



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



Funded by the
European Union

EUonQoL

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

Deliverable number: D8.1

Deliverable title: Collaborative Network Report

Deliverable type	Document, report
Deliverable responsible partner	OUH, UNICANCER
Authors	Alen Brkic (OUH), Tonje Lundebj (OUS), Marianne Grønlie Guren (OUH), Stein Kaasa (OUH), Dominique DELMAS (UNICANCER), Cinzia Brunelli (INT), Roxana Plesoianu (OECI), Norbert Couespel (ECO)
Contractual date of delivery	M12
Actual date of delivery	M13
Dissemination level	Public
Status of deliverable	Final version

Grant Agreement information table

Grant Agreement number	101096362
Project acronym	EUonQoL
Project title	Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe
Start date	1 January 2023
Duration	48 months

"This project has received funding from the European Union's Horizon Europe Research and Innovation Programme under Grant Agreement No 101096362".

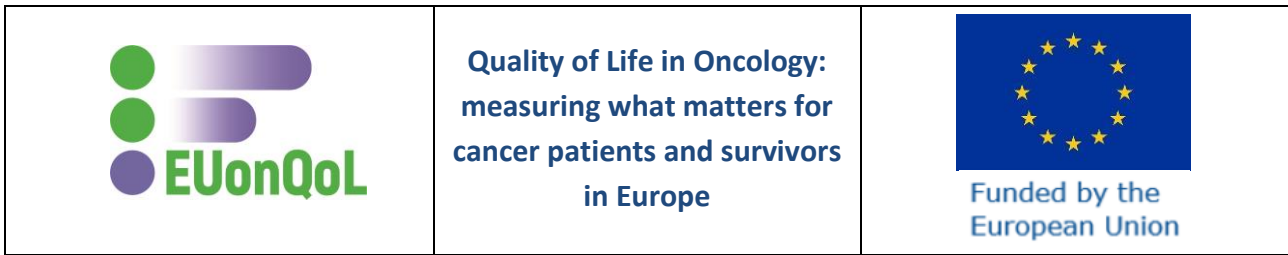
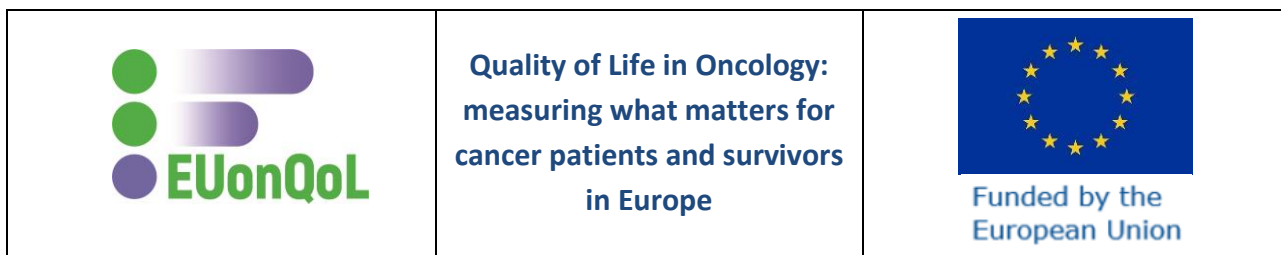


TABLE OF CONTENT

1. Executive Summary	3
2. Introduction	4
2.1 Overview of the EUonQoL project and the development of the EUonQoL Collaborative Network (EUonQoL CoNet)	4
2.2 Purpose of the EUonQoL Collaborative Network (EUonQoL CoNet) and its importance.....	6
2.3 Purpose of the Collaborative Network Report	6
3. The Formation of EUonQoL CoNet	7
3.1 The EUonQoL CoNet	7
3.2 Task Groups.....	8
3.2.1 EUonQoL Implementation Guideline (EUonQoL IG) Advisory Group: National Level	8
3.2.2 EUonQoL Implementation Guideline (EUonQoL IG) Advisory Group: European Level....	9
3.2.3 EUonQoL Sustainability Group	10
3.2.4 EUonQoL-Kit Maintenance Group.....	10
3.2.5 Other Task Groups.....	11
4. The EUonQoL CoNet Timeline: Step I - IV	11
5. Stakeholder Groups	13
5.1 Activities according to Step I-IV	15
5.1.1 Step I: Activities in 2023.....	15
5.1.2 Step II: Activities in 2024.....	16
5.1.3 Step III: Activities in 2025 – 2026	16
5.1.4 Step IV: From 2027 and beyond.....	17
5.2 Activities with various Stakeholder Groups	17
5.2.1 Activities with Politicians	18
5.2.2 Activities with Policymakers	20
5.2.3 Activities with Patient Organisations and other European organisations from the Non-Governmental and Non-Profit Sector	22
5.2.4 Activities with Healthcare Professionals	22
5.2.5 Activities with Public Health Professionals	22
5.2.6 Activities with EU-funded projects	24
6. Conclusions	27
7. Appendix.....	29
8. References	35

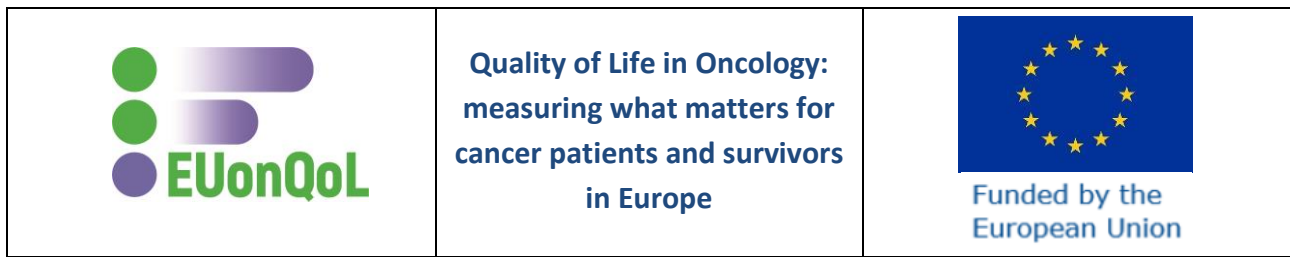


1. Executive Summary

The Quality of Life in Oncology (EUonQoL) project signifies a substantial interdisciplinary advancement in the field of oncology, with a strong emphasis on enhancing the quality of life (QoL) for patients with cancer and survivors of cancer throughout Europe. This project, which received financial support from Horizon Europe, is evidence of the European Union's dedication to improving cancer care. The primary aim of the EUonQoL project is to create and deploy the EUonQoL-Kit, an innovative digital assessment instrument intended exclusively for evaluating the QoL among individuals who have cancer and who have survived cancer. The development of this tool results from a collaborative effort between clinical and scientific experts from diverse European fields and in co-creation with individuals who have personal experience with cancer.

The purpose of the EUonQoL-Kit is to provide extensive aggregated data on cancer-related QoL in all European healthcare sectors, ranging vertically from primary care to specialized oncology care and horizontally from municipal supportive facilities to national health authorities. Politicians, policymakers, patient organisations, the industry, oncology and palliative care research institutes, public health institutes, and governmental and non-governmental stakeholders engaged in healthcare policy may use the collected data. This aligns the EUonQoL project with the EU Mission on Cancer and Europe's Beating Cancer Plan, both supported by a multi-stakeholder approach rooted in Health in All Policies. In order to promote the extensive adoption and sustained utilization of the EUonQoL-Kit in alignment with the aforementioned initiatives, the project intends to establish the EUonQoL Implementation Guideline (EUonQoL IG). Regardless of the user, this dynamic and role-adaptive guideline is designed to facilitate the EUonQoL-Kit's implementation in every European country and at different levels. However, establishing the EUonQoL IG necessitates a comprehensive understanding of each country's diverse operational and infrastructural elements; thus, robust stakeholder engagement, collaboration, and interactions are required. To meet the described objectives required by the project, the EUonQoL Collaborative Network (EUonQoL CoNet) will be formed, consisting of diverse stakeholders from various stakeholder groups (e.g., politicians, policymakers, organisation representatives, healthcare and public health professionals), from which task-oriented groups (Task Groups) can be drawn. These Task Groups will facilitate tasks ranging from the EUonQoL IG's development to the project's and the EUonQoL-Kit's sustainability.

In conclusion, the EUonQoL project aims to provide a novel tool co-developed by individuals with first-hand experience with cancer to evaluate cancer-related QoL among people with cancer or those who had cancer. This tool will be developed and implemented in such a manner that it can function as a benchmarking assessment tool to be applied across the whole of Europe.



2. Introduction

2.1 Overview of the EUonQoL project and the development of the EUonQoL Collaborative Network (EUonQoL CoNet)

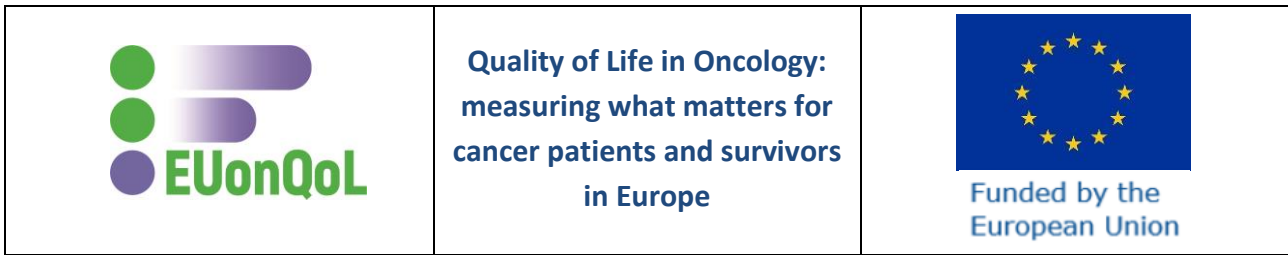
The Quality of Life in Oncology (EUonQoL) project aims to develop a patient-centred method for assessing the quality of life (QoL) among patients with cancer and survivors. This unique project aims to redefine cancer care by improving the QoL for people with cancer and cancer survivors by implementing a novel digital measurement tool (i.e., *EUonQoL-Kit*). To address the requirements of patient-centric digital QoL measuring instruments [1-4], the EUonQoL-Kit will be formed in cooperation between individuals who have experienced cancer first-hand and clinical and scientific experts from diverse European fields.

The EUonQoL-Kit will help provide aggregated data on cancer-related QoL across all European healthcare sectors, i.e., from primary healthcare to specialized oncology care and from municipal supportive facilities to national health authorities. In addition, the data can be collected and utilized by or at industry levels (e.g., pharmaceutical and biotechnology companies), policymakers, patient organisations, oncology and palliative care research settings, and governmental or non-governmental stakeholders involved in healthcare policy. As such, the EUonQoL project aligns with the objectives set forth by *Europe's Beating Cancer Plan* [5] and *EU Mission on Cancer* [6], which are based on the *Health in All Policies* [7] multi-stakeholder approach.

In order to implement the EUonQoL-Kit across all sectors in Europe and, in the long-term, be utilized in conjunction with the Health in All Policies approach, the project intends to develop a dynamic and role-adjusted guideline, i.e., the **EUonQoL IG** (Implementation Guideline), that will facilitate the EUonQoL-Kit's implementation in each country regardless of the user. This aspiration can only materialize through a robust understanding of the various infrastructural and operational aspects, both explicit and tacit, across multiple levels within each country. In turn, this necessitates engagements, interactions, and collaborative endeavours with a diverse spectrum of stakeholders. Stakeholders in the EUonQoL project are defined as "*individuals, organisations or communities that have a direct interest in the process and outcomes of a project, research and policy endeavours*" [8] and include, e.g., politicians, policymakers, patient representatives, researchers, and medical experts.

Stakeholder involvement and engagement will occur throughout the project and have been described in detail in the deliverable *D2.2 - Report on stakeholder needs and requirements* of WP2. As defined in D2.2, the involvement of stakeholders aims to collect and deploy their input into project activities such as:

- **The consensus process for the EUonQoL-Kit.** Stakeholders will be asked to join several consensus meetings with the goal of achieving 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 contribute to developing appropriate and accessible reports and visualizations of the data.



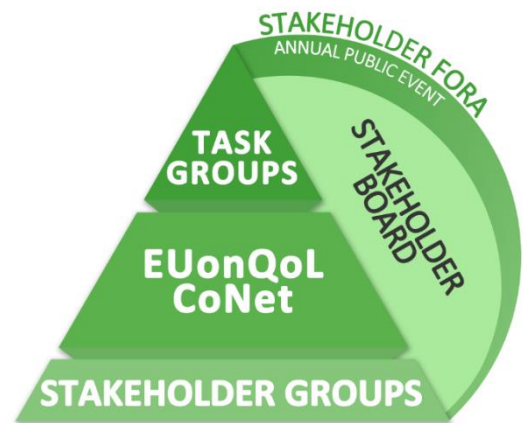
- **Spontaneous data collection of the EUonQoL-Kit.** Stakeholders will contribute to promoting spontaneous data collection following the pilot survey and preparing and disseminating a report on this.
- **Implementation and exploitation of the EUonQoL-Kit.** Stakeholders will contribute as members of the national and European advisory groups [termed External Network in other previous deliverables] to help develop and test the EUonQoL IG.

Furthermore, WP2 identified the following strategies for their involvement and engagement:

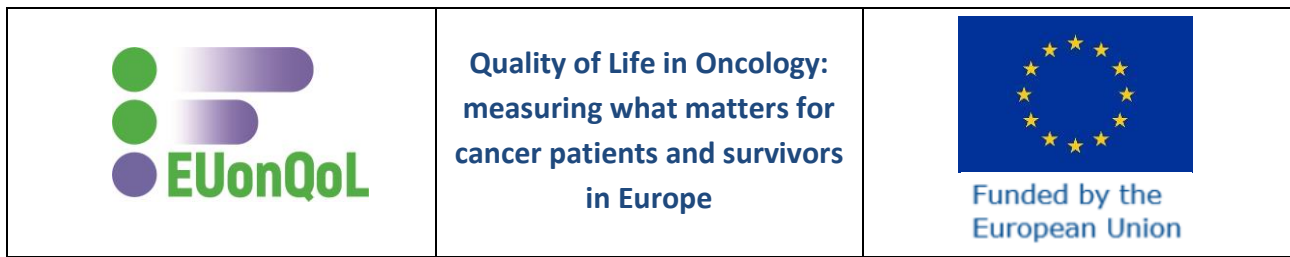
- **Establishment of the EUonQoL Stakeholder Board.** A group of 11 key experts and representatives of relevant institutions/projects to play an expert advisory role.
- **Organisation of EUonQoL Stakeholder Fora.** Yearly online public events organised by WP2 partners to engage a wide audience in ongoing project activities, collecting high-level feedback and raising awareness on project progress.

An example of the early deployment of the EUonQoL Stakeholder Board and Stakeholder Forum to inform project activities has undergone a consensus process on the EUonQoL-Kit that took place through a hybrid meeting of the Stakeholder Board and the project's patients and caregiver co-researchers in October 2023, and the first EUonQoL Stakeholder Forum online in December 2023. The outcomes of this process will be detailed in a separate later deliverable.

The EUonQoL project aims to establish a multifaceted collaborative network, the **EUonQoL CoNet** (Collaborative Network), constituting various *stakeholder groups* designed to support a range of tasks integral to the project's objectives. To effectively handle these diverse tasks, task-oriented groups (i.e., *Task Groups*) from the EUonQoL CoNet will be formed accordingly. **The primary focus of the EUonQoL CoNet includes contributing insights to the development of the EUonQoL IG and ensuring the project's sustainability beyond its initial timeline.** As such, respective Task Groups will be formed to facilitate these aims. Moreover, as the EUonQoL CoNet is adaptive and dynamic, other Task Groups will be created based on the project's needs throughout the project timeline. This document, the Collaborative Network Report, aims to present EUonQoL CoNet development, current status, and future plans for its activities. The EUonQoL CoNet and its Task Groups will align with and integrate existing stakeholder engagement structures developed and operated by WP2 in the following ways:



- **The EUonQoL Stakeholder Board will keep an overarching advisory role on all strategic matters throughout the project.** The Stakeholder Board members will be regularly updated on the specific discussions held within the EUonQoL CoNet Task Groups and have the opportunity to provide advice and steering to them.



- **EUonQoL Stakeholder Board members will have a core role in forming and composing the EUonQoL CoNet Task Groups.** The first step of the latter will be the assessment of the interests and collecting expert advice from Stakeholder Board members on joining the different Task Groups and inviting additional experts to them.
- **EUonQoL CoNet Task Groups will, therefore, be composed of a combination of members of the EUonQoL Stakeholder Board and additional invited experts chosen among the most relevant stakeholder groups** (as detailed below), **as advised by the Stakeholder Board.** To select relevant profiles and invite specific experts to compose the Task Groups, the stakeholder profiling and mapping conducted by WP2 early in the project will be used as a framework.
- **The EUonQoL Stakeholder Fora** will keep representing yearly opportunities to update a wider public audience on the progress achieved in the project, including in the Task Groups of the EUonQoL CoNet, and generate interest from new stakeholder representatives to join the CoNet – that will operate continuously between the yearly Fora.



2.2 Purpose of the EUonQoL Collaborative Network (EUonQoL CoNet) and its importance

The EUonQoL CoNet will have an essential role in implementing the EUonQoL-Kit and in the sustainability of the EUonQoL project, consequently facilitating the Mission on Cancer and the Europe Beating Cancer Plan. Hence, the EUonQoL CoNet will indirectly positively impact the QoL for patients with cancer and survivors across Europe. In summary, the purpose of the EUonQoL CoNet is threefold:

- **Knowledge and expertise exchange:** The EUonQoL CoNet facilitates the dissemination of best practices, expertise, and new solutions among stakeholders. This knowledge exchange contributes to bridging understanding gaps and fostering a more complete approach to cancer care at the patient, provider, and system levels.
- **Interdisciplinary collaboration:** The EUonQoL CoNet comprises diverse stakeholders (e.g., politicians, policymakers, patient representatives, researchers, and medical experts) who are encouraged to collaborate with and support the EUonQoL project in various degrees. This collaboration is voluntary and, as such, may lead to variable involvement.
- **Advocacy for patient-centric cancer care policies:** The EUonQoL CoNet acts as a collective voice advocating for formulating and elaborating policies that emphasize the needs and preferences of patients with cancer and cancer survivors. It is structured to provide insights and information to local, national, and international policy decisions, aligning with the objectives of the Mission on Cancer, the European Beating Cancer Plan, and the Health in All Policies approach.

2.3 Purpose of the Collaborative Network Report

The objective of this document is to define how the EUonQoL CoNet and the subsequent Task Groups will be created and continued throughout the course of the project in coordination with and integration of the existing EUonQoL Stakeholder Board and Fora. Furthermore, as the EUonQoL project spans the next three years, this document will also help keep track of the current and planned

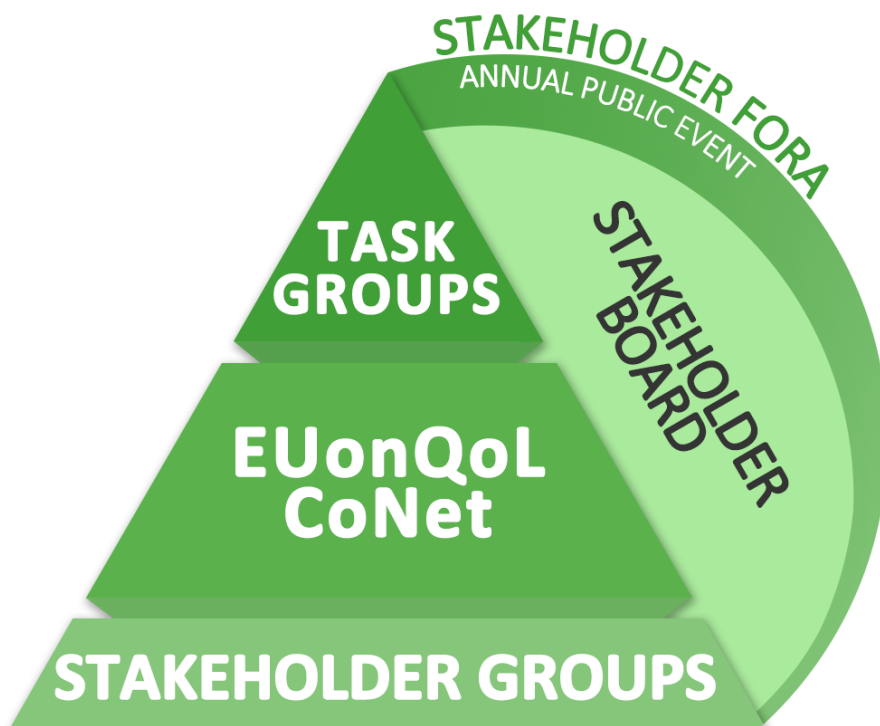
	<p>Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p>Funded by the European Union</p>
---	---	---

communication strategy that aligns with the EUonQoL project's task related to developing an external communication strategy (Task 8.2). Task 8.2 will continue throughout the EUonQoL project's timeline.

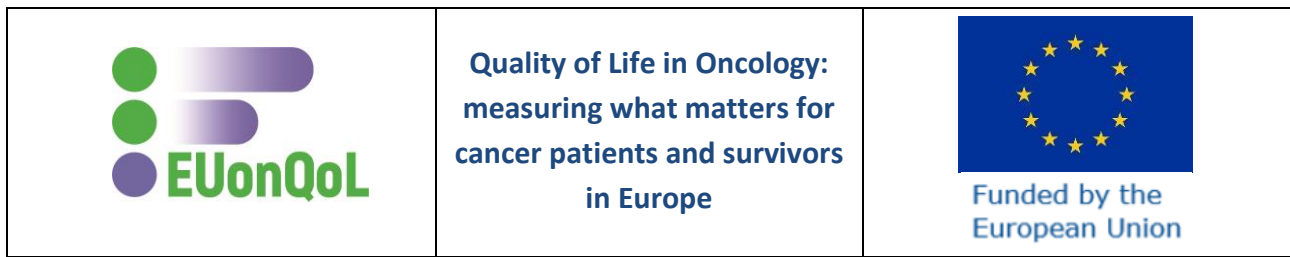
3. The Formation of EUonQoL CoNet

3.1 The EUonQoL CoNet

The EUonQoL CoNet is a multifaceted collective of task-oriented groups (Task Groups) designed to fulfil the overarching objectives of the EUonQoL project. Each of these Task Groups is formed of representatives from various Stakeholder Groups.



Stakeholder Groups form the foundational layer of the EUonQoL CoNet, comprising healthcare professionals, policymakers, patient organisations, NGO representatives, and others. These Stakeholder Groups are crucial in offering insights, support, and advocacy, and their contributions are aligned with broader initiatives like the Mission on Cancer and Europe's Beating Cancer Plan. Some stakeholders from the various groups will mainly provide and receive information, while others will have a more active collaborative role.





3.2 Task Groups

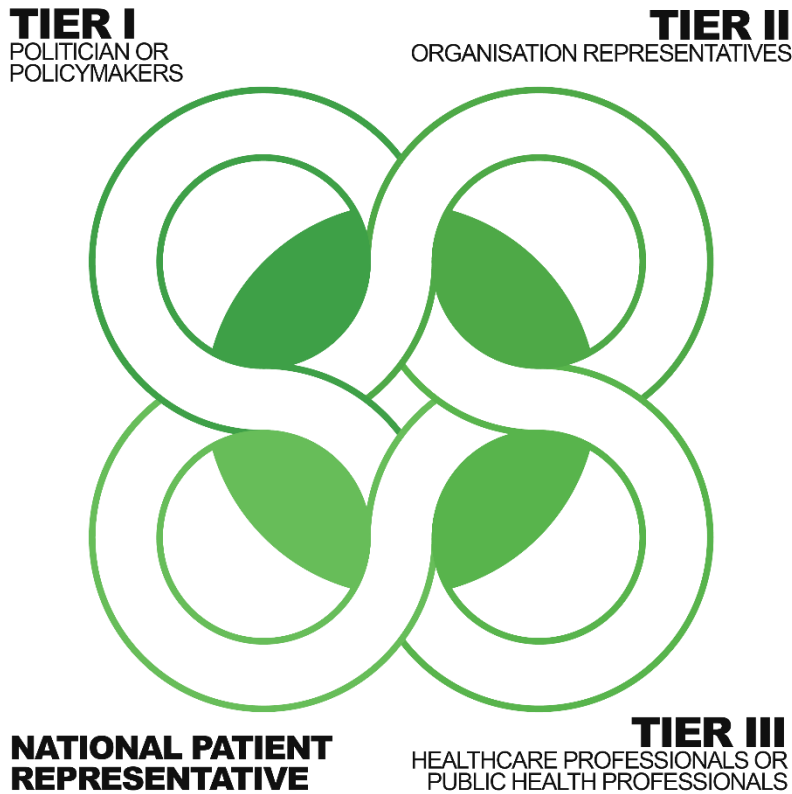
Within EUonQoL CoNet, these groups typically operate independently in their respective domains, playing a vital role in advancing the EUonQoL project's overarching goals. However, while some stakeholders may fulfil multiple positions across the different Task Groups, some will not take part in any of the Task Groups. Task Groups are composed of select stakeholders within the EUonQoL CoNet drawn from various Stakeholder Groups. These Task Groups are formed to address specific operational objectives within the EUonQoL framework, such as facilitating and advising in the development of the two EUonQoL Implementation Guideline (EUonQoL IG) groups, the **EUonQoL IG Advisory Group: National Level** and **EUonQoL IG Advisory Group: European Level**. Two other Task Groups will focus on aspects beyond the EUonQoL project, one ensuring sustainability and extension (**EUonQoL Sustainability Group**) and the other supporting the continuous development of the EUonQoL-Kit (**EUonQoL-Kit Maintenance Group**). Other Task Groups may be formed at a later date. One planned Task Group will interpret and use the collected data (**EUonQoL Data Group**). As described in section 1.1, the Stakeholder Board (11 members), already established and reported in D2.2, will be connected to all Task Groups and the overall EUonQoL CoNET to support, advise, and facilitate their development and operation.

3.2.1 EUonQoL Implementation Guideline (EUonQoL IG) Advisory Group: National Level

The primary aim of the EUonQoL IG Advisory Group on the National Level is to offer insight into the governance and systemic workings of various countries where the EUonQoL-Kit will be deployed and, consequently, where the EUonQoL IG will be tailored accordingly. By acquiring a comprehensive understanding of how these nations operate across various healthcare sectors, i.e., spanning from primary healthcare to specialized oncology care, from municipal supportive facilities to national health authorities and state health agencies, and within the public health research field, the EUonQoL IG can be tailored more individually to each user in each country for the utilization of the EUonQoL-Kit, ensuring effective implementation.

In order to gather contextual insights from each country, four representatives from every country where the EUonQoL IG is intended for development will be selected. These four representatives will comprise a patient representative from the selected country, along with one representative from Tier 1 (i.e., politicians or policymakers), Tier 2 (organisation representatives), and Tier 3 (healthcare professionals or public health professionals). Through this diverse representation, a well-rounded understanding of each country's unique circumstances and needs can be obtained to better tailor the EUonQoL IG. In this process, we will be cognisant of the diverse stakeholder landscapes across different countries, acknowledging that some representatives may fulfil multiple roles.

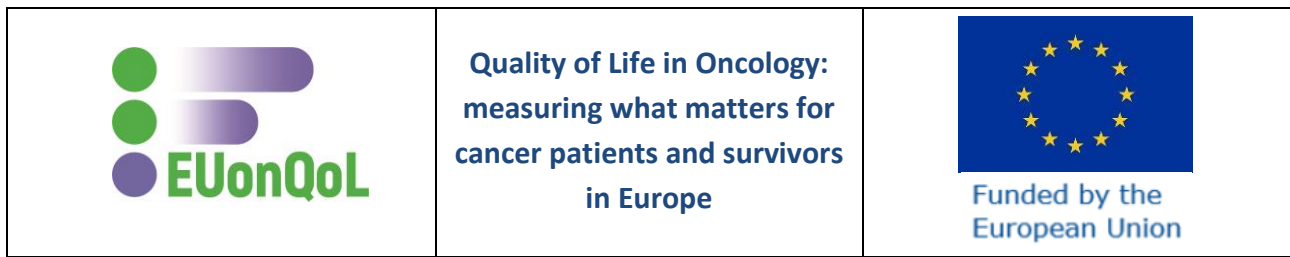
	<p>Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 Funded by the European Union
---	---	--



To make the task more achievable and ensure a comprehensive representation across Europe, six countries were selected for the initial step of the EUonQoL IG Advisory Group: National Level development. These countries are *Belgium, Portugal, Italy, Romania, Norway, and France*. The selection was influenced by the countries' relatively straightforward healthcare systems, geographical representation across Europe, and familiarity among the work package partners responsible for developing the EUonQoL IG. This approach ensures a well-rounded mix of perspectives and operational environments, which is essential for learning and adapting the model before expanding the EUonQoL IG to other parts of Europe. In Step I, we have completed mapping the various tiers in the aforementioned countries and initiated preliminary outreach. The knowledge gained from engaging with the six countries will define how we proceed to reach out to the other countries and also provide a better understanding of whether collecting 120 representatives is feasible. Continuation of complete mapping and engagement with the other countries will be set in Step II. Iterative rounds will be expected through the development of the EUonQoL IG Advisory Group: National Level.

3.2.2 EUonQoL Implementation Guideline (EUonQoL IG) Advisory Group: European Level

While the EUonQoL IG Advisory Group: National Level is dedicated to integrating the EUonQoL-Kit within individual countries, customizing it to each nation's unique healthcare framework, the EUonQoL IG Advisory Group: European Level will oversee the broader, coordinated implementation across Europe.



The objective of the EUonQoL IG Advisory Group: European Level is to ensure harmonization across European countries by promoting a unified, pan-European strategy for implementing the EUonQoL-Kit. This group ensures that integration strategies align with central European projects/initiatives to improve the landscape of cancer data. As such, the primary aims of this initiative are the following: establish a thorough European strategy for the EUonQoL-Kit, promote the exchange of knowledge, identify challenges and opportunities in the European health data space, and maintain strict data privacy, security, and ethics standards. Addressing these aims will facilitate ensuring consistency and efficiency in data collection, analysis, and application, which is crucial for effective cancer care across Europe.

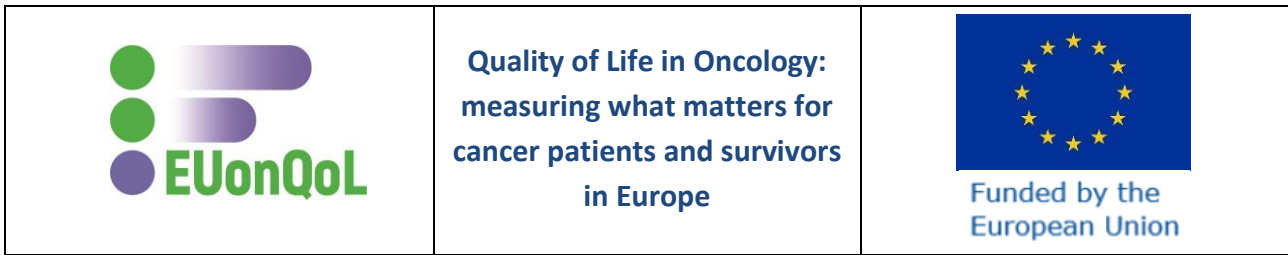
The composition of this Task Group is planned to include various relevant stakeholders from the Stakeholder Groups and representatives who are members of the Stakeholder Board from the European projects/initiatives fit for this Advisory Group. This would include invited representation from 1) [the European Cancer Inequalities Registry](#), 2) [the TEHDAS Joint Action on the development of the European Health Data Space](#), 3) [smartCARE](#), and 4) [ONCORELIEF](#). All projects and their corresponding representatives will have an integral role in the EUonQoL IG Advisory Group: European Level, bringing knowledge in handling large-scale, multi-country data projects and their integration into healthcare systems. Regular meetings will be held to discuss progress, challenges, and opportunities, focusing on leveraging its members' diverse expertise to guide the strategic direction of the EUonQoL-Kit implementation across Europe.

3.2.3 EUonQoL Sustainability Group

The Sustainability Group is tasked with ensuring the long-term viability and impact of the EUonQoL project. This Task Group's primary objective is to develop and implement strategies that maintain and enhance the project's relevance and effectiveness beyond its initial operational Step. This includes identifying potential future funding sources, exploring new partnerships, and considering opportunities for expansion and adaptation in response to evolving healthcare needs. Through its strategic and proactive approach, the Sustainability Group is pivotal in safeguarding the future of the EUonQoL project, ensuring that its impacts are lasting and continually aligned with the needs of cancer care in Europe.

3.2.4 EUonQoL-Kit Maintenance Group

The EUonQoL-Kit Maintenance Group will focus on the continuous evolution of the EUonQoL-Kit, adapting it to advancements in care and technology. As such, this group's objective is to ensure that the Kit remains up-to-date and effective in addressing the changing landscape of cancer and patient needs. Additionally, the group will oversee expanding the Kit's implementation to additional countries, ensuring a broad and inclusive reach. The establishment of this group underscores the commitment to ongoing innovation and responsiveness within and beyond the EUonQoL project period.



3.2.5 Other Task Groups

The EUonQoL acknowledges the ever-evolving landscape of cancer care and the need for continuous adaptation and expansion. In line with this, this project anticipates the need to form additional Task Groups within the EUonQoL CoNet to address emerging challenges and opportunities in cancer care improvement. While the specifics of these future groups are not currently defined, they symbolize EUonQoL CoNet's commitment to staying responsive and adaptable to the changing needs of cancer care and care among cancer survivors. The planning and development of these additional groups will be guided by the insights gained and the lessons learned in Steps II and III. One planned Task Group (EUonQoL Data Group) will primarily focus on developing a methodology for future interpretation of data, ensuring preparedness for when the data becomes available.



4. The EUonQoL CoNet Timeline: Step I - IV



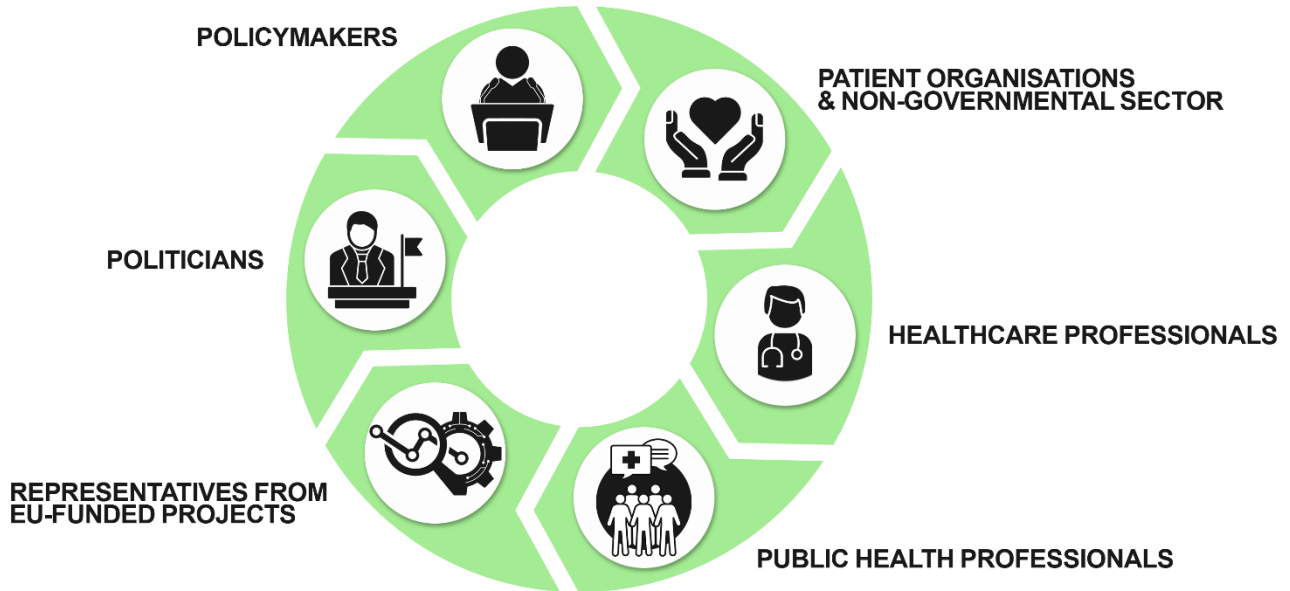
The formation of the EUonQoL CoNet is underpinned by two principal activities: *stakeholder mapping* and *stakeholder engagement*. Stakeholder mapping is the core activity in the EUonQoL CoNet's early step (Step I) and a precursor to stakeholder engagement. This mapping was conducted collaboratively between WP2, WP8, and WP9. Stakeholder engagement enriches the EUonQoL project by merging diverse expertise and perspectives, providing vital data, and fostering a shared understanding crucial for informed decision-making [9]. In the EUonQoL project, the following definition for stakeholder engagement is used: "*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*". While preliminary stakeholder engagement is conducted in Step I, the main interactions with stakeholders will take place in Step II (Stakeholder Group outreach and assessment). The stakeholder engagement strategy is elaborated further in the deliverable D2.2 and is one of the core tasks of WP2. The current Step (Step I: 2023) is followed by three planned Steps (Step II: 2024, Step III: 2025-2026, and Step IV: from 2027 and beyond). The detailed timeline of the formation and application of the EUonQoL CoNet is provided below.

Table 1. Overview of the EUonQoL CoNet Steps

STEPS	OBJECTIVE	PERFORMED ACTIVITIES	APPROACH
<p>STEP I: Stakeholder Mapping and Initial Stakeholder Engagement (M1-M12)</p>	<ul style="list-style-type: none"> • Establishment of the Stakeholder Forum (see D2.2 for further details) • Structure and mapping of Stakeholder Groups • Preliminary outreach to Stakeholder Groups • Participation in conferences and events (Appendix Table 1) 	<ul style="list-style-type: none"> • Activities related to establishing the Stakeholder Forum (see D2.2 for further details) • Information and insight gained following multiple meetings within the consortium and with identified external stakeholders and representatives from other EU projects • In-depth literature exploration on European healthcare systems, primarily focusing on the Health in Transition reviews and implementation science in healthcare • Via diverse meetings and discussions between WP2, WP8, WP9 and co-researcher involvement a 4-tier schema was agreed upon. • European countries were evaluated, and six initial countries were selected for initial testing of the EUonQoL IG. • Mapping and attendance of potential key networking events 	<ul style="list-style-type: none"> • Preliminary identification of various stakeholders followed by the formation of Stakeholder Groups. • Mapping of stakeholders according to the formed Stakeholder Group categorization • Tentative analysis mapping of identified stakeholders based on engagement strategy, outcome, and exploitation • Participation in key events for networking and project dissemination
<p>STEP II: Stakeholder Group outreach and assessment (M13-M24)</p>	<ul style="list-style-type: none"> • Continued outreach and engagement with Stakeholder Groups • Assessment of the Stakeholder Group into categories: <ul style="list-style-type: none"> • Information Recipient & Provider: Stakeholders who will primarily either receive information regarding EUonQoL or provide relevant information on other stakeholders and projects. These will be engaged in a concise and focused manner. • Potential Collaborator: Stakeholders identified as having potential yet uncertain prospects for collaboration will be invited for discussions to assess involvement interest. • Collaborator: Stakeholders recognized for their high potential for active collaboration will be invited to join the CoNet and relevant Task Groups. • Preliminary formation of Task Groups 		<ul style="list-style-type: none"> • Strategic engagement with mapped stakeholders using a standardized communication approach developed with WP2 • The approach will be tailored to each category (<i>Information Recipient/Provider, Potential Collaborators, and Collaborators</i>) • An outreach strategy to disseminate information on EUonQoL and form potential collaborations.
<p>STEP III: Task Group Formation and Engagement (M25-M48)</p>	<ul style="list-style-type: none"> • Continuation of Stakeholder Engagement • Finalization of Task Groups • Engagement and implementation of Task Groups 		<ul style="list-style-type: none"> • Structured engagement via meetings and interactions.
<p>STEP IV: Maintenance of EUonQoL (Beyond M48)</p>	<ul style="list-style-type: none"> • Follow the plan established by and for the EUonQoL Sustainability Group and the EUonQoL-Kit Maintenance Group 		<ul style="list-style-type: none"> • Continued work by the EUonQoL Sustainability Group and by the EUonQoL-Kit Maintenance Group

	<p>Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p>Funded by the European Union</p>
---	--	---

5. Stakeholder Groups



The EUonQoL CoNet will be formed by combining several representatives from various Stakeholder Groups, each holding a significant role in advancing the EUonQoL project. As part of Step I, overview stakeholder mapping was conducted by various EUonQoL work packages (mainly WP2, WP8, and WP9). Based on this overview, the following stakeholder groups were formed: *Politicians*, *Policymakers*, *Patient Organisations & Non-Governmental (NGO) Sector*, *Healthcare Professionals and Public Health Professionals*, and representatives from *the Industry* and from other *EU-funded projects and initiatives*. The table below outlines each Stakeholder Group. The sensitive data of relevant stakeholders will be stored in safe space areas on local computers at and under the responsibility of Oslo University Hospital and the European Cancer Organisation.

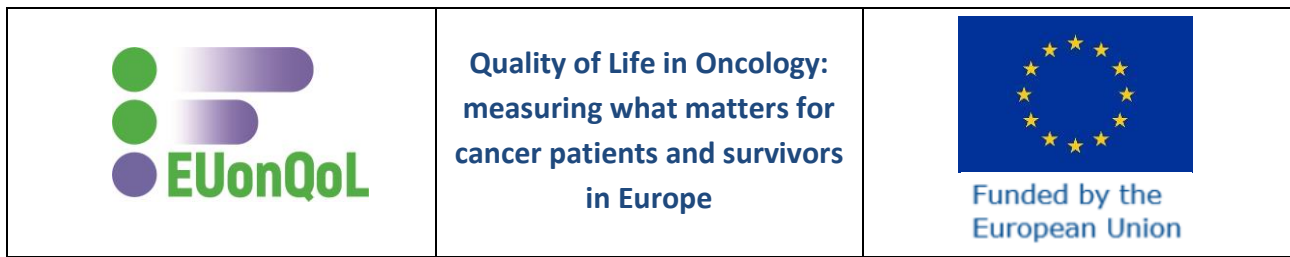
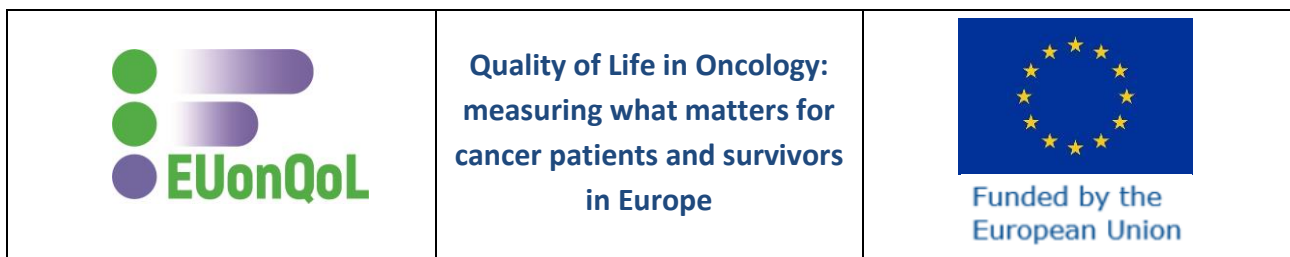


Table 2. Overview of stakeholder groups

STAKEHOLDER GROUP	EXAMPLES	ROLE & INFLUENCE	DESIRED OUTCOME
Politicians	<ul style="list-style-type: none"> Members of the European Parliament National Government officials 	<ul style="list-style-type: none"> Key decision-makers at both national and European levels Responsible for guiding, endorsing, and executing health-related policies. 	<ul style="list-style-type: none"> Acquire insight into the organisational infrastructure at the highest level Gain comprehension of potential support and endorsements Synchronization of EUonQoL project outcomes with overarching EU health strategies and the Mission on Cancer objectives
Policymakers	<ul style="list-style-type: none"> EU health regulators National Regulatory and Policy Bodies National and International Advisory Committees 	<ul style="list-style-type: none"> Individuals and bodies responsible for setting guidelines, regulations, and policies related to health and QoL, especially concerning cancer care. 	<p>Gain a better understanding of health policy decisions, refining health strategies, and how they align with the EU's broader cancer objectives.</p>
Patient Organisations & NGO Sector	<ul style="list-style-type: none"> NGO Representatives Patient Organisation Representatives Survivor Organisation Representatives Caregiver Organisation Representatives 	<ul style="list-style-type: none"> Represent the voice and interests of patients with cancer, survivors, and their families. Influence health policy through advocacy 	<ul style="list-style-type: none"> Collaboration and alignment of goals related to Mission on Cancer and Europe's Beating Cancer Plan Offer and gain assistance in advocating the EUonQoL's objectives and the Mission on Cancer and Europe's Beating Cancer Plan
Healthcare Professionals	<ul style="list-style-type: none"> Healthcare professionals involved in the care of patients with cancer and survivors (oncologists to health administrators) 	<ul style="list-style-type: none"> Insight into the direct and indirect care of patients with cancer and survivors and the practices shaping QoL 	<ul style="list-style-type: none"> Improved understanding of cancer care delivery in Europe Provide information on the EUonQoL objective and development Better understanding of addressing the unmet needs and expectations of patients with cancer and survivors.
Public Health Professionals	<ul style="list-style-type: none"> Public health professionals working with aggregated data collected from patients with cancer and cancer survivors 	<ul style="list-style-type: none"> Insight into the direct and indirect care of patients with cancer and survivors and the practices shaping QoL 	<ul style="list-style-type: none"> Provide information on the EUonQoL objective and development Information on processes and methods in research of aggregated QoL in cancer care and among survivors Knowledge of the various European cancer registries and how they are utilized
Related EU-funded Projects & Industry	<ul style="list-style-type: none"> Project leads and key personnel from other EU cancer-related projects Representatives from the Industry working closely with cancer care and cancer patients and survivors 	<ul style="list-style-type: none"> Partners in the European cancer research and industry ecosystem Potential to shape and drive research directions and collaborations across EU-funded projects in cancer care Potential to impact how occupational health is offered across various levels of the Industry 	<ul style="list-style-type: none"> Synergistic collaboration that can lead to combined efforts and resource optimization Insight on how occupational health and QoL among patients with cancer and survivors are offered at the Industry level



5.1 Activities according to Step I-IV

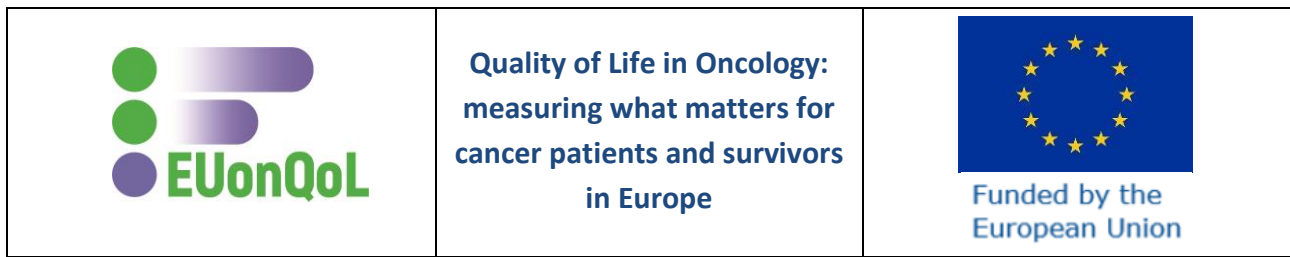


5.1.1 Step I: Activities in 2023

During the first year (Step I) of the EUonQoL CoNet development, the EUonQoL project focused on stakeholder mapping and preliminary stakeholder engagement. This process was undertaken by WP2, WP8, and WP9, who, through multiple collaborative meetings, identified internal (within the consortium) and external stakeholders (outside the consortium), as well as representatives from other EU projects. While this document is the outcome of Step I, the mapping also functioned as a precursor to more detailed and targeted engagement strategies planned after Step I. In addition to mapping, direct and indirect engagement with various representatives from the Stakeholder Groups were conducted. These interactions were essential in establishing initial communication channels, understanding the perspectives and needs of the stakeholders (in order to collaborate), and aligning the project with broader EU health strategies.

This included forming the EUonQoL Stakeholder Board with high-level expert representatives of all identified stakeholder groups (for detailed composition, see Appendix Table 2, Appendix Section), involving it in the consensus process on the EUonQoL-Kit and holding the first EUonQoL Stakeholder Forum event on 13 December 2023. WP8 also interacted with politicians from the EU Commission and Directorate General, which facilitated the identification of other key stakeholders from the political and policymaker Stakeholder Group level. Additionally, multiple policymakers, organisation representatives, and coordinators of other EU projects were approached by WP2, WP8, and WP9. Participation at conferences and similar events (see Appendix Table 1, Appendix Section) served as a platform to engage or inquire about all stakeholder groups, directly or indirectly, on multiple levels. These participations, collaborations, and dissemination of information on EUonQoL not only raised awareness about the EUonQoL project but also facilitated engagement with key stakeholders.

An in-depth literature exploration of European healthcare systems was also conducted, primarily focusing on the Health in Transition reviews and implementation science in healthcare. This provided valuable insights for the project, enriching the stakeholder mapping process and informing engagement strategies. This information, together with diverse meetings and discussions between WP2, WP8, WP9, and co-researcher involvement, facilitated the development of the 4-tier schema (elaborated on in 4.2) for stakeholder mapping for the EUonQoL Implementation Guideline. This schema was designed to map expert stakeholders that could cover as much of a country's healthcare system as possible. Consequently, the initial mapping of these stakeholders was performed using the 4-tier schema in Step I, and as such, the initial formation of the Task Group EUonQoL IG Advisory Group: National Level. The countries involved in this preliminary mapping included six European countries, which were thoroughly selected based on their straightforward healthcare system,



geographical representation, and familiarity among the nationalities of WP8 and WP9. Furthermore, the representatives from these countries were selected based on their expertise, availability, and interest in the topic related to EUonQoL. This strategic selection process was underscored by an extensive literature review on implementation science and policy analysis and aimed to enhance the likelihood of effective implementation. The lessons learned from these six countries will be applied in 24 other countries in Step II.

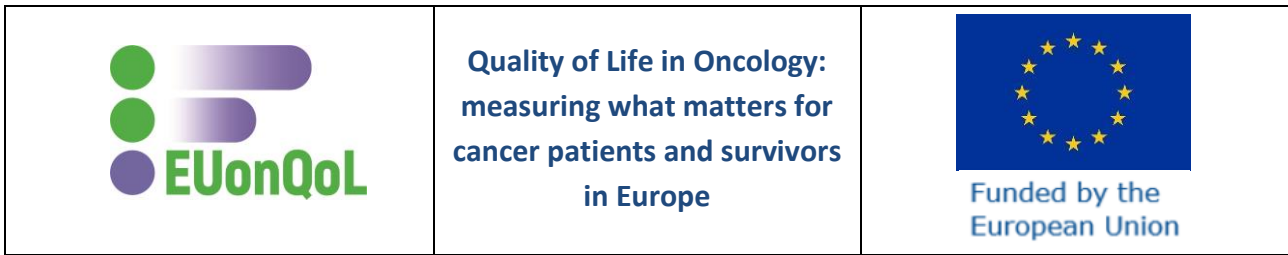
Details of this Task Group's mapping and engagement are described in section 4.2. The details of all the interactions, outcomes, and exploitation acquired in Step I will be reported in conjunction with the engagement conducted in Steps II and III. This information will be documented in the Description of Activity tables in the Appendix section of this document (Appendix Tables 3 and 4).

5.1.2 Step II: Activities in 2024

Over the next twelve months, the EUonQoL project will continue to build upon the foundations established in Step I, aiming to further develop and strengthen partnerships, share knowledge, and identify opportunities for collaborative work with the mapped stakeholders. All Description of Activity tables in the Appendix will be filled out in this Step. This will be possible via various degrees of engagement. In addition, the mapped six countries for the EUonQoL IG Advisory Group: National Level will be fully established, and the entire EUonQoL IG Advisory Group: National Level will be mapped. The majority of the establishment of the Advisory Group: National Level will occur in this Step. Following the complete overview of the stakeholders from the Stakeholder Groups and their interest in participating further, the initial steps for the EUonQoL Sustainability Group and Kit Maintenance Group can be conducted. The comprehensive overview of the eagerness of the stakeholders will also establish the need for and possibility of other Task Groups. While tentative drafting of the EUonQoL IG Advisory Group: European Level was made in Step 1, the complete mapping, invitation, and formation of the Task Group will occur in this Step.

5.1.3 Step III: Activities in 2025 – 2026

In Step III, the remnants of the stakeholder engagement will be performed. Such stakeholders can be new EU-funded projects established in the period 2024-2026 or unmapped stakeholders discovered through a "snowballing method." The finalization of the EUonQoL IG Advisory Groups: National and European Level will occur in the early part of this Step. Mapping, engagement, and completion of the EUonQoL Sustainability Group, EUonQoL-Kit Maintenance Group, and EUonQoL Data Group, as well as other potential Task Groups, will transpire in this Step. Once the Sustainability Group and the Kit Maintenance Group are fully operational, preparations for the activities in Step IV will be arranged in Step III.



5.1.4 Step IV: From 2027 and beyond

Activities in Step IV will be conducted by the EUonQoL Sustainability Group and the EUonQoL-Kit Maintenance Group in the aftermath of the EUonQoL project and will be laid before the end of the project. As previously mentioned, the aim of these activities is to ensure the continuity of the EUonQoL project's purpose and goals, as well as that of the Mission on Cancer and Europe's Beating Cancer Plan. The activities in this step are not a direct part of the EUonQoL project.

5.2 Activities with various Stakeholder Groups

While the core activities will be continued in Steps II and III, numerous key activities were undertaken in Step I. These include preliminary engagement with identified stakeholders and acquiring an in-depth understanding of their needs, expectations, and the potential collaboration effort for the project. It was agreed upon to categorize the communication approach with the stakeholder representatives based on their category placement, i.e., *Information Recipients/Providers*, *Potential Collaborators*, and *Collaborators*. As such, the outreach and interaction will differ based on their agreed-upon category. For Information Recipients/Providers, the interaction activities will primarily involve disseminating relevant information about the EUonQoL project without the necessity for meetings or active dialogue. This category can also serve as an *Information Provider*, particularly on representatives from other Stakeholder Groups. The interaction approach will be flexible for the Potential Collaborator category, where the goal is to assert whether the potential representative belongs in either the Information Recipient/Provider or Collaborator category. For Collaborators, the outreach and the activity will entail more in-depth interactions to discuss and plan collaboration with the goal of inviting them to the EUonQoL CoNet and to relevant Task Groups. Table 3 shows an overview of the various Task Groups and the intended Stakeholder Group involvement for each Task Group, as well as participation in the different work packages.

A thorough overview of all mapped stakeholders in the various Stakeholder Groups will be described according to the *Nature of Collaboration* (i.e., the three aforementioned categories), *Outcome*, and *Exploitation*. This overview will be filled out in the *Description of the Activity* tables provided in the Appendix section of this document (see Appendix Tables 3 and 4). Since initial engagement with politicians was already conducted, the Description of Activity table for the Stakeholder Group – Politicians is displayed below. Several stakeholders have already undergone assessment, with some engagements initiated and others pending. This report will not disclose specific stakeholder details to prevent fragmented reporting and ensure the confidentiality of sensitive information. Instead, this report presents a comprehensive template to be utilized for future detailed reporting in conjunction with Task 8.2 (Develop an External Communication Strategy).

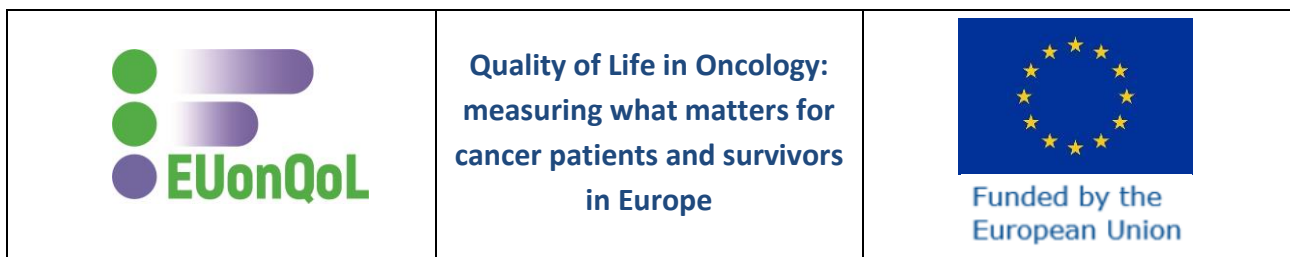


Table 3. Overview of Task Groups

Task Group	EUonQoL IG Advisory Group: European Level	EUonQoL IG Advisory Group: National Level	EUonQoL Sustainability Group	EUonQoL-Kit Maintenance Group	EUonQoL Data Group	Other activities outside of the CoNet's Task Groups
Description	<i>Implement the EUonQoL-Kit on the European level</i>	<i>Implement the EUonQoL-Kit on the national level</i>	<i>Ensure the long-term impact and viability of the EUonQoL project</i>	<i>Continuously update and adaptation of the EUonQoL-Kit</i>	<i>Interpretation, usage, and analysis of EUonQoL-related data</i>	
Politicians						Policy outreach activities (T9.5)
Polymakers	+	+	+			
Patient organisations and NGOs		+	+	+	+	
Healthcare professionals		+	+	+		
Public health professionals		+		+	+	
EU projects	+		+			Clustering activities among QoL EU projects
Proposed Project WPs involved	WP8, WP2, WP9	WP8, WP2, WP5, WP9	WP8, WP2, WP6, WP9	WP8, WP2, WP3, WP4, WP6, WP7	WP8, WP2, WP3, WP4, WP7	WP9

5.2.1 Activities with Politicians

Engagement with key political stakeholders is a pivotal aspect of the EUonQoL project, which aims to enhance the QoL for patients with cancer and cancer survivors across Europe. From the European Parliament's Committee on the Environment, Public Health and Food Safety (ENVI) to the National Health Ministry Departments, this engagement is essential for aligning the EUonQoL project with broader EU health strategies and policies. Top-level stakeholders from this Stakeholder Group may not necessarily become part of the EUonQoL CoNet or any Task Groups, albeit they will have important indirect roles in the EUonQoL project. That said, we believe it is indispensable to actively involve stakeholders from the National Health Departments or Ministries level from various countries in the Task Groups to facilitate the implementation of the EUonQoL-Kit and ensure EUonQoL's sustainability.

The following table outlines our collaborative efforts with various potential political partners, demonstrating how political alliances are instrumental in advancing EUonQoL's mission through policy advocacy and the exploitation of project outcomes for better cancer care policy frameworks within the EU.

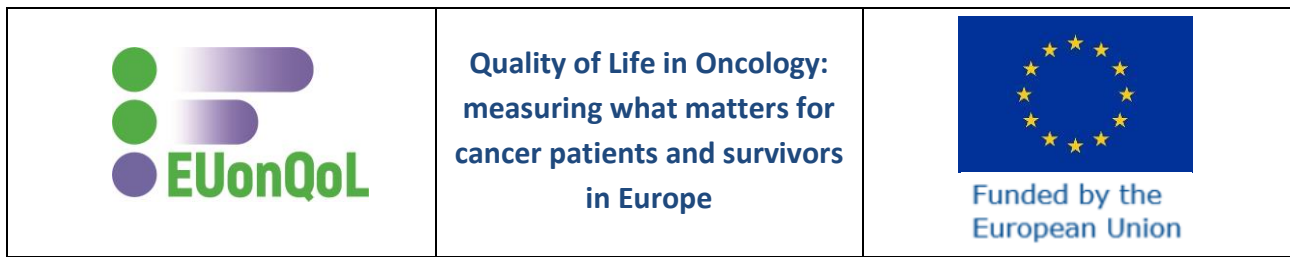
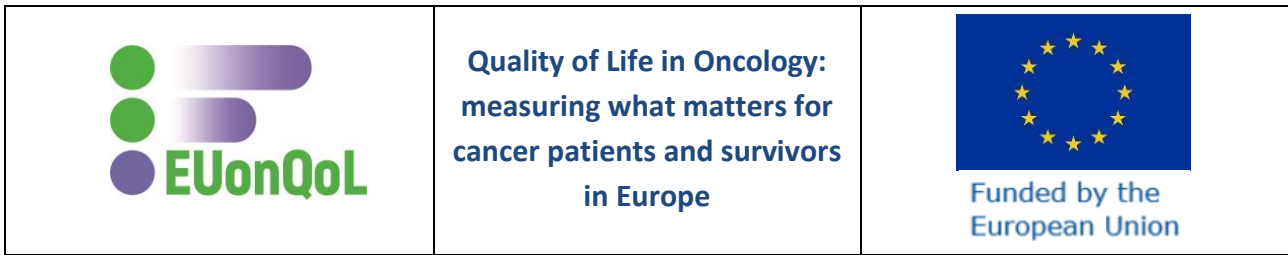


Table 4. Description of Activity for the Stakeholder Group – Politicians

POLITICIANS	DESCRIPTION	NATURE OF COLLABORATION	OUTCOMES	EXPLOITATION
<p>European Parliament's Committee on Environment, Public Health and Food Safety (ENVI), Subcommittee on Public Health (SANT), and Committee on Industry, Research and Energy (ITRE)</p>	<ul style="list-style-type: none"> Involved in public health policy discussions (co-legislator capacity) and legislation (reports and amendment drafting). Hold a pivotal role in steering health policy across the EU and would be integral to any discussions about cancer care and QoL improvements. 	<ul style="list-style-type: none"> Information Recipients/Providers 	<ul style="list-style-type: none"> Elevated awareness among leading national parliamentarians regarding the importance of benchmarking tools for QoL in cancer care. Potential influence on legislation, policies, or funding to enhance cancer care and QoL policies. 	<ul style="list-style-type: none"> Facilitating legislative support for the systematic uptake of EUonQoL objectives into routine healthcare services and industry Promote the utilization of the EUonQoL-Kit and the EUonQoL IG
<p>National, regional, and local parliamentarians and Parliaments' Health, Research and Cancer Committees</p>	<ul style="list-style-type: none"> Involved in public health policy discussions and legislation at national or sub-national level. Hold a pivotal role in steering health and research policy and would be integral to any discussions about cancer care and QoL improvements. 	<ul style="list-style-type: none"> Information Recipients/Providers 	<ul style="list-style-type: none"> Better understanding of national health policy concerning cancer care Increased endorsement and support for EUonQoL objectives from national health ministries. Increased awareness and knowledge exchange between EUonQoL and national health departments or ministries. 	<ul style="list-style-type: none"> Endorsing national policy alignment with EUonQoL objectives Acquiring a need analysis for applying the EUonQoL-Kit and the EUonQoL IG. Lead to better healthcare services and potential commercialization or sponsoring agreements
<p>National, regional, and local governments (Health and Research Ministers)</p>	<ul style="list-style-type: none"> Health Ministers in each EU country are key decision-makers on health policies at a national level. Their support can significantly affect the implementation and success of EUonQoL. 	<ul style="list-style-type: none"> Information Recipients/Providers Potential Collaborators 	<ul style="list-style-type: none"> Better understanding of national health policy concerning cancer care Increased endorsement and support for EUonQoL objectives from national health ministries. Increased awareness and knowledge exchange between EUonQoL and national health departments or ministries. 	<ul style="list-style-type: none"> Endorsing national policy alignment with EUonQoL objectives Acquiring a need analysis for applying the EUonQoL-Kit and the EUonQoL IG. Lead to better healthcare services and potential commercialization or sponsoring agreements



5.2.2 Activities with Policymakers

Engaging with policymakers represents another key aspect of stakeholder engagement, as they draft policy proposals and implement acts, as well as work programs and yearly budgets. In this sense, the European Commission's officials, most notably within the Directorate-Generals for Health and Food Safety (DG SANTE) and for Research and Innovation (DG RTD), as well as the Council of the European Union's officials leading the health portfolio are to be reached out to. The *Comprehensive European Healthcare Policy and Management Bodies*, *European Cancer Institutions*, and *National Cancer Institutions* also represent central actors in the EUonQoL project. These collaborations aim to elevate the QoL among patients with cancer and survivors by influencing healthcare policies and management strategies. As such, policymakers are critical in incorporating innovative cancer care approaches, e.g., using the EUonQoL-Kit into healthcare policy frameworks. This integration will enable a patient-centric approach across Europe, ensuring that the EUonQoL project's findings are effectively translated and implemented into practical healthcare policies. Furthermore, partnerships with policymakers are vital for advocating for policy changes that support research, education, and adopting new tools and methods in cancer care. An in-depth mapping of potential policymakers is provided in Appendix Table 3 in the Appendix Section and will be completed during Step II. Table 5 shows a broader categorization of the policymakers closely aligned with the Stakeholder Group – Politicians.

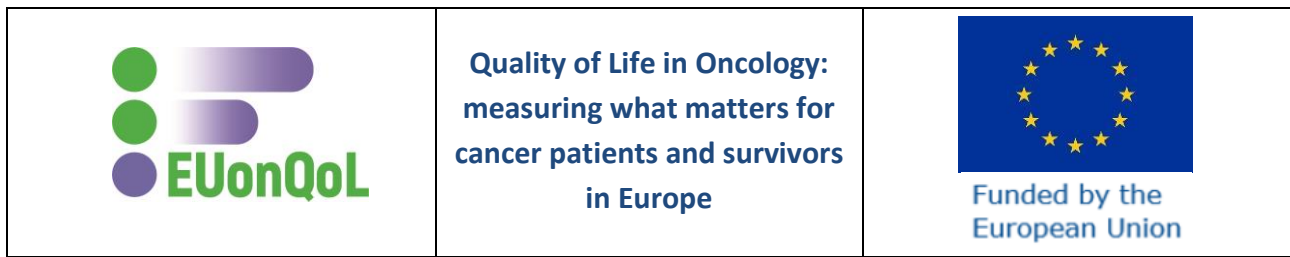
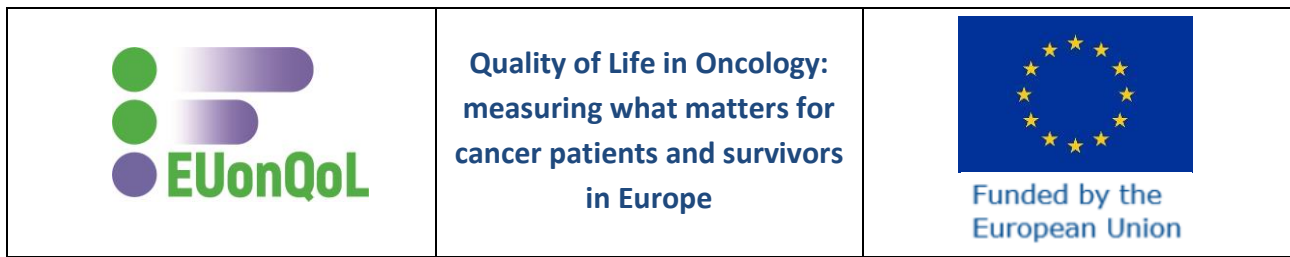


Table 5. Description of Activity for the Stakeholder Group – Policymakers

POLICYMAKERS	DESCRIPTION	NATURE OF COLLABORATION	OUTCOMES	EXPLOITATION
European Commission Directorate-General for Health and Food Safety (DG SANTE) and Directorate-General for Research and Innovation (DG RTD)	Advancing public health, food safety, research, and innovation in Europe.	<ul style="list-style-type: none"> • Information Recipients/Providers • Potential Collaborators 	<ul style="list-style-type: none"> • Enhanced visibility and alignment of the EUonQoL project with EU health policies • Improved knowledge exchange between EUonQoL and the EU Commission. 	<ul style="list-style-type: none"> • Facilitation of policy frameworks that could promote the systematic uptake of the EUonQoL-Kit and the EUonQoL IG. • Lead to better healthcare services
Council of the European Union	Facilitates EU member governments' collaboration in adopting laws and coordinating policies across various policy areas	<ul style="list-style-type: none"> • Information Recipients/Providers • Potential Collaborators – notably the Employment, Social Policy, Health and Consumer Affairs Council Formation & participating health attaches 	<p>Enhanced visibility and alignment of the EUonQoL project with EU health policies</p> <ul style="list-style-type: none"> • Improved knowledge exchange between EUonQoL and the Council 	<ul style="list-style-type: none"> • Facilitation of policy frameworks that could promote the systematic uptake of the EUonQoL-Kit and the EUonQoL IG. • Lead to better healthcare services
National Health Departments or Ministries, State Health/Cancer Agencies, Authorities or Institutes, Cancer Registries	These governmental bodies are crucial for the endorsement and execution of health-related policies.	<ul style="list-style-type: none"> • Information Recipients/Providers • Potential Collaborators • Collaborators 	<ul style="list-style-type: none"> • Better understanding of national health policy concerning cancer care • Increased endorsement and support for EUonQoL objectives from national health ministries. • Increased awareness and knowledge exchange between EUonQoL and national health departments or ministries. 	<p>Endorsing national policy alignment with EUonQoL objectives</p> <ul style="list-style-type: none"> • Acquiring a need analysis for applying the EUonQoL-Kit and the EUonQoL IG. • Lead to better healthcare services and potential commercialization or sponsoring agreements

The above-described outreach and influencing activities with politicians and policymakers form the core of the project's T9.5 on Policy outreach and dissemination; the European Cancer Organisation, who is in charge of that task, will therefore play a leading role in their undertaking.



5.2.3 Activities with Patient Organisations and other European organisations from the Non-Governmental and Non-Profit Sector

In the context of the EUonQoL project, collaborating with diverse Patient Organisations and other organisations from the NGO and non-profit sector of Europe is pivotal and valuable. Herlein also includes organisations representing the voices of patients' caretakers and family members. These collaborative endeavours can significantly broaden the project's horizon, granting access to invaluable resources and expertise, thereby amplifying the impact of efforts to enhance the QoL for individuals afflicted with cancer. These organisations can function as catalysts in elevating awareness regarding the use of the EUonQoL-Kit to assess QoL among patients with cancer and survivors and how it can influence healthcare policies. Collaborations with these organisations can help form guidelines and resources for educational materials and facilitate the dissemination process. The mapping of various organisations was completed in Step I and is detailed in Appendix Table 4. In Step II, full reporting on the activities of these stakeholders will be carried out and subsequently documented in Appendix Table 4.

5.2.4 Activities with Healthcare Professionals

Engaging with Healthcare Professionals (HCPs) involved in the different stages of cancer trajectory, ranging from direct cancer care to survivorship care, is essential in understanding the different roles of HCPs in European countries. As such, engagement with representatives of the various HCP groups, e.g., oncologists, nurses, palliative care specialists, general practitioners, occupational therapists, and non-clinical professionals (health administrators), is required. Collaborations with the HCP representatives will help understand the national pathway in cancer care in the different professions and potentially how the EUonQoL-Kit can be implemented and applied in their context. These interactions will help ensure that the EUonQoL-Kit, through the EUonQoL IG, is aligned with real-world clinical needs and practices, thereby significantly improving cancer patients' and survivors' QoL. The collaboration with HCP representatives also facilitates a comprehensive understanding of patient care, directly influencing the project's effectiveness in addressing the complex needs of cancer patients.

5.2.5 Activities with Public Health Professionals

Collaborating with Public Health Professionals (PHP) on an aggregated level is also crucial for enhancing cancer care quality. PHP representatives, particularly those specializing in health service and public health, can provide key information on collecting and utilizing collected data on an aggregated level. Their expertise can provide a thorough understanding of the various national and international European cancer registries, which are instrumental in collecting and utilizing data on cancer patients and survivors across Europe. This knowledge is essential for the EUonQoL project in order to ensure that the EUonQoL-Kit is implemented effectively at a pan-European level.

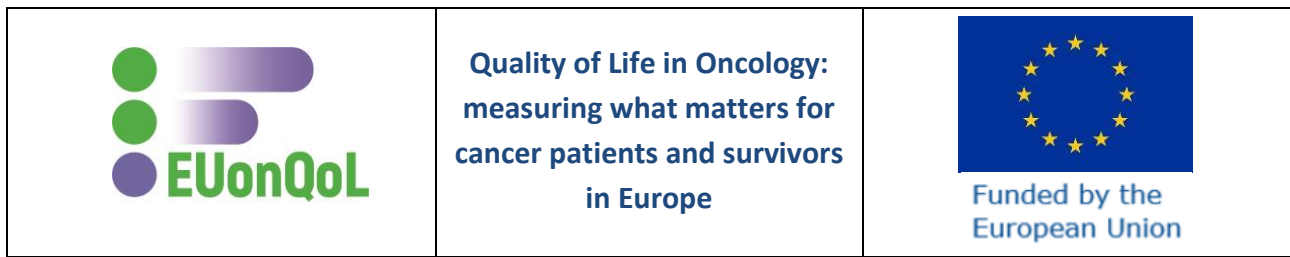




Table 6. Description of Activity for the Stakeholder Groups – Healthcare Professionals and Public Health Professionals

Role	Nature of Collaboration	Outcomes	Exploitation
Healthcare Professionals			
Oncologists (Medical, Radiation, Surgical)	<ul style="list-style-type: none"> • Information Recipients/Providers • Potential Collaborators • Collaborators 	<ul style="list-style-type: none"> • Knowledge of cancer treatment protocols and clinical practice 	<ul style="list-style-type: none"> • Feedback for tool refinement and dissemination of findings in the context of the EUonQoL goals
Palliative Care Specialists		<ul style="list-style-type: none"> • Information on guidelines for integrating QoL considerations in palliative care. 	<ul style="list-style-type: none"> • EUonQoL-Kit's implementation in palliative care settings and contribution to holistic patient care.
Nurses (Oncology, Palliative Care)		<ul style="list-style-type: none"> • Practical insights into patient needs and care improvements. 	<ul style="list-style-type: none"> • Application of the EUonQoL-Kit in nursing practice and patient education.
Psychologists or Psychiatrists (Psycho-oncology Experts)		<ul style="list-style-type: none"> • Strategies for mental health support for cancer patients and survivors 	<ul style="list-style-type: none"> • Integration steps into mental health support protocols for cancer care.
Physiotherapists & Rehabilitation Specialists		<ul style="list-style-type: none"> • Input on physical rehabilitation needs and strategies post-treatment. 	<ul style="list-style-type: none"> • EUonQoL-Kit's use in rehabilitation programs and contribution to patient recovery pathways.
Occupational Therapists & Occupational Physicians		<ul style="list-style-type: none"> • Insights on long-term rehabilitation and daily living among survivors. 	<ul style="list-style-type: none"> • EUonQoL-Kit's application into the context of occupational health among cancer survivors
Dietitians & Nutrition Experts		<ul style="list-style-type: none"> • Understanding of nutritional needs and management for cancer patients. 	<ul style="list-style-type: none"> • Impact of dietary planning and process in cancer care
General Practitioners		<ul style="list-style-type: none"> • Comprehensive understanding of primary care implications in cancer treatment and survivorship. 	<ul style="list-style-type: none"> • Integration of the EUonQoL-Kit into primary and community healthcare for holistic cancer patient management.

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

Pharmacists		<ul style="list-style-type: none"> • Insights into medication management and patient compliance. 	<ul style="list-style-type: none"> • EUonQoL-Kit's implementation in pharmacy practices and patient counselling
Health Administrators		<ul style="list-style-type: none"> • Enhanced understanding of the administrative and operational requirements for implementing QoL assessments in healthcare settings. 	<ul style="list-style-type: none"> • Strategic implementation of the EUonQoL-Kit in healthcare facilities, optimizing resource allocation and workflow efficiency.
Clinical Cancer Researchers		<ul style="list-style-type: none"> • Collection, utilization, and storage of health data on an individual level from digital health tools. 	<ul style="list-style-type: none"> • Value of EUonQoL and its findings in ongoing and future cancer research on the individual level
Public Health Professionals			
Public Health Researchers			
Epidemiologist	<ul style="list-style-type: none"> • Information Recipients/Providers • Potential Collaborators • Collaborators 	<ul style="list-style-type: none"> • Collection, utilization, storage, and promotion of aggregated data from digital health tools. 	<ul style="list-style-type: none"> • Value of EUonQoL and its findings in ongoing and future cancer research and policy
Health Service Researchers			
Public Health Practitioner (non-researcher)			

5.2.6 Activities with EU-funded projects

The EUonQoL project is and will actively collaborate and engage throughout its project timeline with various EU-funded projects that share synergies and complementary objectives. This will allow the project to maximize impact and achieve shared goals more effectively. Through collaboration, the EUonQoL can share resources and avoid duplication of efforts. The collaboration can also foster information dissemination on completed and planned tasks, facilitate scientific activities, and increase recognition in the scientific community. Most EU-funded projects presented below originate from the Horizon Europe and EU4Health funding programs and are either directly or indirectly working towards the objectives outlined by the Mission on Cancer and Europe's Beating Cancer Plan. Overview descriptions related to these projects are presented in Table 7 below.

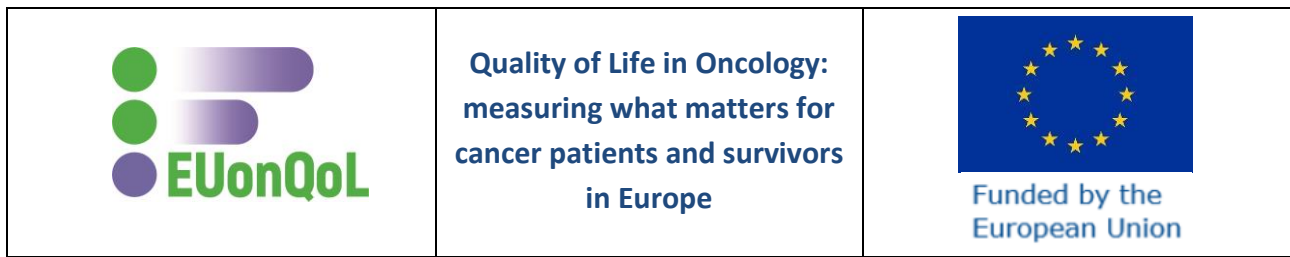


Table 7. Overview of relevant EU-funded projects

EU-FUNDED PROJECT	SIMILARITY	DESCRIPTION	PERIOD	COUNTRY	LEAD / COORDINATOR
RELEVIMUM	<ul style="list-style-type: none"> • QoL • Artificial Intelligence 	Improving the quality of life of advanced pancreatic cancer patients through an AI-guided multimodal intervention, combining pain and cachexia management, nutrition, and physical activity	2022-2026	Germany	Alexander Scherrer
4.UNCAN.eu	<ul style="list-style-type: none"> • Prevention • Survivorship 	A Coordination and Support Action to prepare UNCAN.eu platform	2022-2023	France	Eric Solary
ECHOS	<ul style="list-style-type: none"> • Cancer Cantered Network 	Establishing of Cancer Mission Hubs: Networks and Synergies	2023-2026	Portugal	Anabela Isidro
CCI4EU	<ul style="list-style-type: none"> • Capacity Building 	Comprehensive Cancer Infrastructures for Europe	2023-2026	Europe	Giovanni Apolone
PAL-CYCLES	<ul style="list-style-type: none"> • Palliative Care 	PALliative Care Yields Cancer weLbEing Support	2022-2027	The Netherlands	Jeroen Hasselaar
EU NAVIGATE	<ul style="list-style-type: none"> • Older People • Families 	Intervention for People with Cancer in Old Age and their Family Caregivers: an international pragmatic randomized controlled trial	2022-2027	Belgium	Lieve Van den Block
INSPIRE	<ul style="list-style-type: none"> • QoL • Palliative Care 	INtegrated Short-term Palliative REhabilitation to improve quality of life and equitable care access in incurable cancer	2022-2026	France	Matthew Maddocks
STRONG-AYA	<ul style="list-style-type: none"> • Young Adults • Cancer Care 	Improving the future of young adults with cancer	2022-2027	The Netherlands	Olga Husson and Winette van der Graaf
JANE	<ul style="list-style-type: none"> • Cancer Care 	Joint Action on Networks of Expertise	2022-2024	Italy	Paolo Casali
CRANE	<ul style="list-style-type: none"> • Cancer Cantered Networking 	Network of Comprehensive Cancer Centres: Preparatory activities on creation of National CCCs and EU Networking	2022-2024	Slovenia	Tit Albreht
4D PICTURE	<ul style="list-style-type: none"> • Cancer Journey 	Design-based Data-Driven Decision-support Tools: Producing Improved Cancer Outcomes Through User-Centred Research	2022-2027	The Netherlands	Judith Rietjens
DigiOne	<ul style="list-style-type: none"> • Digital Network 	Digital Infrastructure For Oncology In Europe Building A European Federated Digital Research Network	2023-2024	Belgium	Elin Hallan Naderi
MyPal	<ul style="list-style-type: none"> • Palliative Care 	Designed to foster palliative care for people with cancer by leveraging patient-reported outcome (PRO) systems through their adaptation to the personal needs of the person with cancer and their caregiver(s).	2022-2022	Greece	Kostas Stamatopoulos

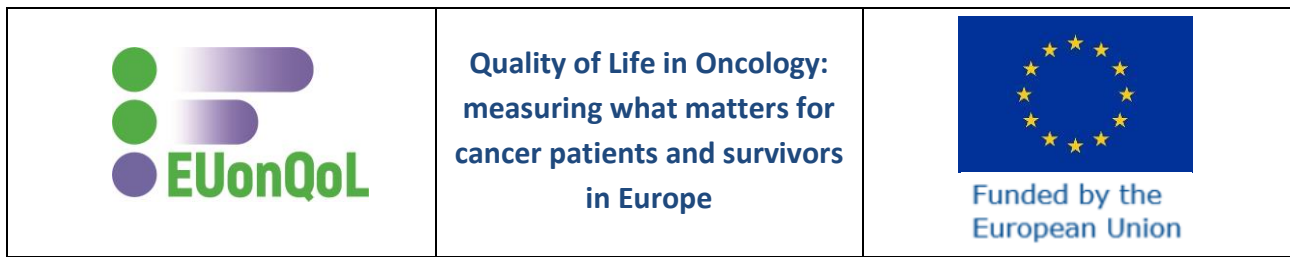


**Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe**



Funded by the
European Union

InAdvance	<ul style="list-style-type: none"> • Patient-centred Care • Pathways • Palliative care 	Patient-centered pathways of early palliative care, supportive ecosystems, and appraisal standard	2018-2022	Spain	Jorge Garcés Ferrer
PanCareFollowUp	<ul style="list-style-type: none"> • QoL • Patient-centred Care • Survivorship • Childhood • Adolescent 	Novel, patient-centred survivorship care to improve care quality, effectiveness, cost-effectiveness, and accessibility for survivors and caregivers	2019-2023	The Netherlands	Leontien Kremer
PREFERABLE	<ul style="list-style-type: none"> • QoL • Breast Cancer • Exercise 	Project on Exercise for Fatigue Eradication in Advanced Breast cancer to improve quality of life	2019-2023	The Netherlands	Anna May
PREFERABLE-II	<ul style="list-style-type: none"> • QoL • Exercise 	Personalized Exercise-Oncology for improvement of supportive care: a super umbrella trial to demonstrate the (cost)effectiveness of live-remote exercise in cancer survivors	2022-2027	The Netherlands	Anna May
MyPath	<ul style="list-style-type: none"> • Patient-centred Care • Pathway • Implementation 	Developing and implementing innovative Patient-Centred Care Pathways for cancer patients	2022-2027	Norway	Stein Kaasa
SISAQOL-IMI	<ul style="list-style-type: none"> • QoL • Clinical Trials 	Establishing international standards in the analysis of patient-reported outcomes and health-related quality of life data in cancer clinical trials	2021-2025	European	EORTC & Boehringer Ingelheim
iLIVE	<ul style="list-style-type: none"> • QoL • Palliative Care 	Living well, dying well. A research program to support living until the end	2019-2023	The Netherlands	Agnes van der Heide
CAPABLE	<ul style="list-style-type: none"> • QoL • Societal Challenges • Digital 	Combining advanced technologies and socio-psychological approaches to develop a coaching system improving the life quality of cancer home patients	2020-2023	Italy	Silvana Quaglini
QUALITOP	<ul style="list-style-type: none"> • QoL • Immunotherapy • Digital 	Monitoring multidimensional aspects of Quality of Life after cancer Immunotherapy - an Open smart digital Platform for personalized prevention and patient management	2020-2024	France	Delphine Maucourt-Boulch
CLARIFY	<ul style="list-style-type: none"> • Cancer Survivor • Artificial Intelligence • Digital 	Cancer Long Survivors Artificial Intelligence Follow-Up	2020-2023	Spain	Maria-Esther Vidal
BD4QoL	<ul style="list-style-type: none"> • QoL • Big Data • Cancer Survivors • Head and Neck 	Big Data Models and Intelligent tools for Quality of Life monitoring and participatory empowerment of head and neck cancer survivors	2020-2024	Italy	Lisa Licitra
LifeChamps	<ul style="list-style-type: none"> • QoL • Big Data • Artificial Intelligence • Platform 	A Collective Intelligence Platform to Support Cancer Champions	2019-2023	Greece	Panos Bamidis



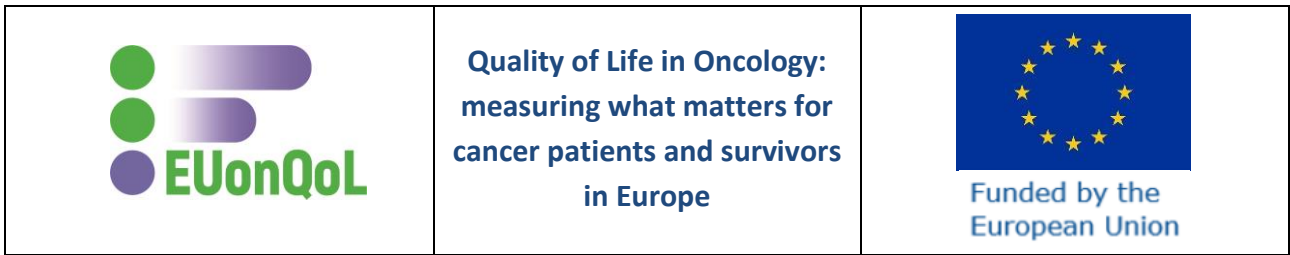
FAITH	<ul style="list-style-type: none"> Artificial Intelligence Depression QoL 	AI analytics for mental health monitoring in cancer patients	2020-2024	Ireland	Phillip O'Brien
PAINLESS	<ul style="list-style-type: none"> Pain Relief QoL Palliative Care 	Pain relief in palliative care of cancer using home-based neuromodulation and predictive biomarkers	2022-2027	Spain	María Teresa Peña
SERENITY	<ul style="list-style-type: none"> Antithrombotic Therapy Empowerment Palliative Care 	Towards Cancer Patient Empowerment for Optimal use of Antithrombotic Therapy at the End of Life	2022-2027	Netherlands	Linda Ouwerkerk
EU-CAYES-NET	<ul style="list-style-type: none"> QoL Survivorship Adolescent Equality, Diversity and Inclusion 	Develop a "European Youth Cancer Survivors Network"	2022-2024	Europe (CCI-E)	Carina Schneider
ONCORELIEF	<ul style="list-style-type: none"> Artificial Intelligence Survivorship QoL Digital 	A digital guardian angel enhancing cancer patient's wellbeing and health status improvement following treatment	2020-2023	United Kingdom	Sotiris Diamantopoulos
SmartCare	<ul style="list-style-type: none"> QoL Palliative Care Digital 	smart Card Application improving cancer survivors quality of life	2023-2024	Belgium	Jack Latteur

6. Conclusions

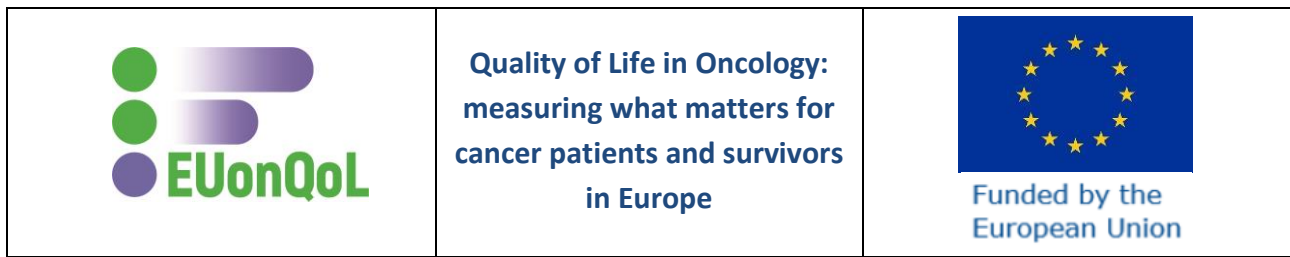
The EUonQoL project is a crucial step towards better cancer care, signifying a substantial advancement towards improved QoL for individuals with cancer and those who have survived the disease throughout Europe. This undertaking is in accordance with the Mission on Cancer, Europe's Plan for Beating Cancer, and follows the Health in All Policy approach.

The EUonQoL CoNet is an adaptable and dynamic network intended to reinforce and expand the EUonQoL project's goals during and beyond its operational duration. The extensive and diverse stakeholder membership of the EUonQoL CoNet consists of politicians, policymakers, healthcare professionals, public health professionals, representatives of various organisations, and representatives from the industry. The diverse collection of experts comprising this network contributes an abundance of knowledge and abilities critical to the project's advancement and achievement. Their participation is crucial in ensuring a broad and inclusive methodology to the cancer trajectory and care pathways, which can meet the diverse needs of both those with a current cancer and those who have had cancer. The EUonQoL project plans to establish supplementary Task Groups within the EUonQoL CoNet. These groups will address unique and essential roles to make the project successful, including covering the aspect of the implementation of the EUonQoL-Kit on the national and European level, the sustainability of the objectives of the projects, and the continuous maintenance of the EUonQoL-Kit.

The EUonQoL project, with its comprehensive and collaborative framework, is poised to make a significant and lasting impact on cancer care, ultimately enhancing the QoL for patients and survivors across Europe and setting a precedent for future healthcare initiatives.



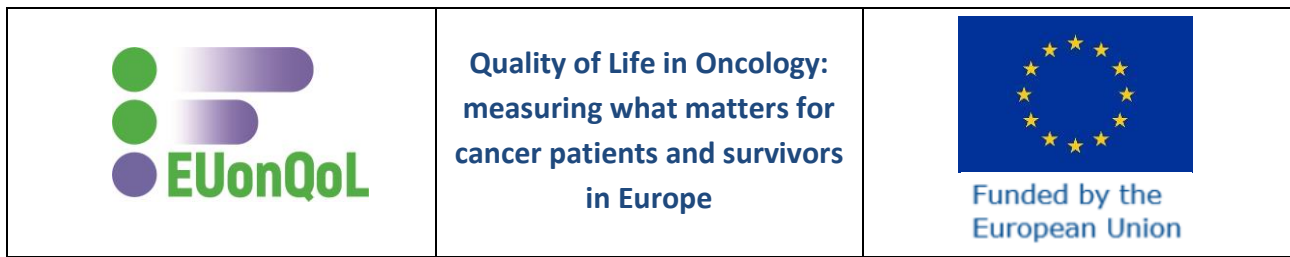
The EUonQoL project, characterized by its comprehensive, co-design, and collaborative framework, is positioned to make a substantial and enduring influence on cancer care in all health sectors in Europe and subsequently enhance QoL among all European people with cancer and survivors of cancer.



7. Appendix

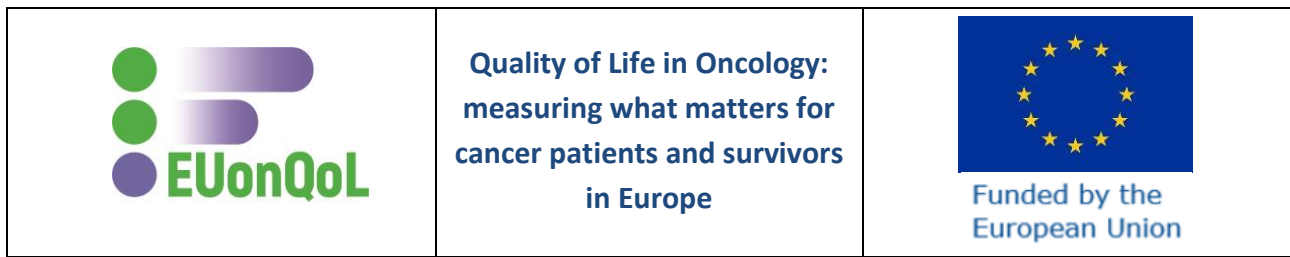
Appendix Table 1. EUonQoL conference activity overview

Organisation Speaker	Conference activity name	Date of Activity	Outcome
The National Cancer Institute of Milan	ECO Cancer Summit	16.11.2022	
The European Association for Palliative Care	Webinar: How research in #PalliativeCare can help improve the lives of patients and families #AIFinaldeLaVida (In Spanish)	12.04.2023	
The National Cancer Institute of Milan	OECI Oncology Days: EU for quality of life "EUonQoL"	14.06.2023	Speech to approx. audience of #300
European Cancer Organisation & Netherlands Institute for Health Services Research	OECI Oncology Days: EU for quality of life "EUonQoL": Stakeholders involvement in the research: the role of co-design	14.06.2023	Speech to approx. audience of #300
Organisation of European Cancer Institutes	OECI Oncology Days: Quality of life as a pillar of cancer care	14.06.2023	Speech to approx. audience of #300
The National Cancer Institute of Milan	OECI Oncology Days: Overview of the EUonQoL project	14.06.2023	Speech to approx. audience of #300
University of Leeds	OECI Oncology Days: Why do we need new quality of life assessment tools?	14.06.2023	Speech to approx. audience of #300
Oslo University Hospital	OECI Oncology Days: The EUonQoL project in the framework of European actions against cancer	14.06.2023	Speech to approx. audience of #300
The European Association for Palliative Care	Promotional materials EAPC Congress 2023 (Highlighters=500; Bags=25)	17.06.2023	
European Institute of Oncology	IPOS 2023 World Congress: Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe (EUonQoL)	03.09.2023	
The National Cancer Institute of Milan	IPOS 2023 World Congress: Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe (EUonQoL)	03.09.2023	
The National Cancer Institute of Milan	European Health Forum in Gastein	27.09.2023	
The National Cancer Institute of Milan	13th International Seminar of the European Palliative Care Research Centre	01.02.2024	



Appendix Table 2. Overview of the Stakeholder Board

Category	Organisation/Project	Individual	Position
Policymakers and health managers	Joint Action Towards the European Health Data Space (TEHDAS)	Member 1	TEHDAS Coordination Team
	Joint Research Center (JRC)	Member 2	Project Leader, European Commission Knowledge Centre on Cancer and European Cancer Inequalities Registry
	European Hospital Management Association (EHMA)	Member 3	Policy Manager - Health Systems
Healthcare professionals and allied professionals	European Oncology Nursing Society (EONS)	Member 4	President
	European Society for Medical Oncology (ESMO)	Member 5	Leading author, ESMO guidelines for Patient Reported Outcome Measurements in clinical practice
	European Social Network (ESN)	Member 6	
Researchers	International Society for Quality of Life Research (ISOQOL)	Member 7	Chair Elect, Special Interest Group the United Kingdom and Ireland
	Organisation of European Cancer Institutes (OECI)	Member 8	Member, OECI Working Group on Cancer economics and benchmarking
Patient organisation	European Cancer Organisation Patient Advisory Committee (ECO PAC)	Member 9	Co-chair
EU projects	Smart Card Application improving cancer survivors' quality of life (smartCARE)	Member 10	Chair, Steering Committee
	A digital guardian angel enhancing cancer patient's well-being and health status improvement following treatment (ONCORELIEF)	Member 11	Consortium partner



Appendix Table 3. Description of Activity for the Stakeholder Group - Policymakers

POLICYMAKERS	DESCRIPTION	NATURE OF COLLABORATION	OUTCOMES	EXPLOITATION
Comprehensive European Healthcare Policy and Management Bodies				
European Institute of Innovation and Technology (EIT) Health				
Innovative Medicines Initiative (IMI)				
International Agency for Research on Cancer (IARC)				
European Medicines Agency				
European Network for Health Technology Assessment (EUnethTA)				
International Association of Mutual Benefit Societies (AIM)				
European Social Insurance Platform (ESIP)				
European Health Management Association (EHMA)				
European Hospital and Healthcare Federation (HOPE)				
European University Hospital Alliance (EUHA)				
European Association Hospital Managers (EAHM)				
Organisation for Economic Cooperation and Development (OECD)				
European Cancer Institutions				
European Association for Cancer Research (EACR)				
European Organisation for Research and Treatment of Cancer (EORTC)				
International Network for Cancer Treatment and Research (INCTR)				
International Society for Quality of Life Research (ISOQOL)				
European Palliative Care Research Centre (PRC)				

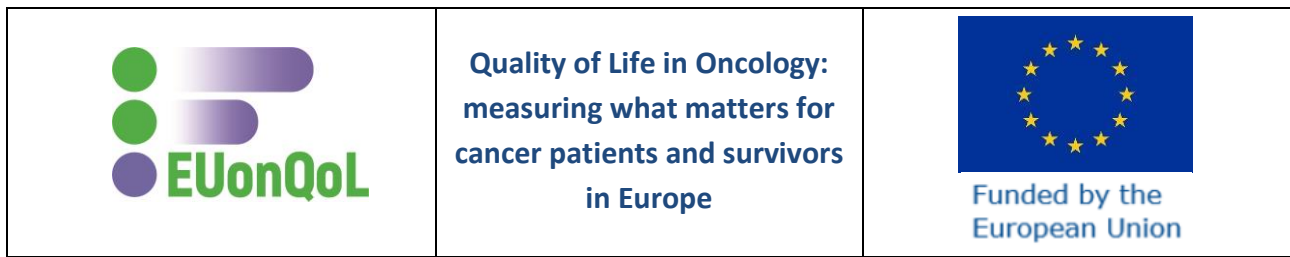


Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

National Cancer Institutions				
French National Cancer Institute (INCa) [France]				
Spanish National Cancer Research Centre (CNIO) [Spain]				
German Cancer Research Centre (DKFZ) [Germany]				
Belgian Cancer Centre (Sciensano) [Belgium]				
Netherlands Cancer Institute (NKI) [Netherlands]				
Austrian Institute of Cancer Research (MedUni Vienna) [Austria]				
Cyprus Cancer Research Institute (CCRI) [Cyprus]				
Masaryk Memorial Cancer (MMC) [Czech Republic]				
Danish Cancer Society Research Center (DCRC) [Denmark]				
Hungarian National Institute for Cancer (ONKOL) [Hungary]				
National Hellenic Research Foundation (EIE) [Greece]				
National Cancer Institute Cancer (NVI) [Lithuania]				
Institut National du Cancer du Luxembourg (INC) [Luxembourg]				
Maria Skłodowska Curie Memorial Cancer Centre and Institute of Oncology (MCMCC) [Poland]				
Oncology Association „Ion Chiricuță” (IOCN) [Romania]				
National Cancer of Slovakia (NOISK) [Slovakia]				
Institute of Oncology Ljubljana [Slovenia]				
Karolinska Comprehensive Cancer Centre (Karolinska CCC) [Sweden]				
MATRIX - Norwegian Centre for Clinical Cancer Research [Norway]				
Croatian Association for Cancer Research (HDIR) [Croatia]				



Appendix Table 4. Description of Activity for the Stakeholder Group – NGO & Non-profit Sector

Organisation	Description	Nature of Collaboration	Outcomes	Exploitation
The European non-governmental/non-profit sector				
European Organisation for Research And Treatment of Cancer (EORTC)				
European Society for Medical Oncology (ESMO)				
Organisation of European Cancer Institutes (OECI)				
European School of Oncology (ESO)				
European Society Radiation Oncology (ESTRO)				
The European Society of Surgical Oncology (ESSO)				
European Association for Palliative Care (EAPC)				
European Cancer Organisation (ECO)				
European Cancer Patient Coalition (ECPC)				
World Organisation of National Colleges, Academies, and Academic Associations of General Practitioners/Family Physicians (WONCA Europe)				
European Forum for Primary Care (EFPC)				
International Society of Oncology Geriatrics (SIOG)				
International Psycho-Oncology Society (IPOS)				
Multinational Association for Supportive Care in Cancer (MASCC)				
European Pain Federation (EFIC)				
European Oncology Nursing Society (EONS)				
European Association of Urology Nurses (EAUN)				
European Society for Clinical Nutrition and Metabolism (ESPEN)				
European Society for Radiotherapy and Oncology (ESTRO)				
European Association for Quality and Safety to General Practice/Family Medicine (EQUIP)				



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



Funded by the
European Union

European Head & Neck Society (EHNS)				
World Physiotherapy Europe				
European Society for Sexual Medicine (ESSM)				
European Federation of Nurses Associations (EFNA)				
Association of European Cancer Leagues (ECL)				
ECO Survivorship and Quality of Life Network				
ECO Quality Cancer Care Network				
AGE Platform				
Ending discrimination against cancer survivors				
ABC Global Alliance				
European Social Network				
Working with cancer				
Patient Organisations				
EUOCARERS				
ECO Patient Advisory Committee				
Workgroup of European Cancer Patient Advocacy Networks (WECAN)				
European Patients' Academy on Therapeutic Innovation (EUPATI)				
Youth Cancer Europe				
Europa Donna				
Europa Uomo				
International Brain Tumour Alliance (IBTA)				

Note: The provided does not contain a complete overview. As such, the list will be extended during the project timeline.



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



Funded by the
European Union

8. References

1. Carr AJ, Higginson IJ. **Are quality of life measures patient centred?** *Bmj*. 2001;322(7298):1357-60.
2. Sanders EBN, Stappers PJ. **Co-creation and the new landscapes of design.** *CoDesign*. 2008;4(1):5-18.
3. Meirte J, Hellemans N, Anthonissen M, Denteneer L, Maertens K, Moortgat P, et al. **Benefits and Disadvantages of Electronic Patient-reported Outcome Measures: Systematic Review.** *JMIR Perioper Med*. 2020;3(1):e15588.
4. Singhal S, Dickerson J, Glover MJ, Roy M, Chiu M, Ellis-Caleo T, et al. **Patient-reported outcome measurement implementation in cancer survivors: a systematic review.** *J Cancer Surviv*. 2022.
5. European Commission. **Europe's Beating Cancer Plan.** 2021.
6. European Commission. **Mission on Cancer Implementation plan.** 2021.
7. World Health Organisation. **Promoting Health in All Policies and intersectoral action capacities** [Available from: <https://www.who.int/activities/promoting-health-in-all-policies-and-intersectoral-action-capacities>].
8. Deverka PA, Lavalley DC, Desai PJ, Esmail LC, Ramsey SD, Veenstra DL, et al. **Stakeholder participation in comparative effectiveness research: defining a framework for effective engagement.** *J Comp Eff Res*. 2012;1(2):181-94.
9. Tamika Heiden and Saia Toni. **Engaging stakeholders for research impact.** Center on Knowledge Translation for Disability and Rehabilitation Research, American Institutes for Research; 2021.

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.