Cancer registries in Europe are needed everywhere

Are cancer registries needed everywhere in Europe?

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History of cancer registration

The first efforts to estimate the number of new and existing cases of cancer in a given population were made at the turn of the XIX and XX century in various European countries.

In Germany, an attempt was made in 1900 to register all cancer patients who were under medical treatment.

The same approach was adopted between 1902 and 1908 in Denmark, Hungary, Iceland, the Netherlands, Portugal, Spain and Sweden.

The first population-based cancer registry was set up in Hamburg (Germany) in 1929.
CANCER REGISTRATION IN EUROPE

1900-1939  Cancer ‘surveys’
1929       Hamburg Public Health Department: voluntary registration
1942       Danish Cancer Registry
           from 1945  England and Wales (SW Region)
           1948     England and Wales (SW Region)
           1950     Slovenia
           1952     Hungary, Norway
           1953     German Democratic Republic, Finland
           1954     Iceland
           ……

Result: Three broad patterns of cancer registration:

1. NATIONAL CANCER REGISTRIES:
   Nordic countries
   Baltic states
   Austria, Slovenia, Slovakia, Czech Rep., Croatia, Ireland, Malta, etc
CANCER REGISTRATION IN EUROPE

2. FEDERAL (National coverage by regional registries)
   Sweden (5), Netherlands (9), England & Wales (10)

3. REGIONAL: France, Italy, Switzerland....

CANCER REGISTRATION
International coordination

1946   Copenhagen meeting (12 experts)
Recommend:
• collection of cancer data from as many different countries as possible
• data to be collected on agreed plan, to be as comparable as possible
• each country should have central registry for recording and collection of data
• Should be international body to correlate data and statistics from each country

1950   WHO Subcommittee on cancer registration and statistics
       recommendations for establishment of cancer registries

       UICC Committee on Geographical Pathology

1965   International Agency for Research on cancer (IARC)

1966   International Association of Cancer Registries (IACR)
EUROPEAN NETWORK OF CANCER REGISTRIES

- Project (established in 1989) within the framework of the:
  - CANCER PROGRAMME OF THE EUROPEAN COMMISSION

- ENCR Secretariat located at IARC, Lyon

Objectives of ENCR

- to promote the use of cancer registries in cancer control, health-care planning, and research
- to improve quality, comparability and availability of cancer incidence data
- to create a solid basis for monitoring incidence and mortality in the European Union
- to provide regular information on the burden of cancer in Europe
Areas covered by registries included in at least one of the two most recent volumes of Cancer Incidence in Five Continents.
Are cancer registries needed everywhere in Europe?

- Every country?

The establishment of a population-based cancer registry is highly desirable in the development of a national cancer control programme.

[population based] registries are useful in the context of documenting the cancer patterns in a given region/country, in measuring cancer burden and in studying survival from cancer as well as in evaluating trends in the incidence of cancers over time.

Thus they are valuable for the evaluation of national cancer control programmes.

Hospital-based information systems provide valuable sources of information regarding methods of diagnosis, stage distribution, treatment methods, response to treatment, and survival, although accurate information on cancer incidence is unobtainable because of case referral and population coverage issues.
World Health Assembly resolution (WHA58.22) May 2005
Cancer prevention and control

requests member states of WHO “to develop appropriate information systems, including outcome and process indicators, that support planning, monitoring and evaluation of cancer prevention, control and palliative care programmes”

asks the Director General of WHO “to advise Member States, especially the developing countries, on development or maintenance of a national cancer registry containing the type, location of the cancer and its geographical distribution”.

Are cancer registries needed everywhere in Europe?

- Every country
- National?
Why not just a sample of the population?
The USA managed fine with just the SEER program for 25+ years

Based on a sample, one can:
- estimate national incidence
- (estimate national survival)
- study time trends, variations by “personal” variables (race, SES, etc)
SAMPLE REGISTRATION: Drawbacks

Not satisfactory for follow up of cohorts (eg, EPIC in France)

Not satisfactory for evaluating National cancer programmes
  ➢ screening
  ➢ studies of cancer care variations

% population coverage (≈ cost)
Are cancer registries needed everywhere in Europe?

- **Every country**
- **National**
- **Single registry or federation of regional registries?**

**SINGLE REGISTRY:**

**PRO:**
- No problem of different definitions & conversions
- No need for “cross notification”
- Economies of scale

**CON:**
- Technical- size of databases, speed of processing
- Organisational- staff management, supervision, morale
There are advantages to a national registry – but consider cost

CONCLUSIONS

Cancer registries in Europe are needed in every country (with a NCCP)

Consider >1 registry for populations greater than 5 million
Thank you