



FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI

Sistema Sanitario  Regione
Lombardia



UNIVERSITÀ DEGLI STUDI DI MILANO

DIPARTIMENTO DI SCIENZE CLINICHE
E DI COMUNITÀ

Augusto Caraceni

The role of OECl in EU funding on HRQOL calls in the Cancer Mission

National Cancer Institute of Milan, Italy

Director Palliative Care Pain and Rehabilitation

Associate Professor of Palliative Medicine University of Milan

Chair European Association for Palliative Care Research Network



Proposed Mission

CONQUERING CANCER: MISSION POSSIBLE

Report of the Mission Board for Cancer

Independent
Expert
Report



Research and
Innovation



Figure 1. Intervention areas for action



Palliative Care

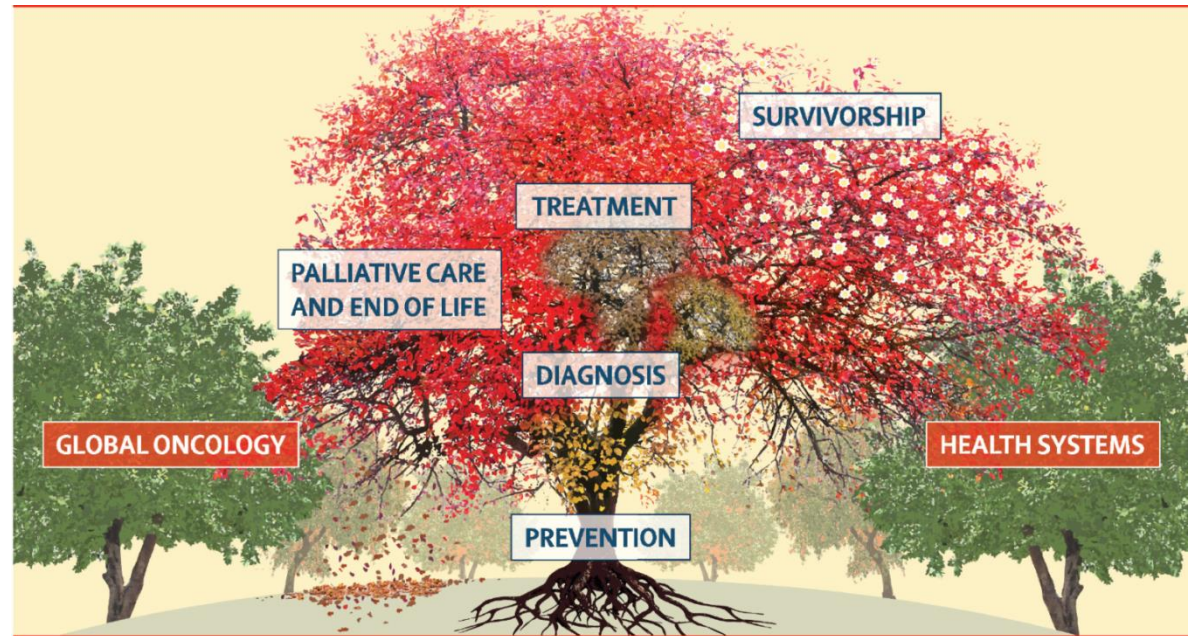
Survivorship Care

Quality of life the content and the clinical meaning of it

- Quality of life is always a component and an outcome of health care interventions
- PROMs implementation in routine clinical practice and in cancer research is considered today standard
- Real world implementation and impact on medical culture in oncology are less clear
- But “Quality of life” it is the only outcome when the target of therapy is no more the tumor such as in palliative care and survivorship care

Addressing patient's needs and patient centred care

- Survivorship definition
- Palliative care and end-of-life care needs



The Lancet Oncology Cancer Control Hub
(a short lasting metaphor)

CONQUER CANCER FOR EVERY ONE Caraceni A , Apolone G
Comment in The Lancet Oncology 2021



OECI44

Oncology Days

June 2022 Valencia, Spain

GENERAL ASSEMBLY
SCIENTIFIC CONFERENCES
AND RELATED EVENTS



The Fundación Instituto Valenciano de Oncología IVO
is proud to host the OECI Oncology Days 2021 in Valencia,
City of Art and Sciences

OECI
Organisation
of European
Cancer Institutes
European Economic
Interest Grouping



DEVELOPING
THE FUTURE IN
COMPREHENSIVE
CANCER CARE

OECI One-Shot Project OECI initiative on strategies of implementation of PROMs and PREMs in oncology clinical practice, research & benchmarking

Giovanni Apolone^{1,2}, Cinzia Brunelli¹, Alice Gallivanone¹, and Augusto Caraceni¹

¹ Fondazione IRCCS Istituto Nazionale Tumori-Milano

² Organisation of European Cancer Institutes

It is now widely accepted that the point of view of patients and citizens on their own life and health is relevant and necessary to evaluate the efficacy, safety and feasibility of health care interventions, and this is mostly true in the context of Outcome Research studies that has been defined as the "... scientific discipline that describes, interprets and predicts the yield of health care interventions on final outcomes that matter for decision makers..." including patients and citizens reports and evaluations. (Figure 1)

A large body of evidence now support the validity, reliability and interpretability of information collected through patients' self reported questionnaires, today mostly known as Patient Reported Outcome Measures (PROMs), when focusing on aspects related to Health Related Quality of Life dimensions, and Patient Reported Experience Measures (PREMs), when focusing on patients' perceptions of their experience of care.

PROMs and PREMs (PRMs) were initially developed to be applied to clinical research in assessing efficacy and effectiveness of medical interventions, but they are also relevant in clinical practice to drive medical decisions as well as in performance evaluation of health care programs to inform quality improvement (patient-centered benchmarking). While the use of PRMs in clinical research is fairly well established, systematic assessment is not widely implemented in routine care delivery and may pose practical challenges, like the burden for healthcare providers in administering questionnaires during the medical encounter or the difficulty in interpreting results. Moreover, systematic symptom assessment in oncology practice is considered one key element of effective integration between oncology and palliative care and there is now convincing evidence that routine use of PROMs with rapid feed-back of results to health care providers, can improve symptom control, patient well-being, cost effectiveness as well as patient engagement and survival.

The European Commission Cancer Mission set the goals to reduce mortality, improve survival and quality of life of patients and citizens, and many of the actions, that are expected to be undertaken and implemented in specific calls, involve the active participation of patients and citizens. To respond to these demands, projects applying to future calls will need to adopt tools to assess and collect to PROMs and PREMs, develop expertise in their use in clinical practice and research and methods to integrate them in electronic clinical records.

For these reasons an OECI initiative was established with the following aims:

- Establish OECI priority of promoting implementation of PROMs and PREMs stepping from rhetoric to practice.
- Underline the role of PROMs and PREMs implementation as one step towards patient centred approach in clinical practice and research.
- Identify PROMs and PREMs that fit the needs of different patient populations: those undergoing treatment with curative intent, patients with advanced or metastatic disease (palliative care population) and disease free long term survivors.

Online Meeting May 3rd 2021

- **Giovanni Apolone** Istituto Nazionale Tumori-Milano OECI
- **Augusto Caraceni** Istituto Nazionale Tumori-Milano
- **Cinzia Brunelli** Istituto Nazionale Tumori-Milano
- **Dominique de Valeriola** OECI
- **Patrick Miqueu** OECI
- **Wim H. van Harten** OECI
- **Giuseppe Recchia** da Vinci Digital Therapeutics, Milano, Italy.
- **Stein Kaasa** Oslo University Hospital, Norway.
- **Marianne Jensen Hjermsstad** Oslo University Hospital.
- **Camilla Zimmermann** Princess Margaret Cancer Centre, Toronto, Canada.
- **Alex Gilbert** Leeds Cancer Centre, United Kingdom.
- **Helle Pappot Oncology** Centre Rigshospitalet Copenhagen, Denmark.

Aims

- Establish OECl priority in promoting implementation of PROMs and PREMs stepping from rhetoric to practice.
- Underline the role of PROMs and PREMs implementation as one step towards patient centred approach in clinical practice and research.
- Identify PROMs and PREMs that fit the needs of different patient populations: those undergoing treatment with curative intent, patients with advanced or metastatic disease (palliative care population) and disease free long term survivors.
- Propose implementation strategies (use of e-devices for the assessment, stakeholder engagement, organizational and reimbursement issues).
- Scope feasibility/implementation experiences within selected collaborating centers
- **BUT ALSO to serve as an infrastructure for OECl participation in CANCER MISSION FUTURE CALLS on QL**

In fact

- HORIZON-MISS-2021-CANCER-02-02: Develop and validate a set of quality of life and patient preference measures for cancer patients and survivors
 - **Only one project to be funded 11 M Euros**
 - **Dead line April 2022**

Purpose of the call

- To develop and validate new metrics for quality of life assessment for the benefit of:
 - Cancer patients, survivors and caregivers
 - Health care professionals, supportive workers, counsellors and industry
 - Regulators and institutions
 - Health Policy Makers
 - Labour market and social protection policy makers

Long term scope within the Mission on Cancer

- Launch newly defined, harmonised and systematic surveys, as well as to collect new and update existing quality of life data and registries information, using appropriate digital tools. These surveys should be launched regularly across all countries.

Requirements

- Revise available instruments and identify existing gaps
- Codesign methodology with multiple stakeholders contribution to develop QL instrument
- Cover subjective perceptions of the positive and negative aspects of cancer patients' symptoms, including physical, mental, emotional, social, cognitive functions, disease symptoms and treatment side effects as well as needs for palliative care.

Requirements

- Prepare and conduct a pilot of newly defined, harmonised and systematic quality of life surveys across the EU-27 and Associated countries

Strongly recommended

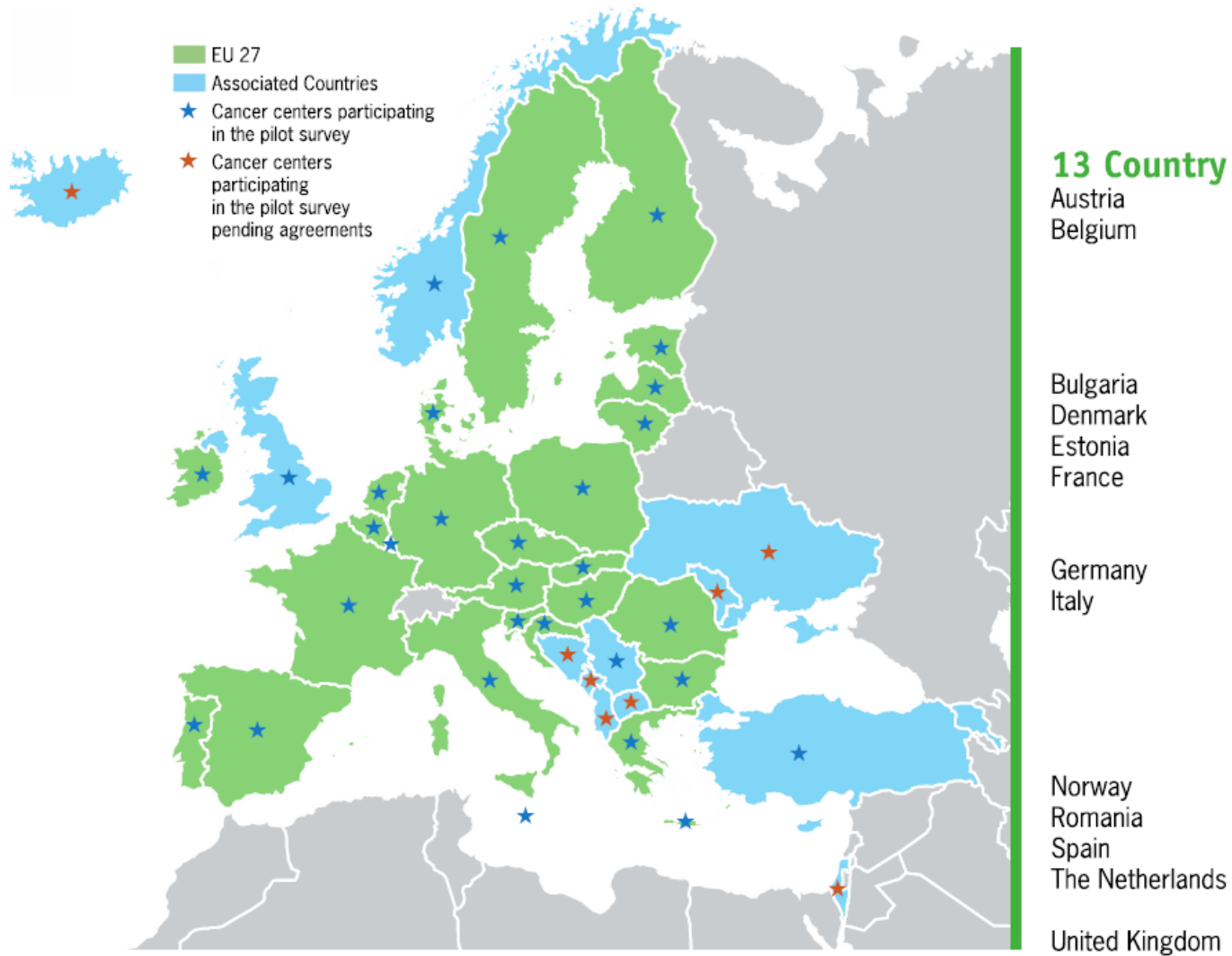
- To participate in networking and joint activities with other ongoing projects under the mission on cancer and other cancer relevant projects, as appropriate
 - Joint actions
 - Horizon projects

OECl is participating in this call

- Consortium Coordination National Cancer Institute of Milano G. Apolone
- Partnership
 - OECl coordination of cancer centers for QL Survey Study
 - And many others

OECl centres consultation and networking

- 113 were contacted
 - 64 responded
 - 89% have experience of using PROMs
 - 59 % PROMs for clinical use
 - 81% PROMs for research
 - 45 % PROMs for benchmarking
 - 40 will participate in the project pilot survey



For QL in Cancer European Survey for this call *and more*