

WP-5 CANCER REGISTRY QUALITATIVE QUESTIONNAIRE PROTOCOL

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POPULATION-BASED CANCER REGISTRY INDICATORS: DISSEMINATION AND PROMOTION

BACKGROUND AND RATIONALE

Since 1960 cancer registries provided population-based, comparative survival statistics for cancer patients. EUROCARE (a co-operative, cancer registry-based project) has collected and analysed survival data on patients diagnosed since 1978. They underlined large differences in cancer survival across Europe. The most recent evaluation on cancer survival among patients diagnosed in 2000-02 (EUROCARE-4 study) showed highest survival rates in the northern European countries and lowest for those in the eastern European countries. Although, patients in eastern Europe had the highest improvement in survival for major cancer sites during 1991-2002.

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

EUROCHIP-1 project started to improve and enlarge a network on cancer including all Member and Candidate States. EUROCHIP-1 proposed a list of health indicators to provide comparable information about the burden, risk factors, management and outcome of cancer, in order to facilitate cancer control across Europe. Among them, three indicators were supposed to be strictly associated with the wide inter-country variation in cancer survival: "stage at diagnosis", "cancer treatment delay" and "compliance with cancer guidelines". The international group of experts engaged by EUROCHIP-2 lease with networks, international agencies, institutions, ministries of health and medical associations by promoting actions, analyzing data, and disseminating results. In addition EUROCHIP-2 promoted pilot studies in 11 countries to study the feasibility of collecting indicators. In most of the countries where pilot studies have been performed, collection was possible but sometimes very expensive. The ongoing EUROCHIP-3 will consider the most important indicators to identify inequalities. Series of specific actions to address them will be developed, so as to establish the pillars of a EU-wide cancer control strategy.

AIMS

The Dutch Comprehensive Cancer Centre North East (CCCNE) is leader of work package 5 from the EUROCHIP-3 project. This work package aims to improve population-based cancer registration of cancer indicators, in particular "stage at diagnosis" (extension of tumour at diagnosis), "cancer treatment delay" and "compliance with cancer guidelines". To promote the collection of these indicators it is necessary to get insight in the present situation in all European cancer registries. Work package 5 addressed the following questions:

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

DESIGN AND DATA RETRIEVAL

To answer the above mentioned questions a questionnaire will be addressed to all European cancer registries. This questionnaire is based on the results of the pilot studies (on the above mentioned indicators) performed by the EUROCHIP-2 project and the ENCR-Cancer Incidence in Five Continents (CI5) questionnaire.

To prevent duplication of effort, the content of the questionnaire has been discussed with other parties like the ENCR and the EUROCOURSE project. To reduce the workload for the CR some questions already asked for other projects (ENCR CI5 questions) were filled out by default.

The final EUROCHIP-3 questionnaire consist of 15 parts: contact details, registry description, conditions of cancer registration, funding of cancer registration, data sources, registration criteria, screening, diagnosis, coding topography and morphology, tumour items, treatment items, follow-up items, guidelines, registry output and finally permission for sharing data.

The complete questionnaire is added in Annex 1.

The invitation to participate and complete the EUROCHIP-3 questionnaire was sent by email to all CR through the ENCR. The email contained an invitational letter (including the webpage and personal code for the CR) and this protocol. The questionnaire was filled out through the web based “gateway”, which was been newly developed at the IARC. This gateway is a protected environment therefore each CR will receive their personal code. The questionnaire was completed by registry staff from existing knowledge of current practice. This might be only one person (a registry manager or director or someone equivalent) or a number of staff with different areas of expertise.

A reminder was send to the CR four weeks after the first invitation.

DATA ANALYSIS AND RESULTS

Descriptive statistics will be used to summarise.

- registry details
- staff and funding
- data sources
- screening
- the use of the CR data

Analysis of the 3 main indicators: “stage at diagnosis”, “cancer treatment delay” and “compliance with cancer guidelines”.

Identification of the CRs who routinely collect data items for these indicators.

Identification of the CRs who can not collect data items for these indicators and identification of the underlying problems.

CONFIDENTIALITY AND DATA SECURITY

Data requested for the EUROCHIP-3 study relate to the European cancer registries. Data requested for this study do not relate to individuals diagnosed with cancer.

For the collection of the data a web based survey tool will be used. The questionnaire will be send to the Cancer Registries who agreed to collaborate through the web based “gateway”, developed at IARC. All CRs receive personal codes to enter the questionnaire. Replies on the questionnaire will be transcribed to a database at the IARC. When the survey is closed the complete database will be send to the CCCNE protected with a password. Analysis will be performed at the CCCNE.

ACCESS TO THE EUROCHIP-3 DATA

The EUROCHIP-3 database is held at the Comprehensive Cancer Centre North East in Enschede the Netherlands, with a backup at IARC. At CCCNE the analysis are carried out. Data will be shared with the ENCR and EUROCOURSE project. In the questionnaire the CR can give permission for sharing data with other ENCR members or sharing data unrestricted to the public.

PUBLICATION POLICY

The EUROCHIP-3 database will be used by WP5 researchers to carry out descriptive statistics. The final report and article of the deliverable results of this study will be send to all participating CRs to provide an opportunity for review. They can comment within four weeks. Other participating projects may publish after the EUROCHIP-3 report and an article has been published. In general, the researchers who performed the analyses and wrote the paper will be first author in the publication.

TIME TABLE

April	2010	Survey distributed to Cancer Registries
June	2010	Survey closed
June – September	2010	Data analyses
October	2010	Report to Cancer Registries

DETAILED RATIONAL

1 Registry details

To improve population based registration it is important to know the current state of the cancer registry in each country and to identify possible problems with the population-based registration. Therefore we ask about the:

- Area covered by de registry: Is the registry national, regional or hospital based. Its population, the surface area, year registry started and area growth in recent years.
These items presents a definition of the area covered by the registry and whether the cancer-registry is population-based (for the entire country).
- Collected tumour types: For which sites are data collected and are besides malignant also benign or in situ cases registered. Most recent complete year and total incidence of this year.
These items present the completeness of registration by tumour types.
- Legislation: Are there specific agreements for cancer registration and is there a legislation limiting the cancer registration.
The presence of laws and rules that make cancer registration a reportable disease can ensure completeness of the registry data collection. However legislation on data privacy can limit data collection and use of data.

2 Staff and funding

Staff and funding are asked to get insight in the possibilities of the CR and the extension of the registration. Therefore we ask about the:

- Staff: Indication of the full-time equivalent (How many working hours a week for 1 FTE). How is the staff distributed.
Total staff in comparison to total incidence and other data gives us information on the registries possibilities. Registration staff can declare possible differences in the method of data collection (passive/active) and the number of different data-items collected, between CR's. The number of epidemiologists can give insight in data analysis and research possibilities.
- Funding: The average annual budget, how the registry is financed and how the budget is distributed.
Total budget in comparison to the incidence and additional data gives information on the registry possibilities. Budget for registration can declare possible differences in data collection between CR's. How the registry is financed gives information on the guaranty on continuity of the registries dataset and gives information on possible differences in the method of data collection (passive/active) and the number of different data-items collected, between CR's.

3 Data sources

This question gives an overview of the availability of different sources for data collection and the effort needed of accessing these sources.

For the collection of data, particularly for the 3 indicators, access to different sources might be of importance. Passive or active data collection gives information on the time and effort needed for collecting data and completeness of the records.

4 Screening

This question gives an overview of the population based screening programmes and whether screening outcomes are included in the cancer registry.

It is important to know whether screening programmes are carried out, because population based screening results in early detection of cancer, is supposed to lower stage at diagnosis and overall survival.

5 Diagnosis

Are date of diagnosis and basis of diagnosis defined according to the ENCR rules.

These questions give information on the comparability of incidence dates.

The possibility of collecting additional dates.

For the indicator treatment delay it is interesting to know which other dates than incidence date are available for registration or are currently collected.

Explanation of the dates

- First visit to primary care physician: date on which patient first consulted the GP with symptoms suggestive of the cancer.
- Screening date: screening date where anything suspicious for cancer was found.
- First out-patient visit to hospital: date on which patient first visit the hospital with symptoms suggestive of the cancer.

- First admission to hospital: hospitalization date for the treatment of the cancer.
- First statement in the medical record by a licensed medical practitioner that the patient has cancer.
- Tumour markers report: Date outcome of tumour markers.
- First Imaging (CT, MRI, ultrasound, mammogram, X-ray): Date of first performed diagnostic imaging.
- Cytology report: Date of first cytology report.
- Histology report: Date of first histology report.
- First multidisciplinary team meeting (pre-treatment): Date of first multidisciplinary meeting where the patient with cancer is discussed.

6 Tumour items

- These questions present which coding systems are used for topography and histology.
These items give information on the comparability of the data between registries.
- Stage: Is stage collected, if not what is the reason and is there an intention to collect stage. If stage is collected since which year, for which tumour types and what staging system is used.
Stage at diagnosis is considered as an important health indicator. If stage is not collected it is important to know the reason why and if there is an intention to collect stage in the near future. If stage is collected it is important to know for which tumour types stage is collected and the what staging system(s) is (are) used, this gives information on the comparability of the data between registries.

7 Treatment

- (Start) date of first treatment, surgical treatment, radiotherapy, chemotherapy and endocrine therapy. If dates are not collected what is the reason and is there an intention to collect treatment dates in the near future. If dates are collected since which year and for which tumour types.
For the indicator cancer treatment delay it is necessary to know the (start) date of treatments. If these items are not collected it is important to know the reason why and whether there is an intention to collect dates in the near future.
- Type of surgical treatment, radiotherapy, chemotherapy and endocrine therapy. If type of treatment is not collected what is the reason and is there an intention to collect these items. If type of treatment is collected since which year and for which tumour types.
For the indicator compliance with guidelines it is necessary to know the type of treatment. If these items are not collected it is important to know the reason why and if there is an intention to collect items in the near future.
- Residue after surgical treatment.
Incomplete resection of the tumour has a strong relation with recurrences and survival but also cancer burden activities. Therefore it is interesting to know whether this item is registered by CRs.

8 Follow-up

Follow-up for local/regional recurrence, distant metastasis, vital status, death certificates used to update vital status, active follow-up and cause of death.

The incidence of recurrences and distant metastasis has a strong relation with cancer survival. Therefore it is important to know whether these items are registered by CRs.

9 Guidelines

This chapter presents which guidelines for what tumour sites exist on national, regional or institutional level.

For the indicator "compliance with clinical guidelines" it is necessary to know which guidelines are currently used by the clinicians working in the geographical area covered by the registry. This question is a first inventory to get more insight in the availability of guidelines. In later stage we will contact some selected registries.

10 Evaluation

This chapter presents how data from the registry are used.

To gain insight in the role of the CR in the improvement of health systems. To obtain an overview how CR data are used.