European
Commission

Involvement of European cancer registries in measuring Patient Reported Outcome Measures in colorectal cancer

LUCIANA NEAMȚIU, SILVIA DEANDREA*, LIISA PYLKKÄNEN (1)

Joint Research Centre, European Commission, Ispra, Italy.
* *Currently,* Health Protection Agency, Milan Metropolitan Area, Milan, Italy. (1) Department of Oncology, University of Turku, Finland.

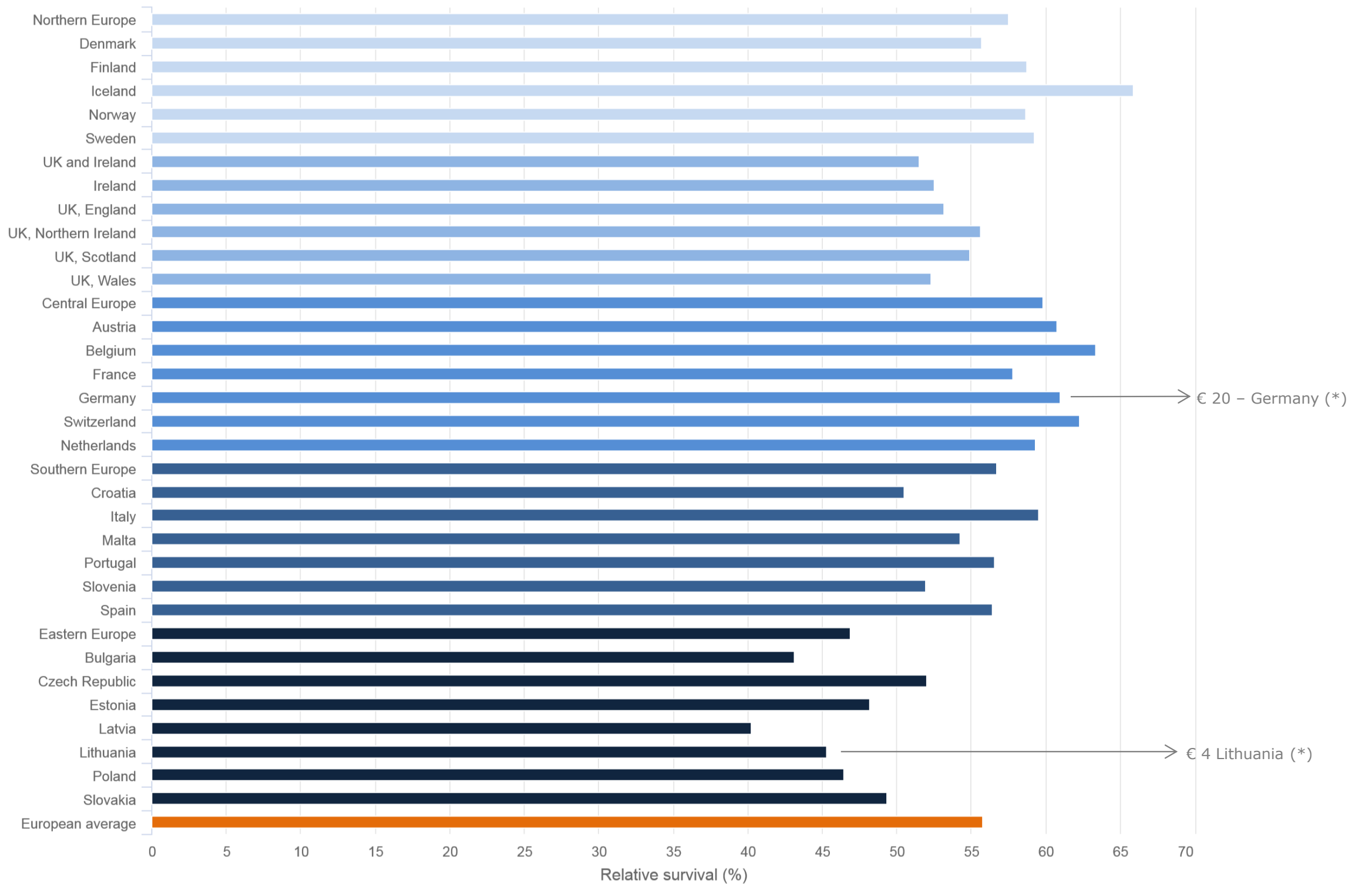
BACKGROUND

The incidence of colorectal cancer in Europe is increasing. The disease and its treatment can have profound impacts on the patients' quality of life (QoL), emphasising the importance of measuring and monitoring the disease burden. An important tool in this process is the Patient Reported Outcome Measures (PROMs).

OBJECTIVE

The goal of this study is to give an overview on the use of PROMs throughout the colorectal cancer care pathway in Europe, and to describe the role of cancer registries (CR) in this process.

Colorectal cancer: inequalities in the EU
Age-standardised 5 years relative survival by country
Both sexes, Colon Rectum, 15+ years, 2000-2007



European regions are defined as following:
- ▨ NORTHERN EUROPE: Denmark; Finland; Iceland; Norway; Sweden
- ▨ UK AND IRELAND: Ireland; UK, England; UK, Northern Ireland; UK, Scotland; UK, Wales
- ▨ CENTRAL EUROPE: Austria; Belgium; France; Germany; Switzerland; The Netherlands
- ▨ SOUTHERN EUROPE: Croatia, Italy, Malta, Portugal, Slovenia, Spain
- ▨ EASTERN EUROPE: Bulgaria, Czech Republic, Estonia, Latvia, Lithuania, Poland, Slovakia
- ▨ EUROPEAN AVERAGE

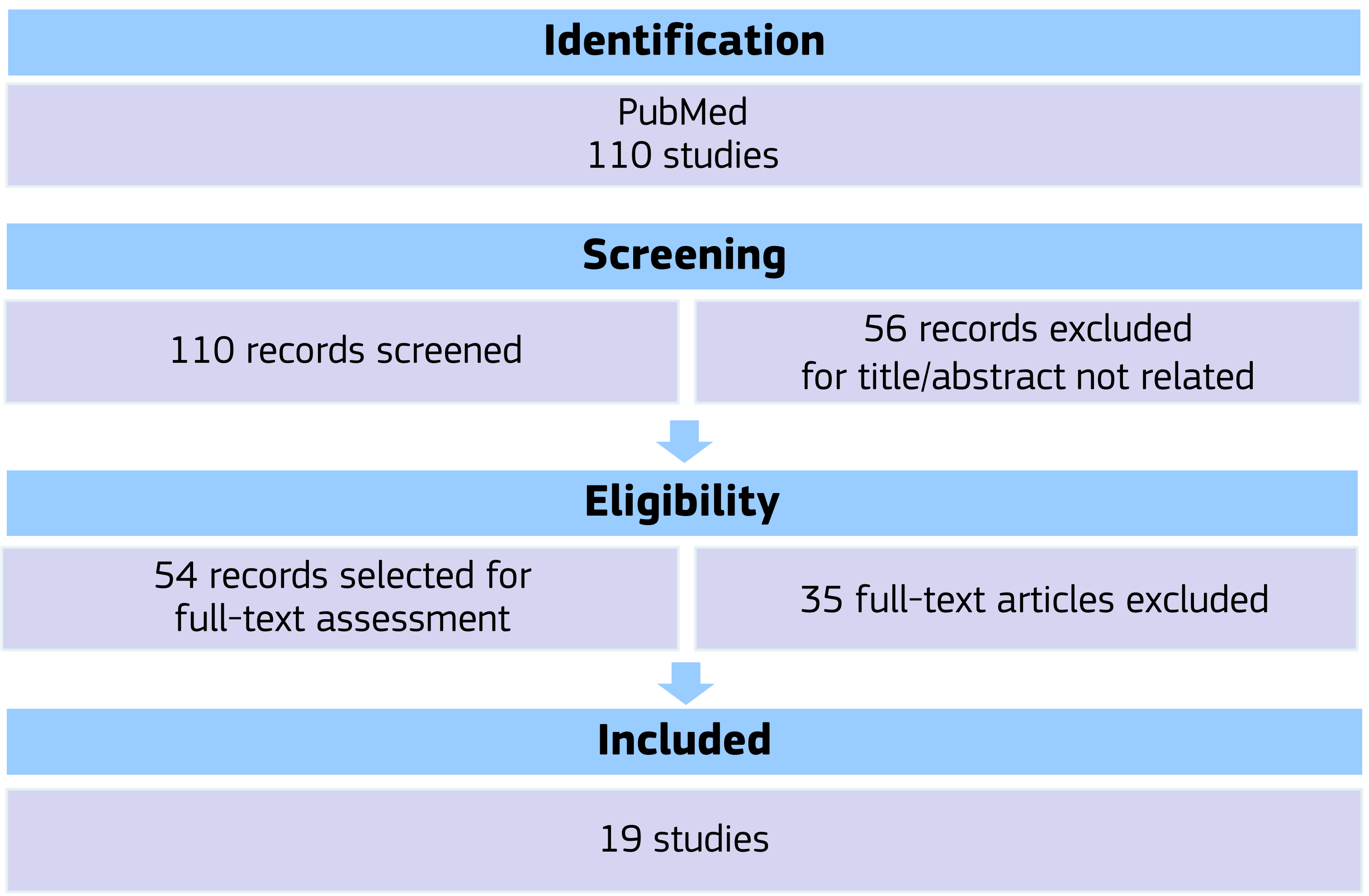
*Adjusted per price differentials with the Purchasing Power Parity method.

Sources: ECIS - European Cancer Information System https://ecis.jrc.ec.europa.eu, accessed on 29/05/2018 © European union, 2018
Luengo Fernandez and all, Lancet, 2013.

METHODS

Studies were searched via PubMed until end of April 2018 regarding the involvement of CRs in measuring PROMs in colorectal cancer, focusing on the whole care pathway, i.e. screening, diagnosis, treatment, follow-up, and palliative care.

Only studies conducted in Europe were included.



Identification

PubMed
110 studies

Screening

110 records screened

56 records excluded
for title/abstract not related

Eligibility

54 records selected for
full-text assessment

35 full-text articles excluded

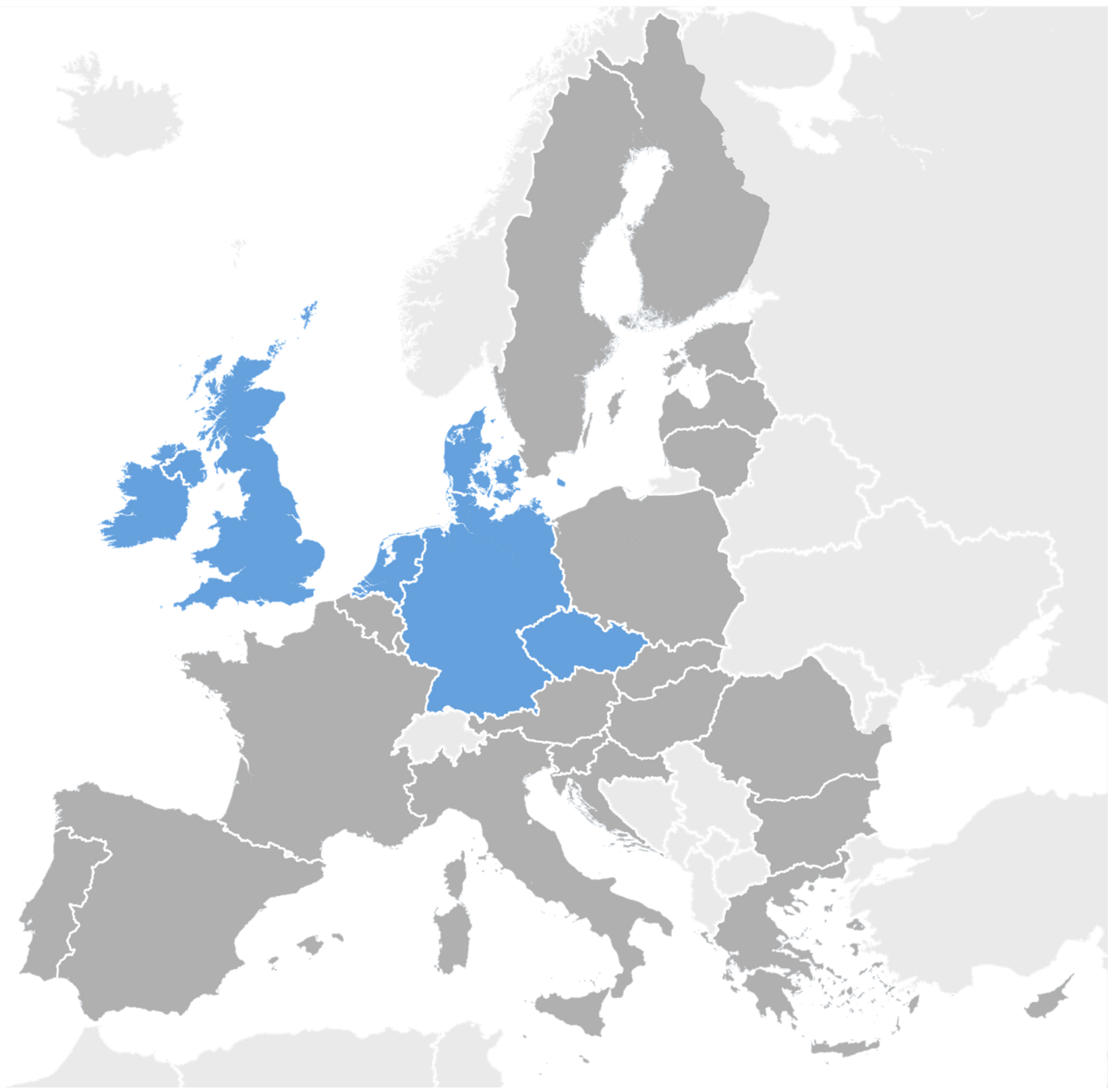
Included

19 studies

RESULTS

Our search retrieved 19 studies. Most of the studies were conducted in the Netherlands (n=10). Other studies used data from Germany (n=3), United Kingdom (3), Denmark (1), Ireland (1) and Czech Republic (1).

Country distribution for studies

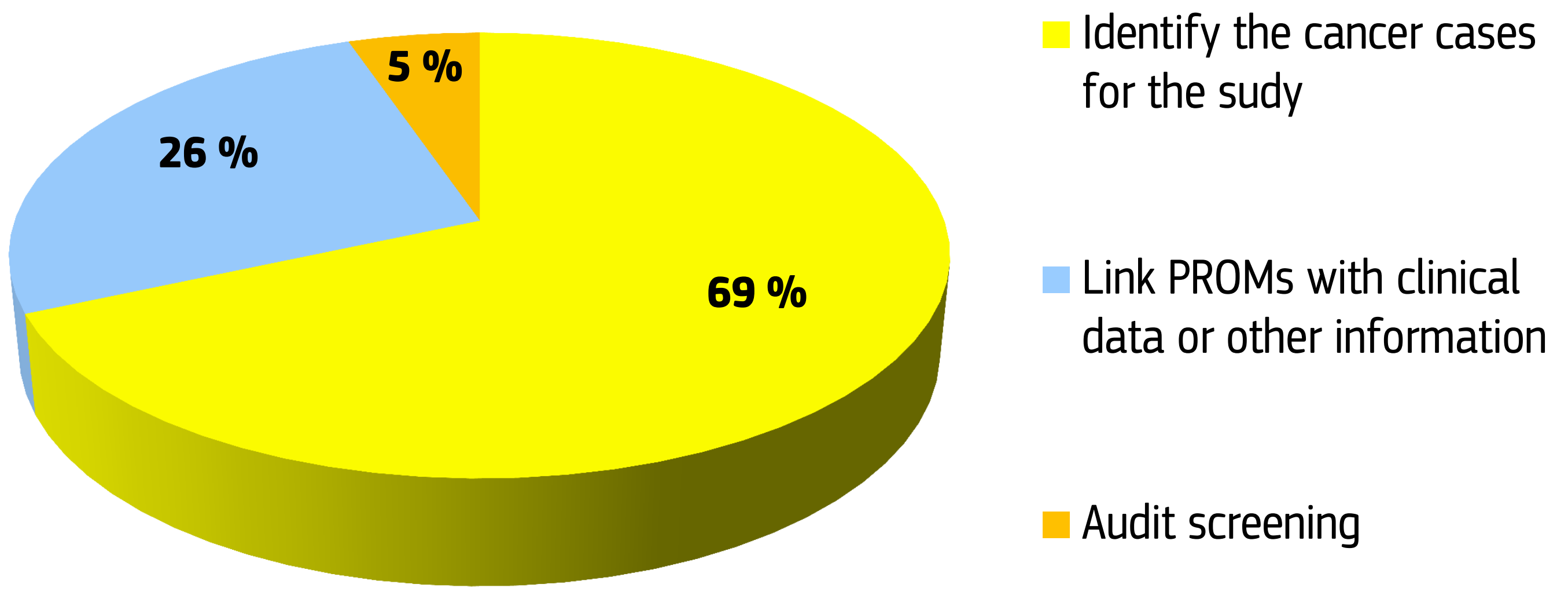


Concerning care processes, most studies focus on treatment (i.e. surgery, systemic therapy). Only one study assessed PROMs in the screening settings.

There is great variation in the PROMs instruments used, as well as in the domains included in them (physical function, symptoms, psychological distress, general QoL, financial aspects, patient satisfaction).

The most used standardised instrument is EORTC QoL C30, sometimes in combination with other colorectal cancer specific questionnaires.

Involvement of European cancer registries in measuring PROMs



CONCLUSIONS

- In Europe, the use and content of PROMs in colorectal cancer varies but is still limited.
- Cancer registries are mostly used to identify patients. In future CRs could play a fundamental role in routine collection of PROMs and linking with clinical data to provide unbiased and comprehensive results.

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Luciana NEAMȚIU
European Commission – Joint Research Centre
Unit F1 "Health in Society"
JRC-CANCER-POLICY-SUPPORT@ec.europa.eu
ecibc.jrc.ec.europa.eu

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