



INTERNATIONAL AGENCY  
FOR RESEARCH ON CANCER



EUROPEAN COMMISSION  
EUROPE AGAINST CANCER



EUROPEAN NETWORK OF CANCER REGISTRIES

# **REGISTRY REVIEW**

*SUMMARY*

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## **REGIONAL CANCER REGISTRY**

**COMPREHENSIVE CANCER CENTRE  
NORTH NETHERLANDS (CCCNN)**

***GRONINGEN, THE NETHERLANDS***

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## **INTRODUCTION**

The new ENCR Steering Committee established in October 1999 was asked to take forward the issue of reviewing cancer registries. A Working Group was set up and met on 21-22 March 2000. The Working Group produced a background document and constructed a draft questionnaire to form the basis of a structured review. The questionnaire was tested by the Slovenia Cancer Registry. The entire review process was then tested in a cancer registry which volunteered to undergo assessment. This report summarises the pilot review carried out in the Regional Cancer Registry of the Comprehensive Cancer Centre North Netherlands (CCCNN) in Groningen. The report is based on the registry's responses to the questionnaire in advance of the visit, supplemented by discussions during the visit and the observations of the review team.

## **CCCNN REGIONAL CANCER REGISTRY**

### ***History***

On 1 April 1985, an experimental regional cancer registry was started in the province of Friesland. Complete coverage was established in January 1987. From 1987 onwards, cancer registration was gradually implemented in the remaining hospitals in the northern parts of the Netherlands. In December 1988, the last of the 20 hospitals in the CCCNN area gave permission to start cancer registration in their hospital and ascertainment is regarded as being essentially complete since 1989. In 1989 the Netherlands Cancer Registry was established to which the regional cancer registry of the CCCNN regularly submits data. In 1991 following an extensive data conversion effort, the current registration software was fully implemented.

### ***Catchment population***

The CCCNN regional cancer registry covers an estimated population of 2,134,205 (cf the Netherlands: 15,863,950) living in an area of 10,647 km<sup>2</sup> (cf the Netherlands: 33,882 km<sup>2</sup>). Population density is therefore 201/km<sup>2</sup>, somewhat lower than in the Netherlands as a whole (468/km<sup>2</sup>).

### ***Legislative framework***

The co-operation of medical specialists and institutes with the cancer registry is voluntary, however in the CCCNN region all participating institutions are contractually associated with the cancer registry by means of a participation agreement. A regional supervising committee ensures that the privacy of the patient, the institutions and the informants (clinicians and pathologists) is well protected. For privacy sensitive data requests, strict regulations have been in place since the establishment of the registry. Cancer registration is registered at the Dutch Legislation Chamber, a governmental body responsible for supervision of privacy regulations relating to identifiable data. Registration of the registry is mandatory under the WPR (or law on person registration).

### ***Funding and staffing of the registry***

Cancer registration is paid for indirectly by the Ministry of Health as one of the tasks of the Comprehensive Cancer Centres (CCC). In addition to the Head of Registration and Research, there are a further 1.7 whole time equivalent (WTE) epidemiologists working in the registry. There are 10.1 WTE involved in registration, training, and data management for clinical trials.

An organisation chart which summarises the management structure of the registry is contained in [Figure 1](#).

### ***Staff training and continuous professional development***

New registry staff receive intensive internal training in cancer registration (and data management). Training consists of theoretical education by one experienced registrar and practical training by senior staff members within the hospitals. Cancer registration training takes about six months.

### ***Registration procedures***

Registrations are identified from the following sources: hospital discharge records, histopathology records, cytopathology records, haematology records, and records from one of the four radiotherapy departments. In addition, registry staff has access to hospital medical records (including inpatient and outpatient records, imaging reports, and reports of hospital autopsies). Registration is an active process for all new tumours involving verification and direct abstraction of relevant items from the medical records of the patient. Electronic records are only available currently for hospital discharge records, histopathology records, cytopathology records and some hospital medical records. The diagnostic coding of hospital discharge records is not reliable enough to make registrations without reference back to medical records. Death records are not available to the registry because of restrictive legislation. CCCNN also receives notifications routinely from other regional cancer registries. Regular matching takes place with breast screening records to ensure that no screen-detected cancers have been missed and to enable studies of interval cancers.

Currently, the registration method is largely manual. It begins with the initial notification (on paper forms) by the pathology laboratories which triggers the actual abstracting of data from medical files and finally the recording of the data in the cancer registry databank. Medical charts act as the gold standard for medical information and pathology reports as the gold standard for pathological information. If the registry receives notification of revision of a pathology diagnosis, this later diagnosis overrules the initial diagnosis. Staging is performed by the registry staff, according to the TNM system, when appropriate, based on all available information in the medical charts and using coding directives. If there are major discrepancies in information or stage the responsible physician is consulted by the registry staff. Registrations are not usually made on the basis of a single type of source record without corroborating evidence.

After the end of the year, the registry holdings are checked against computerised hospital discharge records when they become available with a view to identifying any (mainly clinically diagnosed) cases which have not already come to the attention of the registry through pathology records. Although this procedure initially identifies many apparently missed cases, a high proportion turn out to be ineligible for registration once medical records have been consulted.

Registrations are monitored by month of incidence and hospital. Possible registration deficits result in analysis by pathology laboratory for the number of cases notified by each laboratory for all hospitals in their catchment area for each of several consecutive weeks (since the registry receives weekly lists of all possible new malignancies for all hospitals in the region). Some aspects of data quality, such as the proportion of non-specific topography codes and various coding checks, are monitored regularly. However, other standard IARC indicators of data quality, ie, %MV, (and since death records are not readily available) %DCO and M/I ratio, are not monitored routinely by region/district.

The regional cancer registries submit data annually on all newly diagnosed tumours in their catchment area to the national cancer registry. The national cancer registry in turn submits data on patients resident in one area but diagnosed or treated in another area to the cancer registry in which the person resided at the time of diagnosis of his/her cancer.

The registry procedures are shown in more detail in [Figure 2](#).

### ***Linkage of records within the cancer registry and validation***

Record linkage is based on the unique key code for every individual patient. For practical reasons linkage is based on the first four characters of the (maiden) name (last name) of the patient, the first character of the surname of the patient, the sex (gender) of the patient and the date of birth of the patient. Currently, the cancer registry is basically a tumour registry. The registry is not person-based. However, a number of procedures are in place to minimise the risk of duplicate registrations.

A series of computerised validation checks are in place, including range checks and cross checks, such as sex vs tumour site.

### ***Classification and coding***

From 1993 until 2001, CCCNN used the ICD-O-2 classification for morphology (adapted for the Netherlands) and ICD-O-1 classification for topography. Until 1992 the ICD-O-1 classification was used for morphology. Currently CCCNN is recoding topography codes from ICD-O-1 to ICD-O-2 for the time period 1993 - 2000. ICD-O-3 has been used since January 2001. The registration clerks are responsible for diagnostic coding. They are mainly health care professionals, such as nurses, trained in cancer registration methods and data management. The check program validates their coding. The registry attempts to collect staging information where possible (TNM classification where applicable, extent of disease for the remainder).

### ***Information technology***

The registry computer application was developed and is maintained in cooperation with three other regional cancer registries in the Netherlands. Hardware and software are maintained and serviced by the ICT departments and registry staff of the cancer centres. Daily back-ups are made but only stored for one day. Monthly, a back-up tape is brought to the bank and stored in a safe. It is tested regularly. As noted previously, the back-up system has potential 'gaps' - in the worst case, events from four weeks could be lost. CCCNN has access to e-mail and the internet. The registry has its own website at [www.ikn.nl](http://www.ikn.nl) and records 50-60 hits per day. Some requests for data can be received through the CCCNN website.

### ***Data protection, security and confidentiality***

CCCNN have documented guarantees designed to protect the privacy of individuals and the integrity of the data. In the CCCNN office, only limited details are held about the patient. Identification is only possible by combining the stem (first four letters) of the maiden name, the date of birth, gender, and first initial (encrypted). Registration staff working in hospital, staff processing the information and researchers have to sign an oath of secrecy. Data are only transported on diskettes in encrypted form and in lockable bags. No identifiable data are mailed or e-mailed. There are various security measures in place to protect against illicit entry to the information stored on computer.

### ***Release of potentially identifiable data***

Release of potentially identifiable data is overseen by the regional supervisory committee of CCCNN and involves the signing of a standard agreement which places a number of obligations on the data recipient, designed to protect the privacy and confidentiality of individuals.

### ***Routine output***

The registry has produced and distributed a comprehensive incidence data publication covering the period 1989-94. Currently, there is not a systematic programme or plan for registry output. Until recently all hospitals were provided yearly with data on the number of new malignancies recorded in the cancer registry, stage distribution and initial treatment. Data are routinely fed back to clinicians through the tumour working groups and through the yearly report, to the oncology committees of the hospitals in the CCCNN region. Data are also provided on an *ad hoc* basis to hospitals in the region.

### ***Participation in studies and publications***

The CCCNN conducts research and provides support for studies being conducted by other organisations and research institutes. The CCCNN also conducts research into patient education and counselling and supports mass screening programmes for breast cancer and cervical cancer in the region.

Data from CCCNN are included in the IARC monographs, *Cancer Incidence in Five Continents*, as part of the national Netherlands Cancer Registry. CCCNN have also contributed to the EUROCIIM databases from the outset. Participation in ACCIS will again be through the national Netherlands Cancer Registry.

A number of peer-reviewed articles involving members of staff of CCCNN have been published. The output is balanced towards health service research reflecting the registry's close links to the clinical community. However, there is a desire to expand the research portfolio into other aspects of cancer control and the registry is hoping to obtain funding for a collaborative case-control study of lip cancer, following on from a study of the descriptive epidemiology of this disease in the Netherlands.

## CONCLUSIONS AND RECOMMENDATIONS

The registry has five main areas of weakness, of which staff are already aware:

- 1) Completeness. The registry does not have access to all death records. This is a shortcoming that may have implications for ascertainment. Based on research elsewhere in the Netherlands, CCCNN estimate that they fail to identify approximately 1% of cases (0-5% depending on cancer site) through lack of access to death records. Most of these cases are elderly. The CCCNN also misses all non-hospitalised patients.
- 2) Follow-up. The implications of lacking death certificates (or other means of full-coverage follow-up for vital status and emigration) are more serious for population-based survival analysis, a basic aspect of evaluation of any cancer control strategy.
- 3) Uniqueness of identifying 'key'. The limited items of identifying data held by the registry mean that identifying keys are not necessarily unique to an individual. Although this probably represents a minor problem at present, it will increase in significance as the registry accumulates more data.
- 4) Limited automation. The current cancer registry is very labour intensive with almost no automation. This increases the risk of transcription errors, restricts the number of data items, which can be recorded, and impedes follow-up of registered cases. A new, partly automated cancer registry system is currently being developed and should represent a major step forward. However, this will not obviate the need to access medical records in order to verify information gathered electronically, reconcile apparently conflicting information, and abstract information that cannot be captured electronically at present. Because only coded information is collected, there are limited means to observe errors in basic data or to understand finer details than the codes allow.
- 5) Research. The use of registry data is restricted by a deficit of sufficiently trained epidemiologists and most of the registry's research output is biased towards health services. Ideally, a cancer registry should aim to have a balance of research covering the spectrum of cancer control activities, including research into aetiology, screening and outcome. In relation to research, the

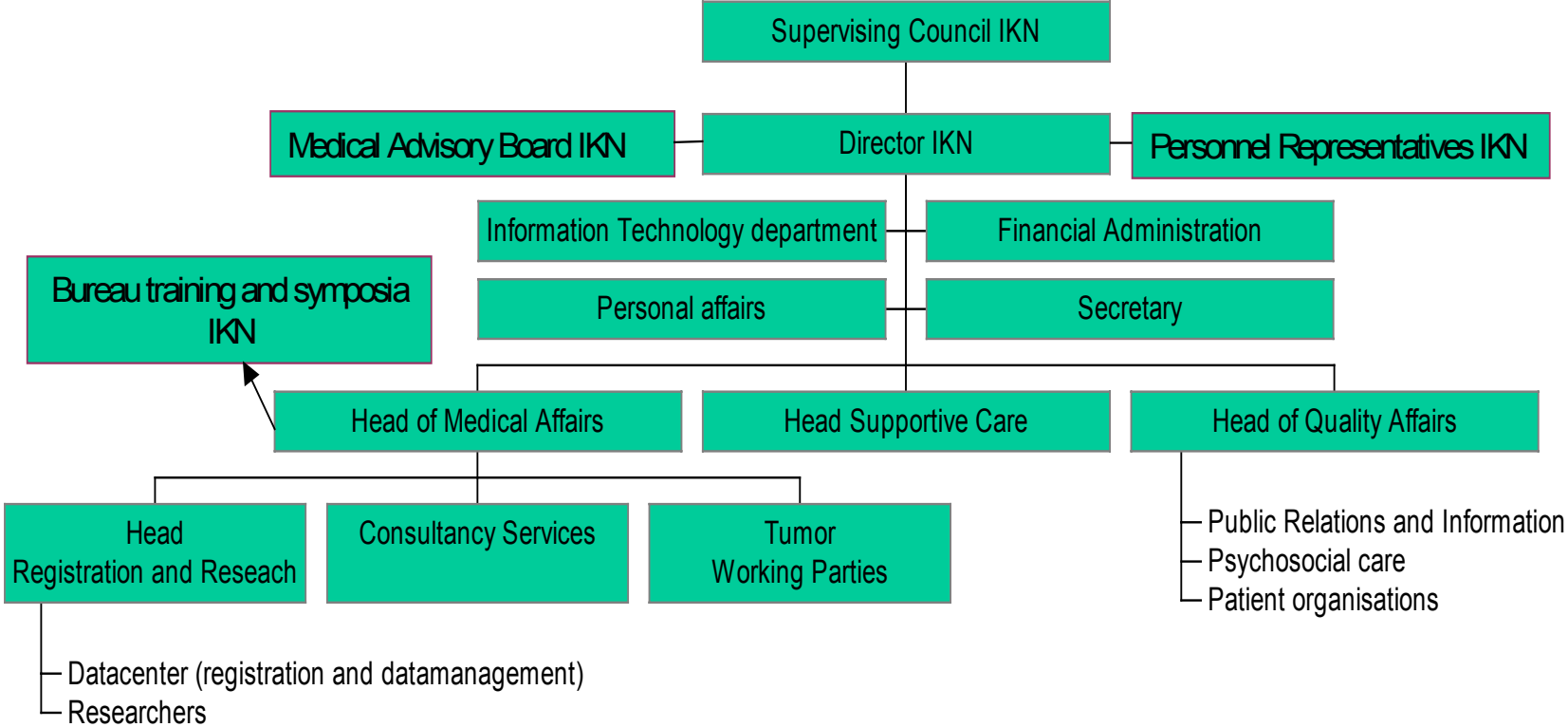
collaboration with other regional cancer registries in the Netherlands and participation in international projects is limited and only two of the regional registries have direct access to the national cancer registry database.

It is recommended that CCCNN, in collaboration with the other Netherlands cancer centres and patient groups, lobby politicians to enable access to death records with appropriate confidentiality safeguards, as is the case in many other European countries.

It is recommended that the registry move to storing all identifying information, including full name. If legislation is required to permit this, we recommend that CCCNN, in collaboration with the other Netherlands cancer centres and patient groups, lobby politicians to enact legislation to safeguard cancer registration and its related activities, while providing reassurances to the public about the privacy and uses of their data. Access to death records (see above) could be encompassed within such legislation. Examples of appropriate legislation are available from other European countries.

It is recommended that efforts are made to increase the amount of collaboration with the other regional cancer registries, thereby minimising any duplication of effort. In addition, it might be possible for the national registry to undertake some functions on behalf of all the regional registries, eg, preparing regional data for publication on the internet. National data should also be readily available to epidemiologists working within regional registries, provided there are safeguards in place to ensure no duplication of research projects. If the epidemiologists in different regional centres collaborated more extensively and specialised in different areas, together they would form a strong research team, and the data covering the whole of the Netherlands would be sufficiently large for meaningful analytical studies.

**FIGURE 1 – CCCNN MANAGEMENT STRUCTURE** (provided by CCCNN, not edited)



**FIGURE 2 - SCHEMATIC DESCRIPTION OF CURRENT REGISTRATION PRACTICE** (provided by CCCNN, not edited)

