



# EU for Quality of Life «EUonQoL»

## Quality of life as a pillar of cancer care Paris, June 14th

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President Elect OEI  
Coordinator EUonQoL



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# Cancer in Europe

- There is a large variability in Epidemiology, Economics, Health Care and Health Care Systems, and Outcomes

- Mortality
- Survival
- Quality of life



- Both between and within countries
- Some of the determinants of variability are actionable

# EBCP and CM

Europe' Beating Cancer Plan and Cancer Mission have the common objectives to **improve quality** and **decrease inequalities** in cancer care in Europe, in order to:

**Decrease mortality, improve survival and ameliorate QoL**

These objectives may be achieved only:

- supporting research and health care activities
- a wider participation of all Member States and Affiliated Countries
- a direct involvement of all the relevant stake-holders in the co-design and project implementation, including citizens and patients
- alignment and coordination at national and European level

# Conquering cancer: mission possible

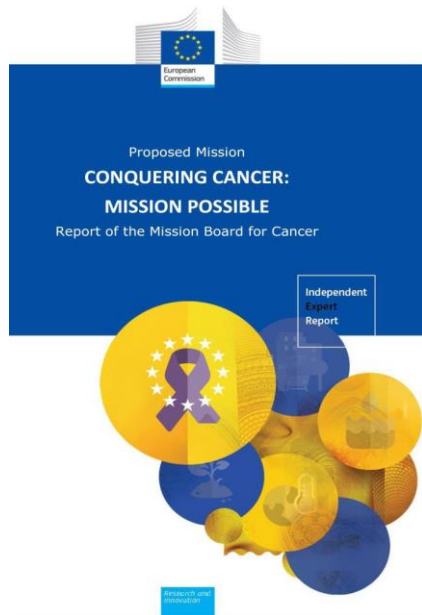


Five intervention areas:

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

13 recommendations for bold actions

# Cancer Mission



**13 bold recommendations**



**13 bold actions**



**13 calls**

## 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



# Cancer Mission Calls

	2021	2022	2023
No.	4	5	4
Budget	128.65	126	110.68



# CM calls Participation

- 140 received proposals in the nine 2021 and 2022 calls
  - 32 accepted
- 107 received in the four 2023 calls
  - Under evaluation
- Large variability in participation
  - From 1 to 50 (mean 13, top 50)
- Large variability in success rate and coordination

# 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

<sup>97</sup> 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](https://knowledge4policy.ec.europa.eu/cancer_en)

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

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

# What EU asks for

- An new\* instrument to assess the (HR)-QoL of cancer patients and survivors in order to monitor the effect/impact of EU funded projects
- Available in all the EU languages

\* All the available tools were developed in the late 90's and were designed to be used prevalently in research

# Definition of QoL

**The Quality of American Life: Perceptions, Evaluations and Satisfaction**  
Angus Campbell, Philip E. Converse and Willard L. Rodgers  
New York: Russell Sage Foundation, 1976, pp. xi, 583

What is the quality of life? For the authors it is the individual's perceived level of satisfaction with life in general, which is related to level of satisfaction in various life domains, such as work, family, residential environment, and so on.

# HR-QoL

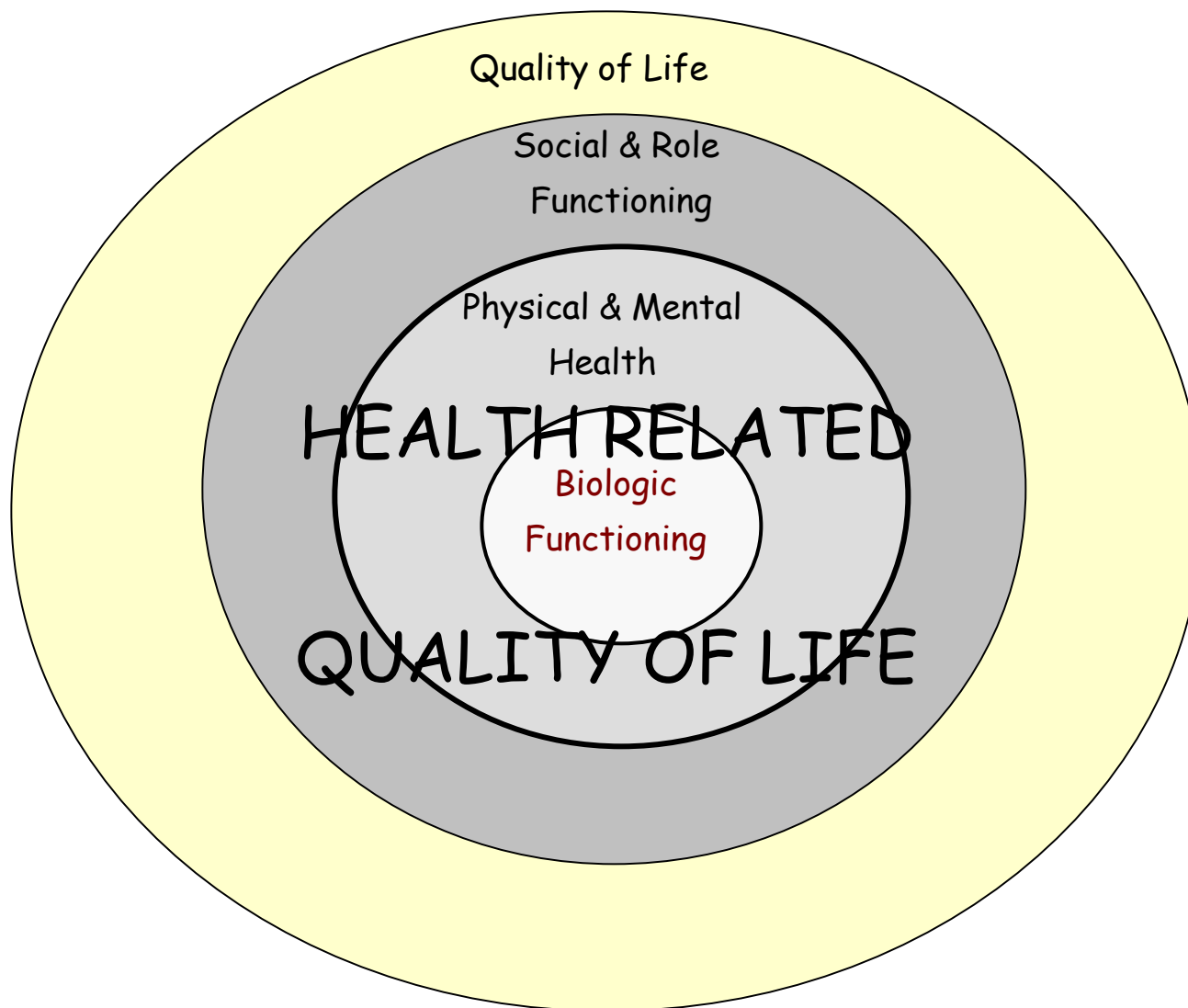
A restricted and operative definition of those components of QoL that are related to Health and thus are correlated with Health Care interventions....

Apolone, 1994

# Health and health status:

- The subjective, self perceived condition of health at a given point of time
- Health: a multi-dimensional concept
  - **Not** merely the absence of diseases or infirmity
  - **But** a physical, mental, and social well-being

# Health and Quality of Life



# Relevant aspects

- Health Related QoL
- Any aspect of health
- Measurement
- Directly from the patient
- Without any interpretation
- Applied in several contexts



# From the patient

Patient as unique and direct source of



Reports

Evaluations

Without any interpretations

# Measurement

Validity  
Reliability  
Responsiveness  
Interpretability



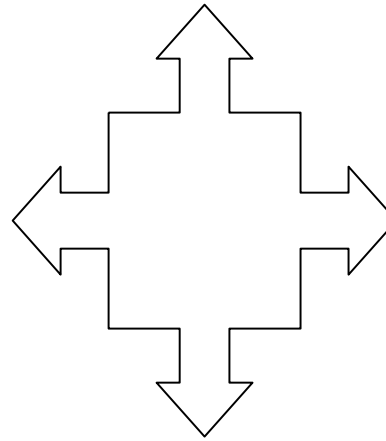
- Conceptual framework
- Item generation
- Scaling, scoring
- Item reduction
- Reproductibility
- Content validity
- Construct validity
- Discriminant validity
- Convergent validity
- Responsiveness
- Cultural adaptation

# Where

**Research**

**Health Care**

**ECONOMICS**



**EPIDEMIOLOGY\***

\* To monitor population health, cross-sectional and/or over time

# OECD2023 ONCOLOGY DAYS

## **EU for quality of life "EUonQoL"**

*Chairpersons: Giovanni Apolone  
and Cinzia Brunelli*

**June 14<sup>th</sup>**

**Novotel  
Paris Vaugirard  
Montparnasse**

**OECD Oncology Days  
2023**

**14.00 Quality of life as a pillar of cancer care**

*Giovanni Apolone*

**Overview of the EUonQoL project**

*Cinzia Brunelli*

**Why do we need new quality of life assessment tools?**

*Galina Velikova*

**Stakeholders involvement in the research: the role of co-design**

*Nanne Bos and Norbert Couespel*

**The EUonQOL project in the framework of European actions  
against cancer**

*Stein Kaasa*

**16.00 Coffee Break**