

OECI WG on Cancer Outcomes Research

Reflections, Objectives and Initiatives

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Cancer, Health Care and Outcomes (1)

Cancer is one of the main health care problems in Europe.

Despite significant progresses in (primary and secondary) prevention and therapy, and increases in average survival, variability in incidence, survival and mortality are present inter and intra countries

Variability of outcomes may be related to:

- 1. variation in structure and process of care (quality)**
- 2. country specific national expenditure for health /GDP**
- 3. molecular differences among patients stratified in same diagnostic group**
- 4. other reasons (comorbidity, unknown..)**
- 5. chance**

Precision/Personalised Medicine and Translational Research may produce new evidences, increase options for health care and eventually improve outcomes

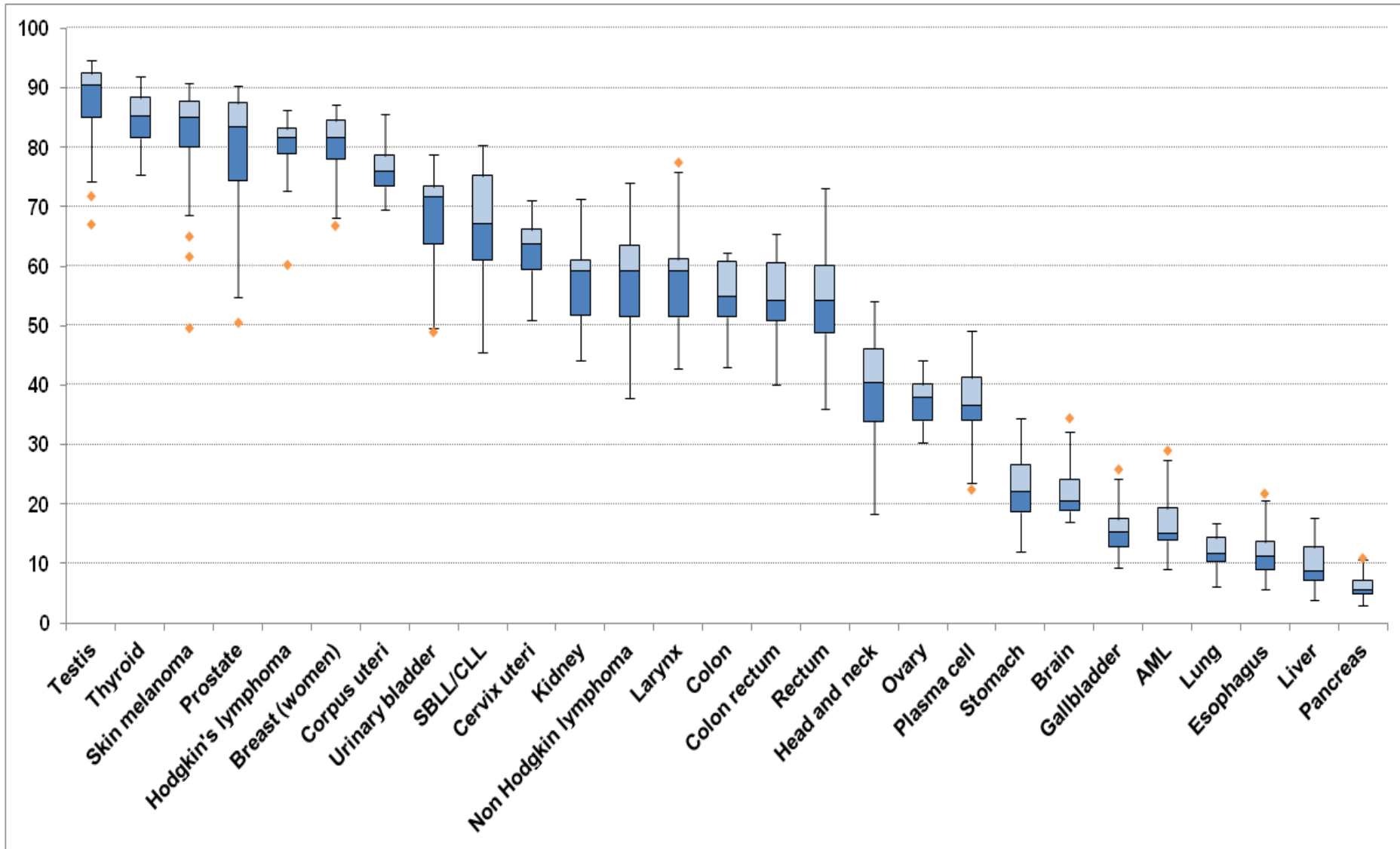
Cancer, Health Care and Outcomes (2)

Political and financial constraints raise concerns about equity and sustainability on the health care scenario

There is too much emphasis on (pharmacological) therapies, less attention on primary and secondary prevention

Data on the effectiveness of most health interventions on population health is lacking (Real Life Evidence from Real World data) and underfinanced

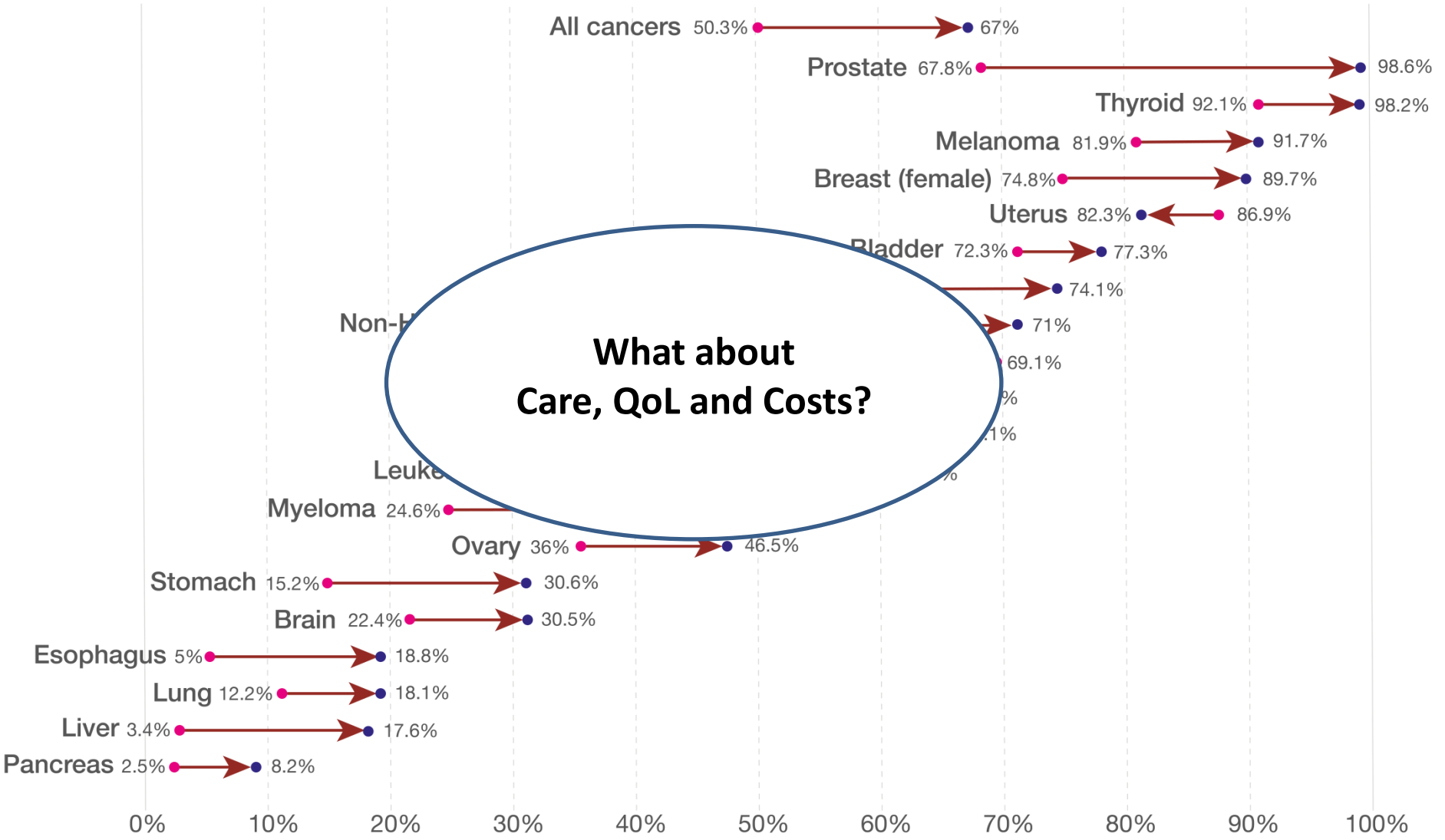
Between-country differences in cancer survival 2000-07



Five-year cancer survival rates in the USA

Average five-year survival rates from common cancer types in the United States, shown as the rate over the period 1970-77 [●] and over the period 2007-2013 [●]: 1970-77 [●] → 2007-2013 [●]

This five-year interval indicates the percentage of people who live longer than five years following diagnosis.



What about Care, QoL and Costs?

Based on data by Journal of the National Cancer Institute; Surveillance, Epidemiology and End Results Program. The data visualization is available at OurWorldinData.org. There you find research and more visualizations on this topic.

Questions/Gaps

Most of clinical research is focused on drugs

RCTs produce data and information mostly using surrogate (clinical) endpoints

RCTs can hardly be generalised to the clinical practice

Population registries only provide some of the data we need

Additional information about Effectiveness, QoL and Costs would be useful

Outcome Research

An umbrella term that covers several different approaches

“... The discipline that describes, interprets and predicts the impact of health care interventions on final outcomes that matter for decision makers (from patients to society at large) using scientific methods...”

To make (the right) decisions in the current complex scenario we need to expand the term of outcomes and increase our knowledge about outcome measures

Outcomes in Cancer Health Care

Response to treatment

Relapse/progression

Survival

Mortality

Safety/Toxicity

Symptoms

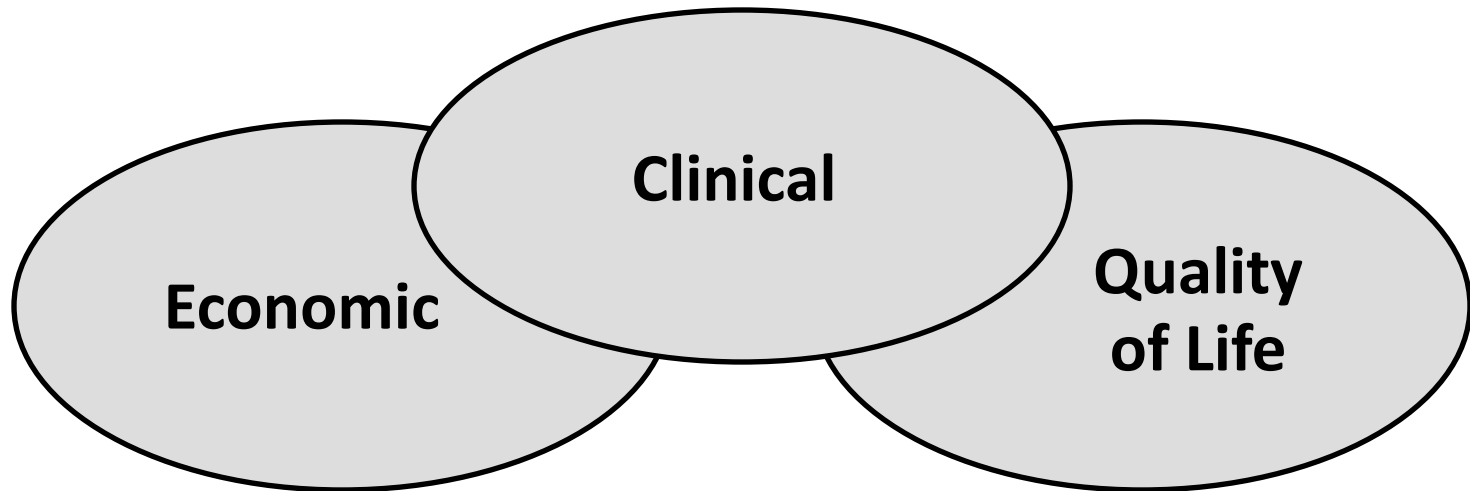
HR-QoL

Satisfaction

QOL


Costs

Outcome Research: The Consequences of Health Care and Medical Interventions



Potenatial studies and expected outputs

RETROSPECTIVE EPIDEMIOLOGIC STUDIES
HIGH RESOLUTION STUDIES
PROSPECTIVE EPIDEMIOLOGIC STUDIES
PROSPECTIVE COMPARATIVE EFFECTIVENESS STUDIES
PRAGMATICAL RCTs



RESEARCH RESULTS SHARING
CLINICAL TRIALS OPTIMIZATION
PATIENT MANAGEMENT IMPROVEMENT
TUMOR REGISTER OPTIMIZATION
DATA SHARING WITH OTHER ORGANIZATIONS

PROs and PREs Measures (1)

PRO, Patients Reported Outcomes: are health outcomes directly reported by the patient (self-reporting) who experienced it (in contrast to an outcome reported by someone else)



PROs and PREs Measures (2)

PREMs, Patient Reported Experience: measures of a patient's perception of their personal experience of the health care they have received



Time spent waiting
Access to health care services
Quality of communication
Involvement in decision making

Potential objectives/initiatives of the OECI OR WG

Identifying health care interventions needing a long term/effectiveness evaluation (gaps identification/priority setting)

Writing a reflection/position paper about the added value of PROs and PREMs in the context of OECI Centres

Collaborating with the Health Economics WG to identify a core of economic outcomes to be eventually collected in a standardized manner

Developing/identifying a common system for data integration (molecular, clinical and health care administrative sources) and data sharing among OECI Centers

next steps: 3 key issues for the OEI OR WG

Identifying needs in oncology

comorbidity & anticancer treatment; Quality of life (PROMS); immunotherapy..

Technicalities

institutional registries or datasets; integration of CCC data with administrative, health, population cancer registry data
type of bio-banking

Data sharing

modalities and facilities for sharing and analysing data
Regulations & confidentiality