

OEI CANCER OUTCOME RESEARCH WG: Proposal for networking enhancement

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Disclosure

I have no actual or potential conflict of interest in relation to this presentation



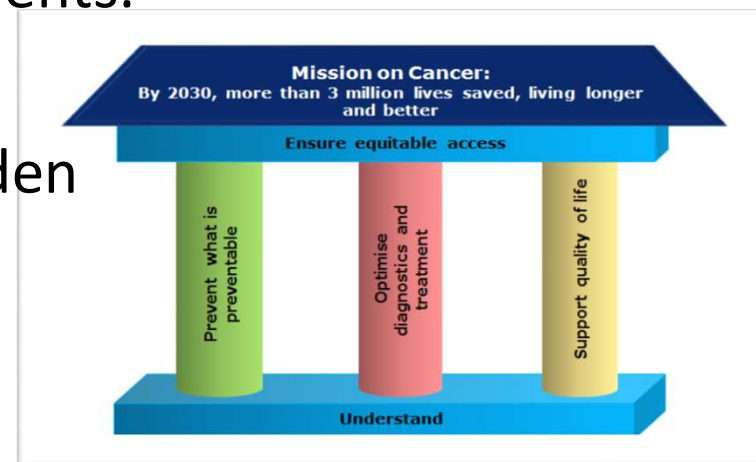
Key questions

- What is the focus of this WG?
- What are the aims and how to pursue them?
- Who is going to actively contribute?
- What is the willingness of OEI centres to actively participate?



The focus

- Survival, recurrence as well as other clinical and process indicator are relevant cancer care outcomes
- However patient-centred outcomes, such as health-related quality of life (HRQoL), functional impairment, pain, psycho-social aspects, experience of care, are factors of great significance for patients.
- Monitoring patient-centered outcomes is then needed to get the whole picture of cancer burden and of treatment outcomes.



AI -RWE to answer patient questions

Patient questions:

- Which group do I belong? (Diagnosis)
- How much time do I have? (Prognosis)
- What are my options? (Prediction)
- How will I live? (quality)



RW Outcome research

- It is a matter of analyzing huge amount of data collected in routine clinical practice
- This implies
 - data harmonization (including data collection process harmonization)
 - data sharing (willingness? Barriers?)
 - data richness (follow data models and establish minimum clinical data set completing PROMs and PREMs data)



RW Outcome research

- Many players on the «cancer RWE» field
- Overlapping? Conflict?
- It should rather be an issue of collaboration and complementarity



The focus

As data harmonization and sharing on traditional cancer outcomes
(survival and other clinical variables)

is somehow already addressed by many other “players”,

**I propose this working group focuses
on patient centered-reported outcomes
(PROMs and PREMs)**



Do we have PROMs/PREMs data to share for RWR?

No.

Despite evidence on the benefits, systematic PRM collection is not widely implemented in routine oncology practice

This hinders the possibility to carry out RWR based on the perception of the most important stakeholder, which is the patient



The aim

To build the foundation for a network of clinical cancer centres adopting a common platform and common procedures for the routine collection and sharing of PROMs and PREMs data.



The how

- Identify PROMs and PREMs that fit the needs of different patient populations.
- Propose implementation strategies (use of e-devices for the assessment, stakeholder engagement, organizational issues, personnel training) in the context of the OEI Institutes.
- Scope feasibility and implementation experiences within a network of selected collaborating centers.



The role of accreditation

Patient satisfaction/experience	
Standard 26	
Patients' experience of cancer care is an integrated part of the quality improvement system of the cancer centre/institute.	
1.	CORE The cancer centre/institute has methods to regularly gather patients' experiences during outpatient and inpatient care.
2.	CORE Satisfaction surveys are analysed, reported and acted upon through the line management of the centre.
3.	The cancer centre/institute uses questionnaires to ascertain the perceptions of the patients' health status, level of impairment, disability and health-related quality of life (e.g. Patient-Reported Outcome Measures (PROM)).
4.	The cancer centre/institute uses questionnaires to assess the impact of the process of care on the patient's experience, e.g. communication and timelines of assistance (e.g. Patient-Reported Experience Measures (PREM)).

What has been done (OEI Mag 2021/1)

OEI Working Groups

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

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1. Fondazione IRCCS Istituto Nazionale Tumori- Milano

2. Organisation of European Cancer Institutes

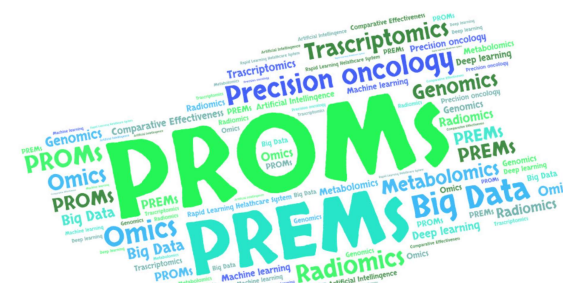


What has been done (OEI Mag 2021/2)

A step forward PROmics

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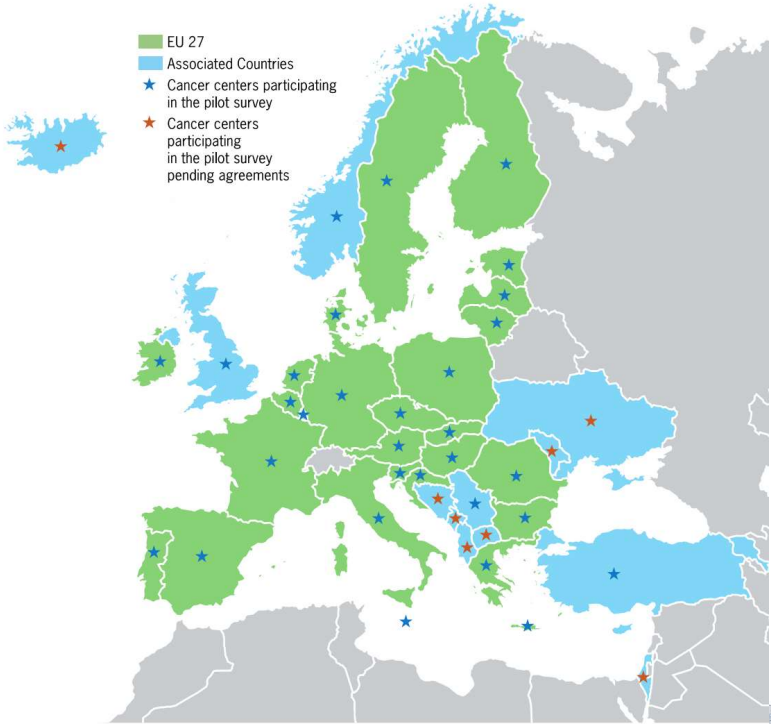
Plan to organize:

- an operative meeting addressed to all OEI centres interested in participating in a real world data collection of PROMs and PREMs in their institutions.
- A survey to explore their experience and use in the field of research and practice with the collection of PROMs and PREMs



HORIZON-MISS-2021-CANCER-02-02: Develop and validate a set of quality of life and patient preference measures for cancer patients and survivors

Scope: The long-term goal of the Mission on Cancer is to support the development of a framework of 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.



Survey on the use of PROMs & PREMs

Invited: 113 centres

Responders: 64 (57%)

Have used any PRO/PREM last 12 months: 57 (89% resp. - 50% invited)

in clinical practice: 60%

in research: 81%

quality measurement: 46%

Only or predominately p&p: 38%

Would share data: 22 (35% resp - 20% invited)



Collaboration – coordination with other OEIC WGs

- Cancer economics and Benchmarking WG
- Collaboration for good practices with patients WG



Key questions

- What is the focus of this WG?
 - PROMs PREMs
- What are the aims and how to pursue them?
 - Establish a network of clinical centres
- Who is going to actively contribute to the COR-WG?
 - cinzia.brunelli@istitutotumori.mi.it
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- What is the willingness of OEI centres to actively participate?
 - Next step after establishing the working group, is to contact OEI centres with a formal proposal



Thank you

