

EUROCHIP-II
FINAL SCIENTIFIC REPORT
ANNEX 3

**REPORT OF
EUROCHIP-2 PILOT STUDIES**

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EUROCHIP-2 Final Report – Annex 3 – EUROCHIP-2 Pilot Studies

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EXECUTIVE SUMMARY FOR ECHIM PROJECT

The EUROCHIP-2 pilot studies were designed in order to give specific information to the ECHIM project on three indicators on cancer diagnosis and treatment (for colorectal and female breast cancers) inserted in the ECHI short list under the waiting list of indicators. Cancer registries of 11 countries participated in the pilot studies.

From these studies we can conclude that:

- 1) the indicator “Percentage of cancer cases with early diagnosis” (for colorectal and female breast cancers) is already available in some countries while is collectable with work and funds in other countries;
- 2) the indicator “Delay of cancer treatment” is collectable in some countries but it needs specific developments according to different national health systems to improve comparability;
- 3) the indicators “compliance with cancer guidelines” (for colon, rectal and female breast cancers) are collectable with work and funds in the majority of countries.

Future activities will be:

- a) improve the definition of the indicator “delay of cancer treatment”;
- b) promote the collection and the application of the indicators “Percentage of cancer cases with early diagnosis” and “Compliance with cancer guidelines” in the various member states. Relations with the European Network of Cancer Registries (ENCR) are recommended.

1. BACKGROUND and RATIONALE

Cancer registries have provided population-based, comparative survival statistics for cancer patients since 1960. Moreover, the EUROCARE project - a co-operative, cancer registry-based study - compares cancer patient survival since 1978.

EUROCARE underlined big differences in cancer survival across Europe.

EUROCHIP focuses on fighting inequalities in cancer. Its aim is to improve information and knowledge on cancer. The EUROCHIP-1 project funded by the European Commission under the large-scale Health Monitoring Program (HMP), identified a list of indicators for cancer including those on treatment and clinical aspects related with cancer survival.

Among them, the indicators “**Percentage of cases with early diagnosis**”, “**Delay of cancer treatment**” and “**Compliance with guidelines**” were supposed to be strictly associated with the wide inter-country variation in cancer survival. Treatment delay in particular, could be related to:

- a) individual condition of the patient;
- b) biological condition of the patient;
- c) health system deficiencies.

The study here proposed is a feasibility study to collect data on percentage of cases with early diagnosis and health system delays (point c) adjusting for individual and biological conditions (points a and b).

The EUROCHIP feasibility study represent a key determinant with respect to the inclusion of “Percentage of cases with early diagnosis”, “Delay of cancer treatment” and “Compliance with guidelines” in the European Commission indicators list on cancer.

2. AIMS

EUROCHIP-2 worked on pilot studies for three sites: breast, colon, and rectal cancers.

The pilot studies are feasibility studies aimed to assess data collection and availability of these indicators. Sources of these data are cancer registries (CRs). Female breast and colorectal cancers are chosen for the present feasibility studies as they are common tumours, with high public health priority, and treated in general hospitals, rather than in specialized structures.

The pilot studies were performed to address the following questions:

- is it possible, in terms of data accessibility, to collect data on percentage of cases with early diagnosis, delay of cancer treatment and compliance with guidelines at population level?
- is the information already available?

And to provide solutions to the following issues:

- Sources: from which sources can (or could) the data be obtained;
- Limits: describe any shortcomings in the data e.g. lack of geographic comparability, incomplete coverage.

So the EUROCHIP pilot studies are not finalised to collect the indicators but only to evaluate the possibility to collect them.

3. INDICATORS

The EUROCHIP Pilot Studies refer to the following indicators:

- 1) “Percentage of cases with early diagnosis”: that is percentage of cancer cases classified as "localised" with the condensed-TNM¹ [classification system of tumour dimension/stage at time of diagnosis].
- 2) “Delay of cancer treatment”
 - For *breast cancer* (female): the dates to collect are
 - First visit with general practitioner
 - First request for clinic/hospital appointment
 - First clinic/hospital appointment
 - Date of definitive diagnosis
 - Date of first treatment (surgery, systemic therapy or radiotherapy)
 - For *colon and rectal cancers*: the dates to collect are
 - First visit with general practitioner
 - First request for clinic/hospital appointment
 - First clinic/hospital appointment
 - Date of definitive diagnosis
 - Date of first treatment (surgery, systemic therapy or radiotherapy)
 - Information on elective or emergency surgery
- 3) “Compliance with guidelines”
 - For *breast cancer* (female):
 - Proportion of post-operative breast radiotherapy after breast conserving surgery
 - Proportion of breast conservation surgery in pT1 cases (multiple cancers excluded)
 - For *colon cancer*:
 - Proportion of patients with Dukes C (or TNM Stage 3) receiving adjuvant chemotherapy
 - Proportion of patients with Dukes B (or TNM Stage 2) not receiving adjuvant chemotherapy
 - For *rectal cancer*:
 - Proportion of patients with Dukes B or C receiving pre-operative radiotherapy.

¹ The extent of disease is recorded in terms of the three digit code of the TNM system. T represents the dimension of tumour (it can assume values T0, T1, T2, T3, T4); N represents the eventual presence of positive lymphonodes (it can assume values N0, N1, N2, N3); M represents the eventual presence of metastasis (it can assume values M0 or M1). For breast cancer localised stages are T1N0M0, T2N0M0 and T3N0M0 while for colorectal cancer localised stages are T1N0M0 and T2N0M0. A stage is not complete when some digit code is not known (in this case TX, NX and/or MX are used). For each patient recorded in the pilot studies a unique stage at diagnosed was defined combining information coming from pathological TNM (pTNM) and clinical TNM (cTNM).

4. MATERIAL AND METHODS

The EUROCHIP pilot studies here described were performed by cancer registries of 11 countries: the Czech Republic, Cyprus, Finland, France, Ireland, the Netherlands, Poland, Portugal, Slovakia, Slovenia, Spain. The cancer registry of Finland performed pilot studies for breast cancer. All the other cancer registries performed pilot studies both for breast and colorectal cancers. Other countries performed actions on the indicators listed in §3 but not participated in this type of pilot studies: Austria (see Annex 4), Belgium (see Annex 5), and the United Kingdom (performing qualitative pilot studies, for details see Annex 16).

Various discussions were organised for the study protocol to define:

- the patient sample inclusion criteria
- the study period
- the list of fields necessary to collect the indicators
- the list of possible sources from which the cancer registry can found data
- the collection forms
- the publication policy.

Various versions of the collection forms was released.

Slovakia and the Netherlands collected data with a non-final version.

The protocol is at www.tumori.net/eurochip/material/Protocol_EUROCHIP_Pilot_Studies.doc.

Final versions of the ACCESS files for data entry are available at http://www.tumori.net/eurochip/material/EPS_Breast.mdb for breast cancer and at http://www.tumori.net/eurochip/material/EPS_Colonrectum.mdb for colorectal cancers.

4.1 INCLUSION CRITERIA

The patient sample included:

- patient with first primary tumour: to control for a condition possibly related with delays, i.e. those with past cancer experience may receive particular attention by health service
- age: over 15 years old
- not DCO (Death Certificate Only) cases [cases recorded by cancer registries only from death certificates]

4.2 CANCER REGISTRY PATIENT SAMPLES AND STUDY PERIOD

Participating bodies were:

- a. CR or body centralizing cancer cases of local CRs with more than 100 breast/colon/rectal cancer cases per year
- b. CR covers a local area of the country with less than 100 breast/colon/rectal cancer cases per year
- c. Several CRs in the same country (without a centralization of cancer cases)

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For each cancer site the target population was formed:

- in the *case a* and *c*, by all incident cases (primary tumours, age over 15, not DCO cases) diagnosed in 2005 (or in the same last available incidence year)
- in the *case b*, by all incident cases (primary tumours, age over 15, not DCO cases) diagnosed in 2003-05 (or in the last available incidence three-year period)

In each of the three cases a sample of the cancer patients will be selected randomly.

The sample numbers requested were 100 patients for female breast cancer, 100 patients for colon and 100 patients for rectal cancers. In the *case b*, if less than 100 cases were diagnosed in the three-year period, all cases were collected. In the *case c* the sample were constituted proportionally to the populations covered by CRs.

4.3 PARTICIPATING CANCER REGISTRIES

The EUROCHIP pilot studies were performed in the following cancer registries (CR):

Country	Cancer Registry	Nr of cases for breast cancer	Nr of cases for colon cancer	Nr of cases for rectal cancer
Czech Republic	West Bohemia	79	57	43
Cyprus	National	100	40	31
Finland	National	100	-	-
France	Bas Rhin	20	16	16
	Doubs	20	16	16
	Tarn	20	16	16
	Loire Atlantique	20	16	16
	Calvados (general)	20	-	-
	Calvados (digestive)	-	16	20
	Cote d'Or	-	18	18
Ireland	National	100	129	70
The Netherlands	Northern Netherland	104	87	125
Poland	Holycross	90	42	52
	Opole	60	30	29
	Silesia	41	49	31
Portugal	Abrantes (Hospital)	11	13	1
	Beja (Hospital)	9	9	5
	Evora (Hospital)	20	15	15
	IPO-Lisboa (Hospital)	12	18	30
	San José (Hospital)	15	16	14
	Santarem (Hospital)	26	13	24
	Setubal (Hospital)	9	6	9
	Torres Novas (Hosp)	5	4	5
Slovakia	National	104	99	99
Slovenia	National	125	127	128
Spain	Murcia	34	-	-
	Castellon	33	-	-
	Girona	33	-	-
	Albacete	-	20	20
	Basque country	-	20	20
	Granada	-	15	25
	Navarra	-	20	20
	Zaragoza	-	22	22
Total		1210	949	920

5. COLLECTED VARIABLES

For each cancer patient of the samples the various cancer registries collected these variables:

- A. Cancer registry and country name.
- B. Year of birth and sex. No data or codes allowing the identification of patients are requested. The day and the month of birth are omitted.
- C. Date of diagnosis (recorded in the CR as incidence date).
- D. Primary tumour site (ICD-9 or ICD-10): breast cancer (ICD-9: 174x; ICD-10: C50x); colon cancer (ICD-9: 153x; ICD-10: C18x); rectal cancer (ICD-9: 154x; ICD-10: C19 and C20).
- E. Morphology and ICD-O code of the tumour.
- F. Stage at diagnosis:
 - Pathological TNM (pTNM). It can be stated or reconstructed by the CR according to TNM classification (TNM Atlas). Available pTNM is reported (distinguishing pT, pN, and M);
 - Clinical TNM (cTNM). It can be stated or reconstructed by the CR according to TNM classification (TNM Atlas). Available cTNM is reported (distinguishing T, N, and M).
- G. Date of first visit with general practitioner [General practitioner could be a medical doctor or screening programmes and so on].
- H. Date of first request for clinic/hospital appointment: date at which appointment is requested.
- I. Date of first clinic/hospital appointment: date of 1st hospital admission or 1st visit as outpatient.
- J. Date of definitive diagnosis. It is in order of precedence as follows: microscopic diagnosis, radiological diagnosis (if microscopic diagnosis was not performed or unknown), clinical diagnosis (if microscopic and radiological diagnosis were not performed or unknown).
- K. Date of first surgery with distinction whether surgery has been performed.
- L. Type of first surgery:
 - Breast cancer: “Breast conserving surgery” includes quadrantectomy, tumour excision, lumpectomy; “Mastectomy” includes simple mastectomy, Halmsted mastectomy, any modified radical mastectomy.
 - Colorectal cancers: three lists of surgical procedures are listed, one for colon cancers, one for rectal cancers and one for both these localizations. It was also collected whether surgery was planned or the patient was operated in emergency.
- M. Date of first chemotherapy, radiotherapy, and endocrine treatment (for breast cancer) with distinction whether the treatment has been performed.

If variables E, F, G, H, I, J, K, M were found, also the source were reported distinguishing whether it was hospital administrative records, multidisciplinary team records, clinical records, pathological records, question to General Practitioners (GP), screening files, social insurance records or other (to specify). If source was found it was specified if the information was: a) routinely available, and easy to code/find; b) routinely available, and not easy to code/find; c) not routinely available, and easy to code/find; d) not routinely available, and not easy to code/find.

6. RESULT: “PERCENTAGE OF CASES WITH EARLY DIAGNOSIS” INDICATOR

Partial information on stage at diagnosis is available in 98.5% of breast cancer (table A.1) cases and in 90.8% of colorectal cancer cases (table A.2). The stage at diagnosis was complete in 81.7% of breast cancer cases (table A.1) and in 70.6% of colorectal cancer cases (table A.2). Countries with low availability of complete stage are Cyprus and Poland.

Table 1. “Stage at diagnosis” variable: percentage of cases by type of collection. Breast cancer

	Unknown stage at diagnosis	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	5%	1%	-	94%	-	-
Czech Republic	3%	96%	-	1%	-	-
Finland	-	99%	-	-	-	1%
France	1%	2%	-	39%	58%	-
Ireland	-	88%	6%	4%	2%	-
Poland	3%	65%	2%	10%	1%	19%
Portugal	1%	66%	6%	25%	1%	1%
Slovakia	-	94% easy to find & 3% not easy to find				3%
Slovenia	2%	84%	14%	-	-	-
Spain	1%	74%	1%	21%	2%	1%
The Netherlands	1%	95%	-	-	-	4%

“Routinely collected” means that cancer registry have already the variable in own databases

“Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable

Table 2. “Stage at diagnosis” variable: percentage of cases by type of collection. Colorectal cancer

	Unknown stage at diagnosis	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	20%	-	1%	79%	-	-
Czech Republic	3%	95%	1%	-	-	1%
France	1%	7%	1%	25%	67%	-
Ireland	3%	84%	2%	9%	3%	-
Poland	35%	45%	2%	2%	-	16%
Portugal	1%	86%	3%	7%	3%	-
Slovakia	2%	92% easy to find & 3% not easy to find				3%
Slovenia	10%	86%	4%	-	-	-
Spain	14%	65%	3%	17%	-	1%
The Netherlands	3%	91%	-	-	-	6%

“Routinely collected” means that cancer registry have already the variable in own databases

“Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable

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Table 1 and Table 2 show for the variable “stage at diagnosis” the percentage of cases collected by the pilot studies according to their type of collection. In general we can affirm that the variable is routinely available and easy to find in the majority of registries participating in the study.

The indicator proposed by EUROCHIP-1 is “Percentage of cases with early diagnosis” that use the variable “stage at diagnosis”. This indicator is unknown when the variable “stage at diagnosis” is not available or is not complete. Table 3 shows the indicator in the present pilot studies.

Table 3. Indicator “Percentage of cases with early diagnosis”

	Breast cancer cases			Colorectal cancer cases		
	Indicator unknown or not complete	% cases with early diagnosis	% cases without early diagnosis	Indicator unknown or not complete	% cases with early diagnosis	% cases without early diagnosis
Cyprus	38%	25%	37%	24%	1%	75%
Czech Republic	8%	55%	37%	12%	13%	75%
Finland	0%	57%	43%	-	-	-
France	4%	60%	36%	8%	10%	83%
Ireland	23%	26%	51%	9%	8%	84%
Poland	10%	30%	59%	39%	7%	54%
Portugal	17%	47%	36%	1%	13%	86%
Slovakia	4%	46%	50%	3%	19%	79%
Slovenia	3%	49%	48%	10%	11%	79%
Spain	11%	44%	45%	16%	12%	72%
The Netherlands	9%	44%	47%	11%	17%	71%

Table 4 summarizes the situation of this indicator in each country.

Table 4. Is the indicator available?

	When data are found, is the variable routinely available in the CR?	When data are found, is the variable easy to find for the CR?	Percentage of cases for which the indicator is available	Percentage of cases for which the indicator is available	Conclusion
			Breast cancer	Colorectal cancer	
Cyprus	No	Yes	62%	76%	Difficulties
Czech Republic	Yes	Yes	92%	88%	Available
Finland	Yes	Yes	100%	-	Available
France	No	No	96%	92%	Collectable
Ireland	Yes	Yes	77%	91%	Difficulties (for breast cancer) Collectable (for colorectal cancer)
Poland	Yes	Yes	90%	61%	Available (for breast cancer) Difficulties (for colorectal cancer)
Portugal	Yes	Yes	83%	99%	Available
Slovakia	-	Yes	96%	97%	Collectable
Slovenia	Yes	Yes	97%	90%	Available
Spain	Yes	Yes	89%	84%	Available
The Netherlands	Yes	-	91%	89%	Available

“Routinely collected” means that cancer registry have already the variable in own databases

“Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable

Available: all data necessary to calculate the indicator are already present in the CR database

Collectable: all data necessary to calculate the indicator can be obtained with work (and funds)

Difficulties: the indicator can be estimated but it is necessary to give attention to the results

7. RESULT: “DELAY OF CANCER TREATMENT” INDICATOR

The EUROCHIP pilot studies evaluate the possibility to collect specific dates in the patient history:

- three pre-diagnostic dates: date of first visit with general practitioner, date of first request for clinic/hospital appointment, date of first clinic/hospital appointment;
- date of definitive diagnosis;
- first treatment date: to estimate this date pilot studies collected dates of first surgery, first chemotherapy, first radiotherapy and first endocrine treatment (only for breast cancer).

Tables A.1 e A.2 show that:

- the “date of first visit with general practitioner” is available in 48.1% of breast cancer cases and 46.6% of colorectal cancer cases;
- the “date of first request for clinic/hospital appointment” is available in 50.5% of breast cancer cases and 51.9% of colorectal cancer cases;
- the “date of first clinic/hospital appointment” is available in 86.4% of breast cancer cases and 88.2% of colorectal cancer cases;
- the availability of at least one pre-diagnostic date is 89.4% for breast cancer and 91.8% for colorectal cancer. None pre-diagnostic date is available in Cyprus.
- the availability of the information (treatment not performed or date of treatment) on at least one treatment is 99.8% for breast and 99.3% for colorectal cancer.

Tables B (in the annexes) show the distribution of cases by type of collection of various variables:

- the “date of first visit with general practitioner” is routinely collected or easy to find only in the Czech Republic. In the other countries the availability is low;
- the “date of first request for clinic/hospital appointment” is routinely collected or easy to find in Slovakia and in the Czech Republic (only for colorectal cancer);
- the “date of first clinic/hospital appointment” is routinely collected or easy to find in the Czech Republic, Finland, Portugal, Slovakia, Spain, and The Netherlands;
- the “date of first surgery” is routinely collected or easy to find in the majority of countries;
- the “date of first chemotherapy”, the “date of first radiotherapy” and the “date of first endocrine treatment” are routinely collected or easy to find in Cyprus, the Czech Republic, Finland, Poland, Slovakia, and Slovenia.

The information on “treatment not found” seems to be collected differently by cancer registries: Cyprus, the Czech Republic, Poland, Portugal, Slovakia, Slovenia, Spain have higher percentages for “Treatment non performed” while France, Ireland, the Netherlands have higher percentages for “Treatment unknown”.

Tables C (in the annexes) show the distribution of cases by data source of various variables. The main sources are the multidisciplinary team records in the Czech Republic, the hospital administrative records for some variables in Slovakia, the clinical records for the majority of variables in the other countries. France, Slovenia and Slovakia cancer registries interviewed GPs for considerable percentage of cases in order to collect pre-diagnostic dates.

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One of the pilot study aims was to evaluate which definition of the indicator “delay of cancer treatment” is applicable in various countries. The “delay of cancer treatment” indicator can be calculated as the difference between the “date of first treatment” and one of the pre-diagnostic dates collected by the pilot studies. To understand which pre-diagnostic date can be used we calculated the “minimum available pre-diagnostic date”. Table 5 and 6 show the distribution of breast and colorectal cancer cases according to “minimum available pre-diagnostic date”.

Table 5. Distribution of breast cancer cases according to the “minimum available pre-diagnostic date” among the three pre-diagnostic dates.

	Date of 1 st visit to GP	Date of 1 st request of clinical appointment	Date of 1 st clinical appointment	Any pre-diagnostic date available
Cyprus	-	-	-	100%
Czech Republic	100%	-	-	0%
Finland	35%	30%	35%	0%
France	75%	1%	19%	5%
Ireland	12%	34%	20%	34%
Poland	43%	43%	12%	2%
Portugal	4%	9%	86%	1%
Slovakia	76%	16%	8%	0%
Slovenia	78%	3%	16%	2%
Spain	53%	37%	8%	2%
The Netherlands	19%	35%	46%	0%
Total	46%	21%	23%	11%

Table 6. Distribution of colorectal cancer cases according to the “minimum available pre-diagnostic date” among the three pre-diagnostic dates.

	Date of 1 st visit to GP	Date of 1 st request of clinical appointment	Date of 1 st clinical appointment	Any pre-diagnostic date available
Cyprus	-	-	-	100%
Czech Republic	100%	-	-	0%
France	79%	4%	15%	4%
Ireland	26%	22%	27%	26%
Poland	39%	41%	15%	5%
Portugal	-	11%	87%	3%
Slovakia	84%	12%	4%	0%
Slovenia	63%	7%	27%	2%
Spain	53%	18%	28%	0%
The Netherlands	3%	28%	68%	1%
Total	45%	16%	30%	8%

Table 5 and 6 show that when the “date of first visit to general practitioner” is available (Table A.1: 48.1% of breast cancer cases; table A.2: 46.6% of colorectal cancer cases), it is the minimum pre-diagnostic date. Moreover the variable “date of first clinic/hospital appointment” seems to assume different meanings in different countries (data not showed). For example in the Czech Republic, it is in the majority of cases equal to the “date of first treatment” and consequently the indicator “delay of cancer treatment” [calculated as the difference between “date of first treatment” and “date of first clinic/hospital appointment”] should be zero.

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In conclusion the indicator “delay of cancer treatment” can be calculated in the majority of countries as the difference between “date of first treatment” and “date of first visit to general practitioner”. Table 7 and 8 show the variability in the availability of this indicator in various countries. It is important to underline that the unavailability of “date of first visit to general practitioner” could be also related with different health organizations present in different countries.

In conclusion pilot study shows that the indicator is collectable in some countries but it needs specific developments according to different national health systems to improve comparability.

Table 7. The availability of the indicator “Delay of cancer treatment” as difference between the “date of first treatment” and the “date of first visit to general practitioner”. Breast cancer

	Availability of date of first visit to general practitioner (Table A.1)	Availability of at least one date of treatment (Table A.1)	% cases for which the indicator “delay of cancer treatment” is calculable*
Cyprus	0%	99%	0%
Czech Republic	100%	95%	94%
Finland	36%	100%	36%
France	75%	100%	73%
Ireland	12%	98%	12%
Poland	43%	98%	43%
Portugal	4%	100%	4%
Slovakia	97%	100%	90%
Slovenia	78%	97%	76%
Spain	53%	99%	51%
The Netherlands	20%	99%	18%

* The indicator is calculable if the pre-diagnostic date is available, the treatment date is available and the pre-diagnostic is inferior or equal to the treatment date

Table 8. The availability of the indicator “Delay of cancer treatment” as difference between the “date of first treatment” and the “date of first visit to general practitioner”. Colorectal cancer

	Availability of date of first visit to general practitioner (Table A.2)	Availability of at least one date of treatment (Table A.2)	% cases for which the indicator “delay of cancer treatment” is calculable*
Cyprus	0%	100%	0%
Czech Republic	100%	100%	87%
France	80%	98%	74%
Ireland	26%	100%	24%
Poland	39%	100%	39%
Portugal	0%	100%	0%
Slovakia	97%	100%	92%
Slovenia	63%	100%	60%
Spain	53%	100%	50%
The Netherlands	3%	97%	3%

* The indicator is calculable if the pre-diagnostic date is available, the treatment date is available and the pre-diagnostic is inferior or equal to the treatment date

8. RESULT: “COMPLIANCE WITH GUIDELINES” INDICATOR

To evaluate the possibility to estimate this indicator it is necessary to consider different variables for each definition described in §3. The following tables show the availability of various variables necessary to estimate each single indicator.

Table 9. Availability of various variables necessary to estimate the indicator “Proportion of breast cancer cases receiving post-operative radiotherapy after conserving surgery”

	Availability of information			Type of collection (when data are found)		Conclusion
	Date of 1 st radiotherapy (Table A.1)*	Date of 1 st surgery (Table A.1)*	Type of 1 st surgery *	Date of 1 st radiotherapy (Table B.11)	Date and type of 1 st surgery (Table B.7)	
Cyprus	96%	91%	81%	Easy		Collectable
Czech Republic	100%	100%	90%	Routinely		Available
Finland	100%	100%	100%	Routinely		Available
France	88%	99%	99%	Not easy	Routinely	Collectable
Ireland	80%	99%	99%	Not so easy	Routinely	Collectable
Poland	97%	98%	96%	Routinely or easy		Collectable
Portugal	92%	100%	100%	Not so easy	Routinely	Collectable
Slovakia	97%	100%	98%	Easy		Collectable
Slovenia	100%	100%	98%	Routinely		Available
Spain	94%	99%	97%	Routinely or easy		Collectable
The Netherlands	75%	95%	95%	Routinely		Available

*This percentages include the “treatment not performed” as declared by the cancer registries

“Routinely” means that cancer registry have already the variable in own databases

“Easy” is a qualitative indication of cancer registrars on the difficulties to find the variable

Available: all data necessary to calculate the indicator are already present in the CR database

Collectable: all data necessary to calculate the indicator can be obtained with work (and funds)

Table 10. Availability of various variables necessary to estimate the indicator “Proportion of breast cancer conservation surgery in pT1 breast cancer cases”

	Availability of information		Type of collection (when data are found)		Conclusion
	Stage at diagnosis (Table A.1)	Type of 1 st surgery *	Stage at diagnosis (Table 1)	Type of 1 st surgery (Table B.7)	
Cyprus	95%	81%	Easy		Collectable
Czech Republic	97%	90%	Routinely		Available
Finland	100%	100%	Routinely		Available
France	99%	99%	Not so easy	Routinely	Collectable
Ireland	100%	99%	Routinely		Available
Poland	97%	96%	Routinely or easy		Collectable
Portugal	99%	100%	Routinely or easy	Routinely	Collectable
Slovakia	100%	98%	Easy		Collectable
Slovenia	98%	98%	Routinely		Available
Spain	99%	97%	Routinely or easy	Routinely	Collectable
The Netherlands	99%	95%	Routinely		Available

“Routinely” means that cancer registry have already the variable in own databases

“Easy” is a qualitative indication of cancer registrars on the difficulties to find the variable

*This percentages include the “treatment not performed” as declared by the cancer registries

Available: all data necessary to calculate the indicator are already present in the CR database

Collectable: all data necessary to calculate the indicator can be obtained with work (and funds)

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Table 11. Availability of various variables necessary to estimate the indicators “Proportion of colon cancer patients with stage TNM Stage 3 receiving adjuvant chemotherapy” and “Proportion of colon cancer patients with TNM Stage 2 not receiving adjuvant chemotherapy”

	Availability of information		Type of collection (when data are found)		Conclusion
	Stage at diagnosis (Table A.3)	Date of 1 st chemotherapy * (Table A.3)	Stage at diagnosis (Table 2)**	Date of 1 st chemotherapy ** (Table B.10)**	
Cyprus	88%	100%	Easy		Collectable
Czech Republic	96%	100%	Routinely		Available
France	99%	37%	Not easy		Difficulties
Ireland	98%	89%	Routinely	Routinely or easy	Collectable
Poland	60%	92%	Routinely or easy		Difficulties
Portugal	100%	95%	Routinely	Not so easy	Collectable
Slovakia	100%	100%	Easy		Collectable
Slovenia	91%	100%	Routinely		Available
Spain	84%	95%	Routinely or easy		Collectable
The Netherlands	95%	49%	Routinely		Available

*This percentages include the “treatment not performed” as declared by the cancer registries

** Data for colorectal cancer in general

“Routinely” means that cancer registry have already the variable in own databases

“Easy” is a qualitative indication of cancer registrars on the difficulties to find the variable

Available: all data necessary to calculate the indicator are already present in the CR database

Collectable: all data necessary to calculate the indicator can be obtained with work (and funds)

Difficulties: the indicator can be estimated but it is necessary to give attention to the results

Table 12. Availability of various variables necessary to estimate the indicator “Proportion of rectal cancer patients with Dukes B or C receiving pre-operative radiotherapy”

	Availability of information			Type of collection (when data are found)			Conclusion
	Stage at diagnosis (Table A.4)	Date of 1 st radiotherapy (Table A.4)*	Date of 1 st surgery (Table A.4)*	Stage at diagnosis (Table 2)	Date of 1 st radiotherapy (Table B.12)*	Date of 1 st surgery (Table B.8)*	
Cyprus	71%	100%	94%	Easy			Difficulties
Czech Republic	98%	100%	100%	Routinely			Available
France	99%	50%	97%	Not easy		Not so easy	Difficulties
Ireland	97%	90%	99%	Routinely	Not so easy	Routinely	Collectable
Poland	70%	99%	100%	Routinely or easy			Collectable
Portugal	99%	96%	97%	Routinely	Not so easy	Routinely	Collectable
Slovakia	97%	96%	100%	Easy			Collectable
Slovenia	88%	100%	100%	Routinely			Collectable
Spain	88%	92%	100%	Routinely or easy			Collectable
Netherlands	98%	76%	90%	Routinely			Available

*This percentages include the “treatment not performed” as declared by the cancer registries

** Data for colorectal cancer in general

“Routinely” means that cancer registry have already the variable in own databases

“Easy” is a qualitative indication of cancer registrars on the difficulties to find the variable

Available: all data necessary to calculate the indicator are already present in the CR database

Collectable: all data necessary to calculate the indicator can be obtained with work (and funds)

Difficulties: the indicator can be estimated but it is necessary to give attention to the results

ANNEX TABLES

Tables A. Availability of various variables collected by single country

Tables B. Percentage of cases by type of collection of various variables

Tables C. Percentage of cases by data source of various variables

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Table A.1. Availability of various variables collected by single country. Breast cancer

BREAST CANCER	Cyprus	Czech Republic	Finland	France	Ireland	Poland	Portugal	Slovakia	Slovenia	Spain	The Netherlands	Total
Nr of cases	79	100	100	100	100	191	107	104	125	100	104	1210
Availability of morphology or ICD-O	100%	100%	100%	100%	100%	99%	100%	100%	97%	100%	100%	99.6%
Availability of stage (pTNM a/o cTNM)	95%	97%	100%	99%	100%	97%	99%	100%	98%	99%	99%	98.5%
Availability of complete stage	34%	83%	99%	96%	63%	80%	76%	88%	94%	83%	89%	81.7%
Availability of "Date of first visit with GP"	0%	100%	36%	75%	12%	43%	4%	97%	78%	53%	20%	48.1%
Availability of "Date of first request for clinical appointment"	0%	0%	56%	41%	45%	59%	13%	99%	82%	86%	49%	50.5%
Availability of "Date of first hospital appointment"	0%	100%	100%	87%	63%	85%	99%	100%	98%	98%	100%	86.4%
Availability of "Date of definitive diagnosis"	97%	100%	100%	100%	100%	99%	100%	100%	100%	99%	100%	99.7%
Availability of info on "Date of first surgery"	91%	100%	100%	99%	99%	98%	100%	100%	100%	99%	95%	98.5%
Availability of info on "Date of first chemotherapy"	97%	100%	100%	47%	88%	98%	90%	97%	99%	97%	56%	88.8%
Availability of info on "Date of first radiotherapy"	96%	100%	100%	88%	80%	97%	92%	97%	100%	94%	75%	93.0%
Availability of info on "Date of first endocrine treatment"	96%	100%	100%	81%	73%	97%	85%	94%	96%	93%	50%	88.3%
Availability of at least one pre-diagnostic date	0%	100%	100%	95%	66%	98%	99%	100%	98%	98%	100%	89.4%
Availability of all pre-diagnostic dates	0%	0%	27%	39%	11%	15%	2%	97%	78%	48%	13%	30.4%
Availability of at least one treatment	100%	100%	100%	100%	99%	99%	100%	100%	100%	100%	100%	99.8%

Table A.2. Availability of various variables collected by single country. Colorectal cancer

COLORECTAL CANCER	Cyprus	Czech Republic	France	Ireland	Poland	Portugal	Slovakia	Slovenia	Spain	The Netherlands	Total
Nr of cases	71	100	200	199	233	197	198	255	204	212	1869
Availability of morphology or ICD-O	100%	100%	98%	100%	100%	100%	99%	96%	100%	100%	99.1%
Availability of stage (pTNM a/o cTNM)	80%	97%	99%	97%	65%	99%	98%	90%	86%	97%	90.8%
Availability of complete stage	13%	74%	82%	74%	36%	87%	85%	82%	71%	70%	70.6%
Availability of "Date of first visit with GP"	0%	100%	80%	26%	39%	0%	97%	63%	53%	3%	46.6%
Availability of "Date of first request for clinical appointment"	0%	94%	38%	39%	55%	11%	99%	71%	64%	31%	51.9%
Availability of "Date of first hospital appointment"	0%	93%	95%	70%	77%	97%	99%	98%	99%	99%	88.2%
Availability of "Date of definitive diagnosis"	100%	99%	100%	100%	98%	98%	100%	100%	100%	100%	99.5%
Availability of info on "Date of first surgery"	96%	100%	97%	99%	99%	98%	100%	100%	100%	92%	98.2%
Availability of info on "Date of first chemotherapy"	100%	100%	43%	92%	94%	95%	98%	100%	94%	47%	84.8%
Availability of info on "Date of first radiotherapy"	100%	100%	26%	80%	98%	97%	97%	100%	91%	49%	82.4%
Availability of at least one pre-diagnostic date	0%	100%	97%	74%	95%	97%	100%	98%	100%	99%	91.8%
Availability of all pre-diagnostic dates	0%	93%	35%	18%	12%	0%	97%	63%	46%	3%	36.3%
Availability of at least one treatment	100%	100%	98%	100%	100%	100%	100%	100%	100%	97%	99.3%

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Table A.3. Availability of various variables collected by single country. Colon cancer

COLON CANCER	Cyprus	Czech Republic	France	Ireland	Poland	Portugal	Slovakia	Slovenia	Spain	The Netherlands	Total
Nr of cases	40	57	98	129	121	94	99	127	97	87	949
Availability of morphology or ICD-O	100%	100%	97%	100%	100%	100%	99%	95%	100%	100%	98.9%
Availability of stage (pTNM a/o cTNM)	88%	96%	99%	98%	60%	100%	100%	91%	84%	95%	90.5%
Availability of complete stage	15%	79%	82%	74%	32%	90%	89%	86%	72%	64%	71.0%
Availability of "Date of first visit with GP"	0%	100%	80%	24%	31%	0%	98%	59%	53%	5%	45.4%
Availability of "Date of first request for clinical appointment"	0%	89%	40%	36%	45%	5%	99%	69%	65%	32%	49.8%
Availability of "Date of first hospital appointment"	0%	88%	95%	68%	83%	97%	100%	99%	100%	98%	87.4%
Availability of "Date of definitive diagnosis"	100%	98%	100%	100%	99%	98%	100%	100%	100%	100%	99.6%
Availability of info on "Date of first surgery"	98%	100%	96%	100%	98%	100%	100%	100%	99%	95%	98.6%
Availability of info on "Date of first chemotherapy"	100%	100%	37%	89%	92%	95%	100%	100%	95%	49%	85.2%
Availability of info on "Date of first radiotherapy"	100%	100%	1%	74%	98%	99%	99%	100%	90%	9%	76.4%
Availability of at least one pre-diagnostic date	0%	100%	97%	73%	94%	98%	100%	99%	100%	98%	90.5%
Availability of all pre-diagnostic dates	0%	88%	36%	16%	8%	0%	98%	59%	44%	5%	35.3%
Availability of at least one treatment	100%	100%	97%	100%	99%	100%	100%	100%	99%	95%	99.1%

Table A.4. Availability of various variables collected by single country. Rectal cancer

RECTAL CANCER	Cyprus	Czech Republic	France	Ireland	Poland	Portugal	Slovakia	Slovenia	Spain	The Netherlands	Total
Nr of cases	31	43	102	70	112	103	99	128	107	125	920
Availability of morphology or ICD-O	100%	100%	98%	100%	100%	100%	100%	96%	100%	100%	99.2%
Availability of stage (pTNM a/o cTNM)	71%	98%	99%	97%	70%	99%	97%	88%	88%	98%	91.1%
Availability of complete stage	10%	67%	82%	73%	40%	84%	81%	79%	70%	74%	70.2%
Availability of "Date of first visit with GP"	0%	100%	79%	29%	48%	0%	97%	67%	54%	2%	47.8%
Availability of "Date of first request for clinical appointment"	0%	100%	36%	44%	64%	17%	99%	73%	63%	30%	54.0%
Availability of "Date of first hospital appointment"	0%	100%	95%	73%	71%	97%	99%	96%	98%	99%	89.1%
Availability of "Date of definitive diagnosis"	100%	100%	100%	100%	96%	98%	100%	100%	100%	100%	99.3%
Availability of info on "Date of first surgery"	94%	100%	97%	99%	100%	97%	100%	100%	100%	90%	97.7%
Availability of info on "Date of first chemotherapy"	100%	100%	48%	97%	96%	95%	97%	100%	93%	45%	84.2%
Availability of info on "Date of first radiotherapy"	100%	100%	50%	90%	99%	96%	96%	100%	92%	76%	88.5%
Availability of at least one pre-diagnostic date	0%	100%	96%	76%	96%	97%	100%	97%	99%	100%	93.1%
Availability of all pre-diagnostic dates	0%	100%	34%	20%	17%	0%	96%	66%	47%	2%	37.4%
Availability of at least one treatment	100%	100%	99%	100%	100%	100%	100%	100%	100%	98%	99.6%

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Table B.1. “Date of first visit to general practitioner” variable: percentage of cases by type of collection. Breast cancer

	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	100%	-	-	-	-	-
Czech Republic	-	99%	1%	-	-	-
Finland	64%	32%	2%	-	-	2%
France	25%	-	-	4%	71%	-
Ireland	88%	1%	-	8%	3%	-
Poland	57%	21%	16%	1%	-	5%
Portugal	96%	-	-	-	4%	-
Slovakia	3%	45% easy to find & 51% not easy to find				1%
Slovenia	22%	-	-	27%	51%	-
Spain	47%	20%	1%	13%	19%	-
The Netherlands	80%	20%	-	-	-	-

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

Table B.2. “Date of first visit to general practitioner” variable: percentage of cases by type of collection. Colorectal cancer

	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	100%	-	-	-	-	-
Czech Republic	-	100%	-	-	-	-
France	20%	-	1%	-	79%	-
Ireland	74%	10%	3%	4%	9%	-
Poland	61%	12%	-	24%	2%	1%
Portugal	100%	-	-	-	-	-
Slovakia	3%	70% easy to find & 23% not easy to find				4%
Slovenia	37%	-	-	11%	53%	-
Spain	47%	28%	2%	7%	17%	-
The Netherlands	97%	2%	-	-	-	1%

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

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Table B.3. “Date of first request for clinical appointment” variable: percentage of cases by type of collection. Breast cancer

	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	100%	-	-	-	-	-
Czech Republic	100%	-	-	-	-	-
Finland	44%	51%	1%	-	-	4%
France	59%	-	-	-	41%	-
Ireland	55%	13%	18%	12%	2%	-
Poland	41%	56%	1%	1%	-	2%
Portugal	87%	-	-	3%	10%	-
Slovakia	1%	90% easy to find & 9% not easy to find				-
Slovenia	18%	-	-	28%	54%	-
Spain	14%	45%	17%	15%	8%	1%
The Netherlands	51%	49%	-	-	-	-

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

Table B.4. “Date of first request for clinical appointment” variable: percentage of cases by type of collection. Colorectal cancer

	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	100%	-	-	-	-	-
Czech Republic	6%	94%	-	-	-	-
France	62%	-	-	-	38%	-
Ireland	61%	18%	9%	9%	5%	-
Poland	45%	52%	-	1%	-	1%
Portugal	89%	2%	-	-	8%	2%
Slovakia	1%	78% easy to find & 18% not easy to find				3%
Slovenia	29%	-	-	11%	60%	-
Spain	36%	39%	1%	5%	19%	-
The Netherlands	69%	31%	-	-	-	-

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

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Table B.5. “Date of first hospital appointment” variable: percentage of cases by type of collection. Breast cancer

	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	100%	-	-	-	-	-
Czech Republic	-	99%	-	-	-	1%
Finland	-	95%	-	1%	-	4%
France	13%	-	-	12%	75%	-
Ireland	37%	46%	3%	4%	10%	-
Poland	15%	76%	1%	4%	-	4%
Portugal	1%	77%	15%	-	5%	2%
Slovakia	-	88% easy to find & 7% not easy to find				5%
Slovenia	2%	-	-	60%	37%	1%
Spain	2%	53%	17%	22%	5%	1%
The Netherlands	-	99%	-	-	-	1%

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

Table B.6. “Date of first hospital appointment” variable: percentage of cases by type of collection. Colorectal cancer

	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	100%	-	-	-	-	-
Czech Republic	7%	93%	-	-	-	-
France	5%	14%	-	-	82%	-
Ireland	30%	50%	11%	5%	4%	1%
Poland	23%	62%	1%	13%	-	-
Portugal	3%	86%	6%	2%	3%	2%
Slovakia	1%	77% easy to find & 16% not easy to find				6%
Slovenia	2%	-	-	45%	53%	-
Spain	1%	83%	2%	13%	1%	-
The Netherlands	1%	99%	-	-	-	-

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

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Table B.7. “Date of first surgery” variable: percentage of cases by type of collection. Breast cancer

	Treatment not performed	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	1%	9%	-	-	90%	-	-
Czech Republic	17%	-	83%	-	-	-	-
Finland	1%	-	98%	-	-	-	1%
France	-	1%	77%	-	3%	19%	-
Ireland	3%	1%	96%	-	-	-	-
Poland	15%	1%	62%	-	20%	-	2%
Portugal	1%	-	89%	6%	1%	1%	2%
Slovakia	8%	-	87% easy to find and 4% not easy to find				1%
Slovenia	18%	-	82%	-	-	-	-
Spain	2%	1%	94%	2%	1%	-	-
The Netherlands	2%	5%	89%	-	-	-	4%

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

Table B.8. “Date of first surgery” variable: percentage of cases by type of collection. Colorectal cancer

	Treatment not performed	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	3%	4%	-	-	92%	-	1%
Czech Republic	18%	-	82%	-	-	-	-
France	10%	3%	66%	-	-	21%	-
Ireland	11%	1%	85%	3%	-	1%	-
Poland	4%	1%	59%	-	34%	-	1%
Portugal	2%	2%	89%	2%	-	-	6%
Slovakia	7%	-	83% easy to find & 6% not easy to find				4%
Slovenia	8%	-	92%	-	-	-	-
Spain	8%	-	84%	-	7%	-	-
The Netherlands	5%	8%	84%	-	-	-	4%

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

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Table B.9. “Date of first chemotherapy” variable: percentage of cases by type of collection. Breast cancer

	Treatment not performed	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	52%	3%	-	-	45%	-	-
Czech Republic	53%	-	47%	-	-	-	-
Finland	57%	-	42%	-	-	-	1%
France	-	53%	-	-	4%	43%	-
Ireland	31%	12%	34%	1%	3%	19%	-
Poland	26%	2%	56%		16%	-	-
Portugal	47%	10%	19%	12%	1%	11%	-
Slovakia	37%	3%	54% easy to find & 6% not easy to find				-
Slovenia	52%	1%	47%	-	-	-	-
Spain	39%	3%	38%	1%	10%	9%	-
The Netherlands	1%	44%	53%	-	-	-	2%

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

Table B.10. “Date of first chemotherapy” variable: percentage of cases by type of collection. Colorectal cancer

	Treatment not performed	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	35%	-	-	-	65%	-	-
Czech Republic	65%	-	35%	-	-	-	-
France	1%	57%	-	-	-	42%	-
Ireland	37%	8%	30%	11%	7%	8%	-
Poland	33%	6%	43%	-	18%	-	-
Portugal	39%	5%	15%	26%	2%	11%	2%
Slovakia	51%	1%	30% easy to find & 13% not easy to find				5%
Slovenia	69%	-	31%	-	-	-	-
Spain	46%	6%	40%	-	7%	-	-
The Netherlands	17%	53%	24%	-	-	-	6%

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

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Table B.11. “Date of first radiotherapy” variable: percentage of cases by type of collection. Breast cancer

	Treatment not performed	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	15%	4%	-	-	81%	-	-
Czech Republic	56%	-	44%	-	-	-	-
Finland	39%	-	61%	-	-	-	-
France	-	12%	-	-	7%	81%	-
Ireland	27%	20%	19%	1%	14%	19%	-
Poland	37%	3%	43%	16%	-	-	1%
Portugal	37%	8%	20%	8%	1%	23%	3%
Slovakia	22%	3%	57% easy to find & 16% not easy to find				2%
Slovenia	51%	4%	44%			-	1%
Spain	42%	-	31%	5%	7%	15%	-
The Netherlands	1%	25%	65%	-	-	-	9%

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

Table B.12. “Date of first radiotherapy” variable: percentage of cases by type of collection. Colorectal cancer

	Treatment not performed	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	61%	-	-	1%	38%	-	-
Czech Republic	78%	-	22%	-	-	-	-
France	-	74%	-	-	-	26%	-
Ireland	60%	20%	12%	5%	-	3%	-
Poland	55%	2%	26%	-	16%	-	-
Portugal	62%	3%	11%	15%	3%	6%	1%
Slovakia	64%	3%	24% easy to find & 9% not easy to find				1%
Slovenia	80%	-	19%	-	-	-	1%
Spain	64%	9%	23%	-	4%	-	-
The Netherlands	8%	51%	35%	-	-	-	5%

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

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Table B.13. “Date of first endocrine treatment” variable: percentage of cases by type of collection. Breast cancer

	Treatment not performed	Unknown date	Routinely collected & easy to find	Routinely collected & not easy to find	Not routinely collected & easy to find	Not routinely collected & not easy to find	Info not available
Cyprus	80%	4%	-	-	16%	-	-
Czech Republic	50%	-	50%	-	-	-	-
Finland	21%	-	78%	-	-	-	1%
France	-	19%	-	-	7%	73%	1%
Ireland	9%	27%	32%	18%	7%	6%	1%
Poland	45%	3%	37%	-	13%	-	2%
Portugal	21%	15%	8%	7%	7%	42%	-
Slovakia	48%	6%	35% easy to find & 9% not easy to find				2%
Slovenia	35%	4%	61%	-	-	-	-
Spain	31%	7%	39%	-	5%	18%	-
The Netherlands	11%	50%	36%				3%

“Routinely collected” means that cancer registry have already the variable in own databases; “Easy to find” is a qualitative indication of cancer registrars on the difficulties to find the variable.

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Table C.1. “Date of first visit to general practitioner” variable: percentage of cases by source of data. Breast cancer

	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	100%	-	-	-	-	-	-	-	-	-
Czech Republic	-	-	100%	-	-	-	-	-	-	-
Finland	64%	-	-	26%	-	-	8%	-	-	2%
France	25%	-	-	61%	-	10%	4%	-	-	-
Ireland	88%	-	-	12%	-	-	-	-	-	-
Poland	57%	-	-	42%	-	-	-	-	-	1%
Portugal	96%	1%	-	2%	-	1%	-	-	-	-
Slovakia	3%	6%	-	84%	-	-	2%	-	3%	2%
Slovenia	22%	-	-	54%	-	24%	-	-	-	-
Spain	47%	11%	1%	20%	-	5%	16%	-	-	-
The Netherlands	80%	-	-	20%	-	-	-	-	-	-

Table C.2. “Date of first visit to general practitioner” variable: percentage of cases by source of data. Colorectal cancer

	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	100%	-	-	-	-	-	-	-	-	-
Czech Republic	-	-	99%	1%	-	-	-	-	-	-
France	20%	-	-	44%	1%	34%	-	-	-	2%
Ireland	74%	1%	-	24%	-	-	-	-	1%	-
Poland	61%	-	-	36%	-	-	-	-	-	2%
Portugal	100%	-	-	-	-	-	-	-	-	-
Slovakia	3%	43%	1%	31%	1%	4%	2%	-	15%	2%
Slovenia	37%	-	-	23%	-	40%	-	-	-	-
Spain	47%	2%	-	46%	-	4%	-	-	-	1%
The Netherlands	97%	-	-	2%	-	-	-	-	-	-

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Table C.3. “Date of first request for clinical appointment” variable: percentage of cases by source of data. Breast cancer

	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	100%	-	-	-	-	-	-	-	-	-
Czech Republic	100%	-	-	-	-	-	-	-	-	-
Finland	44%	1%	-	51%	-	-	-	-	-	4%
France	59%	-	-	36%	-	5%	-	-	-	-
Ireland	55%	-	-	44%	-	-	-	-	1%	-
Poland	41%	1%	-	57%	-	-	1%	-	-	-
Portugal	87%	6%	-	5%	-	-	-	-	-	2%
Slovakia	1%	2%	-	1%	-	27%	3%	-	66%	-
Slovenia	18%	-	-	56%	-	26%	-	-	-	-
Spain	14%	29%	31%	18%	-	-	4%	-	-	4%
The Netherlands	51%	4%	-	45%	-	-	-	-	-	-

Table C.4. “Date of first request for clinical appointment” variable: percentage of cases by source of data. Colorectal cancer

	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	100%	-	-	-	-	-	-	-	-	-
Czech Republic	6%	-	94%	-	-	-	-	-	-	-
France	62%	-	-	34%	-	4%	-	-	-	-
Ireland	61%	1%	-	37%	1%	-	-	-	1%	-
Poland	45%	-	-	54%	-	-	-	-	-	-
Portugal	89%	5%	-	4%	-	-	-	-	-	2%
Slovakia	1%	16%	-	36%	1%	22%	2%	-	23%	1%
Slovenia	29%	-	-	30%	-	41%	-	-	-	-
Spain	36%	3%	-	58%	-	3%	-	-	-	-
The Netherlands	69%	1%	-	30%	-	-	-	-	-	-

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Table C.5. “Date of first clinical appointment” variable: percentage of cases by source of data. Breast cancer

	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	100%	-	-	-	-	-	-	-	-	-
Czech Republic	-	-	100%	-	-	-	-	-	-	-
Finland	-	-	-	96%	-	-	-	-	-	4%
France	13%	11%	1%	74%	-	-	-	-	1%	-
Ireland	37%	1%	-	55%	7%	-	-	-	-	-
Poland	15%	-	-	81%	-	-	-	-	3%	1%
Portugal	1%	-	-	94%	2%	-	-	-	-	3%
Slovakia	-	91%	-	4%	-	-	-	-	-	5%
Slovenia	3%	-	-	94%	1%	2%	-	-	-	-
Spain	2%	31%	32%	29%	2%	-	3%	-	-	1%
The Netherlands	-	11%	-	88%	-	-	-	-	-	1%

Table C.6. “Date of first clinical appointment” variable: percentage of cases by source of data. Colorectal cancer

	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	100%	-	-	-	-	-	-	-	-	-
Czech Republic	7%	-	93%	-	-	-	-	-	-	-
France	5%	13%	1%	80%	1%	2%	-	-	-	-
Ireland	30%	10%	-	58%	2%	-	-	-	-	-
Poland	23%	-	-	70%	-	-	-	-	6%	-
Portugal	3%	1%	-	93%	1%	-	-	-	-	2%
Slovakia	1%	54%	1%	39%	1%	1%	1%	-	-	5%
Slovenia	2%	-	-	93%	-	5%	-	-	-	-
Spain	1%	14%	-	80%	4%	-	-	-	-	-
The Netherlands	1%	7%	-	92%	-	-	-	-	-	-

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Table C.7. “Date of first surgery” variable: percentage of cases by source of data. Breast cancer

	Treatment not performed	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	1%	9%	-	-	90%	-	-	-	-	-	-
Czech Republic	17%	-	-	83%	-	-	-	-	-	-	-
Finland	1%	-	-	-	96%	2%	0%	1%	-	-	-
France	-	1%	-	3%	18%	77%	1%	-	-	-	-
Ireland	3%	1%	-	-	16%	80%	-	-	-	-	-
Poland	15%	1%	1%	1%	82%	-	-	-	-	-	-
Portugal	1%	-	-	1%	74%	23%	-	-	-	-	1%
Slovakia	8%	-	88%	-	3%	-	-	-	-	-	1%
Slovenia	18%	-	-	-	79%	3%	-	-	-	-	-
Spain	2%	1%	3%	29%	37%	25%	-	3%	-	-	-
The Netherlands	2%	5%	19%	-	70%	-	-	-	-	-	4%

Table C.8. “Date of first surgery” variable: percentage of cases by source of data. Colorectal cancer

	Treatment not performed	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	3%	4%	-	-	93%	-	-	-	-	-	-
Czech Republic	18%	-	-	82%	-	-	-	-	-	-	-
France	10%	3%	-	-	19%	66%	-	-	-	-	3%
Ireland	11%	1%	-	-	40%	49%	-	-	-	-	-
Poland	4%	1%	-	1%	92%	-	-	-	-	-	1%
Portugal	2%	2%	-	-	81%	14%	-	-	-	-	2%
Slovakia	7%	-	31%	1%	58%	-	-	-	-	2%	3%
Slovenia	8%	-	-	1%	91%	-	-	-	-	-	-
Spain	8%	-	1%	4%	68%	18%	-	-	-	-	-
The Netherlands	5%	8%	19%	-	65%	-	-	-	-	-	4%

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Table C.9. “Date of first chemotherapy” variable: percentage of cases by source of data. Breast cancer

	Treatment not performed	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	52%	3%	-	-	45%	-	-	-	-	-	-
Czech Republic	53%	-	-	47%	-	-	-	-	-	-	-
Finland	57%	-	-	-	42%	-	-	-	-	-	1%
France	-	53%	-	4%	43%	-	-	-	-	-	-
Ireland	31%	12%	-	-	57%	-	-	-	-	-	-
Poland	26%	2%	-	1%	71%	-	-	-	-	-	-
Portugal	47%	10%	-	-	43%	-	-	-	-	-	-
Slovakia	37%	3%	47%	-	9%	-	-	-	-	-	4%
Slovenia	52%	1%	-	-	47%	-	-	-	-	-	-
Spain	39%	3%	-	21%	37%	-	-	-	-	-	-
The Netherlands	1%	44%	13%	-	40%	-	-	-	-	-	2%

Table C.10. “Date of first chemotherapy” variable: percentage of cases by source of data. Colorectal cancer

	Treatment not performed	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	35%	-	-	-	65%	-	-	-	-	-	-
Czech Republic	65%	-	-	35%	-	-	-	-	-	-	-
France	1%	57%	-	1%	40%	2%	-	-	-	-	-
Ireland	37%	8%	-	-	55%	-	-	-	-	-	-
Poland	33%	6%	-	-	61%	-	-	-	-	-	-
Portugal	39%	5%	-	-	53%	1%	-	-	-	-	2%
Slovakia	51%	1%	4%	1%	33%	-	-	-	-	5%	5%
Slovenia	69%	-	-	-	31%	-	-	-	-	-	-
Spain	46%	6%	2%	3%	43%	-	-	-	-	-	-
The Netherlands	17%	53%	4%	-	20%	-	-	-	-	-	6%

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Table C.11. “Date of first radiotherapy” variable: percentage of cases by source of data. Breast cancer

	Treatment not performed	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	15%	4%	-	-	81%	-	-	-	-	-	-
Czech Republic	56%	-	-	44%	-	-	-	-	-	-	-
Finland	39%	-	-	-	61%	-	-	-	-	-	-
France	-	12%	-	7%	81%	-	-	-	-	-	-
Ireland	27%	20%	3%	-	48%	-	-	-	-	2%	-
Poland	37%	3%	-	1%	59%	-	-	-	-	-	-
Portugal	37%	8%	-	-	52%	-	-	-	-	-	3%
Slovakia	22%	3%	36%	-	36%	-	-	-	-	-	3%
Slovenia	51%	4%	-	-	45%	-	-	-	-	-	-
Spain	42%	-	-	18%	39%	-	-	-	-	-	1%
The Netherlands	1%	25%	13%	-	52%	-	-	-	-	-	9%

Table C.12. “Date of first radiotherapy” variable: percentage of cases by source of data. Colorectal cancer

	Treatment not performed	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	61%	-	-	-	39%	-	-	-	-	-	-
Czech Republic	78%	-	-	22%	-	-	-	-	-	-	-
France	-	74%	-	-	24%	-	1%	-	-	-	1%
Ireland	60%	20%	-	-	19%	-	-	-	-	1%	-
Poland	55%	2%	-	-	43%	-	-	-	-	-	-
Portugal	62%	3%	-	-	33%	-	-	-	-	-	2%
Slovakia	64%	3%	3%	1%	23%	-	-	-	-	3%	3%
Slovenia	80%	-	-	-	20%	-	-	-	-	-	-
Spain	64%	9%	2%	3%	22%	-	-	-	-	-	-
The Netherlands	8%	51%	8%	-	28%	-	-	-	-	-	5%

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Table C.13. “Date of first endocrine treatment” variable: percentage of cases by source of data. Breast cancer

	Treatment not performed	Unknown Date	Hospital administr. records	Multidisc. team records	Clinical records	Pathologic reports	Questions to GP/Family doctors	Screening files	Social insurance records	Other sources	Source unknown
Cyprus	80%	4%	-	-	16%	-	-	-	-	-	-
Czech Republic	50%	-	-	50%	-	-	-	-	-	-	-
Finland	21%	-	-	-	77%	-	-	-	-	-	2%
France	-	19%	-	7%	72%	-	1%	-	-	-	1%
Ireland	9%	27%	-	3%	60%	1%	-	-	-	-	-
Poland	45%	3%	1%	-	50%	-	-	-	-	-	1%
Portugal	21%	15%	-	1%	62%	1%	-	-	-	-	-
Slovakia	48%	6%	20%	-	22%	-	-	-	-	2%	2%
Slovenia	35%	4%	-	-	61%	-	-	-	-	-	-
Spain	31%	7%	-	23%	38%	-	-	-	-	-	1%
The Netherlands	11%	50%	10%	-	27%	-	-	-	-	-	2%