OVERVIEW OF CANCER REGISTRATION PRACTICES
ENCR Questionnaire

Eurochip-3 WP5
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International Agency for Research on Cancer
World Health Organization

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 XXXXXXXXXX .

The address of your registry is displayed below:
XXXXXXXXXXXXXXXXXXXX

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 pharnyx (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 km2):

……

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[1] patient data?

- □ YesGo 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 ……

[1] *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.encr.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.encr.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.encr.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:

	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
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					

11.4.1. 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:

	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
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 (,).

……