EUonQoL	Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe	Funded by the European Union

EUonQoL

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Preface

This report is written as a product of the project “Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe (EUonQoL)”. This project is funded by the European Union.

The authors would like to thank the EUonQoL Executive Committee for providing us with valuable feedback on this report.

Hopefully, this report will prove to be a useful tool in the collaboration with stakeholders in the EUonQoL project.

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1. Introduction

In this chapter we will introduce the aim and content of the current report, and introduce the EUonQoL project as well as the work package in which context this report is written.

1.1. Aim of the Report on stakeholder needs and requirements

The aim of deliverable D2.2 is to provide an insight into the specifics of our stakeholder involvement and engagement plan - in line with the *D2.1 Handbook & checklist: Collaborations in participatory cancer research*. It outlines the means and strategies that we will employ to reach and engage wide-ranging stakeholders in the project, ensuring the provision of the necessary input into all aspects of its conduct, including its long-term uptake, sustainability and impact. Thus, D2.2 focuses on outlining the methods and planned activities on stakeholder involvement and does not report on any results or meetings.

The original aim of deliverable 2.2 was to write a report on stakeholder needs and requirements. However, as the stakeholder board will only be constituted in month 6 and the stakeholder forum is envisioned to happen in month 12, we will not be able to collect and describe their specific needs and requirements at this point. Therefore, there has been a slight change of the scope for the deliverable. The European Commission was informed and accepted the adaptions of the deliverable 2.2.

1.2. The EUonQoL project

The EUonQoL project aims to review existing scales and to develop new metrics by harnessing the strengths and overcoming the limitations of previous tools. The EUonQoL consortium was founded to develop, validate and disseminate the European Oncology Quality of Life toolkit (EUonQoL-Kit) among European cancer patients. The EUonQoL-Kit will be a new digital system for QoL self-assessment, available in several European languages and developed from the patient’s perspective. The overall project is based on participatory research principles, through the involvement of a representative panel of patients and public members throughout all project phases.

The EUonQoL project consists of 10 work packages in total, of which this current report is written in the context of work package 2 (WP2). This work package is focused on involving patients, caregivers and stakeholders in general in the EUonQoL project. The involvement of patients, caregivers and stakeholders is essential to this project to ensure that the EUonQoL-Kit captures the aspects of QoL that matter most to patients and caregivers, as well as to ensure that the EUonQoL-Kit produces output that stakeholders can use to address (unmet) needs, expectations and preferences of cancer patients and caregivers. The work package leader of WP2 is Nivel (Netherlands Institute for Health Services Research), in good collaboration with participating partner the European Cancer Organisation (ECO). Further description of the project, its work packages and the participating organisations can be found on the EUonQoL website: http://www.euonqol.eu/

2. Background

In this chapter we will give background information on stakeholder involvement and engagement in cancer research, starting with information on the main topics of the EUonQoL project: cancer and quality of life. After this we will give a more general introduction into the topic of stakeholder involvement in research.

2.1. Cancer and quality of life

Cancer is the second cause of death and the first cause of suffering for patients and caregivers in Europe, as well as having an enormous financial impact on health services and individuals. There were 2.7 million new cases of cancer and 1.3 million deaths in 2020, which is expected to increase with about 25% by 2035. Additionally, there is an unacceptable variability in terms of access to innovation, quality of care, and outcomes (including quality of life), within and between countries in Europe. Quality of life (QoL) can be interpreted as satisfaction and happiness measured as the achievement of aspirations and/or the realization of individual expectations. In this definition, the perception that an individual has of one's health is one of the many possible determinants of QoL. The burden of cancer and cancer treatment on QoL is well-recognized. Nonetheless, implementation of QoL assessment in routine oncology practice is not yet part of standard of care. In the same way, health care systems and cancer control programs do not take into consideration QoL measures when developing clinical, societal, and healthcare policymaking systems [1].

2.2. Stakeholder involvement

2.2.1. The value of stakeholder involvement

Stakeholder engagement in research is the process of working together with stakeholders for a common goal [2]. Stakeholders have been defined as *"individuals, organizations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavour"*. Studies have identified some form of collaboration between researchers and end-users as one of the factors most likely to lead to the research making an impact [3]. Engaging stakeholders in research ensures the delivery of useful and usable knowledge. Stakeholder engagement can bring knowledge and expertise from different experiences and perspectives to the research project, provide data and resources, build shared understanding, and make information from research relevant for effective decision making [2]. Research and technological advances only make sense if they are useful, usable, and embraced by consumers. This requires the public to be made aware of new scientific developments and to have the opportunity to communicate and interact with researchers. Therefore, engagement with stakeholders is of paramount importance [4]. Furthermore, research shows that the take-up or usage of scientific research findings by non-academic practitioners in their work and policy practices is directly related to their involvement or engagement in the knowledge production process associated with such findings. Stakeholder engagement in research ensures that appropriate people are identified and involved throughout a research process so that they are in a position to inform study design, implementation and then make use of the results when a study is completed [5].

There exists some overlap with the available literature on patient and public involvement (PPI) in research. However, here we focus on multi-stakeholder engagement, where diverse groups of stakeholders take part in the research process. Stakeholder engagement can be defined as *"an iterative process of actively* *soliciting the knowledge, experience, judgment and values of individuals selected to represent a broad range of direct interest in a particular issue, for the dual purposes of: creating a shared understanding; making relevant, transparent and effective decisions”* [3]. For more in-depth information on patient and public involvement, we refer to *D2.1 Handbook & checklist: Collaborations in participatory cancer research*.

2.2.2. Objectives of stakeholder involvement

On this basis, the project plans to include stakeholder involvement and engagement throughout its workplan, collecting and deploying their input into:

- **The consensus process for the EUonQoL-Kit.** Stakeholders will be asked to join several consensus meetings with the goal to achieve consensus on the newly developed EUonQoL-Kit.
- **The pilot survey of the EUonQoL-Kit.** Stakeholders will be included in the pilot survey to interpret and review the results, and to contribute to the development of appropriate and accessible reports and visualizations of the data.
- **Spontaneous data collection of the EUonQoL-Kit.** Stakeholders will contribute to the promotion of spontaneous data collection following the pilot survey and to the preparation and dissemination of a report on this.
- **Implementation and exploitation of the EUonQoL-Kit.** Stakeholders will contribute to the creation of an External Network and help to develop and test the EUonQoL Implementation Guideline.

2.2.3. Methodology of stakeholder involvement and engagement

This section aims to outline the methodology that was used to develop the different elements of the stakeholder involvement and engagement plan. First, based on a consolidated understanding of the project objectives and of its positioning among the wider research and political landscape, the WP2 project team identified the stakeholder profiles most relevant to the project as will be explained in section 2.2.1. Secondly, based on ECO’s previous contacts and experience to gather relevant stakeholders on the field of cancer, an initial profiling and mapping of stakeholder groups and organisations of potential relevance to the project took place. After an initial stakeholder mapping was established, discussions took place with project coordinators to collect their input and views into this early stakeholder mapping. Additionally, input was collected into the planning of potential activities to involve and engage the identified stakeholder organisations. Furthermore, a bilateral meeting was held with work package leaders of WP8 and WP9, as these two work packages will also include stakeholder related activities and there is an interconnection between the work conducted in WP2 and these two other work packages:

- Within WP8 the task 8.2 *Develop an external communication strategy targeting projects, professional organisations and other relevant stakeholders*
- WP9 focuses on dissemination and communication activities

The meeting was an opportunity for the three WPs to align on which were the most relevant stakeholders, proposed stakeholder activities, avoid duplication of efforts and further strengthen the outreach of the project.

Lastly, a stakeholder mapping and planning table (see Annex Tables II and II) will be continuously developed and has been circulated to the wider EUonQoL consortium to collect input. Particular feedback was collected related to local stakeholder contacts from the project's clinical partners and country leads, both in respect to civil society organisations and national policy-makers and public authorities. The collected contribution also allows to further define means, tools and strategies that will need to be used to ensure successful stakeholder outreach and generate stakeholder involvement and engagement throughout the project.

2.3. Stakeholder definition and identification

2.3.1. Relevant stakeholders profile

Stakeholders come from different groups and organizations, such as funders, community members, advocacy organizations, patients, businesses, policymakers, and product developers. A stakeholder may serve multiple roles and bring several perspectives to a project (e.g., research participant, end-user, co-production partner) [2].

The cancer community is constituted by a heterogeneous group of stakeholders with a variety of perspectives, needs, resources, skills, and interests. Stakeholder organisations do not always fit in nice categorical groupings and do not necessarily represent the perspectives or interests of the groups they may be perceived to fit in. Within each categorisation, there are divergent perspectives, competing interests, and the potential for splintered subgroups. Therefore, it is important to consider all cancer stakeholders when determining who gets a seat at the table and to value the diversity of perspectives among those at the table [6].

Based on the methodology presented in section 2.2.3, relevant stakeholders were categorised in profiles according to their role or potential involvement in the project:

- **Stakeholders involved in the early-stage design.** This category includes stakeholders with high experience (i.e., patient representative organisations) and expertise (i.e., researchers) in quality of life for cancer patients. Therefore, their involvement will be key to initially identify the most relevant needs for cancer patients and the gaps of existing tools.
- **Ongoing co-developers.** This group gathers stakeholders that can contribute to and guide the ongoing work and progress of the project to ensure the final outcomes of the project are relevant and of the highest quality, such as medical societies and policy makers.
- **Users.** This last category includes those stakeholders that in the future might either use the EUonQoL-Kit to evaluate the quality of life of cancer patients or use the data collected to advocate and foster better quality of life and support health and social policies (i.e., healthcare professionals).

Stakeholder groups were classified according to the stakeholder profiling mentioned above, see Annex Table I.

2.3.2. Mapping of relevant stakeholders

Following the profiling, stakeholder organisations were mapped based on the stakeholder categories previously identified. The Annex Table II provides a detailed list of the individual stakeholder organisations that were identified through this mapping at the time of development of the present report. It is intended that this table keeps being updated during the course of the project, as additional relevant stakeholders will be identified.

3. Stakeholder engagement plan

In this chapter we will present the specifics of our stakeholder engagement plan. The following stakeholder engagement plan aims to suggest how project partners from different work packages will be contacted, involved and engaged with diverse stakeholders throughout the various phases of the project.

3.1. Strategies for involvement and engagement

Based on the profiling and identification of relevant stakeholder organisations, a set of strategies were developed in order to generate stakeholder involvement and engagement throughout the project.

The strategies that were defined are the following:

1. Identifying key stakeholder representatives to play a strong or even leading role in stakeholder involvement and engagement into the project, via the constitution of a EUonQoL **Stakeholder Board**

This will include a selection of highly engaged, committed and influential stakeholder representatives. These representatives are seen as most relevant to ensure both the provision of input from identified critical stakeholder groups, and the generation of a complex tree of mutual information flow between the project and the respective communities they represent. When choosing the members of the Stakeholder Board, we will strive for inclusion of diversity.

A multi-disciplinary group of 10-12 experts from different fields of expertise, more specifically one or two experts from each stakeholder group identified in Annex Table I, will be constituted. Once selected, these stakeholder representatives will be invited and convened for provision of in-depth stakeholder input into the project's workplan via regular meetings with the ECO project team and other project partners. Members of the Stakeholder Board will have a key role on the governance of the project and great visibility towards the EUonQoL cancer community. The role may include financial compensation for the time contribution of Stakeholder board members.

The Stakeholder Board will meet at least twice a year and more if needed and will be consulted on varying topics, see Annex Table III.

2. Raising awareness of the project among a wide audience through open meetings (EUonQoL **Stakeholder Fora**)

Partners from WP2 will organise one Stakeholder Forum per year. The agenda of these meetings will include a presentation by the EUonQoL project partners of the project background, objectives and first achievements, as well as of the opportunities to provide input. They will, in this sense, serve as a common platform of public engagement for all work packages of the project, rather than separate activities taking place on the different elements of its workplan.

The EUonQoL Stakeholder Board and co-researchers will be invited to the Fora. Additionally, attendance to these meetings will be encouraged via a combination of public promotion via ECO's dissemination channels, with voluntary contribution by project partners, and specific outreach to the previously mapped relevant stakeholder groups. They may be invited to participate in these meetings to ensure that their perspectives or opportunities to collaborate can be heard.

3. Receiving feedback on the EUonQoL-Kit development (EUonQoL **Stakeholder consensus meeting** on the EUonQoL-Kit)

The purpose of the meeting is to get as many perspectives on the table as possible, from patients and potential end users of the QoL data to 1) confirm that the work leading up to first drafts of EUonQoL-Kit instrument is consistent with the perspectives of patients and stakeholders; 2) to inform the finalization of the instruments. These meetings will include the stakeholder board, the co-researchers and consortium partners. Potential items of the meeting will include:

- Stakeholders sharing ideas on how they envisage the use of the quality of life data;
- Report from patient co-researchers on how the patient perspective has been considered and what they consider important for next steps;
- Consortium presenting activities and draft instruments, pending decisions for finalization;
- Debate on important considerations to consider for finalisation.

3.2. Means of outreach

In order to implement the above-defined strategies, the second step towards the development of an overarching stakeholder involvement and engagement plan was the definition of the means we will employ to reach, involve and engage identified stakeholder organisations effectively.

Stakeholder organisations will initially be approached via:

- Using the pre-existing ECO Focused Topic Networks

Led by co-chairs from ECO Member Societies, these Networks have been established to convene wide-ranging stakeholders around policy topics of common interest to the European cancer community, and facilitate consensus and joint projects. Each Network brings together more than 45 organisations and 90 individual representatives. Among the areas of focus of the ten ECO Focused Topic Networks, two appear as of most major relevance to the project: Quality Cancer Care and Survivorship and Quality of Life. These two Networks will be deployed for the implementation of the EUonQoL stakeholder involvement and engagement plan through:

- Ongoing presentation of the EUonQoL project and its latest developments on the meetings of the two Networks (two per year), where possible and relevant;
- Dissemination of information on opportunities for stakeholder involvement and engagement into EUonQoL to the Network participants, via the established Secure Area of the ECO website allowing direct communication with all part of ECO Focused Topic Networks.

- Using the pre-existing Engaged External Consultative Supporters ECO platform

This platform has been set up on the ECO website to:

- Enable close engagement of relevant external stakeholders into the implementation of EU-funded projects that ECO is coordinating or participating in. In the context of the latter playing a major role in the implementation of Europe's Beating Cancer Plan, the EU Cancer Mission and other flagship health and cancer policy initiatives, the aims of this platform are to: promote inclusiveness in the delivery of EU flagship health policy and EU-funded projects; and,
- Optimise impact and create avenues to influence policy.

The platform operates via a simple registration process on the ECO website for any external stakeholder organisation to register its interest in getting involved and engaged on a certain project. It is, in particular, open to health professionals' and researchers' organisations, healthcare institutions, non-governmental organisations, and patients and representatives. Following registration, expressions of interest that have been received get reviewed together with the relevant governance structures of the respective projects, ahead of deciding on whether or not to indeed involve the interested stakeholder organisation or representative in providing input into the project's workplan. The portal is promoted on an ongoing basis via ECO's dissemination channels.

In agreement with the project coordinators, ECO's Engaged External Consultative Supporters platform will be deployed for the EUonQoL project by promoting stakeholder involvement and engagement opportunities (e.g., Stakeholder Fora) on the platform, stimulating further responses and expressions of interest by external stakeholder groups.

- Leveraging project partners' respective networks and connections via the dissemination of a bespoke call for interest

The EUonQoL consortium includes the highest level of expertise across Europe on palliative care and quality of life for cancer patients. As such, consortium partners have a wealth of contacts, at international, European, national and local levels that are crucial to tap onto in order to implement a successful and optimised stakeholder involvement and engagement plan.

In order to ensure this, a call for interest to stakeholders template on the EUonQoL project was developed by the WP2 to be disseminated by all voluntary consortium partners to their respective contacts and networks, by such means as direct outreach, inclusion in regular newsletters, or others.

The template call for interest can be seen in Annex IV. It provides a one-page summary of:

- The EUonQoL project overview;
- The aims of involving and engaging stakeholders in the project;
- The practical means in which interested stakeholders will be engaged;
- The steps to follow to signal interest and to contact the project team.

Additional outreach to stakeholders will take place via social media platforms such as LinkedIn and Twitter.

3.3. Planning of activities

The activities that are currently planned to engage stakeholders can be found in Annex Table III.

3.4. Practicalities

3.4.1. Preparing stakeholders for their involvement

To prepare stakeholders for their involvement in EUonQoL, all WP leaders and co-leaders were enquired to send information on the tasks that the stakeholders will need to participate in. These tasks are reflected in the stakeholder engagement planning (Annex Table III). In order to provide information to the stakeholders on the EUonQoL project and the specific tasks they will be involved in, a Stakeholder Forum will be organised.

3.4.2. Agreements on collaboration

Before collaboration starts with stakeholders, it is important to inform them on the roles and tasks they will be expected to fulfil. Furthermore, agreements need to be made about the means of contact and how to further collaborate with each other. The Stakeholder Board will meet twice a year, and the meetings will be online. Meetings can be scheduled more often on request from the Stakeholder Board or the EUonQoL researchers. Furthermore, the Stakeholder Board might be involved in other consortium meetings besides the Stakeholder Board meetings. During the meetings, the Stakeholder Board has an advisory role on the EUonQoL project.

3.4.3. Data management for the purpose of stakeholder engagement

The data of relevant stakeholders will be stored on a secured computer disc under the responsibility of the European Cancer Organisation.

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Annexes

I. Stakeholder profiling

Potential stakeholders	**Stage of involvement**			
	Involved in the early-stage design	**Ongoing co-developers**	**Users**	
			Using the tool	**Acting up on the data**
Patients, informal caregivers, specific communities/marginalised groups and their representative/supporting organisations, including grassroot social health organisations	Having their say on what data they are willing to share and what are the gaps when tackling QoL		To give input on their QoL	
Stakeholder organisations involved in QoL advocacy (e.g. patient organisations and support groups, field-specific charities)		Ensuring that the questionnaire is fitted to identify patients' needs		To advocate for QoL and support patients how it might be needed
Civil Society Organisations	Identifying social barriers and facilitators to QoL			
Researchers e.g. from academia, public health professionals, from market research organisations..	Input on already existing tools	Data gathering, conducting research and translating research into practice	In charge of collecting the data	Having data to compare QoL at international level
Medical Societies		Ensuring that the questionnaire is aligned with the organisations need and the overall "Beating cancer plan" goals		Using the data to improve their action lines on their specific scope

Policy-makers working on cancer quality of life and care policies (Specific departments in European Commission, national cancer/health authorities)		Envisioning and discussing the opportunities on how evidence-based policy can be improved		Using the data to support health and social policies
Regulatory authorities and payers (EMA, health insurers, HTA)				Using the data to improve their action lines on their specific scope
Healthcare professionals, services, centres and networks involved in QoL	Early involved as first-hand experiencers		They might be in charge of collecting the data	Using the data to improve healthcare practices and methodologies used in practice. Ensuring/ discussing what/how solutions can be implemented in the field
Hospital managers and hospital federations			They might help in promoting and facilitating data collection and future use of the EUonQoL-Kit	
Chief medical information officers (CMIO)			In charge of managing collected data	
Similar projects and initiatives		Ensuring good alignment of EUonQoL with other major initiatives in the space		

II. Stakeholder engagement mapping and tracking

Organisation	Group	Country
Patients, caregivers, specific communities/marginalised groups and representative/supporting organisations		
EUROCARERS	Caregiver Representative Organisation	Europe
ECO Patient Advisory Committee	Group of Cancer Patient Organisations	Europe
Workgroup of European Cancer Patient Advocacy Networks (WECAN)	Group of Cancer Patient Organisations	Europe
European Patients' Academy on Therapeutic Innovation (EUPATI)	Patient Empowerment	Europe
Youth Cancer Europe	Patient Representative Organisation	Europe
Europa Donna	Patient Representative Organisation	
Europa Uomo	Patient Representative Organisation	
International Brain Tumour Alliance (IBTA)	Patient Representative Organisation	
Melanoma Patient Network Europe	Patient Representative Organisation	
European Patients' Forum (EPF)	Patient Representative Organisation	Europe
Stakeholder organisations involved in QoL advocacy		
Association of European Cancer Leagues (ECL)	Stakeholder organisation	Europe

ECO Survivorship and Quality of Life Network	Group of stakeholders	
ECO Quality Cancer Care Network	Group of stakeholders	
AGE Platform	Stakeholder organisation for the elderly	
Ending discrimination against cancer survivors	Stakeholder organisation for cancer	Europe
ABC Global Alliance	Stakeholder organisation on breast cancer	International
Civil Society Organisations		
European Social Network	Civil Society Organisation	Europe
Working with cancer	Social enterprise supporting cancer patients returning to work	United Kingdom
Researchers		
European Association for Cancer Research (EACR)	Researchers	Europe
European Organisation for Research and Treatment of Cancer (EORTC)	Researchers	Europe
International Network for Cancer Treatment and Research (INCTR)	Researchers	Europe
International Society for Quality of Life Research (ISOQOL)	Researchers	Europe
European Palliative Cancer Research Centre (PRC)	Researchers	Europe

Medical Societies		
European School of Oncology (ESO)	Researchers	Europe
European Association of Palliative Care (EAPC)	Medical Society	Europe
Associations of General Practitioners/Family Physicians (WONCA Europe)	Primary Care advocate	Worldwide
European Forum for Primary Care (EFPC)	Primary Care advocate	Europe
American Society for Clinical Oncology (ASCO)	Medical Society	US
International Society for Oncology Geriatrics (SIOG)	Medical Society	Europe
International Psycho-Oncology Society (IPOS)	Medical Society	Europe
Multinational Association for Supportive Care in Cancer (MASCC)	Medical Society	Europe
European Pain Federation (EFIC)	Medical Society	Europe
European Oncology Nursing Society (EONS)	Medical Society	Europe
European Association of Urology Nurses (EAUN)	Medical Society	Europe
European Society of Pathology (ESP)	Medical Society	Europe
European Society for Clinical Nutrition and Metabolism (ESPEN)	Medical Society	Europe

European Society of Surgical Oncology (ESSO)	Medical Society	Europe
European Society of Oncology Pharmacy (ESOP)	Medical Society	Europe
European Society for Radiotherapy and Oncology (ESTRO)	Medical Society	Europe
European Society for Medical Oncology (ESMO)	Medical Society	Europe
European Association for Quality and Safety to General Practice/Family Medicine (EQUIP)	Medical Society	Europe
European Head & Neck Society (EHNS)	Medical Society	Europe
World Physiotherapy Europe	Medical Society	Europe
European Society for Sexual Medicine (ESSM)	Medical Society	Europe
European Federation of Nurses Associations (EFNA)	Medical Society	Europe
Policy-makers		
WHO	Policy-makers	
European Commission	Policy-makers	
Organisation for Economic Co-operation and Development (OECD)	Policy-makers	Europe
National Comprehensive Cancer Network	Alliance of National Authorities on Cancer	US

French National Cancer Institute (INCa)	National Authority on Cancer	France
Spanish National Cancer Research Centre (CNIO)	National Authority on Cancer	Spain
German Cancer Research Centre (DKFZ)	National Authority on Cancer	Germany
Belgian Cancer Centre (Sciensano)	National Authority on Cancer	Belgium
Netherlands Cancer Institute (NKI)	National Authority on Cancer	The Netherlands
Austrian Institute of Cancer Research (MedUni Vienna)	National Authority on Cancer	Austria
Comprehensive Cancer Centre – Vratsa (CCC – Vratsa)	National Authority on Cancer	Bulgaria
Cyprus Cancer Research Institute (CCRI)	National Authority on Cancer	Cyprus
Masaryk Memorial Cancer (MMC)	Research and clinical organisation	Czech Republic
Complex Oncology Center (COC)	Cancer centre	Czech Republic
Danish Cancer Society Research Center (DCRC)	National Authority on Cancer	Denmark
Estonian Cancer Society	National Authority on Cancer	Estonia
Hungarian National Institute for Health (ONKOL)	National Authority on Cancer	Hungary
National Hellenic Research Foundation (EIE)	National Authority on Cancer	Greece

Irish Cancer Society	National Authority on Cancer	Ireland
Italian National Institute for Health (ISS)	National Authority on Cancer	Italy
National Cancer Institute Cancer (NVI)	National Authority on Cancer	Lithuania
Institut National du Cancer du Luxembourg (INC)	National Authority on Cancer	Luxembourg
Emanuele Cancer Research Foundation Malta (ECRFM)	National Authority on Cancer	Malta
Maria Skłodowska Curie Memorial Cancer Centre and Institute of Oncology (MCMCC)	National Authority on Cancer	Poland
Portuguese Institute of Oncology (IRCA)	National Authority on Cancer	Portugal
Oncology Association „Ion Chiricuţă” (IOCN)	National Authority on Cancer	Romania
National Cancer of Slovakia (NOISK)	National Authority on Cancer	Slovakia
Institute of Oncology Ljubljana	National Authority on Cancer	Slovenia
Karolinska Comprehensive Cancer Centre (Karolinska CCC)	Research organisation	Sweden
Institute for Cancer Research (OUS)	National Authority on Cancer	Norway
Croatian Association for Cancer Research (HDIR)	National Research Association	Croatia
Regulatory Authorities and payers		

European Medicines Agency	Regulators and payers	Europe
Food and Drug Administration (FDA)	Regulators and payers	US
European Network for Health Technology Assessment (EUnetHTA)	Regulators and payers	Europe
International Association of Mutual Benefit Societies (AIM)	Regulators and payers	Europe
Insurance Europe	Regulators and payers	Europe
European Social Insurance Platform (ESIP)	Regulators and payers	Europe
Hospital managers and hospital federations		
European Health Management Association (EHMA)	Health Management Association	Europe
European Hospital and Healthcare Federation (HOPE)	Federation of hospitals	Europe
Organisations of European Cancer Institutes (OECI)	Federation of cancer centres	Europe
European University Hospital Alliance (EUHA)	Health Management Association	Europe
European Association Hospital Managers (EAHM)	Health Management Association	Europe
Similar projects and initiatives		
EORTC Library (QoL tools)	Development of similar tools	

Europa-Uomo. Questionnaire through website on QoL for prostate cancer patients	Development of similar tools	
EU Network of Youth Cancer Survivors (EU-CAYAS-NET)	Project of similar topic	
MyPal: Fostering Palliative Care of Adults and Children with Cancer through Advanced Patient Reported Outcome Systems	Project of similar topic (palliative care)	
The use of proportional palliative sedation for the relief of refractory symptoms: an international multicenter study (Palliative Sedation)	Project of similar topic (pain relief)	
Patient-centred pathways of early palliative care, supportive ecosystems and appraisal standard (InAdvance)	Project of similar topic (palliative care)	
PanCareFollowUp: Novel, patient-centred survivorship care to improve care quality, effectiveness, cost-effectiveness and accessibility for survivors and caregivers	Project of similar topic (survivorship care)	
Project on Exercise for Fatigue Eradication in Advanced Breast cancer to improve quality of life (PREFERABLE)	Project of similar topic (QoL)	
INtegrated Short-term PallIative REhabilitation to improve quality of life and equitable care access in incurable cancer (INSPIRE)	Project of similar topic (QoL)	
Developing and implementing innovative Patient-Centred Care Pathways for cancer patients (MyPath)	Project of similar topic (survivorship care)	
Pain relief in palliative care of cancer using home-based neuromodulation and predictive biomarkers (PAINLESS)	Project of similar topic (pain relief)	
PALliative Care Yields Cancer welLbEing Support (PAL-CYCLES)	Project of similar topic (palliative care)	
PREFERABLE-II - Personalised Exercise-Oncology for improvement of supportive care: a super umbrella trial to demonstrate the (cost)effectiveness of live-remote exercise in cancer survivors (PREFERABLE-II)	Project of similar topic (QoL)	

Improving quality of life of advanced pancreatic cancer patients through an AI-guided multimodal intervention, combining pain and cachexia management, nutrition, and physical activity (RELEVIUM)	Project of similar topic (QoL)	
Establishing international standards in the analysis of patient reported outcomes and health-related quality of life data in cancer clinical trials (SISAQOL-IMI)	Project of similar topic (QoL)	
Network of Comprehensive Cancer Centres: Preparatory activities on creation of National CCCs and EU Networking (CraNE)	Project related to cancer centres networking	
EU Joint Action on Networks of Expertise (JANE)	Project related to cancer care	
A digital guardian angel enhancing cancer patient’s wellbeing and health status improvement following treatment (ONCORELIEF)	Project of similar topic (QoL)	
Living well, dying well. A research programme to support living until the end (iLIVE)	Project of similar topic (QoL)	
CAncer PAtients Better Life Experience (CAPABLE)	Project of similar topic (QoL)	
Monitoring multidimensional aspects of QUAlity of Life after cancer ImmunoTherapy - an Open smart digital Platform for personalized prevention and patient management (QUALITOP)	Project of similar topic (QoL)	
Patients-centered SurvivorShIp care plan after Cancer treatments based on Big Data and Artificial Intelligence technologies (PERSIST)	Project of similar topic (survivors cancer care)	
Cancer Long Survivors Artificial Intelligence Follow Up (CLARIFY)	Project of similar topic (survivors cancer care)	
Big Data Models and Intelligent tools for Quality of Life monitoring and participatory empowerment of head and neck cancer survivors (BD4QoL)	Project on health data and similar topic (QoL)	
A Collective Intelligence Platform to Support Cancer Champions (LifeChamps)	Project of similar topic (QoL)	
a Federated Artificial Intelligence solution for moniToring mental Health status after cancer treatment (FAITH)	Project of similar topic (QoL)	

Big Data for Better Outcomes (BD4BO)	Project on health data	
Health Outcomes Observatory (H2O)	Project on health data	
Join Action on Rare Cancers (JARC)	WP focused on QoL	

III. Stakeholder engagement planning

Suggested activity	Suggested WPs to participate	Suggested timing of engagement	Suggested means of engagement	Suggested focus of engagement
First Stakeholder Board meeting	WP2 –WP4 – WP7	July 2023	Online	Pre-consensus meeting on the draft EUonQoL-Kit
Stakeholder Board biannual meetings	WP2 – WP7	June 2024 – December 2024	Online	Help to develop and review possible metrics and visualizations of the results from the pilot survey based on stakeholders needs
	WP2 – WP7	June 2024 – December 2024	Online	Contribute to results interpretation of the pilot survey
	WP2 – WP7	June 2024 – December 2024	Online	Contribute to the preparation of target technical reports of the pilot survey for different stakeholder groups
	WP2 – WP7 - WP9	June 2024 – December 2025	Online	Contribute to the ideation and promotion of spontaneous data collection of the EUonQoL-Kit
	WP2 – WP7 - WP9	December 2025 – December 2026	Online	Contribute to the preparation and dissemination of a report on results of spontaneous data collection of the EUonQoL-Kit
	WP2 – WP8	August 2023 – December 2023	Online	Creation of the External Network
	WP2 – WP8	September 2023 – June 2026	Online	Development of the EUonQoL Implementation Guideline
	WP2 – WP8	October 2024 – April 2025	Online	Testing of the EUonQoL Implementation Guideline (V0)
Stakeholder Board meeting	WP2 –WP4 – WP7	September 2023	In-person (Utrecht)	First actual consensus meeting on the first version of the EUonQoL-Kit
Stakeholder Forum	WP2 –WP4 – WP7	December 2023	Online	Second consensus meeting on the draft EUonQoL-Kit after usability testing

IV. Call to stakeholders for interest and engagement in the EUonQoL project

Stakeholder input wanted for the EUonQoL research programme: measuring what matters for cancer patients and survivors in Europe

If you are a stakeholder organisation or representative with an interest in quality of life, palliative and/or supportive care for patients with cancer, then we are looking to receive your input during the EUonQoL research project.

What is EUonQoL?

The EUonQoL project led by Istituto Nazionale Tumori (INT) **aims to develop, pilot and validate the EUonQoL-Kit, a patient-driven, unified system for the assessment of quality of life (QoL)** based on evaluations and preferences of cancer patients and survivors. The EUonQoL-Kit will be developed from a patient perspective, administered digitally, available in the EU27 and Associated countries languages, and applicable in future, periodic surveys to contribute to the EU's Cancer Mission.

EUonQoL is composed of research institutions, cancer centres, as well as scientific, professional, and patient representative organisations, all with extensive experience and robust scientific background in the development of self-report QoL measures.

What is the aim of EUonQoL stakeholder involvement?

As the 4-year project kicked off in January 2023, a central component of its approach is the ongoing co-design methodology with most relevant stakeholders who will inform, benefit from, and use it in the long-term. In this context, the EUonQoL consortium is presently looking to identify all those interested among such stakeholders to take part in shaping the project based on their expertise.

A particular focus will be to contribute and ensure that the landmark EUonQoL questionnaire and its implementation adequately consider all of the major quality of life challenges faced by cancer patients and are fit for driving better policies across Europe.

What to expect?

Following an ongoing mapping and definition of an overarching plan in the first half of 2023, bespoke activities may include for interested stakeholders:

- Consensus building of the cancer community on the EUonQoL-Kit;
- Contribution to the first roll-out of the EUonQoL-Kit across Europe;
- Discussion on the future implementation of the EUonQoL-Kit and its uptake by national health systems;
- Opportunities to leverage EUonQoL to drive positive policy change on quality of life for cancer patients in Europe.

What to do if interested?

All interested stakeholder organisations are kindly invited to register their interest via the bespoke page of the European Cancer Organisation (pressing 'Contact Us'). Any question may be addressed to: norbert.couespel@europeancancer.org

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