



Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe

Brunelli Cinzia, MSc PhD

Fondazione IRCCS Istituto Nazionale Tumori

OECI Cancer Outcome Research WG

 Fondazione IRCCS
Istituto Nazionale dei Tumori

Sistema Socio Sanitario

 Regione
Lombardia



Disclosure

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

Patient quality of life and cancer care

The burden of cancer on quality of life is well recognized

Bottomley 2002, Wu 2015

QoL measures (HRQOL-PROMs) have been used to test the impact of interventions on such a relevant domain of patients health.

Clinical trials and real-world data have shown the positive effects of routine PROMs assessment on patient wellbeing, use of health care resources and on survival.

Kotronoulas 2016 - Basch 2016, Denis 2017 - Lizée 2019

BarberaL JOP 2020, BarberaL Cancer med 2020, BarberaL BMJ SUPP Pall Care 2020

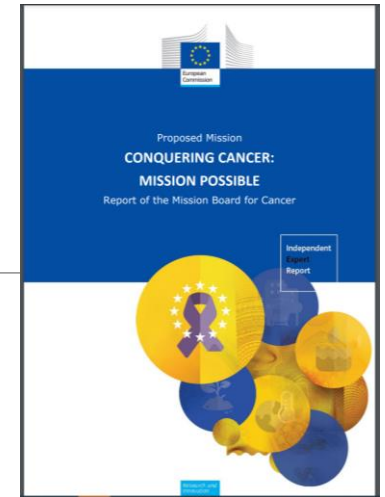
Fjell 2020, Absolom 2021, Maguire 2021 Mir 2022, Basch 2022

....but

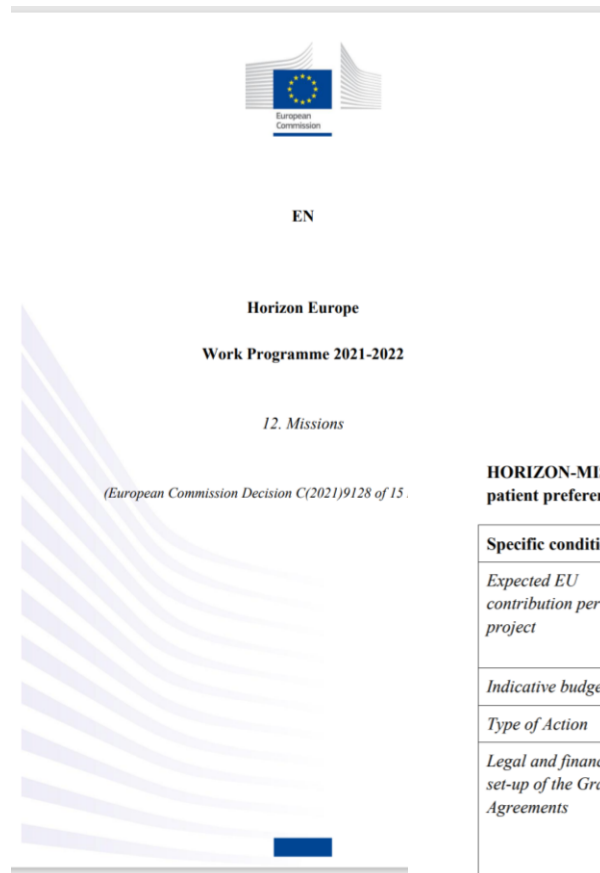
- full implementation of **QoL assessment** in routine oncology practice **is not yet part of standard of care.**
- health care systems and cancer control programs **do not take into consideration QoL outcomes** when devising clinical, societal, and healthcare policymaking systems.

Mission on cancer & QOL

In parallel with prevention and treatment of cancer, the **improvement or preservation of patients quality of life** is one of the three pillars of the EC Mission on Cancer.



HORIZON-MISS-2021-CANCER-02-02



Develop and validate a set of quality of life and patient preference measures for cancer patients and survivors

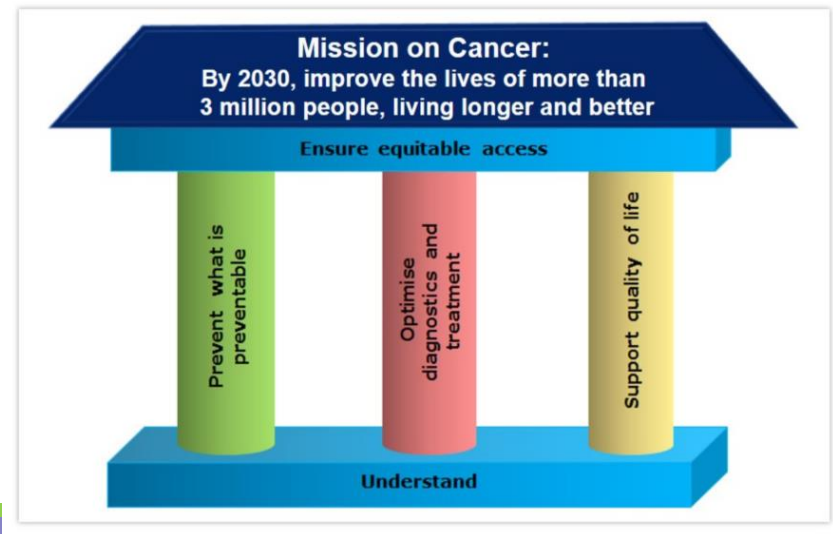
HORIZON-MISS-2021-CANCER-02-02: Develop and validate a set of quality of life and patient preference measures for cancer patients and survivors

Specific conditions	
<i>Expected EU contribution per project</i>	The Commission estimates that an EU contribution of around EUR 11.00 million would allow these outcomes to be addressed appropriately. Nonetheless, this does not preclude submission and selection of a proposal requesting different amounts.
<i>Indicative budget</i>	The total indicative budget for the topic is EUR 11.00 million.
<i>Type of Action</i>	Research and Innovation Actions
<i>Legal and financial set-up of the Grant Agreements</i>	The rules are described in General Annex G. The following exceptions apply: Beneficiaries will be subject to the additional access rights: The selected beneficiaries must provide the results from the survey, including validation of the metrics, within two years from the start of the project for the purpose of developing EU policies and

⁹⁷ Especially through the 'European Guidelines and Quality Assurance Schemes for Breast, Colorectal and Cervical Cancer Screening and Diagnosis', and the 'European Cancer Information System (ECIS)', see https://knowledge4policy.ec.europa.eu/cancer_en

⁹⁸ <https://eithhealth.eu/who-we-are/>

⁹⁹ <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32021R0694&qid=1623079930214>



EUonQoL project



Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe

Is aimed at developing, validating and disseminating the European Oncology Quality of Life toolkit (EUonQoL-Kit) among European cancer patients and survivors.



The EUonQoL – Kit

It will be a **new unified system for the self-assessment of quality of life** in cancer patients undergoing treatment, in cancer survivors and in patient palliative care phase. It will be:

- developed from the patient perspective
- available in several European languages
- based on CAT (Computer Adaptive Testing)
- digitally administrable
- psychometrically sound
- applicable in future periodic surveys for health policy intervention evaluation

State of the art

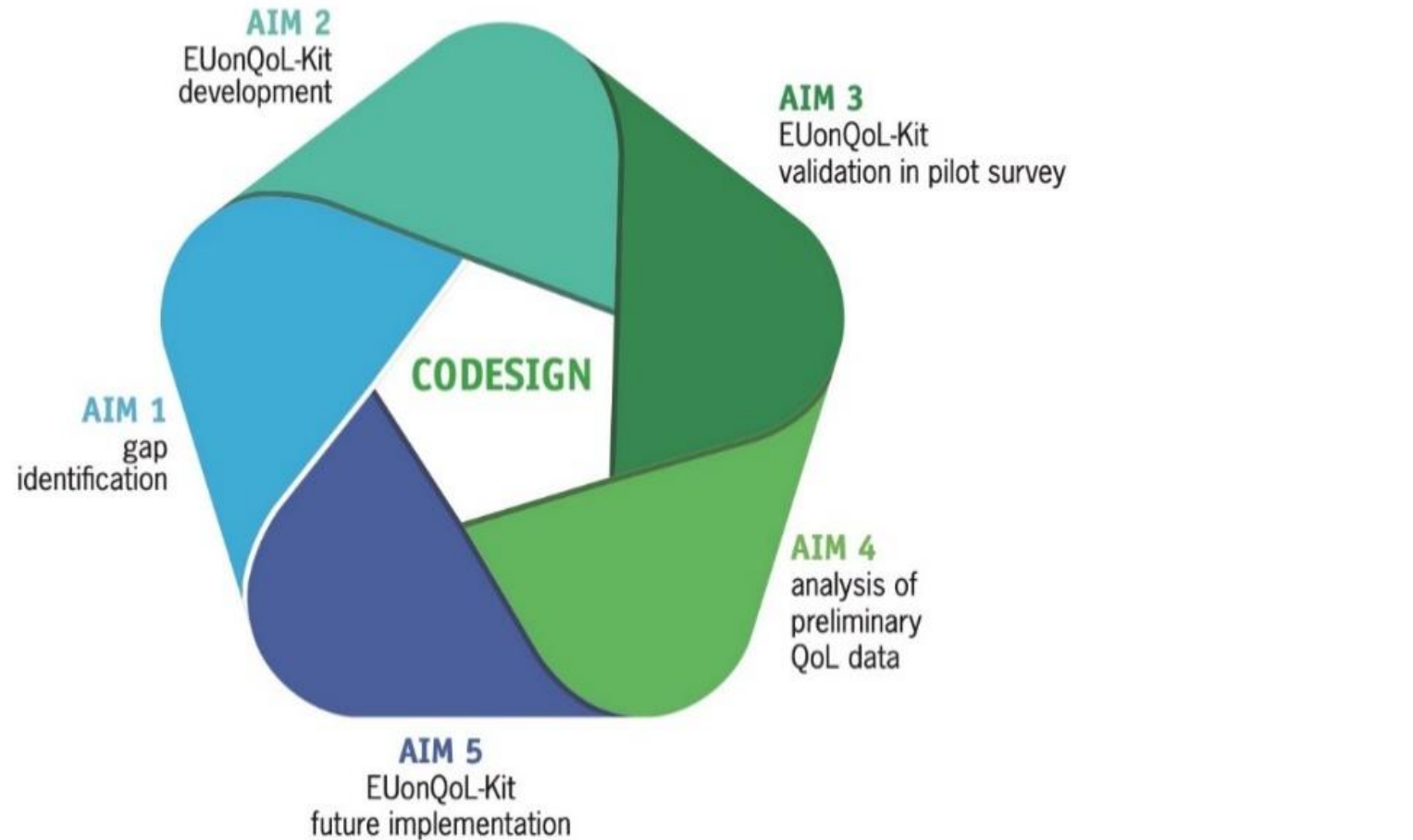
- Many generic and either disease or treatment-specific questionnaires have been developed and validated to measure HRQoL of patients with cancer.
- They have been often translated and culturally adapted into many different languages
- Easily available, at least for paper and pencil administration

Why do we need a «new» QoL tool?

Most QoL instruments have been developed a few decades ago, to be filled in by p&p and are often “static”.

- Emerging needs related to new cancer treatments along with societal developments, require a revision of the dimensions to assess
- The rapid acceleration in the development of IT, big data, and AI analytic techniques calls for a wide implementation of QoL assessment tools that can be electronically captured.
- CAT/IRT allow the development of more personalized dynamic tools.

EUonQoL objectives

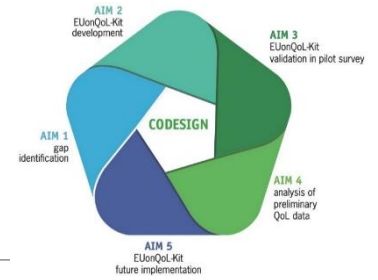


Participatory research

The overall project will be based on participatory co-design research principles through the involvement of a representative panel of stakeholders, including patients and their caregivers.

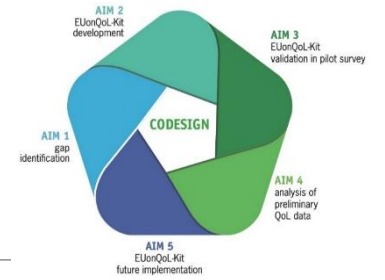


To identify gaps in QoL tools and evidence



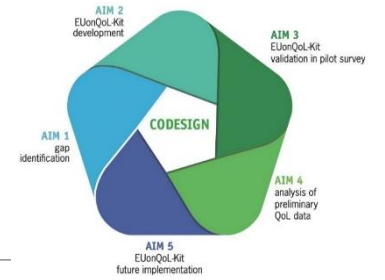
- Systematic identification and collection of currently available HRQoL tools, item banks and databases.
- Analysis of the above body of evidence to identify QoL dimensions not adequately covered by currently existing tools.

To develop the EUonQoL – kit.



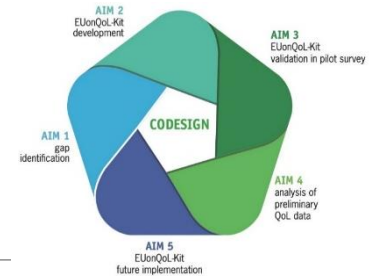
- The EUonQoL-Kit will be developed from existing QoL tools, integrated with new dimensions defined through a co-design process.
- The kit will include both generic aspects of QoL, and specific ones which may differ according to disease stage.
- IRT based computer-adaptive testing (CAT) will be applied to provide personalized assessment.
- Formal linguistic and cultural adaptation will ensure that the EUonQoL-Kit covers the linguistic and cultural diversity across EU countries.

To validate the EUonQoL-Kit in a pan European pilot survey.



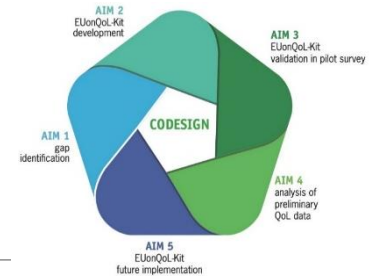
- The EUonQoL-Kit will be validated in a pilot cross-sectional survey involving the EU27 member states and Associated Countries
- An overall sample of 4,000 among cancer patients under treatment, cancer survivors and patients in palliative care phase will be enrolled in a cooperative network of cancer centres most of which are affiliated to the Organization of European Cancer Institution (OECI)

Analysis of factors potentially associated to QoL



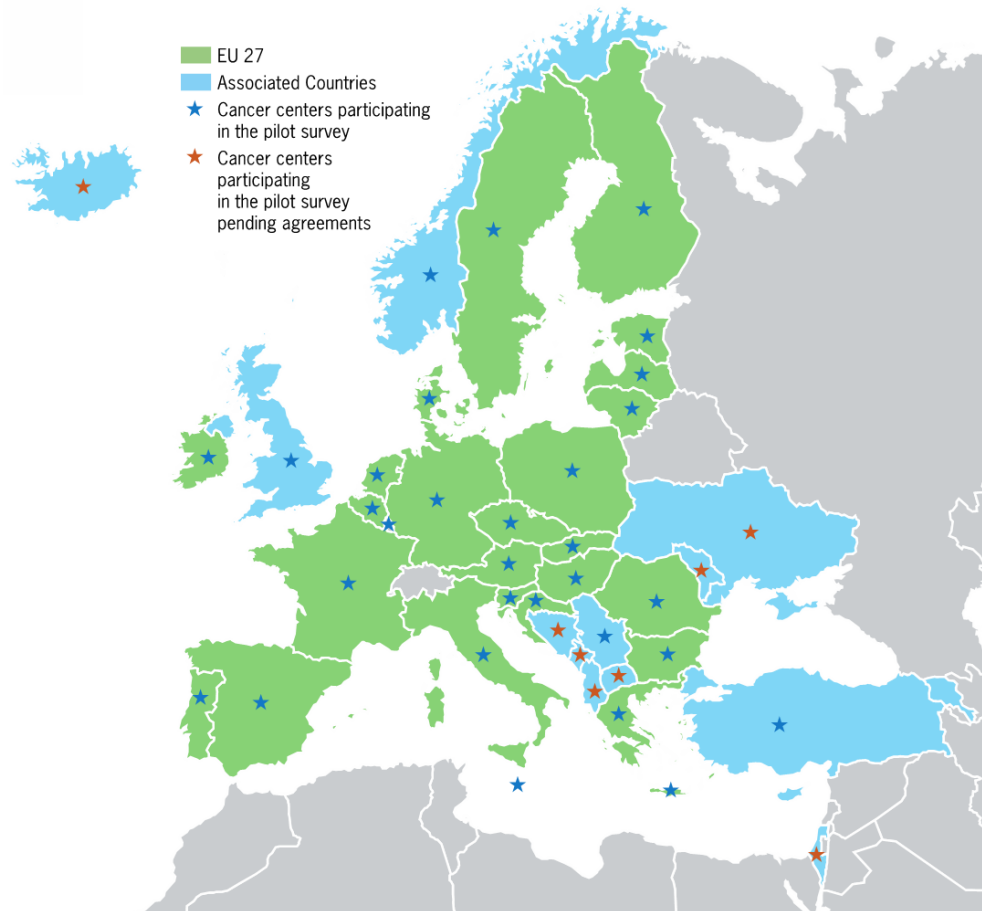
Patient characteristics (demographic, psychosocial, and clinical variables) as well as country/system level variables will be considered to study their association with various QoL dimensions and potentially identify inequalities across populations, countries, healthcare systems.

To develop procedures and actions for future EUonQoL-Kit implementation



- Development and dissemination of implementation guidelines for the use of the EUonQoL-Kit.
- Establishing interactions with all relevant EU-funded initiatives and projects
- Development of a digital platform for voluntary data collection from patients and survivors, aimed at a widespread dissemination of the EUonQoL-Kit to enrich the QoL data collection beyond the pilot survey.
- Network of cancer centres active within OEIC COR WG

EUonQoL consortium



Coordinator

Fondazione Irccs Istituto Nazionale Dei Tumori (INT), Milan, Italy

13 Country

- Austria
- Belgium
- Bulgaria
- Denmark
- Estonia
- France
- Germany
- Italy
- Norway
- Romania
- Spain
- The Netherlands
- United Kingdom

25 Partner/Affiliated

- Medical University of Innsbruck (MUI)
- Digital Institute For Cancer Outcomes Research (DIGICORE)
- European Organisation For Research And Treatment Of Cancer Aisbl (EORTC)
- European Association Of Palliative Care (EAPC)
- European Cancer Organisation (ECO)
- Organisation Of European Cancer Institutes (OECI)
- Association Of Cancer Patients And Friends (APOZ)
- Region Hovedstaden (RH)
- Sporedata OÜ (SPOREDATA)
- Institut Curie (CURIE)
- Institut Gustave Roussy (GR)
- Unicancer (UNICANCER)
- Deutsches Krebsforschungszentrum Heidelberg (DFKZ)
- Alleanza Contro il Cancro (ACC)
- Federazione Italiana Delle Associazioni Di Volontariato In Oncologia (FAVO)
- Istituto Europeo di Oncologia (IEO)
- Istituto Nazionale Tumori Fondazione Pascale (INT-NA)
- Istituti Fisioterapici Ospitalieri (IFO)
- Universita Degli Studi Di Milano (UMIL)
- Oslo Universitetssykehus Hf (OUS)
- Asociatiilor Bolnavilor De Cancer (FABC)
- Fundacio Institut Mar D'Investigacions Mediques (IMIM)
- Stichting Het Nederlands Kanker Instituut-Anton (NKI)
- Stichting Nederlands Instituut Voor Onderzoek Van De Gezondheidszorg (NIVEL)
- University Of Leeds (UNIVLEEDS)

EUonQoL expected impact

- Availability EUonQoL-Kit could potentially provide a public health system to identify and assess the patients needs and impact of health policies or interventions.
- Implementation and results dissemination through a wide stakeholder network will likely promote the routine use of PROMs in clinical care.
- Routine collection of PROMs data will add patient perspectives within multi-omics personalized oncology, ultimately constitutes an important new opportunity in the progress toward patient-centred care



Thank you for your attention

