

Cancer registration in Europe

Results of the ENCR questionnaire

UKACR NCIN meeting London June 2011

Annemiek Kwast, Researcher

Sabine Siesling, PhD, epidemiologist

Head of the department of Research

Comprehensive Cancer Centre the Netherlands

EUROCHIP Wp5

Annemiek Kwast, researcher CCCNL

Renee Otter, foreign affairs CCCNL

Anna Gavin, Northern Ireland CR

Jean Michel Lutz, NICER, Switzerland

ENCR/EUROCOURSE

Marc O'Callaghan, National Cancer Registry of Ireland

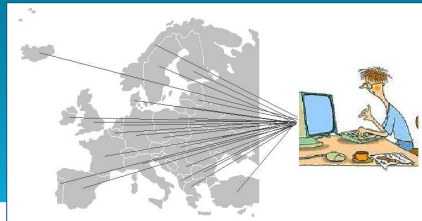
Eva Steliarova-Foucher, ENCR Scientific Coordinator

Jan Willem Coebergh, leader EUROCOURSE

Stefano Rosso, chair ENCR

**Aim: To get insight in the present situation
in all European cancer registries**

**Invitation to complete the questionnaire
was send to 206 cancer registries (ENCR
members).**



Topics covered by the survey 1

- Start of the CR
- Budget and funding
- Data sources used
- Registration criteria
- Cancer screening

Topics covered by the survey 2

- Cancer diagnosis
- Tumour stage
- Treatment information
- Follow-up information
- Available guidelines
- Registry output

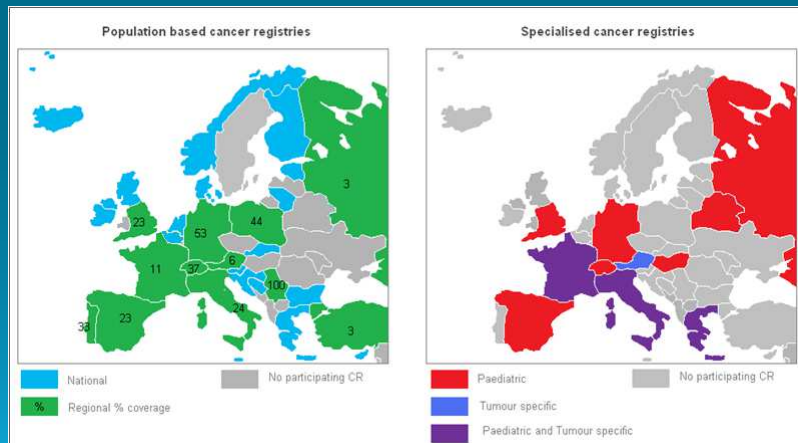
Responders

103 CR from 35 countries reacted (50%)

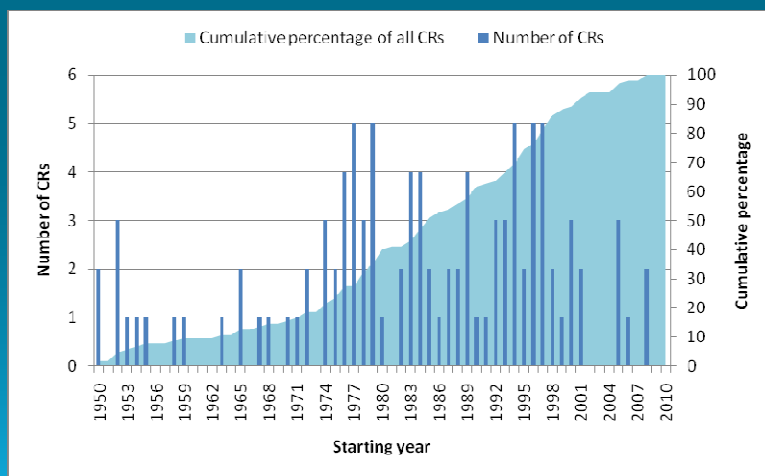
Population based:
21 national CRs,
65 regional CRs

17 specialised CRs

Heterogeneous



- Number of started CRs over time and the cumulative percentage of the CRs over time.



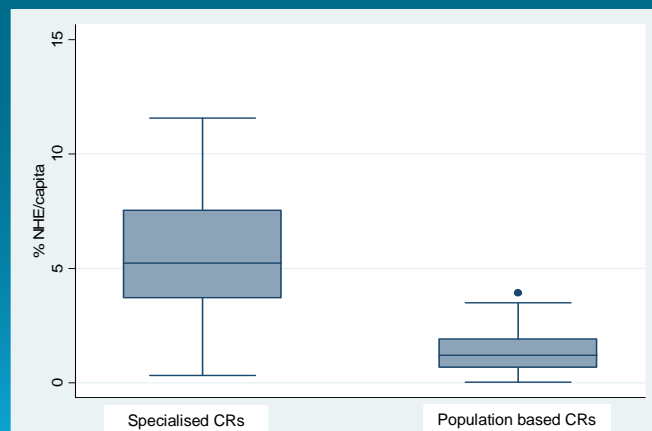
Funding

- Available budget for specialised and population based CRs.
- Two outliers for the specialised CRs were excluded

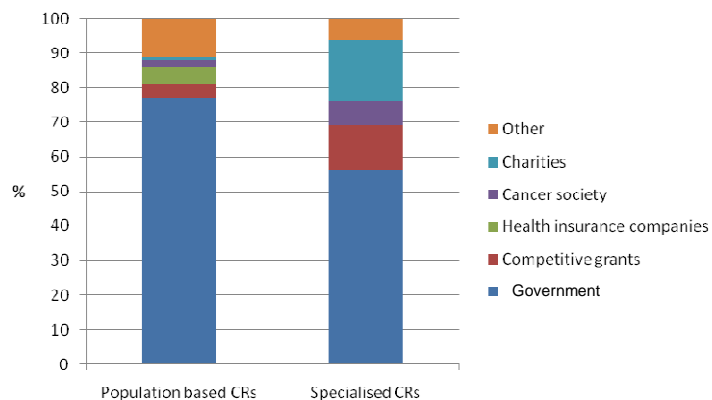
Formula:

$$\frac{\text{Budget for data collection and processing per cancer case}}{\text{NHE per capita}} \times 100$$

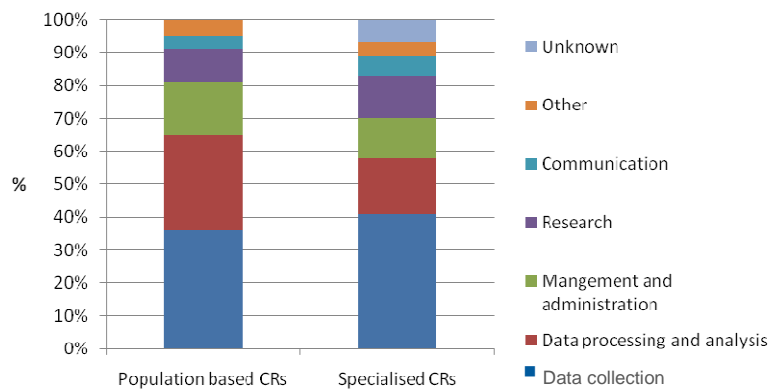
Available budget for specialised and population based CRs .



Distribution of budget sources



Available budget per activity



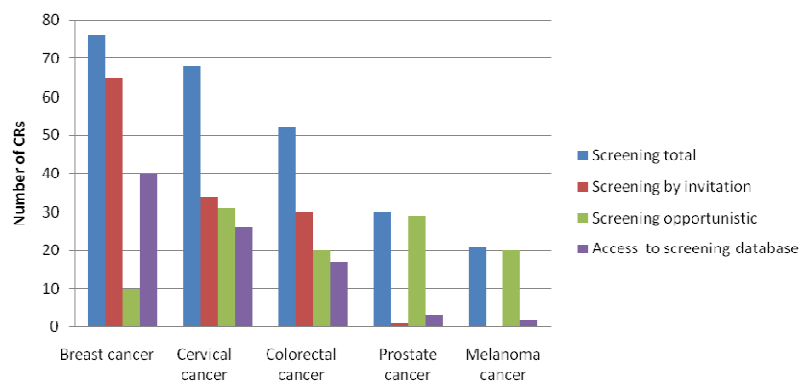
Data sources used

- 100% pathology reports
- 93% hospital records
- 83% radiotherapy departments
- 78% death certificates

Registration criteria

- Benign and in situ
 - All 31%
 - Brain 69%
 - Urinary bladder 62%
 - Cervix 62%
 - Breast 69%

Screening activities for population based CRs (N=86)



Cancer diagnosis:

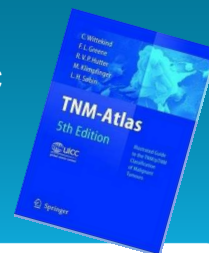
- Incidence date 92% according to ENCR rules
- 69% includes date of registration

Pre diagnostic dates:

- 10% first visit to primary care physician
- 21% screening date
- 16% first out-patient visit to hospital
- 35% first hospital admission
- 38% first mention of cancer in a medical record

Tumour stage

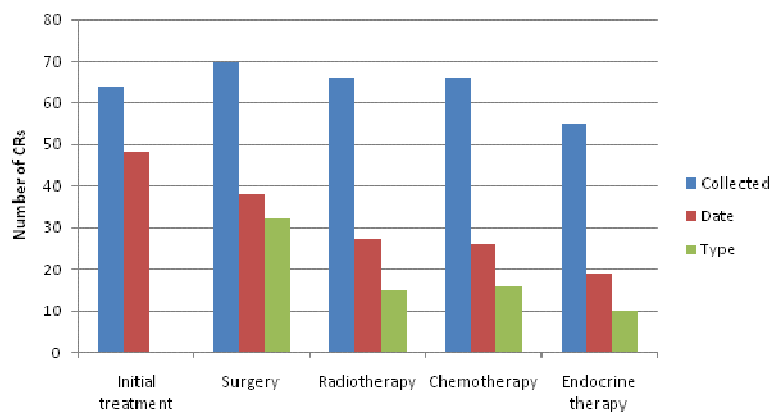
- 93% basis diagnosis ENCR
- 90% collect stage
 - 39% TNM
 - 42% TNM and tumour specific



Reasons for not collecting stage (9 CR)

- 44% lack of finances
- 67% lack of staff
- 67% lack of acces

Available treatment items



Not gathering dates on treatment mainly

- lack of finances: 30%
- lack of access: 30%
- lack of staff: 30%
- And less due to lack of interest

Follow-up

- 88% vital status
- 78% date of follow-up
- 77% cause of death
- 33% distant metastases
- 24% local recurrences
- 79% death certificate is used for vital status

Ongoing work:

- Report
- Feedback to CR (webbased)
- Aim for 100% participation