

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 HISTORY

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:

CANCER REGISTRATION IN EUROPE

1. NATIONAL CANCER REGISTRIES:

Nordic countries

Baltic states

Austria, Slovenia, Slovakia,
Czech Rep., Croatia,
Ireland, Malta , etc

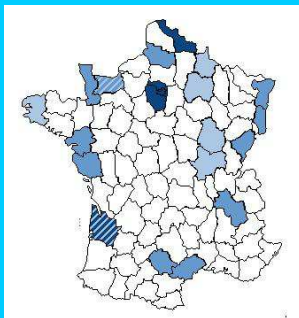


CANCER REGISTRATION IN EUROPE

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)



**E
N
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R**

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**



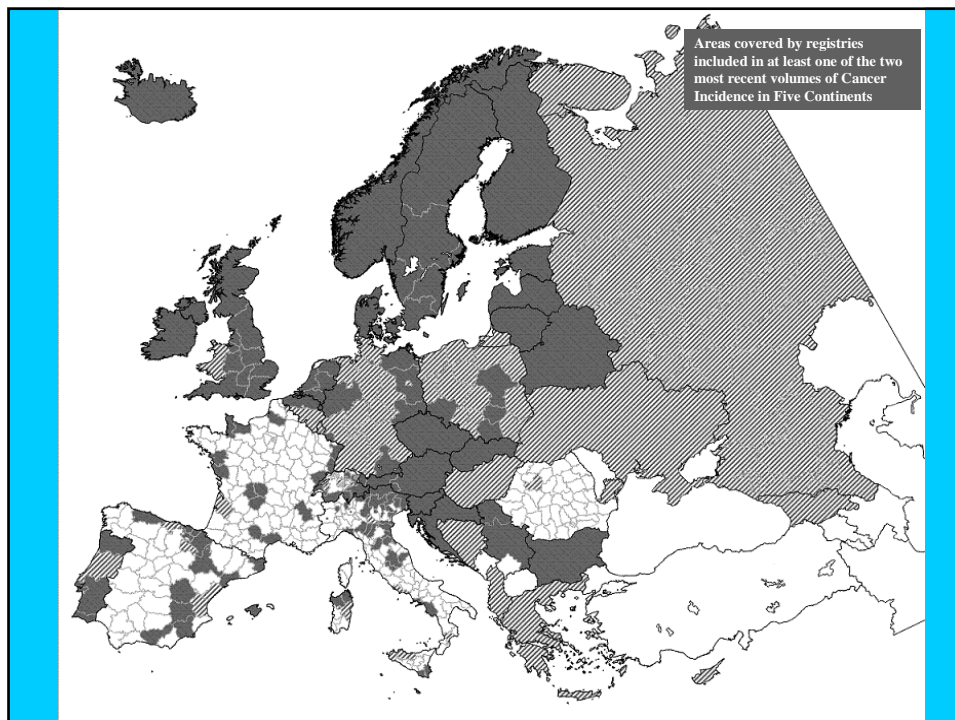
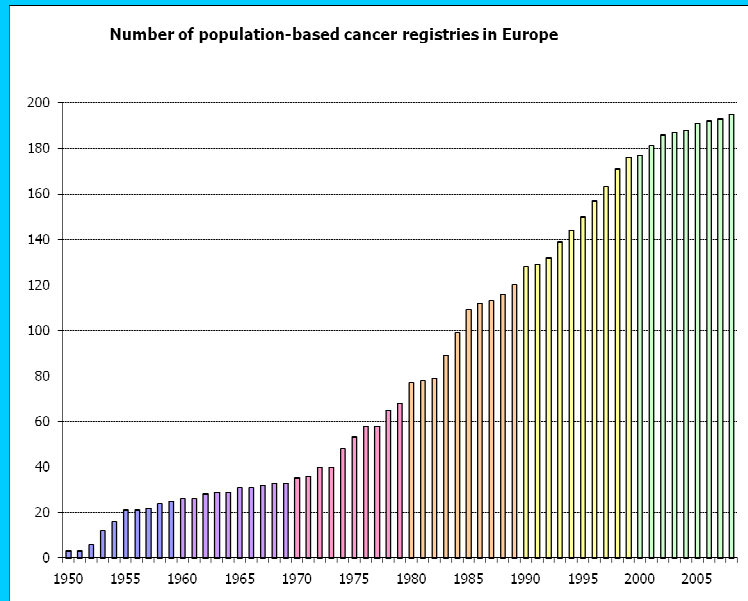
**to promote the use of
cancer registries in cancer
control, health-care
planning, and research**

**to improve quality,
comparability and
availability of cancer
incidence data**

Objectives of ENCR

**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**



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**

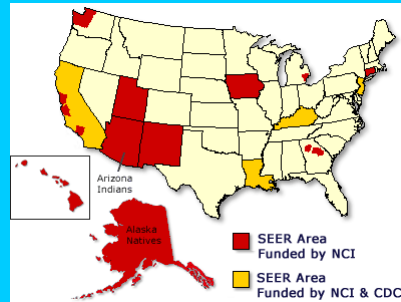
requests member states of WHO “to develop appropriate information systems, including outcome and process indicators, that support planning, monitoring and evaluation of cancer prevention, control and palliative care programmes”

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

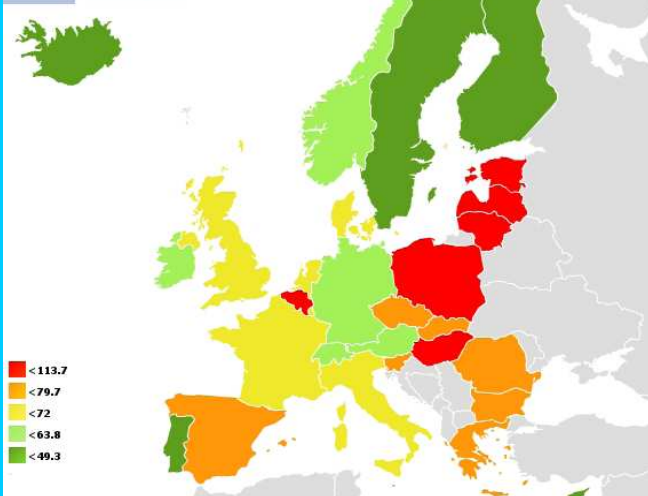


European Cancer Observatory

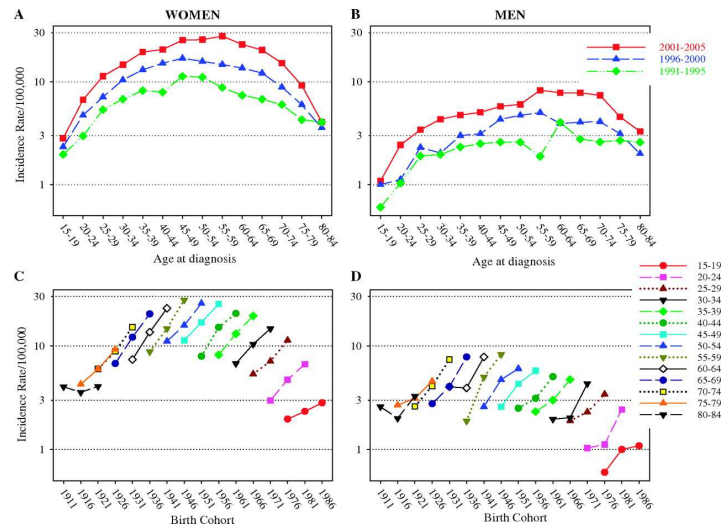
International Agency for Research on Cancer

World Health Organization

CLARA



Age-specific incidence rates of papillary thyroid carcinoma by period of diagnosis (A, B) and birth cohort (C, D) and sex, Italy, 1991–2005. Fifteen cancer registries.



Dal Maso L et al. Ann Oncol 2011;22:957-963

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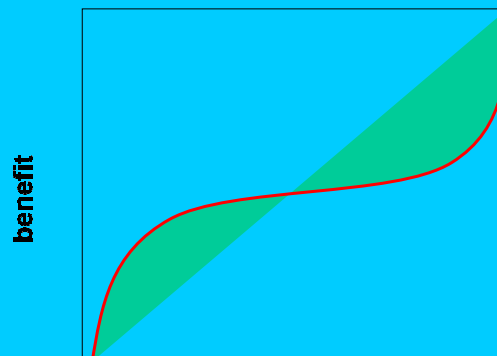
Annals of
Oncology

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



EUROCOURSE

% population coverage (~ cost)

Are cancer registries needed everywhere in Europe?

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



SINGLE REGISTRY:

PRO:

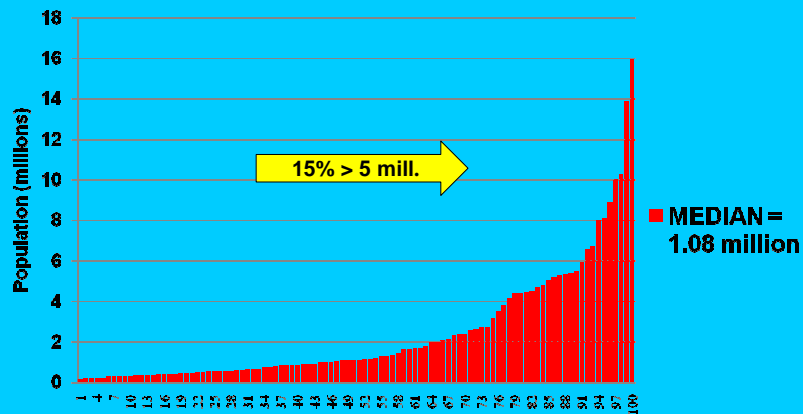
- No problem of different definitions & conversions**
- No need for “cross notification”**
- Economies of scale**

CON:

- Technical- size of databases, speed of processing**
- Organisational- staff management, supervision, morale**



European registries in C15 ix ($n = 100$)



CONCLUSIONS

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

There are advantages to a national registry
– but consider cost

Consider >1 registry for populations greater than 5 million

Thank you



EUROPEAN NETWORK OF
CANCER REGISTRIES