

Cancer registration practices ENCR short questionnaire

Fields marked with * are mandatory.

Section 1: Contact information

1.1 Are you the director of the cancer registry?*

- Yes
 No

1.2. Please enter your name

1.3. Please enter your email address

1.4 Name of the director of the registry*

1.5. Email address of the director of the cancer registry*

1.6. In which email would you like to have notifications send by the ENCR?*

2. Registry description

2.1. In which country is the registry situated?*

2.2. Whats is the name of the registry?*

2.3 Registry type*

- Population-based
- Facility-based (Hospital, free-standing laboratory etc.)
- Other

Please describe the type of your registry

2.4 Registry coverage*

- National
- Regional (non-national)
- Other

Please describe the coverage of your registry

2.5 For population-based registries: Please indicate the current or most recent estimation of the area covered by the registry (in Km2)*

2.6 For population-based registries: What is the geographic area covered by the registry?*

2.7 For population-based registries: Please enter the current or most recent estimation of the size of the population covered by the registry (number of inhabitants).*

2.8 For population-based registries: Please enter the year of reference for the number of inhabitants: *
between 1900 and 2014

2.9 Do you collect information on all tumours?*

- No
- Yes, including ONLY malignant melanoma skin cancers
- Yes, including ALL malignant skin cancers

2.10 Which if the following tumours do you register (ICD-O-3)?

- Lip, Oral cavity and pharynx (C00-C14)
- Digestive (C15-C26)
- Respiratory (C30-C39 & Mesothelioma)
- Bone (C40-C41)
- Skin (C44)
- Connective and soft tissue (C47, C49)
- Retroperitoneum & peritoneum (C48)
- Breast (C50)
- Female reproductive (C51-C58)
- Male reproductive (C60-C63)
- Urinary system (C64-C68)
- Nervous system (C69-C72)
- Eye (C69)
- Nervous system (C70-C72)
- Endocrine (C73-C75)
- Haematopoetic (C81-C96)
- Heamatopoetic (9590-9992)
- Other

Please specify which other tumors you register

2.11 Age specificity:

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

Please specify the age

- 0-14 years old
- 0-19 years old

2.12 Please indicate the first year for which there are data in **electronic** form available at your registry
between 1900 and 2014

2.13 What year was your registry established?

between 1900 and 2014

2.14. If your registry coverage area or tumour specialization changed, or the questions above do not reflect accurately your registry's state, please explain briefly below

3. Conditions of cancer registration

3.1. Is there legislation concerning cancer registration in your country/region?*

- No
- Yes

3.2 According to the legislation is cancer registration compulsory?

- Yes
- No

3.2.1 Is such legislation under consideration?

- Yes
- No

3.3 Does any law on privacy (or subsidiary regulations) apply to cancer registration?*

- No
- Yes

3.3.1 Does this law provide exemption from the requirement of informed consent from the patient for the purposes of **cancer registration**?

- No
- Yes

3.2.3. Does this law provide exemption from the requirement of informed consent from the patient for the purpose of **cancer research**?

- No
- Yes

3.4 Do you maintain patient identifiers (ID number, name etc) in your registry?*

- No
- Yes

3.5 Do you have access to death certificates in your registry's coverage area?

- Yes
- No

3.5.1 Are you allowed to use personal identifiers to link cancer registry records to death certificates?

- No
- Yes
- Not applicable

3.5.2 Are you allowed to capture cause of death as well as the date of death?

- No
- Yes
- Not applicable

3.6 Are you allowed to provide data to research projects with personal identifiers of subjects?

- No
- Yes, unrestricted
- Yes, with restrictions
- Not applicable

3.6.1 Please elaborate on restrictions

3.7 Are you allowed to share and publish anonymised individual data?

- No
- Yes, unrestricted
- Yes, with restrictions
- Not applicable

3.7.1. Please explain

4. Funding of cancer registration

4.2. Please estimate the percentage of the available budget coming from each of the different sources listed below (please make sure the figures add to 100%):

	Percent
Government	
Competitive grants	
Health insurance companies	
Cancer society	
Charities	
Other	

5. Data sources

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

Active: Registry personnel actively ascertain cancer records, possibly during visits to data providers.

Passive: Data are received without any requests by the registry

Please select all that apply

	Active	Passive
Hospital oncology registries	<input type="checkbox"/>	<input type="checkbox"/>
Radiotherapy departments	<input type="checkbox"/>	<input type="checkbox"/>
Other hospital records	<input type="checkbox"/>	<input type="checkbox"/>
Autopsy reports	<input type="checkbox"/>	<input type="checkbox"/>
Outpatient clinics	<input type="checkbox"/>	<input type="checkbox"/>
Hospices	<input type="checkbox"/>	<input type="checkbox"/>
Pathology laboratories	<input type="checkbox"/>	<input type="checkbox"/>
Haematology laboratories	<input type="checkbox"/>	<input type="checkbox"/>
Screening programmes	<input type="checkbox"/>	<input type="checkbox"/>
General practitioners	<input type="checkbox"/>	<input type="checkbox"/>
Death certificates (identifiable)	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

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

If applicable to your registry please select systematic OR occasional, otherwise leave blank

	Systematic routine regular	Occasional exceptional ad hoc	Non applicable
Hospital oncology registries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Radiotherapy departments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other hospital records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autopsy reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outpatient clinics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pathology laboratories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Haematology laboratories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Screening programmes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General practitioners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Deth certificates (identifiable)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

If applicable to your registry please select paper OR electronic OR mixed, otherwise leave blank

	Paper	Electronic	Mixed	Non applicable
Hospital oncology registries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Radiotherapy departments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other hospital records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autopsy reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outpatient clinics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pathology laboratories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Haematology laboratories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Screening programmes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General practitioners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Death certificates (identifiable)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. Registration criteria and procedures

6.1 Please provide a detailed description of the tumours collected by your registry (For example: all malignant, newly diagnosed tumours are reportable with the following exceptions: In situ carcinoma of the cervix (CIS), intraepithelial neoplasia grade III of the cervix (CIN III) and intraepithelial neoplasia of the prostate (PIN III) . Basal and squamous cell carcinoma of non-genital skin sites are not reportable. ...)

*

6.2. Do you record in-situ cases for the following sites? If you don't record in-situ cases please skip the question

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

Please specify

6.3. Do you record benign cases for the following sites? If you don't record benign cases please skip the question

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

6.4. Do you record uncertain/borderline behaviour for the following sites? If you don't record uncertain/borderline cases please skip the question

- Urinary bladder
- Ovary
- Other

Please specify

6.5 Do you have a procedure manual or documentation in your registry where all registry functions and coding are described?*

- No
- Yes

6.5.1 Would you make it available for publication on the ENCR website?

- Yes
- No
- Not sure

7. Data collected and coding

7.1. In your registry is the date of incidence defined according to the ENCR recommendations?

Recommendations can be found at <http://www.encl.eu/images/docs/recommendations/incideng.pdf>*

- No
- Yes

7.1.1. Please specify coding rule used for incidence date

7.2. Do you include **date of registration** for incident cases?

- No
- Yes

7.2.1. Please select the definition 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
- Other

7.2.2. Do you have a different definition or any further comments regarding the date of registration? Please describe below

7.3. Regarding the original coding of topography in your registry, please indicate the years of application for each system used:

	From year	To year
ICD-O-3		
ICD-O-2		
ICD-O-1		
ICD-O field trial edition		
ICD-10		
ICD-9		
Other		

Please report other topography coding systems used by your registry, if any

7.3.1 For registries using ICD-O-3 currently: Are all the (old) topography data converted to ICD-O-3?

- No
 Yes

7.4 Regarding the original coding of **morphology** in your registry, please indicate the years of application for the system used:

	From year	To year
ICD-O-3		
ICD-O-2		
ICD-O-1		
ICD-O field trial edition		
ICD-10		
ICD-9		
Other		

Please report other morphology coding systems used by your registry, if any

7.4.1 For registries using ICD-O-3 currently: Are all the (old) morphology data converted to ICD-O-3?

- No
 Yes

7.5 Is the basis of diagnosis recorded according to the ENCR rules?

Recommendations can be found at <http://www.encl.eu/images/docs/recommendations/basisd.pdf>*

- No
- Yes
- Not applicable

Please specify the rules used

7.6 Do you record stage?*

- No
- Yes

7.7 Do you record first course of therapy?*

- No
- Yes

7.8 Please indicate if the following first course of therapy items are collected by your registry:

	No	Yes
Surgery	<input type="radio"/>	<input type="radio"/>
Date of surgery	<input type="radio"/>	<input type="radio"/>
Radiotherapy	<input type="radio"/>	<input type="radio"/>
Date radiotherapy started	<input type="radio"/>	<input type="radio"/>
Chemotherapy	<input type="radio"/>	<input type="radio"/>
Date chemotherapy started	<input type="radio"/>	<input type="radio"/>
Hormonal therapy	<input type="radio"/>	<input type="radio"/>
Date hormonal therapy started	<input type="radio"/>	<input type="radio"/>
Other therapy	<input type="radio"/>	<input type="radio"/>

Please indicate other treatment modalities you collect

8 Permission

Could you please indicate if the data disclosed on this questionnaire could be shared with:

	Yes	No
Other ENCR members*	<input type="radio"/>	<input type="radio"/>
Unrestricted public*	<input type="radio"/>	<input type="radio"/>

If your registry has a web site please provide the address