

CANCER OUTCOME RESEARCH GROUP SESSION

A step forward Patients Reported Outcomes

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Synopsis

- Why this Group and this Section
- A few definitions
 - Outcome Research
 - Patients Reported Measures
 - Real World Data
- The Cancer Mission
- Preliminary work done by OECI



The context

- Need of RWD and RWE to complement evidence from (efficacy) CT
- Central role of citizens and patients in decision making
- Well established role of PRM (PROMs and PREMs) in clinical research
- Increasing interest to integrate collection of PRM in routine practice to improve health care and quality
- The presence of new tools/topics to take into considerations (Big Data, AI, data sharing, etc)
- Despite potential benefits, obstacles with the integration into practice
- Challenges are for costs, administrative and technical issues



OR: A few definitions from the literature

- *C. Anderson*: measuring **what works** in health care...**using health care records** (Science, 1994)
- *MT Youngs*: a line of **HSR** that focussed on identifying variations in medical procedures and associated **health outcomes** (The Medical Outcome & Guidelines Sourcebook, 1995)
- *RS Epstein*: systematic measurement of clinical and other outcomes to understand **how well effective therapies** work in the usual practice setting, **and how much they cost** (Ann Intern Med, 1996)



A definition in Oncology

OR is an umbrella term that covers a broad range of study **questions**, from effectiveness to prediction rules, **methods**, from analysis of databases to decision analysis, and **endpoints**, from quality of life to costs

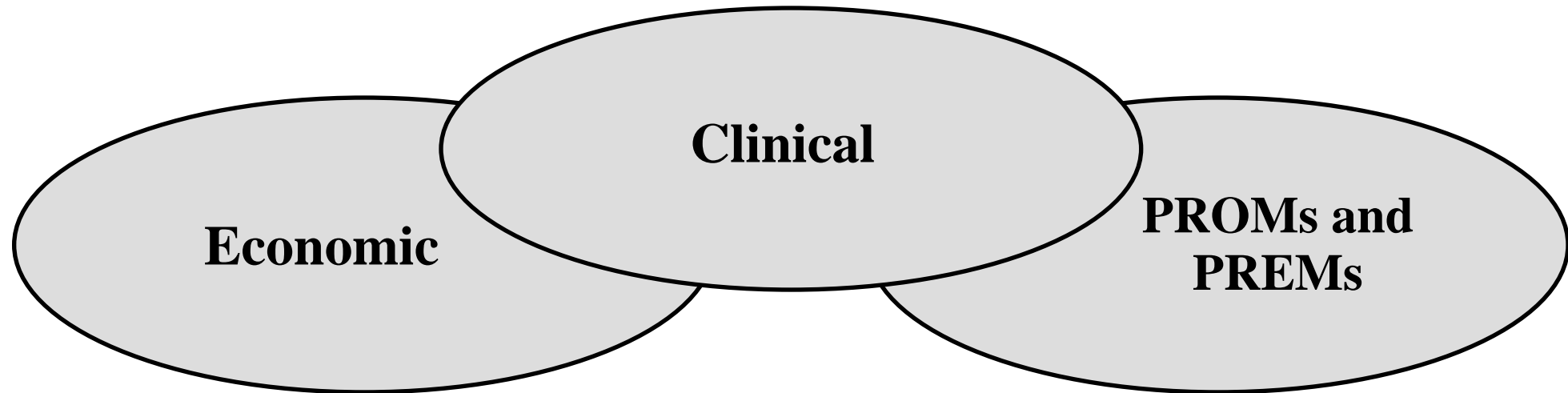
SJ Lee et al, JNCI 2000; 92: 195-204



From Marcia Testa: (Personal Communication, 1997).

A scientific discipline that describes, interprets and predicts the impact of health care intervention on final outcomes that matter for decision makers

The Consequences of Health Care and Medical Interventions



RWD and RWE

According to an inclusive definition from the FDA *"Real-world data are the data relating to patient health status and/or the delivery of health care routinely collected from a variety of sources. RWD can come from a number of sources, for example:*

- *Electronic health records (EHRs)*
- *Claims and billing activities*
- *Product and disease registries*
- *Patient-generated data including in home-use settings*
- *Data gathered from other sources that can inform on health status, such as mobile devices"*

RWD may be used to produce Real World Evidences (RWEs), that ". RWEs can be generated by different study designs or analyses, including but not limited to, randomized trials, including large simple trials, pragmatic trials, and observational studies (prospective and/or retrospective).



Patient Reported Measures

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)

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



**Adaptation to climate
change, including societal
transformation**

**Healthy
oceans,
seas,
coastal
and inland
waters**



**Mission
areas**

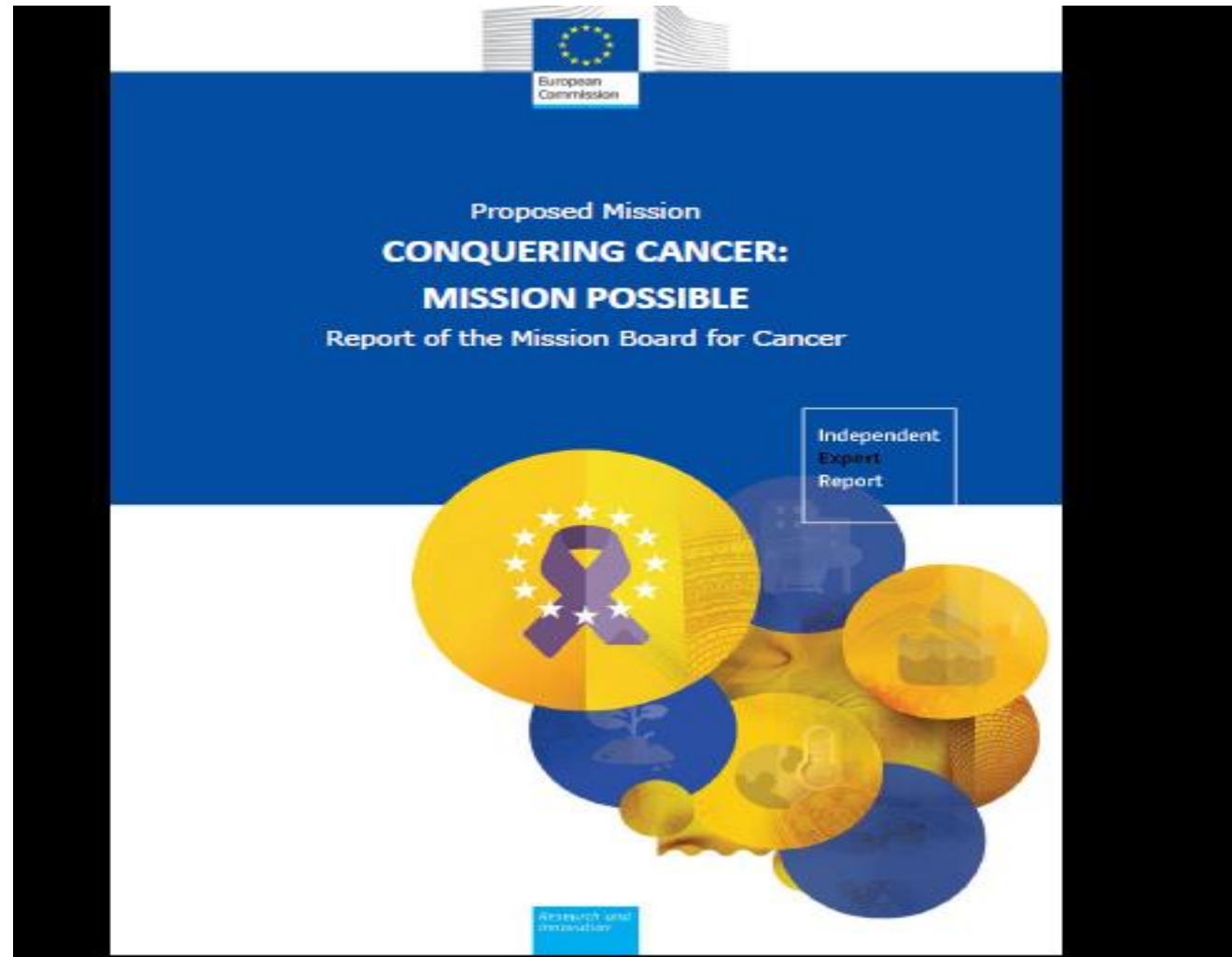


Cancer

**Climate-neutral
and smart cities**



**Soil health
and food**





Mission on Cancer:
By 2030, more than 3 million lives saved, living longer and better

Ensure equitable access

Prevent what is preventable

Optimise diagnostics and treatment

Support quality of life

Understand

Five intervention areas:

1. understanding
2. prevention
3. diagnosis and treatment
4. quality of life
5. equitable access

13 recommendations for bold actions



13 Recommendations for bold actions

- 1 Launch **UNCAN.eu** – a European Initiative to Understand Cancer
- 2 Develop an EU-wide research programme to identify **(poly-) genic risk scores**
- 3 Support the development and implementation of **effective cancer prevention strategies** and policies within Member States and the EU
- 4 Optimise existing screening programmes and develop **novel approaches for screening and early detection**
- 5 Advance and implement **personalised medicine approaches** for all cancer patients in Europe
- 6 Develop an EU-wide research programme on **early diagnostic and minimally invasive treatment technologies**
- 7 Develop an EU-wide research programme and policy support to improve the **quality of life of cancer patients and survivors, family members and carers**, and all persons with an increased risk of cancer
- 8 Create a **European Cancer Patient Digital Centre** where cancer patients and survivors can deposit and share their data for personalised care
- 9 Achieve **Cancer Health Equity** in the EU across the continuum of the disease
- 10 Set up a network of **Comprehensive Cancer Infrastructures** within and across all EU Member States to increase quality of research and care
- 11 **Childhood cancers** and cancers in adolescents and young adults: cure more and cure better
- 12 Accelerate innovation and implementation of new technologies and **create Oncology-focused Living Labs** to conquer cancer
- 13 **Transform cancer culture**, communication and capacity building

The EU Cancer Mission

Goal:

“By 2030, more than 3 million lives saved, living longer and better”

ANNEX III: CITIZEN ENGAGEMENT ACTIVITIES

As explained in this Draft Mission outline, the Mission on Cancer aims to generate a substantial impact on the lives of all European citizens exposed to cancer. Therefore, it is of utmost importance that the Mission is being developed together with citizens and cancer patients, survivors and their families or carers (hereafter, citizens and patients), and that it reflects the voice of these people.



The OECC Initiative on PRM (1)

Cancer Mission has the goal to reduce mortality, improve survival and the quality of life of patients and citizens, and many of the actions that are expected to be undertaken and made operative with specific calls, involve the active participation of patients and citizens. Each project concerning future calls will need to equip themselves with the best tools relating to PROMs and PREMs and with expertise in their implementation in clinical practice, research and electronic records.



OECC One Shot Project on PR Measures



The final aim was to offer a common framework for future European research initiatives in the context of the Cancer Mission calls.



Participants



**Thank you and enjoy
the Session**

