
		Bas-Rhinois	R	A	A
		Basse-Normandie	R	S	A
		Calvados	R	S	A
		Calvados	R	A	A
		Cote d'Or & Saone-et-Loire	R	S	A
		Doubs	R	A	A
		France	N	S	P
		France	N	S	A
		Gironde	R	S	A
		Gironde	R	A	A
		Hérault	R	A	A
		Isère	R	A	A
		Nord France (Lille)	R	A	A
		Tarn	R	A	A
		<b>GERMANY</b>	Bayern	R	A
Bremen	R		A	A	
Germany	N		A	P	
Hamburg	R		A	A	
München	R		A	A	
Neuen Bundesländer / Berlin	R		A	A	
Rheinland-Pfalz	R		A	A	
Saarland	R		A	A	
Schleswig-Holstein	R		A	A	
<b>GIBRALTAR</b>	Gibraltar		N	A	A
<b>GREECE</b>	Greece	N	S	P	
	Greece	N	A	A	
<b>HUNGARY</b>	Hungary	N	A	P	
<b>ICELAND</b>	Iceland	N	A	A	
<b>IRELAND</b>	Ireland	N	A	A	

\* N National R Regional; ‡ A All tumour sites S Specific tumour sites; ‡ A All ages P Paediatric

Country	Registry	Registry details			
		Type*	Tumour <sup>‡</sup>	Age <sup>‡</sup>	
<b>ITALY</b>	Biella	R	A	A	
	Brescia	R	A	A	
	Ferrara	R	A	A	
	Genova	R	A	A	
	Macerata	R	A	A	
	Milano	R	A	A	
	Modena	R	S	A	
	Modena	R	A	A	
	Piemonte	R	A	P	
	Ragusa	R	A	A	
	Romagna	R	A	A	
	Siracusa	R	A	A	
	Sondrio	R	A	A	
	Torino	R	A	A	
	Toscana	R	A	A	
	Trento	R	A	A	
	Trento	R	A	A	
	Veneto	R	A	A	
<b>LITHUANIA</b>	Lithuania	N	A	A	
<b>MALTA</b>	Malta	N	A	A	
<b>NETHERLANDS</b>	Netherlands	N	A	A	
<b>NORWAY</b>	Norway	N	A	A	
<b>POLAND</b>	Kielce	R	A	A	
	Lower Silesian	R	A	A	
	Lublin	R	A	A	
	Rzeszow	R	A	A	
	Warsaw	R	A	A	
	Wielkopolska (Greater Poland)	R	A	A	
<b>PORTUGAL</b>	Azores	R	A	A	
	North Region	R	A	A	
<b>ROMANIA</b>	Cluj	R	A	A	
	Timisoara	R	A	A	
<b>RUSSIA</b>	Moscow	R	A	P	
	St. Petersburg	R	A	A	
<b>SERBIA</b>	Central Serbia	R	A	A	
<b>SLOVAKIA</b>	Slovakia	N	A	A	
	Slovenia	N	A	A	
<b>SPAIN</b>	Albacete	R	A	A	
	Asturias	R	A	A	
	Balearic Islands	R	A	A	
	Basque	R	A	A	
	Canary Islands	R	A	A	
	Cuenca	R	A	A	
	Girona	R	A	A	
	Granada	R	A	A	
	Navarra	R	A	A	
	Spain	N	A	P	
		Tarragona	R	A	A

\* N National R Regional; <sup>‡</sup> A All tumour sites S Specific tumour sites; <sup>‡</sup> A All ages P Paediatric

Country	Registry	Registry details		
		Type*	Tumour <sup>†</sup>	Age <sup>‡</sup>
<b>SWITZERLAND</b>	Fribourg	R	A	A
	Neuchâtel	R	A	A
	Switzerland	N	A	P
	Ticino	R	A	A
	Vaud	R	A	A
	Zürich	R	A	A
<b>TURKEY</b>	Antalya	R	A	A
	Samsun	R	A	A
<b>UK ENGLAND</b>	Northern Region	R	A	P
	Northern Yorkshire	R	A	A
	Trent	R	A	A
<b>UK NORTHERN IRELAND</b>	Northern Ireland	N	A	A
<b>UK SCOTLAND</b>	Scotland	N	A	A

\* N National R Regional; <sup>†</sup> A All tumour sites S Specific tumour sites; <sup>‡</sup> A All ages P Paediatric