Cancer registration in Europe
Results of the ENCR questionnaire

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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:

\[
\text{Budget for data collection and processing per cancer case} \times 100 \div \text{NHE per capita}
\]
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%
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
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