EUonQoL

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

Deliverable number: D5.4

Deliverable title: Indicators for health system characteristics

Deliverable type	Document, report
Deliverable responsible partner	Nivel
Contractual date of delivery	August 2024
Actual date of delivery	August 2024
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

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.

Merel Engelaar (Nivel)
Iris van der Heide (Nivel)
Carina Dantas (EUonQoL co-researcher)
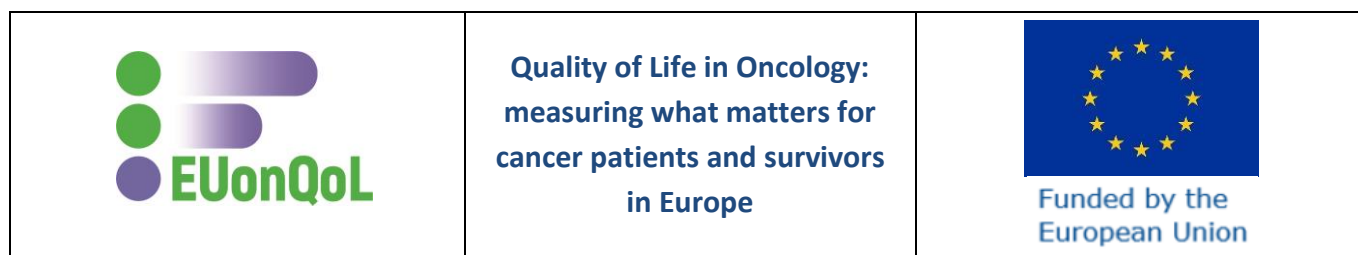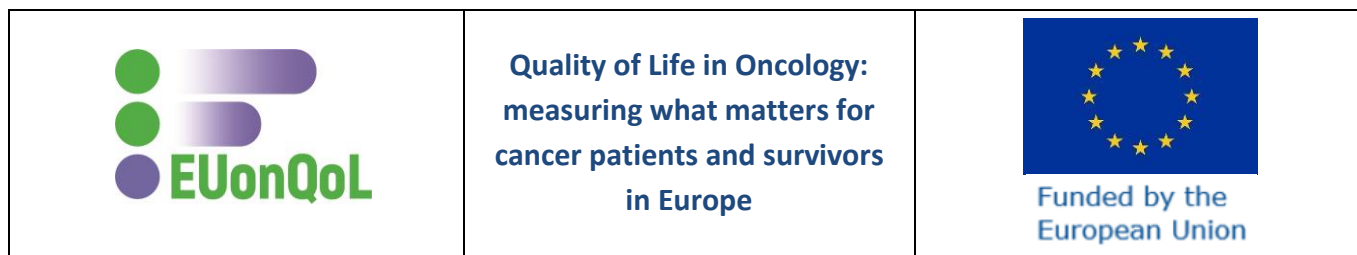Laura Pinnavaia (EUonQoL co-researcher)
Nanne Bos (Nivel)

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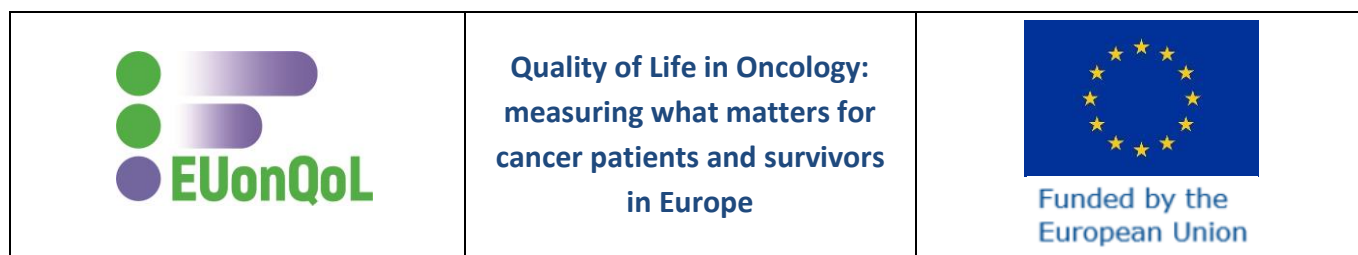in Europe

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Summary

There is a substantial variability in terms of the quality of cancer care and outcomes, including survival and quality of life, within and between countries in Europe. These international differences in health care delivery, quality and outcomes suggest wide variations in the performance of national health care systems in which cancer patients are being cared for and treated. To better identify possible differences between countries in the quality of life of cancer patients, it is important to have insight into characteristics at the national health system level that can affect their quality of life.

One of the goals of the project called "Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe" (EUonQoL) is to obtain a better understanding of health system level characteristics that might help explain differences in the quality of life outcomes of cancer patients between European Union (EU) Member States and Associated Countries. The overall aim of the EUonQoL project is to improve the assessment of the quality of life of cancer patients in Europe.

In our previous work, we established a conceptual framework of health care system domains and subdomains, and provided insight into what is currently known in the scientific literature about health care system determinants in relation to the quality of life of cancer patients. The current report, building upon our previous work, will provide an overview of the relevant indicators based on scientific literature and suggest additional indicators for which evidence of their relationship with the quality of life of cancer patients is lacking.

A set of system level indicators was constructed based on our results from: the identification of existing health system frameworks; a rapid review on health system level factors of quality of life of cancer patients; a grey literature search; the identification of existing databases containing data on health system level indicators; a stakeholder survey; interviews; and consultation of the EUonQoL Stakeholder Board. This comprehensive list contains 58 indicative measures, yet there are only 14 indicative measures for which evidence was found in literature on the relation with the quality of life of cancer patients. For 4 of these indicative measures, data is available from publicly accessible sources.

In line with our previous report, we found that, to date, the relation between health care system factors and the quality of life of cancer patients remains understudied. Therefore, in future research, it is recommended to explore to what extent the various health system level indicators, as specified in the current study, relate to the quality of life of cancer patients. In part, this will be done in the pilot study of EUonQoL. However, besides the EUonQoL pilot study, other cross-country studies on the quality of life of cancer patients are encouraged to explore the role of the various health system level indicators as outlined in the current report.

1. Background of the EUonQoL project and aim of the current report

The EUonQoL project

The EUonQoL consortium was founded to develop, validate, and disseminate the European Oncology Quality of Life toolkit (EUonQoL-Kit) among European cancer patients[1], thereby contributing to the EU mission on cancer. The EUonQoL project aims to review existing scales and develop new metrics by harnessing the strengths and overcoming the limitations of previous tools. The EUonQoL-Kit will be a new set of questionnaires, specifically designed for the digital self-assessment of quality of life, 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 cancer patients and informal caregivers as 'co-researchers', and other stakeholders as members of the Stakeholder Board in all project phases.

The EUonQoL project consists of ten work packages that all focus on a different step in the toolkit development process: from reviewing the literature to implementation. Table 1 provides a brief description of the different work packages. Further description of the project, its work packages, and the participating organisations can be found on the EUonQoL website: http://www.euonqol.eu/

Table 1: Description of the work packages in the EUonQoL project

Work package (WP)	Description
WP1	Ethic requirements
WP2	Involvement of stakeholders and patients
WP3	Review of existing quality of life databases, measures, and item libraries
WP4	Development of the EUonQoL-Kit
WP5	Cross-cultural determinants of quality of life, and linguistic and cultural adaptation of EUonQoL-Kit
WP6	Digital tools for data collection
WP7	EUonQoL-Kit pilot survey
WP8	Implementation and exploitation
WP9	Dissemination and communication
WP10	Project management and coordination

EUonQoL work package 5

This current report is written in the context of work package 5, which focuses on cross-cultural determinants of quality of life and the linguistic and cultural adaptation of the EUonQoL-Kit. The EUonQoL-Kit will allow country comparisons of quality of life data among EU Member States and Associated Countries, as well as the identification of patient characteristics associated with better or worse quality of life outcomes. Countries can use these comparisons to improve the quality of cancer care. This requires that key actors in EU Member States and Associated Countries not only know *how* their country's results compare with other countries, but also *why* results are more or less favourable for their country. The aim

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[1]The term 'cancer patients' is used in this report for practical reasons, but in using this term, we also refer to people who have had cancer in the past.
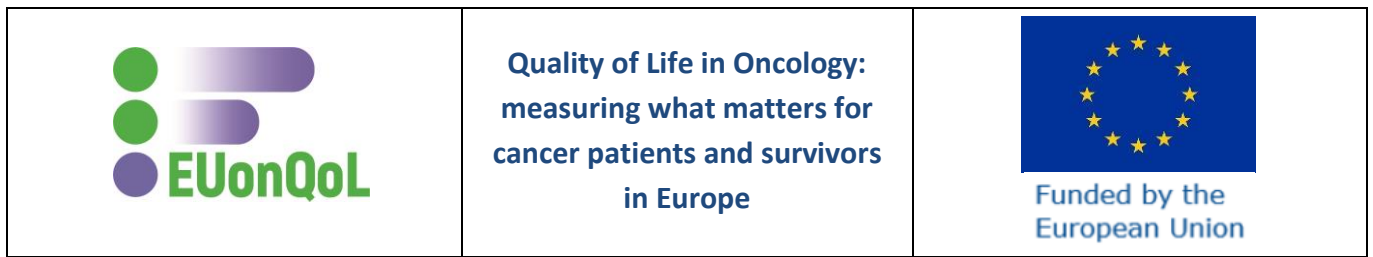
of work package 5 is, therefore, also to obtain a better understanding of health system level characteristics that might help explain differences in the quality of life outcomes of cancer patients.

The work package leader of work package 5 is the European Institute of Oncology (IEO), in collaboration with participating partners Sporedata and the Netherlands Institute for Health Services Research (Nivel). Within work package 5, Nivel was responsible for the task and deliverables on the identification and specification of health care system factors that could affect the quality of life of cancer patients.

Aim of the current report

In deliverable 5.1, titled "Health care system determinants of quality of life", the main health system level determinants of quality of life of cancer patients were described based on a rapid review. The overview of these determinants, clustered into four overarching health system domains, formed the starting point of our next activity: the specification of health system indicators and the identification of sources providing country level data on these indicators. The aim of the current report is to provide insight into the approach that was used for this activity and the outcomes.
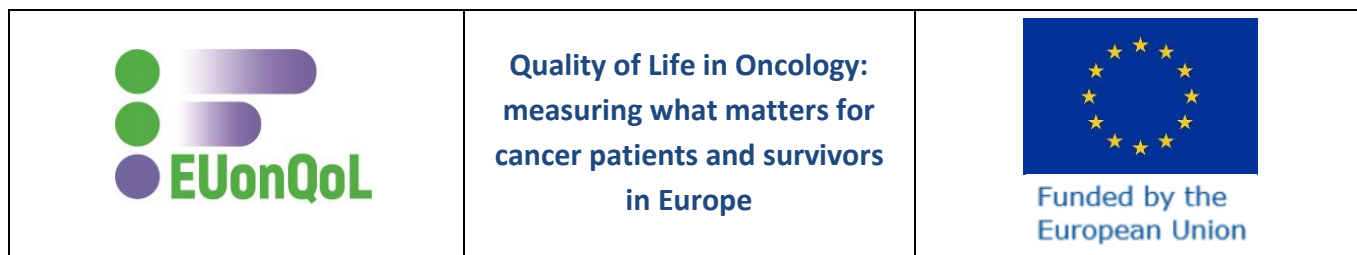
2. Introduction

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 (1). There were 2.7 million new cases of cancer and 1.3 million deaths in 2020, which is expected to increase by about 25% by 2040 (2). Additionally, there is a substantial variability in quality of cancer care and outcomes, including survival and quality of life, within and between countries in Europe (1). The burden of cancer and cancer treatment on quality of life is well-recognised and directly important to the patient (3, 4). Nonetheless, the implementation of quality of life assessment in routine oncology practice is not yet part of standard care nor on an aggregated national level. In the same way, quality of life is usually not taken into account as an aim and/or outcome measure in the development of policy and interventions by health care systems and cancer control programs (1).

International differences in health care delivery, quality and outcomes suggest wide variations in the performance of national health care systems in which cancer patients are being cared for and treated (5). The literature knows various definitions of national health care systems, ranging from a broader perspective, including public health systems addressing social determinants of health, to a narrower perspective focusing on the actions and organisations with the primary intent of improving and maintaining health (6-8). In this report, we define a health system as 'all organisations, people and actions whose primary intent is to promote, restore or maintain health', in line with the World Health Organisation (WHO) 2000 definition (7, 8).

To better identify possible differences between countries in the quality of life of cancer patients, it is important to have insight into characteristics at the national health system level that can affect their quality of life. Within our task of the EUonQoL project (task 5.2), we aim to obtain this insight.

In this current report, we build upon the work described in our previous report (deliverable 5.1), in which we established a conceptual framework of health care system domains and subdomains and provided insight into what is currently known in the scientific literature about health care system determinants in relation to the quality of life of cancer patients. One of our main conclusions was that it remains largely unknown to what extent health care system determinants relate to the quality of life outcomes of European cancer patients. The current report will, therefore, not only provide an overview of the few indicators that could be considered relevant based on scientific literature but will also offer suggestions for indicators for which evidence on the relation with quality of life of cancer patients is lacking.

In addition to macro-level factors, which are the focus of our task, micro- and meso-level factors can also affect the quality of life of people with cancer. Micro-level factors are individual factors (i.e., physical, psychological, and social characteristics), such as coping strategies and social support. Meso-level factors are institutional characteristics, such as the scope of services delivered in a hospital and the availability of personnel in a care facility. Another task of the EUonQoL study (task 5.1) was to conduct research into micro-level factors and indicators. Meso-level factors and indicators are not addressed in the EUonQoL study.
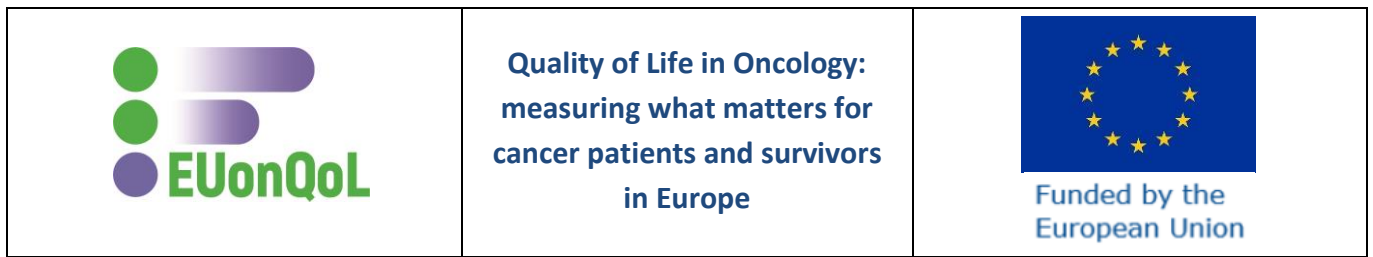
3. Methods

3.1. Patient and public involvement

The EUonQoL project is based on Patient and Public Involvement (PPI) research principles by involving cancer patients and informal caregivers as 'co-researchers' throughout. Therefore, two co-researchers, who are both former cancer patients, were involved in each of the steps taken to obtain an overview of system level indicators. For a complete and detailed description of PPI activities within the EUonQoL project, see Engelaar et al. (2024) (9).

Consultation took place with the co-researchers prior to and during each step. They were involved in the planning of the research, in meetings about the development of the survey and interviews, in meetings about the analysis of the findings, in the writing of the report, and they actively employed their own network to contact stakeholders and experts for us to consult.

3.2. Desk research

Since the current deliverable is based in part on the work described in deliverable 5.1, the paragraphs below will, in part, repeat and summarize the methods and outcomes that preceded the activities conducted for the current deliverable.

3.2.1. Identification of health system frameworks

As described in our previous deliverable, we selected the Health System Performance Assessment Framework (8) as the foundational model for our conceptual framework. We adapted and simplified this model, tailoring it to our specific objective of pinpointing systemic features of health care systems that may be associated with quality of life in cancer patients (Figure 1).
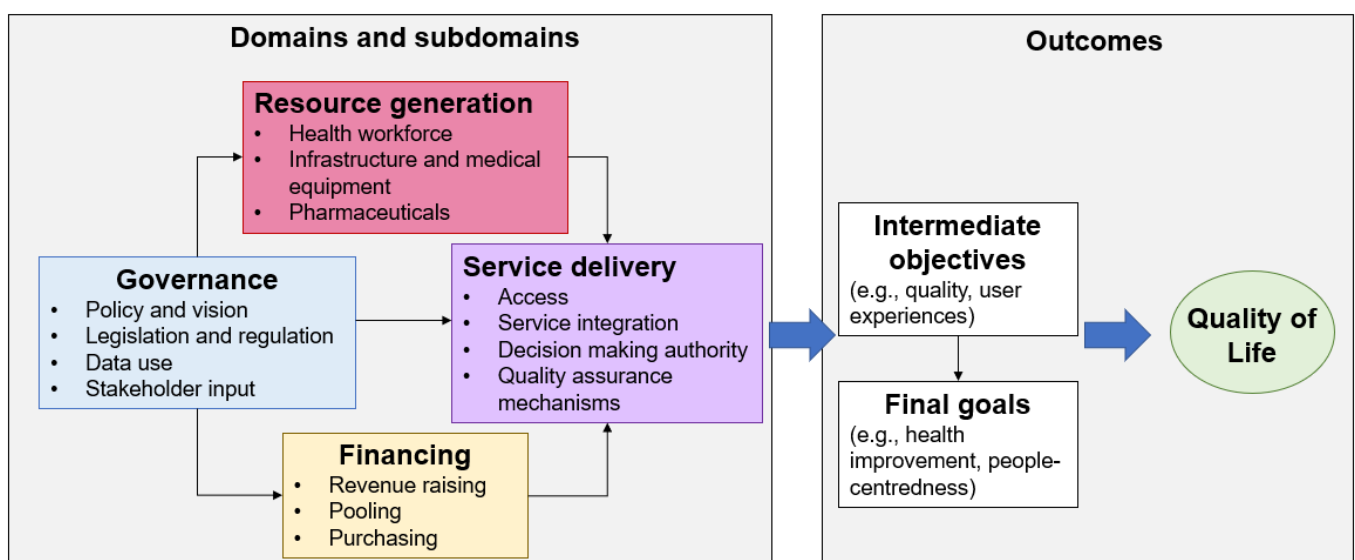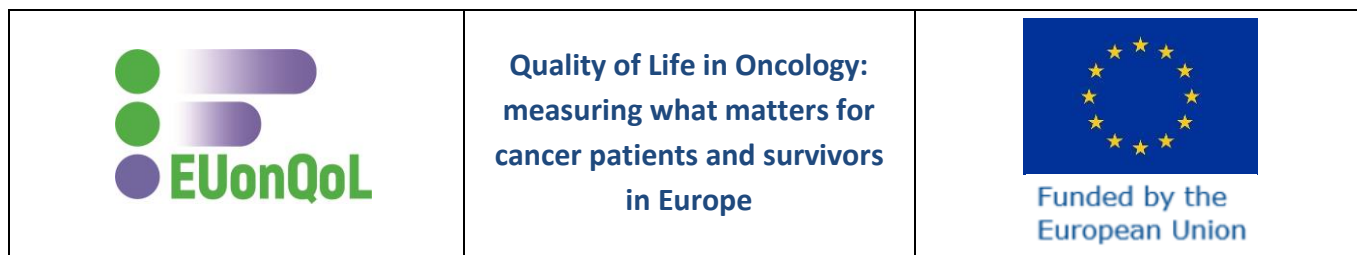

Figure 1: Simplified and adapted version of the Health System Performance Assessment framework (Papanicolas et al. (2022))

The figure depicts that the four domains of the health care system (i.e., governance, resource generation, financing, and service delivery) are related to intermediate objectives and final goals of the health care

system. The intermediate objectives are the direct results of service delivery and relate to the quality of the care delivered. The final goals include overall population level outcomes such as health improvement and can point to the performance of a health system. Finally, the quality of life of patients can be expected to be affected by the health care system determinants through the mediating factors.

We used the Health System Performance Assessment Framework (8) to make a first draft list of indicators. As these indicators reflected the performance of health systems in general, we modified the indicators deemed needed to fit the context of cancer care better. For example, the indicator 'existence of a comprehensive set of policies, laws, and/or guidelines' was adapted to 'existence of a national cancer plan/strategy'. This modification was done based on insights obtained from the (grey) literature and existing databases (see following paragraphs), as well as the expertise of the research team.

3.2.2. Rapid review on health system level factors of quality of life of cancer patients

We used the adapted Health System Performance Assessment Framework (8) as a basis for our literature search on the association between health care system characteristics and the quality of life of cancer patients. We performed a rapid literature review in PubMed (see Appendix A for the search strategy) to gain insight into what is already known regarding the domains of health care system determinants in relation to quality of life in cancer patients.

As described in our previous deliverable, most results were found in the domain of financing, followed by the domain of service delivery. Only one study was conducted within the area of resource generation and no studies were identified on the domain of governance. Some examples of these results are that many studies reported a significant negative impact of financial toxicity on the quality of life of cancer patients (10-20), two studies reported that cancer patients from countries with low per capita health expenditures had significantly lower quality of life (21, 22), and it was reported by several studies that having a higher level of unmet needs resulted in significantly lower quality of life in cancer patients (23-27). However, our main finding was that, to date, the relation between health care system determinants and quality of life in cancer patients remains understudied.

In view of these limited results, we decided to extend the rapid review by reapplying our search strategy (see Appendix A) in PubMed and applied the same search to Scopus and Web of Science. In PubMed, this yielded 40 new, potentially relevant manuscripts, while in Scopus and Web of Science, this yielded 313 and 432 results, respectively. Additionally, we applied a snowball search to the references of the relevant articles. Papers were regarded eligible for inclusion if they were written in the English or Dutch language; if the research subjects were adult cancer patients; if quality of life was measured or evaluated; and if health care system characteristics were studied as an explanatory variable of quality of life. Articles were excluded if they were protocol papers. In total, four relevant publications were found. Most papers were excluded because health system level factors were not evaluated as an explanatory variable of quality of life in cancer patients.

3.2.3. Grey literature and existing databases

In addition to the review of health system frameworks and the scientific literature, a search was conducted for grey literature, including reports from, for instance, the Organisation for Economic Cooperation and Development (OECD) and the WHO. In our grey literature search, we identified six reports and one book
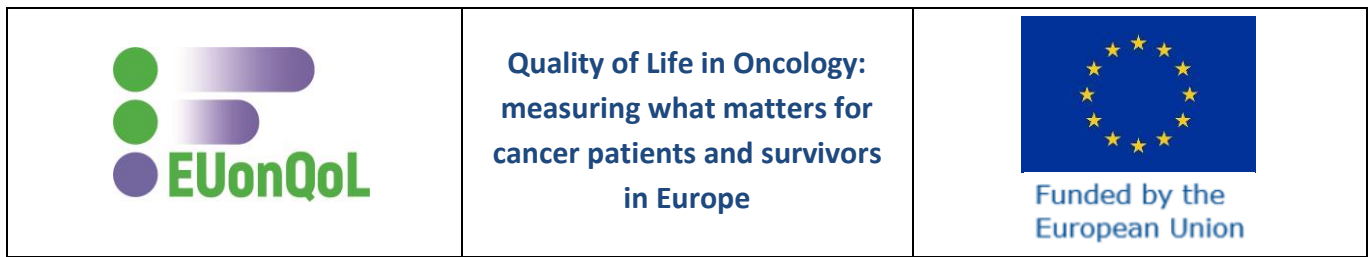
section. Additionally, publicly accessible databases containing data on health system level indicators were sought. This exercise served two purposes: a) to identify (new) indicative measures; b) and to identify data sources that could be used to collect data on these measures. The integrated health system framework (Figure 1) was used as the basis for the selection of indicators from the grey literature and from existing databases. This means that only indicative measures matching the domains and subdomains as outlined in this integrated framework were selected if considered relevant.

3.3. Collection of stakeholder views

Since little evidence exists on the relationship between health system level indicators and quality of life, we aimed to back up the relevance of identified indicators with stakeholder views. Stakeholder views were gathered through different methods. First, we created a survey, using the EUSurvey tool, in which stakeholders could indicate for every draft indicator how important they perceive it to be in relation to the quality of life of cancer patients (see Appendix B for the survey questions). Additionally, the option to provide comments and additional indicators was available. The survey was distributed among a wide range of stakeholders via e-mail. The survey link was also shared on the EUonQoL project's LinkedIn page. The survey remained open for a month, from 28 March 2024 until 30 April 2024.

In total, we received 36 responses to the survey. Of these responses, about half (n=17) were provided by cancer patient representatives. The second-largest group of respondents consisted of healthcare professionals (n=10), followed by researchers (n=3), insurers (n=3), and those who answered to belong to the 'other' stakeholder group (n=3). In the last category, there were two respondents who worked for a Non-Governmental Organisation (NGO) and one who worked at a health information service. Respondents were residents of a wide range of countries in Europe (see Figure 2).
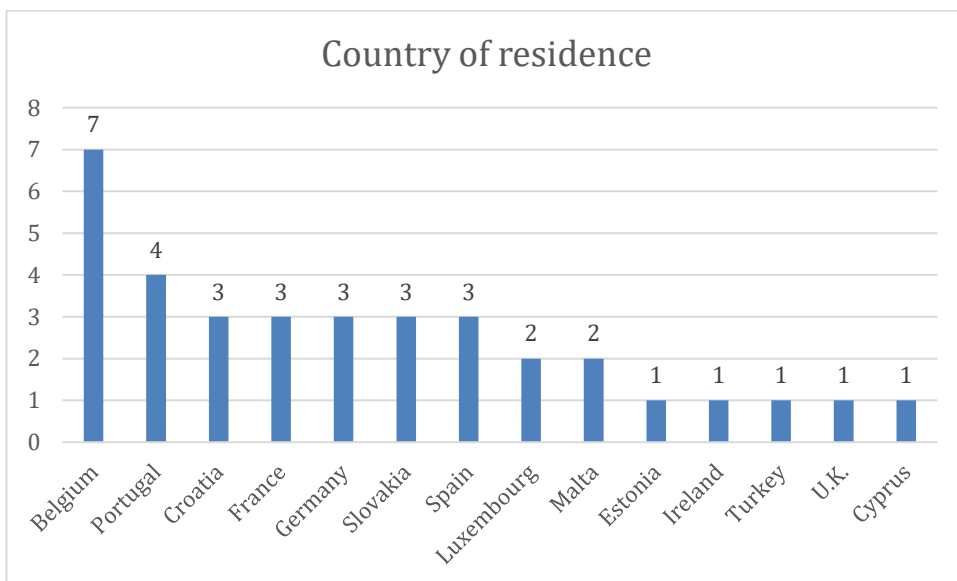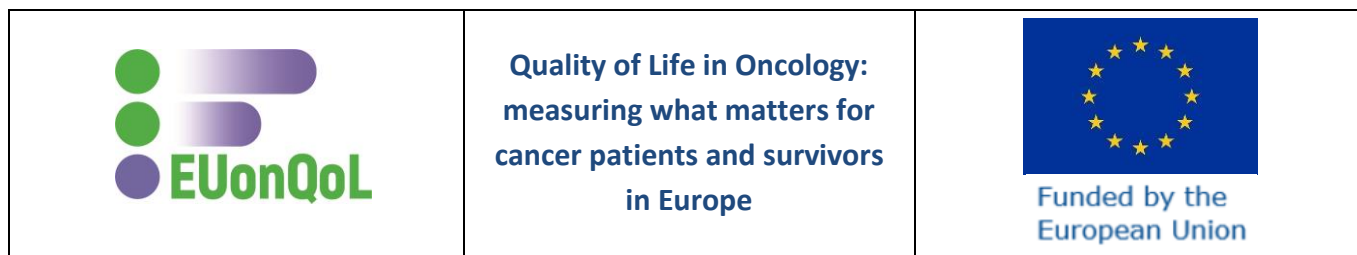

Figure 2: Countries of residence of survey respondents

In the final question of the survey, we asked the respondents if they would be interested in participating in a dedicated online focus group discussion on factors and measures in any of the health care system domains that were addressed in the survey. We invited eight stakeholders divided over two online focus

group discussions to elaborate more on the answers they provided in writing (see Appendix C for the focus group script). We aimed to gain more in-depth insights into why indicators are important in relation to quality of life in cancer patients and to gather real-life examples of the impact of health system-level factors on quality of life. In the end, only one participant per session was present. Therefore, two extensive interviews with the participants were held instead of focus groups. Both participants were cancer patient representatives, one originating from Spain and one from Croatia. In addition to these semi-structured interviews, we consulted a professor in health services research to help us shape the draft indicators more toward actual measurable and applicable indicators.

Finally, we consulted the EUonQoL Stakeholder Board during an online plenary Stakeholder Board meeting on 10 July 2024. Six of the twelve Stakeholder Board members were present. We presented our pre-final list of indicative measures and data sources to them, including the rationale underlying it, and collected their input. Additionally, they were given the opportunity to send us their input via email before 5 August 2024. Their comments and suggestions were included in the final set of indicators.

3.4. Specifying indicators and data sources

Using the information we gathered from (grey) literature, stakeholders, experts, and existing data sources, we developed a final list of indicators and data sources. We made an overview of which indicators we found evidence that they are important in relation to the quality of life of cancer patients.

4. Results

4.1. Outcomes desk research

4.1.1. Insights derived from scientific literature

As described in section 3.2.2., we reapplied the search strategy in PubMed and applied the same search strategy in Scopus and Web of Science to identify any additional publications to complement the information we found in our rapid review (deliverable 5.1).

Three of the identified manuscripts reported on the domain of service delivery (Table 2), whereas one reported on the domain of financing (Table 3). We found no additional scientific evidence for the domains of governance and resource generation. Regarding the domain of service delivery, we identified two papers that reported on the benefits of integrated palliative care for the quality of life of cancer patients (28, 29). The third manuscript we identified reported on the importance of accessibility of care and the downside of waiting times, for the quality of life of patients with cancer (30).

Table 2: Results on health care domain 'service delivery'

Authors	Study type	Country/region	Health care system subdomain	Results on quality of life
Gaertner et al. (28)	Review	N/A	Integration, coordination, and continuity of care	• Integration of specialised palliative care was associated with a small effect on the quality of life.
Skrabek (30)	Review	Canada	Accessibility and timeliness of care	• Accessibility is a fundamental principle of government-run health systems. Waiting for health care is a barrier to access that can result in significant anxiety and stress, deterioration in functional status and loss of income. Prompt access to diagnosis and treatment are key requirements for improving survival and quality of life for patients with cancer.
Alikhani et al. (29)	Review	UK, Malaysia, South Africa	Integration, coordination, and continuity of care	• Many studies show that palliative care policies and the integration of these services in each country's health system can bring about

				benefits such as reducing undesired hospitalization, improving the quality of life, increasing the rate of survival, and reducing the economic burden of cancer on the shoulders of the patients' families and the health system.

The only manuscript we found reporting on the financing domain described how out-of-pocket expenses negatively affect the quality of life of cancer patients (31).

Table 3: Results on health care system domain 'financing'

Authors	Study type	Country/region	Health care system subdomain	Results on QoL
Tran & Zafar (31)	Review	USA	Affordability of treatment	• Cost-sharing policies have increased out-of-pocket expenses for patients, leading to poorer financial well-being, quality of life, psychosocial health, and treatment adherence.

4.1.2. Insights derived from grey literature and existing databases

Another approach within our desk research was to search for grey literature providing information on health system level indicators that could be relevant for explaining between-country variation in the quality of life of cancer patients. We found evidence on the domains of service delivery (Table 4), governance (Table 5), and resource generation (Table 6) in these sources. We did not find any accounts in the domain of financing in our grey literature search.

In the domain of service delivery, we found reports describing several aspects of service delivery. One report described the added value, including improved quality of life, of digital tools for patient monitoring (32). Other reports described the effects of service provision by multidisciplinary teams on the quality of life of cancer patients (33, 34). Furthermore, the benefits of screening and early diagnosis (35, 36), as well as the provision of supportive care and the existence of quality assurance systems (34), on the quality of life of cancer patients, were described.

Table 4: Results on health care domain 'service delivery'

Authors	Publication type	Country/region	Health care system subdomain	Results on quality of life
European Observatory on Health Systems and Policies (32)	Report	Europe	Accessibility and timeliness of care	• In patient monitoring, digital tools can reduce the costs of unnecessary visits and too-late interventions while improving survival and quality of life.
National Institute of Public Health of the Republic of Slovenia & European Observatory on Health Systems and Policies (33)	Report	Europe	Integration, coordination, and continuity of care	• The project team carried out a systematic review of the evidence, which showed how multidisciplinary teams resulted in better clinical and process outcomes for cancer patients in terms of survival, reduction of waiting times and quality of life, among other indicators.
OECD (35)	Report	Europe	Quality of cancer care delivery	• There is clear evidence that breast, colorectal and cervical cancer screening increases the likelihood of successful treatment and leads to a reduction in mortality rates. Early diagnosis of cancer also leads to better survival probabilities, fewer complications, and better quality of life.
European Parliament (34)	Report	Europe	Availability of cancer care and support services; Integration, coordination, and continuity of care; Quality of cancer care delivery	• On survivorship and quality of life more specifically, this section indicates needs in ensuring improved access of patients to high-quality palliative, supportive care, and psycho-oncology. • Specialist cancer nursing has also been associated with improved quality of life outcomes through

- better supportive care of the patient.
- The concept of supportive care can be seen as an "umbrella", covering all the needs of cancer patients in addition to their anticancer therapy and maximising their quality of life.
- Psychosocial interventions have been demonstrated to be effective in improving psychosocial outcomes in cancer patients, including emotional distress/well-being, anxiety, depression, and quality of life.
- The benefits of early palliative care intervention have also been reported in terms of symptom control, emotional status, and quality of life.
- Organising cancer care by multidisciplinary teams within established cancer centres and associated networks is key to providing high-quality cancer care to patients and eliminating inequalities in cancer survival and cancer patients' quality of life across Europe.
- The implementation of quality assurance systems at the level of the network, of healthcare providers, and of single patients, allows for protecting and enhancing quality of diagnosis and care, improving survival and patient quality of life, educating network

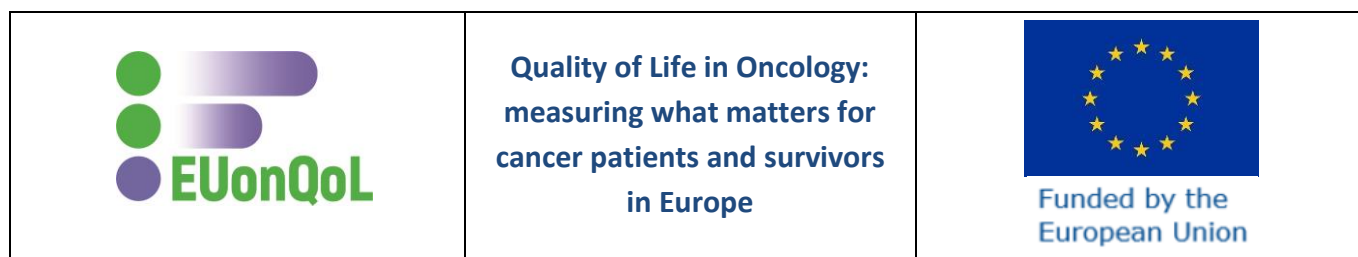|				• professionals, and providing a secure basis of clinical research in rare cancers.
Leemrijse et al. (36)	Report	Europe	Quality of cancer care delivery	• Many lives may be saved, and the quality of life of patients and survivors improved when cancer is diagnosed at an early stage.

In the domain of governance, we found information about the importance of an integrated national approach, such as National Cancer Control Programmes (NCCPs), for the quality of life of cancer patients (33). Additionally, we found that policies that ensure fair access to services, employment, and insurance are especially important for cancer survivors (37).

Table 5: Results on health care domain 'governance'

Authors	Publication type	Country/region	Health care system subdomain	Results on quality of life
National Institute of Public Health of the Republic of Slovenia & European Observatory on Health Systems and Policies (33)	Report	Europe	Policy and vision	• As an integrated approach that seeks innovative solutions to challenges associated with care pathways, continuity of care, and multidisciplinary teams, National Cancer Control Programmes (NCCPs) are increasingly seen as essential to optimising resource use, reducing the number of cancer cases and deaths, and improving quality of life for cancer patients.
Institute of Medicine and National Research Council (37)	Book	USA	Legislation and regulation	• It is recommended to improve the quality of life of cancer survivors through policies to ensure their access to psychosocial services, fair employment practices, and health insurance.

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In the domain of resource generation, we found that new developments resulting from cancer research and innovation have already improved the quality of life of cancer patients, and failure to incorporate these developments in daily practice may affect their quality of life negatively (33, 38). Additionally, we found that referral to centralised points of expertise should be limited, if possible, because it may affect the quality of life negatively (34).
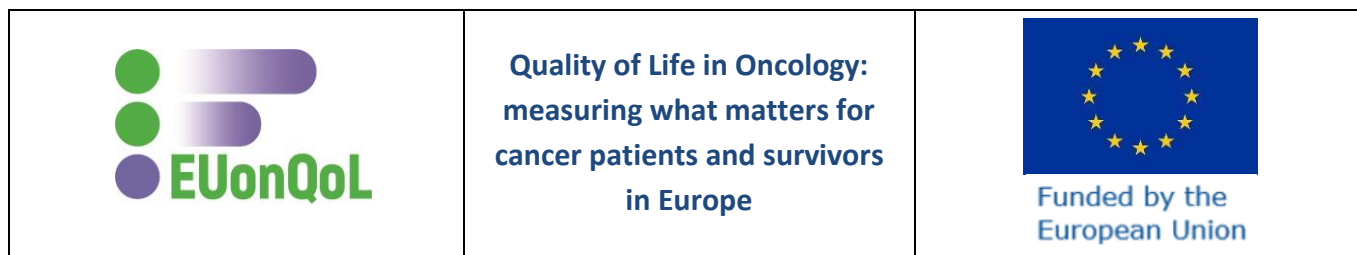
Table 6: Results on health care domain 'resource generation'

Authors	Publication type	Country/region	Health care system subdomain	Results on quality of life
National Institute of Public Health of the Republic of Slovenia & European Observatory on Health Systems and Policies (33)	Report	Europe	Research and innovation	• Failure to incorporate innovations into the care continuum may also affect the quality of life of cancer patients and all the populations at risk, as it is clearly related to success in early diagnosis and effective treatment of cancer.
European Commission (38)	Report	Europe	Research and innovation	• Recent developments in cancer diagnosis and treatment have dramatically improved survival rates and quality of life for cancer patients.
European Parliament (34)	Report	Europe	Workforce capacity and training	• Health migration generated by centralised referral to centres of expertise should be limited, as it implies an adverse impact on the quality of life of patients, as well as costs for them, their families and society.

Our desk research not only aimed at identifying relevant indicators, but also to identify existing sources providing publicly available data on the selected indicators. The following websites, reports, and databases provided information on health system level indicators and were deemed relevant as data sources when collecting data on health system level indicators.

European Cancer Pulse
Short description: The European Cancer Pulse is an interactive data visualisation tool launched by the European Cancer Organisation. It aims to track and highlight cancer care inequalities across Europe. The tool includes over 120 measurements from 34 countries, offering insights into various aspects of cancer

care, such as workforce availability and access to diagnostic equipment. One of the primary goals of the European Cancer Pulse is to provide comprehensive data to support evidence-based policymaking and reduce cancer inequalities. The tool complements the European Commission's Cancer Inequalities Registry by incorporating additional data indicators and sources, helping to address disparities not only between countries but also within them, particularly among different social groups.

Available data on indicative measures: The European Cancer Pulse provides data on the existence of population-based cancer screening programs in EU Member States, as well as the existence of a population-based cancer registry. Furthermore, it provides data on the density of radiologists, pathologists, and nurses. It also provides data on Research & Development (R&D) expenditures, health care spending, and cancer treatment reimbursements. In addition, data is available on cancer care services, including hospital care, psycho-oncology support, and palliative care. Lastly, data is provided on the unmet care needs of cancer patients.

European Cancer Inequalities Registry (ECIR)

Short description: The European Cancer Inequalities Registry (ECIR) is a flagship initiative of Europe's Beating Cancer Plan. It provides sound and reliable data on cancer prevention and care to identify trends, disparities, and inequalities between Member States and regions in cancer incidence, treatment outcomes, and survival rates. It aims to identify and address factors such as socioeconomic status, ethnicity, geography, and access to healthcare that contribute to unequal cancer outcomes. The registry helps to inform public health policies and interventions to reduce inequities and improve overall cancer care and outcomes for all populations.

Available data on indicative measures: The Cancer Inequalities Registry provides data on the density of the workforce in cancer care, including the density of oncologists. It also provides data on the existence of legislation that prohibits discrimination against persons with a history of cancer, such as legislation on the right to be forgotten. Furthermore, it provides data on the density of medical equipment needed for cancer treatment, such as the number of MRI units and PET and CT scanners.
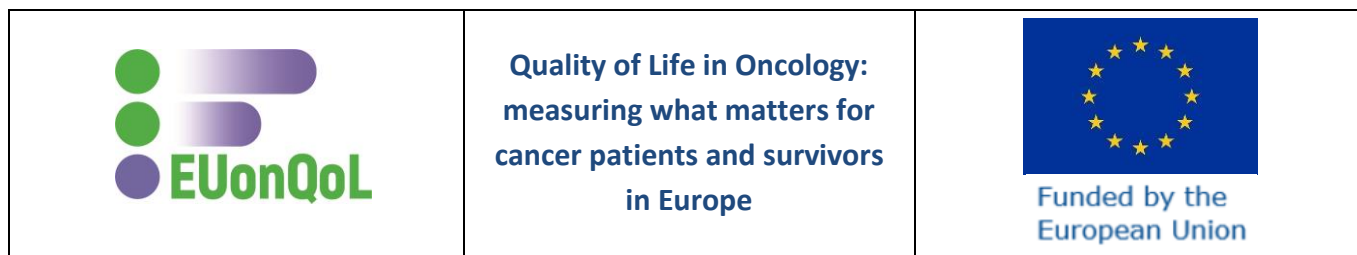
EPAAC

Short description: The European Partnership for Action Against Cancer (EPAAC) was established in 2009 by the European Commission to tackle the burden of cancer across Europe. EPAAC's primary goals are to prevent and control cancer through a series of strategic work packages. These include health promotion and prevention, screening and early diagnosis, healthcare improvement, and research and data collection. EPAAC also focuses on creating synergies between cancer screening and other early detection methods, promoting best practices in cancer care, and centralising data and research to support effective cancer control policies.

Available data on indicative measure: EPAAC provides insight into the existence of national cancer plans or strategies in European Member States.

Eurostat

Short description: Eurostat is the statistical office of the European Union, responsible for providing high-quality statistical information to support decision-making at the EU level. It collects and publishes data on various aspects of European economies, societies, and the environment. This includes data on health system related indicators.

Indicative measures: For the current project and in addition to the data that could be obtained from the Cancer inequalities registry and ECIR, Eurostat provides data on the density of general practitioners within countries.

[WHO's Atlas on eHealth](#)

Short description: The WHO Atlas on eHealth is a comprehensive resource that highlights the use of eHealth in supporting universal health coverage. Based on the findings from the third global survey conducted by the WHO Global Observatory for eHealth (GOe), Atlas provides detailed profiles of eHealth implementations across 125 WHO Member States.

Available data on indicative measures: The WHO Atlas on eHealth provides data on the percentages of health facilities that use electronic health records (EHR), including primary care facilities, secondary care facilities, and tertiary care facilities.
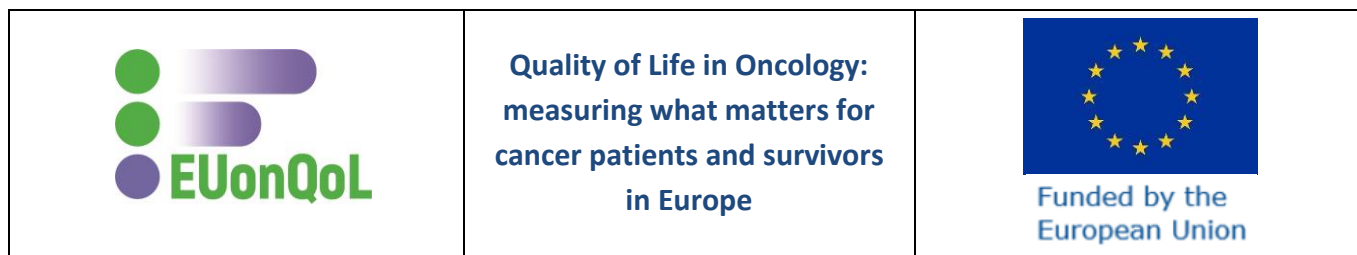
4.2. Stakeholder views

4.2.1 Stakeholder survey

Given our finding that little evidence exists on the relationship between health system level indicators and quality of life, we aimed to substantiate the relevance of identified indicators with stakeholder views. Our first step was to develop and distribute a survey among a wide range of stakeholders (Appendix B).

When analysing the results of the survey, we paid specific attention to the indicative measures rated to be 'very important' in relation to the quality of life of cancer patients by at least 75% of respondents. Within the domain of governance, we found that most of the indicative measures were perceived to be very important. Especially the measures related to the subdomains 'policy and vision', 'health information systems', and 'legislation and regulation' were deemed to be important. In contrast, the indicative measures related to the subdomain 'stakeholder voice' were rated as less important. For the domain resource generation, none of the indicative measures were rated as 'very important'. For the domain financing, only the indicative measure within the subdomain 'comprehensiveness of cancer care coverage' was rated as being very important, in contrast to the indicative measures in the subdomain 'affordability of treatment'. For the domain service delivery, indicative measures within all subdomains were rated to be 'very important'. This includes the subdomains 'accessibility and timeliness of care', 'availability of cancer care and support services', 'integration, coordination and continuity of care', 'quality of cancer care delivery', and 'patient-centredness'.

Additionally, we looked at the answers provided in the open questions. We asked respondents to list any other measures related to health system level factors that they considered important but were not included in the survey. For the domain of governance, these open answers included:

- public transparency regarding conflicts of interest of health care professionals;
- involvement of patient representatives in health policy making;
- the existence of a Cancer Centre Certification Programme;
- the existence of a network of palliative care services;
- availability and accessibility of electronic health records;
- legislation on the right to work during treatments;

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- the existence of monitoring mechanisms of National Cancer Control Plans;
- centralization of cancer treatment;
- number of research projects led by an institution;
- availability of psychological support to patients and healthcare professionals;
- number of publications by an institution;
- the availability and accessibility of screening programs.

Regarding the domain of financing, there were also answers provided to the open questions. These included:

- the amount of cancer-related health costs;
- inclusion of new treatments in insurance coverage;
- the affordability of clinical trials;
- whether or not health insurance is obligatory;
- and the possibility of receiving off-label treatments without financial repercussions.

For the domain of resource generation, there were also answers provided in the open questions, including:

- the availability of sufficient nursing staff and supportive care staff;
- provision of support to healthcare professionals;
- the availability of epidemiological information for healthcare professionals;
- availability of clinical trials for all patients;
- and the availability and accessibility of spiritual support for patients and their relatives.

Lastly, there were also answers provided to the open questions relating to the domain of service delivery. These included:
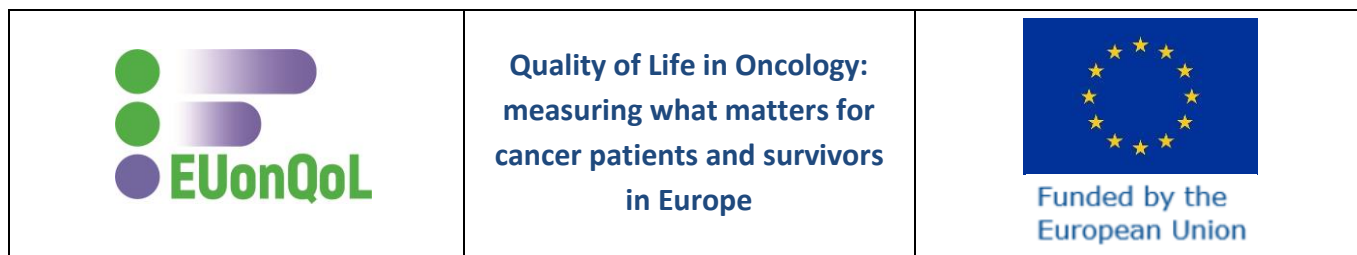
- the ratio of psychologists/pain specialists/physiotherapists/nutritionists per 1,000 cancer patients;
- the availability of support for the patient's relatives;
- the employment of Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) in the cancer care pathway;
- the availability of genetic counselling;
- and the time that passes between European Medicines Agency (EMA) approval and the first prescription of a new drug in a country.

4.2.2 Stakeholder interviews

In addition to the survey, we organised two focus group sessions. In the end, only one participant was present per session. Therefore, two extensive interviews with the participants were held.

Several important insights on the health system factors were derived from these interviews. Regarding the domain of governance, participants indicated that it is important to:

- Have a centralised point that controls the standardisation of cancer care of all cancer institutes in a country, in this way increasing the accessibility and quality of care and the quality of life.

- Involve stakeholders in policy making and be transparent about the stakeholders involved. One participant gave an example of a platform for cancer patients formed by his organisation, which pressured the government about the national cancer strategy and, in the end, was involved in making this strategy.
- Have a system of quality control, so choices that are made by the government are not financially driven, but quality driven.
- Have legislation or regulation in place on financial support, because the number of patients will grow, and with this will also the number of patients who cannot work and deserve financial aid. Also, financial support for travelling to treatment was deemed important.
- They both still experience financial discrimination against cancer patients in their countries, and therefore monitoring mechanisms of legislation are found to be important.
- Not only was the use of electronic health records deemed important, but rather the integration of health information systems, as this makes it possible to have all the right information in one place.

Regarding the domain of resource generation, participants deemed it important to:

- Have a centralised cancer research institute, because when research groups collaborate, you can do a lot more. There should be no competition between research groups This is counterproductive.

When talking about the domain of financing, participants indicated that:

- It is important to describe the total expenditure on cancer care as a percentage of total health expenditure on a national level.
- Out-of-pocket expenditures and insurance coverage were not deemed very important topics to discuss, because most people in Europe are insured well enough according to the participants.
- Not only is the existence of financial support deemed important, but also making people aware of it.
- The time that passes between EMA approval of a new drug and actual market availability in a country is also discussed. Sometimes there is a lot of delay (this differs between European countries), which can harm a patient's quality of life.

Lastly, we also discussed the domain of service delivery, and participants indicated that:

- The availability of remote oncology care might be less important because people still prefer to communicate face-to-face with their doctor.
- It is important for patients to have quick access to diagnostics and treatment.
- Good collaboration between different professionals is important. Sometimes the general practitioner prescribes a certain medication without considering its interaction with cancer drugs.
- Not only are integration and collaboration between different professionals needed, but also between centres and sectors. For example, an integrated network of cancer centres was deemed important so that patients would know which centres offer specific types of treatments.
- Not only is the density of healthcare professionals important, but rather how well they are distributed across the country.
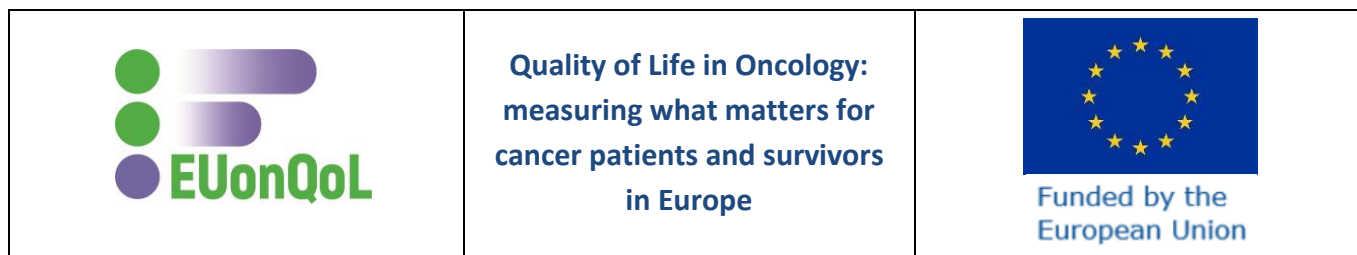
- Not only is the existence of clinical guidelines important, but rather the implementation of these. Not all centres deliver care according to the guidelines.
- Patient satisfaction with cancer care is deemed a too broad criterion, more specifically we could use PREMs and PROMs as measures.
- The availability of palliative care/end-of-life care is deemed an important measure.

4.2.3 Stakeholder Board consultation

During the Stakeholder Board meeting, the Stakeholder Board members were very interested in our presentation on the identification of health system level indicators and agreed with the pre-final list of indicative measures. No input was provided that warranted changes to the list of indicators.

4.3. Final list of indicators and data sources

Based on the steps and results as outlined in paragraphs 4.1 and 4.2, a final set of system level indicators was constructed. Table 7 includes the complete list of indicators, including: a) on which grounds they were included; b) whether scientific evidence was found on the association between the indicator and quality of life of cancer patients; and c) whether there is publicly available data on the indicator.

This comprehensive list contains 58 indicative measures: 16 in relation to the domain of governance, 9 in relation to the domain of resource generation, 11 in relation to the domain of financing and 22 in relation to service delivery. Yet there are only 14 indicative measures for which evidence was found in the literature on the relation with quality of life of people with cancer. The table shows that for 4 of these indicative measures, data is available from publicly accessible sources. For the other 10 indicative measures data would need to be obtained, for instance via country contact points, or alternative indicators should be selected for which data is available.

Table 7: List of health system level indicators of quality of life of cancer patients and data sources

Health system domains	Subdomains	Indicative measures	Selection based on: a) literature; b) stakeholder survey; c) expert interviews; d) data repositories; e) existing health system frameworks	Evidence found on relationship with quality of life?	Is data publicly available?
Governance	Policy and vision on cancer care	The existence of a national cancer plan/strategy	a; b; c; d	Yes	Yes, via EPAAC
		The existence of monitoring mechanisms to assess the implementation of the national cancer plan/strategy	b	No	No
		The existence of an organised populated-based breast cancer screening programme	d	No	Yes, via European Cancer Pulse
		The existence of an organised populated-based cervical cancer screening programme	d	No	Yes, via European Cancer Pulse

Health system domains	Subdomains	Indicative measures	Selection based on: a) literature; b) stakeholder survey; c) expert interviews; d) data repositories; e) existing health system frameworks	Evidence found on relationship with quality of life?	Is data publicly available?
		The existence of an organised populated-based colorectal cancer screening programme	d	No	Yes, via European Cancer Pulse
		The existence of an organised populated-based prostate cancer screening programme	d	No	Yes, via European Cancer Pulse
		The existence of an organised populated-based lung cancer screening programme	d	No	Yes, via European Cancer Pulse
		The existence of an organised populated-based gastric cancer screening programme	d	No	Yes, via European Cancer Pulse
	Stakeholder voice	Documented stakeholder participation in the development of the national cancer plan	c	No	No
		The existence of dialogue platforms to ensure involvement of key stakeholders in the decision-making process	c	No	No
	Health information systems	The existence of a monitoring and evaluation plan or a documented methodology for monitoring the process, outputs, and outcomes of cancer care	b; c	No	No
		The percentage of cancer centres that use electronic health records	c	No	No
		The existence of a population-based cancer registry	d	No	Yes, via European Cancer Pulse
	Legislation and regulation	The existence of legislation that prohibits discrimination of persons (with a history of) cancer, such as legislation on the right to be forgotten	a; b; c; d	Yes	Yes, via Cancer Inequalities Registry

Health system domains	Subdomains	Indicative measures	Selection based on: a) literature; b) stakeholder survey; c) expert interviews; d) data repositories; e) existing health system frameworks	Evidence found on relationship with quality of life?	Is data publicly available?
		The existence of governmental financial benefits, including benefits for travel expenses for traveling to cancer treatment and care facilities	b; c	No	No
		The existence of legislation or regulation on financial support (e.g., financial support when being unable to work)	b; c	No	No
Resource generation	Workforce capacity and training	The existence of mechanisms or models for cancer care workforce planning	a	Yes	No
		Density of oncologists per 100,000 inhabitants	c	No	Yes, via Cancer Inequalities Registry
		Density of radiologists per 100,000 inhabitants	d	No	Yes, via European Cancer Pulse
		Density of pathologists per 100,000 inhabitants	d	No	Yes, via European Cancer Pulse
		Density of nurses per 100,000 inhabitants	c; d	No	Yes, via European Cancer Pulse
		Density of general practitioners per 100,000 inhabitants	c; d	No	Yes, via Eurostat nr. of practising physicians
	Research and innovation	The existence of a national cancer research institute	a; c	Yes	No
		Total R&D expenditure by pharmaceutical industry	d	No	Yes, via European Cancer Pulse
		R&D expenditure by the pharmaceutical industry per capita	d	No	Yes, via European Cancer Pulse

Health system domains	Subdomains	Indicative measures	Selection based on: a) literature; b) stakeholder survey; c) expert interviews; d) data repositories; e) existing health system frameworks	Evidence found on relationship with quality of life?	Is data publicly available?
Financing	Affordability of treatment	Total expenditure on cancer care as percentage of total health care expenditure	a; c	Yes	No
		Percentage out-of-pocket cancer care expenditure as percentage of total cancer care expenditure	a; c	Yes	No
		Health care spending on cancer care per capita (not PPP-adjusted)	d	No	Yes, via European Cancer Pulse
		Health care spending on cancer care per capita (PPP-adjusted)	d	No	Yes, via European Cancer Pulse
		Expenditure on cancer drugs per capita (PPP-adjusted)	d	No	Yes, via European Cancer Pulse
		Expenditure on cancer drugs per capita (not PPP-adjusted)	d	No	Yes, via European Cancer Pulse
	Comprehensiveness of cancer care coverage	Reimbursement status of new oncology medicines	c; d	No	Yes, via European Cancer Pulse
		Average reimbursement time of new oncology medicines	c; d	No	Yes, via European Cancer Pulse
		Insurance coverage of all available cancer treatments	a; b; c	Yes	No
		Reimbursement of single biomarker testing	d	No	Yes, via European Cancer Pulse
		Reimbursement of multi-biomarker testing	d	No	Yes, via European Cancer Pulse
Service delivery	Accessibility and timeliness of care	Percentage of the cancer centres offering remote oncology care (including patient monitoring)	a; c	Yes	No

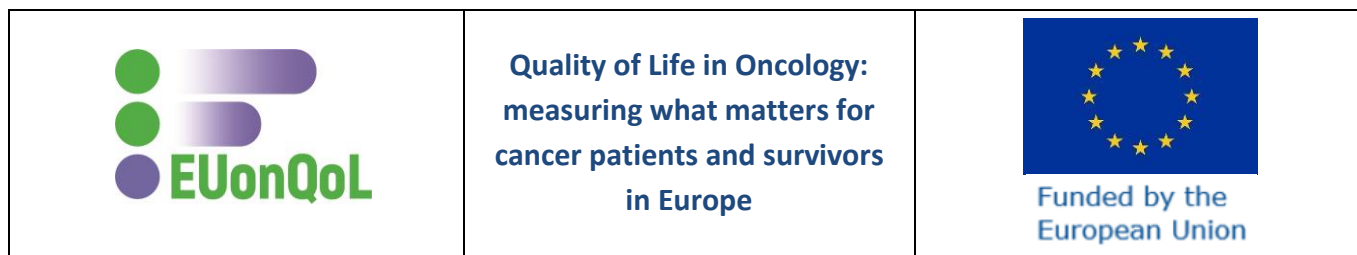| Health system domains	Subdomains	Indicative measures	Selection based on: a) literature; b) stakeholder survey; c) expert interviews; d) data repositories; e) existing health system frameworks	Evidence found on relationship with quality of life?	Is data publicly available?
		Average waiting times for the start of cancer treatment	a; b; c	Yes	No
		Single biomarker test access	d	No	Yes, via European Cancer Pulse
		Multi-biomarker (NGS) test access	d	No	Yes, via European Cancer Pulse
	Availability of cancer care and support services	Number of Magnetic Resonance Imaging units per 100,000 inhabitants	d	No	Yes, via Cancer Inequalities Registry
		Number of PET scanners per 100,000 inhabitants	d	No	Yes, via Cancer Inequalities Registry
		Number of Computed Tomography Scanners per 100,000 inhabitants	d	No	Yes, via Cancer Inequalities Registry
		Number of Gamma cameras per 100,000 inhabitants	e	No	Yes, via Cancer Inequalities Registry
		Number of Radiation therapy equipment per 100,000 inhabitants	e	No	Yes, via Cancer Inequalities Registry
		Hospital beds per 10,000 inhabitants	d	No	Yes, via European Cancer Pulse
		Radiation therapy centres per 1 million inhabitants	d	No	Yes, via European Cancer Pulse
		Psycho-oncology support with recommendation in NCP	a; b; c; d	Yes	Yes, via European Cancer Pulse

Health system domains	Subdomains	Indicative measures	Selection based on: a) literature; b) stakeholder survey; c) expert interviews; d) data repositories; e) existing health system frameworks	Evidence found on relationship with quality of life?	Is data publicly available?
		Access to pain management	b; c	No	No
		Access to nutritional counselling	b; c	No	No
		Rehabilitation services for adults per 100,000 inhabitants	b; c	No	No
		Palliative care services for adults per 100,000 inhabitants	c; d	No	Yes, via European Cancer Pulse
	Integration, coordination, and continuity of care	Availability of support in the transition from paediatric to adult care	c	No	No
		Availability of support in the transition from specialised care to community care	c	No	No
		The existence of multidisciplinary cancer care teams	a; b; c	Yes	No
	Quality of cancer care delivery	The existence of up-to-date evidence-based guidelines on cancer diagnosis and treatment	a; b; c	Yes	No
		The existence of a surveillance or monitoring system to assess outcomes of cancer care	a; b	Yes	No
	Patient-centeredness	Unmet care needs	a; b; c; d	Yes	Yes, European Care Pulse

5. Discussion

The aim of the current report was to provide insight into the used approach and results of the specification of health system indicators, and sources providing country level data on these indicators. Based on the (grey) literature and stakeholders' consultation, we constructed a list of 58 indicative measures. For 14 of these indicative measures, we found evidence in the literature on the relationship with the quality of life of people with cancer. For 4 of these indicative measures, data is available from publicly accessible sources.

In line with our previous report, we found that, to date, the relationship between health care system factors and quality of life in cancer patients remains understudied. For example, most of the evidence-based indicative measures identified relate to the domain of service delivery. Within the other health system domains, we merely identified two or three evidence-based indicative measures. For several governance subdomains (i.e., stakeholder voice and health information systems), no evidence-based indicative measures were specified at all. It is therefore recommended for future research to explore to what extent the various health system level indicators, as specified in the current study, relate to quality of life of cancer patients and survivors. Specifically, those for which no evidence could be found in the literature.

In part, this will be done in the pilot study of EUonQoL. During this pilot study, health system level indicators will be included in cross-country analyses as explanatory variables for the potential differences in quality of life outcomes of cancer patients among EU Member States and Associated Countries. The pilot study of EUonQoL provides a unique opportunity to explore the explanatory value of indicative measures for which the scientific evidence is not yet established. Besides the EUonQoL pilot study, other cross-country studies on the quality of life of cancer patients and survivors are encouraged to explore the role of the various health system level indicators as outlined in the current report.

It is thereby important to stress that some indicators might be more relevant when the study population consists of patients undergoing or waiting for active treatment, and other indicators might be more relevant when the study population concerns persons who are in remission. For instance, average waiting times to start treatment can impact the quality of life of persons waiting for or undergoing treatment, but to a lesser extent, those who are in remission. On the other hand, legislation on the 'right to be forgotten' might be more relevant for the quality of life of those who are in remission than for those who are under active treatment. This illustrates that more research is needed to determine which indicators are especially relevant for quality of life and in which phase of the disease.

The relevance of health system level indicators might also be dependent on broader population or country socioeconomic and demographic characteristics. For instance, in countries that face major challenges when it comes to poverty and unemployment, the 'right to be forgotten', which often relates to obtaining a life insurance to buy a house, might be less relevant than in countries that do not face these challenges.

In line with that, it is important to note that in this study, we focussed on health system level indicators that relate to cancer prevention, treatment, and care. We know socioeconomic and demographic characteristics of populations within EU Member States and Associated Countries, could also play an important role in explaining differences in quality of life of cancer patients between or within countries. For instance, living in remote or deprived areas could impact quality of life as it might limit access to cancer treatment and care (39). Furthermore, the prosperity of a population in terms of education, employment,

and income might be important indicators of the extent to which people could cope with cancer (40). In addition, social capital within populations might be related to the quality of life of cancer patients (41) (in some countries, this relation might be stronger than in others, perhaps depending on the availability of social support and care services). For future cross-country comparative studies on quality of life of cancer patients, it could be relevant to take not only health system level indicators into account as possible explaining mechanisms, but also socioeconomic and demographic population level characteristics.

Like the health system level indicators specified in the current study, socioeconomic and demographic characteristics address macro-level factors. Beyond these macro-level factors, we recognise that meso-level factors, which pertain to organisation-level characteristics, can be equally or even more important, depending on the level of analysis. For example, when comparing regions or cancer centres, the average waiting time for treatment at the centre level is more relevant for explaining differences in quality of life than the average waiting time at the country level. Many of the macro-level indicators we identified are also suitable for measuring meso-level factors, albeit in a slightly modified form. Therefore, it is recommended that, for those interested in comparing cancer centres across or within countries, these indicators should be measured at the meso-level.

Additionally, we are aware that quality of life is a term that can have different definitions and interpretations, depending on the context it is used in. In the health care setting, the concept of health-related quality of life has been introduced to narrow the field of interest. Additionally, many measurement tools exist, which can be either generic or disease and treatment specific, to evaluate quality of life (1). As the current study is exploratory, we have not made a distinction between the different definitions and measurement possibilities of quality of life. Our aim was to gain as much insight as possible in the limited resources that currently exist, not to (statistically) compare these results.

A strength of our study is that, to our knowledge, this is the first exploration of the relationship between health system characteristics and the quality of life of cancer patients, and the first attempt to construct a list of measurable indicators to analyse this relation. In doing so, we employed many different methods, i.e., scientific literature, grey literature, and stakeholder views, ensuring a wide exploration of available sources and views. A limitation of our study is that a limited number of stakeholders were consulted, due to only two participants being present for the focus group discussions. A possible reason for this could be that the collection of stakeholder views, i.e., the stakeholder survey and the focus groups, were all scheduled within a month's time. Possibly, this timeline was too strict for the focus group participants we invited. Actual focus groups, including various stakeholders from multiple countries, would potentially have provided greater insight into the relevance of the health system level indicators we specified.

5.1. Conclusion

In conclusion, we constructed a list of health system level indicators to help explain the potential differences in quality of life of cancer patients and survivors between EU Member States and Associated Countries. The content of this list was based on different sources of information, namely scientific literature, grey literature, and stakeholder views. Given the limited amount of evidence on the relation between health system level indicators and quality of life of cancer patients and survivors, it is recommended to conduct further research in this area.

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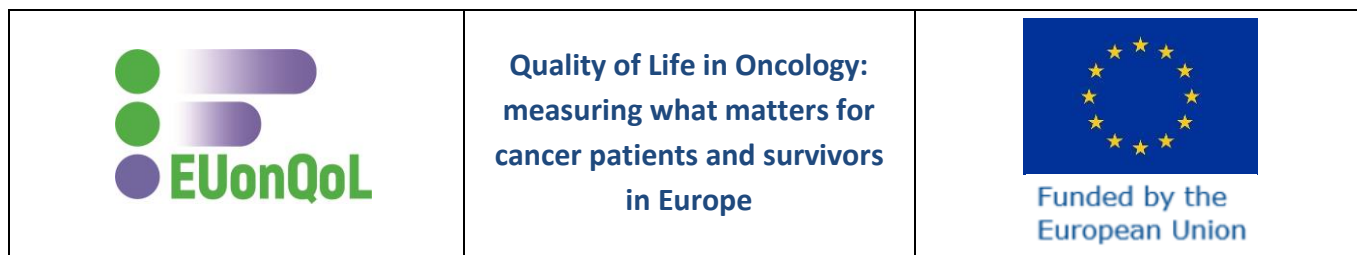
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Appendix A. Search strategy literature review

The search strategy that we employed in May 2023 for our rapid review (see below), was repeated in PubMed in March 2024. This yielded 476 results, whereas ten months earlier there were 436 results, so 40 new, potentially relevant, manuscripts have been published during that time.

1. "health system*"[Title/Abstract] OR "health care system*"[Title/Abstract] OR "healthcare system*"[Title/Abstract] OR "health economic*"[Title/Abstract] OR "health care economic*"[Title/Abstract] OR "healthcare economic*"[Title/Abstract] OR "health cost*"[Title/Abstract] OR "health care cost*"[Title/Abstract] OR "healthcare cost*"[Title/Abstract] OR "health expenditure*"[Title/Abstract] OR "health care expenditure*"[Title/Abstract] OR "healthcare expenditure*"[Title/Abstract] OR "health policy"[Title/Abstract] OR "health care policy"[Title/Abstract] OR "healthcare policy"[Title/Abstract] OR "health policies"[Title/Abstract] OR "health care policies"[Title/Abstract] OR "healthcare policies"[Title/Abstract] OR "medical education*"[Title/Abstract] OR "nursing education*"[Title/Abstract] OR "health workforce"[Title/Abstract]

2. factor*[Title/Abstract] OR indicator*[Title/Abstract] OR characteristic*[Title/Abstract] OR predictor*[Title/Abstract] OR determinant*[Title/Abstract]

3. affect[Title/Abstract] OR effect[Title/Abstract] OR related[Title/Abstract] OR impact[Title/Abstract]

4. "quality of life"[Title/Abstract] OR qol[Title/Abstract] OR "health-related quality of life"[Title/Abstract] OR hrqol[Title/Abstract]

5. cancer[Title/Abstract] OR tumor[Title/Abstract] OR tumour[Title/Abstract] OR neoplasm[Title/Abstract] OR carcinoma[Title/Abstract] OR oncolog*[Title/Abstract]

6. #1 AND #2 AND #3 AND #4 AND #5

We specifically searched for reviews in publication years 2023-2024, which yielded three results. Titles and abstracts were scanned of these results. One of the publications was already included within the rapid review, and the other two were irrelevant. Following this, we applied the same search strategy in Scopus. This yielded 313 results, of which 63 were reviews. We screened the titles and abstracts, however, none of the articles were deemed relevant for our research. The same search strategy was applied in Web of Science, which yielded 432 results. 110 of these were reviews. Again, the titles and abstracts of these publications were screened, and three relevant articles were found. Additionally, we applied a snowball search to the references of the relevant articles, which yielded one other publication that was included in our study.

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

Appendix B. Stakeholder survey questions

Introduction

This survey was developed in the context of an ongoing European project named EUonQoL, that aims to improve the measurement of quality of life of persons with (a history of) cancer in EU Member States, Iceland, and Norway.

The quality of life of persons with (a history of) cancer can be affected by a range of individual and social factors. For instance, being physically and mentally able to engage in meaningful activities, or having a social network that could offer emotional and practical support.

In addition, quality of life could be affected by factors that are related to the health systems within a country. For instance, legislation that enables persons with (a history of) cancer to obtain healthcare insurance, or the availability of psychological support after being diagnosed with cancer.

Yet, little literature exists on what health system-level factors affect quality of life of persons with (a history of) cancer and on data sources that provide insights into these factors at a national or regional level.

The aim of this survey is to obtain the views of different stakeholders on what health system-level factors could affect the quality of life of persons with (a history of) cancer, how these factors could be measured and what data sources are available that provide insight in these factors on a national or regional level.

Your views on this topic are highly valued and can contribute to a better measurement of quality of life of persons with (a history of) cancer. We kindly ask you to provide a response to this survey by **18 April 2024** at the latest.

If you have any questions about this questionnaire or the study itself, please contact m.engelaar@nivel.nl.

Thank you for your contribution.

About us:

The EUonQoL project (Funded by the European Union - Horizon Europe - Grant Agreement n. 101096362) aims to review existing quality of life (QoL) scales and to develop new metrics by harnessing the strengths and overcoming the limitations of previous tools. The EUonQoL-Kit, a toolkit of QoL questionnaires which will be the product of this effort, 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 Patient and Public Involvement (PPI) principles, through the involvement of a representative panel of patients and public members throughout all project phases. Within the EUonQoL project, 24 partner organisations from 13 European countries work together. The project duration is 4 years: from January 2023 to December 2026. Further description of the project, its work packages and the participating organisations can be found on the EUonQoL website: http://www.euonqol.eu/

Start questionnaire

Background questions

1. Which **stakeholder group** do you represent?
   Multiple answers possible
   - o Cancer patient representatives
   - o Healthcare professionals
   - o Researchers
   - o Policy makers
   - o Insurers
   - o Other, namely:

2. In which **country** do you live?
   - o Austria
   - o Belgium
   - o Bulgaria
   - o Croatia
   - o Republic of Cyprus
   - o Czech Republic
   - o Denmark
   - o Estonia
   - o Finland
   - o France
   - o Germany
   - o Greece
   - o Hungary
   - o Iceland
   - o Ireland
   - o Italy
   - o Latvia
   - o Lithuania
   - o Luxembourg
   - o Malta
   - o Netherlands
   - o Norway
   - o Poland
   - o Portugal
   - o Romania
   - o Slovakia
   - o Slovenia
   - o Spain
   - o Sweden
   - o Other, namely:

Questions on the relevance of health system-level factors and measures for quality of life of persons with (a history of) cancer

In this section you will be asked to review the importance of various health system-level factors and accompanying measures for the quality of life of persons with (a history of) cancer. You will also be given the opportunity to add any measures that you consider important, but that are not on the list. The questions are grouped according to the following four health system domains: governance, financing, resource generation and service delivery.

3. How important would you consider the following factors and measures in relation to the quality of life of persons with (a history of) cancer in the domain of health system **governance**?

Health system level factors and *measures* in the domain of governance	Important in relation to the quality of life of persons with (a history of) cancer?				
	Not important	Slightly important	Fairly important	Very important	Do not know
Policy and vision on cancer care: The availability of guidelines, principles, and directives formulated by governmental or organisational bodies to guide decision-making, resource allocation, and actions related to cancer care.	○	○	○	○	○
Existence of a national cancer plan / strategy	○	○	○	○	○
Existence of monitoring mechanisms to assess the implementation of the national cancer plan / strategy	○	○	○	○	○
Legislation and regulation: The protection of cancer patients from financial hardship associated with the cost of cancer care, including out-of-pocket expenses, as well as access to health insurance coverage and financial assistance programs.	○	○	○	○	○
Existence of legislation that prohibits discrimination of persons (with a history of) cancer, such as legislation on the right to be forgotten	○	○	○	○	○
Existence of legislation or regulation on financial support (e.g., financial support when being unable to work)	○	○	○	○	○
Stakeholder voice: The involvement of key-stakeholders in the development of cancer-related policies.	○	○	○	○	○
Documented stakeholder participation in the development of the national cancer plan	○	○	○	○	○
Existence of dialogue platforms to ensure involvement of key stakeholders in the decision-making process	○	○	○	○	○

Health information systems: The availability and use of health information systems for cancer care, as well as the integration of electronic health records and decision support tools to support evidence-based cancer care delivery.	○	○	○	○	○
Existence of a monitoring and evaluation plan or a documented methodology for monitoring the process, outputs, and outcomes of cancer care	○	○	○	○	○
The percentage of cancer centres that use electronic health records	○	○	○	○	○

4. Are you familiar with any **sources that hold national or regional data** on any of the measures referred to in the previous question?

5. Are there any **other measures** related to health system **governance** that you consider important? Do you have any reference to **sources that hold national or regional data** on these measures? Please list a maximum of five.

Measures in the domain of health system governance	Sources

6. How important would you consider the following factors and measures in relation to the quality of life of persons with (a history of) cancer in the domain of health system **financing**?

Health system level factors and *measures* in the domain of financing	Important in relation to the quality of life of persons with (a history of) cancer?				
	Not important	Slightly important	Fairly important	Very important	Do not know
Affordability of treatment: The cost of cancer treatments, medications, and supportive care services.	○	○	○	○	○

Total expenditure on cancer care as percentage of total health care expenditure	○	○	○	○	○
Percentage out-of-pocket cancer care expenditure as percentage of total cancer care expenditure	○	○	○	○	○
Percentage of cancer care spendings covered by mandatory prepayment (for instance through social health insurance)	○	○	○	○	○
Comprehensiveness of cancer care coverage: The coverage of various cancer treatments, including chemotherapy, radiation therapy, surgery, and supportive care services such as pain management, psychosocial support, and rehabilitation, by insurance schemes.	○	○	○	○	○
Insurance coverage of all available cancer treatments	○	○	○	○	○

7. Are you familiar with any **sources that hold national or regional data** on any of the measures referred to in the previous question?

8. Are there any **other measures** related to health system **financing** that you consider important? Do you have any reference to **sources that hold national or regional data** on these measures? Please list a maximum of five.

Measures in the domain of health system financing	Sources

9. How important would you consider the following factors and measures in relation to the quality of life of persons with (a history of) cancer in the domain of health **resource generation**?

Health system level factors and *measures* in the domain of resource generation	Important in relation to the quality of life of persons with (a history of) cancer?				
	Not important	Slightly important	Fairly important	Very important	Do not know
Workforce capacity and training: The availability, competency and ongoing training of healthcare professionals involved in cancer care, including oncologists, nurses, allied health professionals, and primary care providers.	○	○	○	○	○
Existence of mechanisms or models for cancer care workforce planning	○	○	○	○	○
Existence of national and/or sub-national mechanisms for accreditation of cancer care workforce education and training institutions and their programmes	○	○	○	○	○
Density of oncologists per 100,000 inhabitants	○	○	○	○	○
Density of family medicine practitioners per 100,000 inhabitants	○	○	○	○	○
Research and innovation: The level of investment and engagement in cancer research and innovation to advance scientific knowledge, develop new therapies and technologies, and improve cancer care for patients.	○	○	○	○	○
The existence of a national cancer research institute	○	○	○	○	○

10. Are you familiar with any **sources that hold national or regional data** on any of the measures referred to in the previous question?

11. Are there any **other measures** related to health system **resource generation** that you consider important? Do you have any reference to **sources that hold national or regional data** on these measures? Please list a maximum of five.

Measures in the domain of resource generation	Sources

12. How important would you consider the following factors and measures in relation to the quality of life of persons with (a history of) cancer in the domain of **service delivery**?

Health system level factors and *measures* in the domain of service delivery	Important in relation to the quality of life of persons with (a history of) cancer?				
	Not important	Slightly important	Fairly important	Very important	Do not know
Accessibility and timeliness of care: How easily patients can access cancer care services and the promptness with which they receive necessary treatments and interventions. This includes equitable access to cancer care regardless of socioeconomic status and geographic location.	○	○	○	○	○
Percentage of the cancer centres offering remote oncology care (including patient monitoring)	○	○	○	○	○
Availability of governmental financial benefits, including for instance benefits for travel expenses for traveling to cancer treatment and care facilities	○	○	○	○	○
Average waiting times for the start of cancer treatment	○	○	○	○	○
Availability of cancer care and support services: The availability of specialised cancer treatment facilities, as well as advanced diagnostic and therapeutic technologies and the availability of support services.	○	○	○	○	○
Number of cancer treatment facilities per 100,000 inhabitants	○	○	○	○	○
Number of family medicine practitioners per 100,000 inhabitants	○	○	○	○	○
Number of Magnetic Resonance Imaging units per 100,000 inhabitants	○	○	○	○	○
Number of PET scanners per 100,000 inhabitants	○	○	○	○	○
Number of Computed Tomography Scanners per 100,000 inhabitants	○	○	○	○	○
Number of Gamma cameras per 100,000 inhabitants	○	○	○	○	○
Number of Radiation therapy equipment per 100,000 inhabitants	○	○	○	○	○
Availability of psychological support services for persons with (a history of) cancer	○	○	○	○	○
Availability of pain management	○	○	○	○	○
Availability of nutritional counselling	○	○	○	○	○
Availability of rehabilitation services	○	○	○	○	○
Integration, coordination, and continuity of care: The level of coordination among different	○	○	○	○	○

healthcare providers involved in cancer care, to ensure seamless transitions between different stages of treatment and follow-up care. It also includes the existence of multidisciplinary cancer care teams.					
Availability of support in the transition from paediatric to adult care	○	○	○	○	○
Availability of support in the transition from specialised care to community care	○	○	○	○	○
Existence of multidisciplinary cancer care teams	○	○	○	○	○
Quality of cancer care delivery: Adherence to evidence-based guidelines and protocols for cancer care services to ensure the delivery of high-quality, standardised care across different healthcare settings.	○	○	○	○	○
Existence of up-to-date evidence-based guidelines on cancer diagnosis and treatment	○	○	○	○	○
Existence of a surveillance or monitoring system to assess outcomes of cancer care	○	○	○	○	○
Patient-centeredness: The extent to which cancer care services are tailored to meet the individual needs, preferences, and values of patients, including shared decision-making, patient-centred communication, emotional support, and respect for patients' autonomy and dignity.	○	○	○	○	○
Average patient satisfaction with cancer care	○	○	○	○	○

13. Are you familiar with any **sources that hold national or regional data** on any of measures referred to in the previous question?

14. Are there any **other measures** related to health system **service delivery** that you consider important? Do you have any reference to **sources that hold national or regional data** on these measures? Please list a maximum of five.

Measures in the domain of service delivery	Sources

Other comments and availability for further discussion

15. Are there any **other comments** that you would like to make with respect to this survey?

16. Would you be interested to participate in a dedicated **focus group discussion** on factors and measures in any of the health care system domains that were addressed in this survey? Multiple answers allowed.
    The focus group discussions will be scheduled on the 25th and 26th of April.
    o Yes, I am interested to participate in the discussion on health system **governance**
    o Yes, I am interested to participate in the discussion on health system **financing**
    o Yes, I am interested to participate in the discussion on health **resource generation**
    o Yes, I am interested to participate in the discussion on **service delivery**
    o No, I am not interested to participate

17. Please indicate your **availability** for the focus group discussion. [will only be shown if participants indicated their interest]
    o I would be available on the 25th of April in the morning
    o I would be available on the 25th of April in the afternoon
    o I would be available on the 26th of April in the morning
    o I would be available on the 26th of April in the afternoon
    o I am not available on either the 25th or 26th of April

18. Please provide the **email** address that we can use to send you the invite for the online focus group discussion. [will only be shown if participants indicated their interest and that are available on the 25th or 26th of April]

You have now reached the end of this survey. Thank you for your contribution!

Appendix C. Focus group script

Introduction

- Ask whether the conversation can be recorded for project/research purposes (after that, make sure to record the meeting).
- Indicate that we will ensure that everyone has the opportunity to speak, and that participants can speak freely about how they think about certain topics. There is no right or wrong, our intention is to learn from their expertise through this group discussion.
- Ask participants to introduce themselves: name, stakeholder group you represent, country, …

Background of the EUonQoL project and aim of this focus group discussion

- Introduce the EUonQoL project, its aims, and its methods. Introduce our research on health system level factors that affect quality of life of cancer patients.
- Introduce the four health system domains that we previously identified:
    - o <u>Governance</u> includes the policy, legislation, and regulation of cancer care, as well as the involvement of key stakeholders in the development of policies, and the use of health information systems.
    - o <u>Financing</u> includes the affordability of cancer care and the comprehensiveness of insurance coverage.
    - o <u>Resource generation</u> includes health workforce capacity and training, and cancer research and innovation.
    - o <u>Service delivery</u> includes the accessibility, availability, integration, quality, and patient-centeredness of cancer care.
- Introduce the aim of the survey and the aim of the focus group discussion

Discussion on factors related to governance

- Health system level factors are the subdomains of the four overarching. Indicative measures are specific measures that can be used to assess the performance of the health system level factors.
- Discuss the subdomains of governance:
    - o <u>Policy and vision on cancer care</u> entails the availability of guidelines, principles, and directives formulated by governmental or organisational bodies to guide decision-making, resource allocation, and actions related to cancer care.
    - o <u>Legislation and regulation</u> means the protection of cancer patients from financial hardship associated with the cost of cancer care, including out-of-pocket expenses, as well as access to health insurance coverage and financial assistance programs.
    - o <u>Stakeholder voice</u> is the involvement of key-stakeholders in the development of cancer-related policies.
    - o <u>Health information systems</u> stands for the availability and use of health information systems for cancer care, as well as the integration of electronic health records and decision support tools to support evidence-based cancer care delivery.
- Questions to ask during the discussion: Do participants recognize these factors? Do these factors need refinement? In addition to these factors, are there any other factors that are not currently

listed related to governance? What do participants think of the indicative measures? Do they have additions to this list? Perhaps they have their own experiences to draw on?

- If certain respondents have not voiced their opinion, ask if they would like to respond before we move on to the next domain. It is important that everyone has the opportunity to make their voice heard.

Discussion on factors related to financing

- Discuss the subdomains of financing:
    - <u>Affordability of treatment</u> entails the cost of cancer treatments, medications, and supportive care services.
    - <u>Comprehensiveness of cancer coverage</u> means the coverage of various cancer treatments, including chemotherapy, radiation therapy, surgery, and supportive care services such as pain management, psychosocial support, and rehabilitation, by insurance schemes.
- Questions to ask during the discussion: Do participants recognize these factors? Do these factors need refinement? In addition to these factors, are there any other factors that are not currently listed related to financing? What do participants think of the indicative measures? Do they have additions to this list? Perhaps they have their own experiences to draw on?
- If certain respondents have not voiced their opinion, ask if they would like to respond before we move on to the next domain. It is important that everyone has the opportunity to make their voice heard.

Break

- Ask if participants would like to take a short break and agree on the time that everyone will be back to the meeting.

Discussion on factors related to resource generation

- Discuss the subdomains of resource generation:
    - <u>Workforce capacity and training</u> is the availability, competency and ongoing training of healthcare professionals involved in cancer care, including oncologists, nurses, allied health professionals, and primary care providers.
    - <u>Research and innovation</u> stands for the level of investment and engagement in cancer research and innovation to advance scientific knowledge, develop new therapies and technologies, and improve cancer care for patients.
- Questions to ask during the discussion: Do participants recognize these factors? Do these factors need refinement? In addition to these factors, are there any other factors that are not currently listed related to resource generation? What do participants think of the indicative measures? Do they have additions to this list? Perhaps they have their own experiences to draw on?
- If certain respondents have not voiced their opinion, ask if they would like to respond before we move on to the next domain. It is important that everyone has the opportunity to make their voice heard.

Discussion on factors related to service delivery

- Discuss the subdomains of service delivery:
  - <u>Accessibility and timeliness of care</u> entails how easily patients can access cancer care services and the promptness with which they receive necessary treatments and interventions. This includes equitable access to cancer care regardless of socioeconomic status and geographic location.
  - <u>Availability of cancer care and support services</u> is the availability of specialised cancer treatment facilities, as well as advanced diagnostic and therapeutic technologies and the availability of support services.
  - <u>Integration, coordination, and continuity of care</u> stands for the level of coordination among different healthcare providers involved in cancer care, to ensure seamless transitions between different stages of treatment and follow-up care. It also includes the existence of multidisciplinary cancer care teams.
  - <u>Quality of cancer care delivery</u> means adherence to evidence-based guidelines and protocols for cancer care services to ensure the delivery of high-quality, standardised care across different healthcare settings.
  - <u>Patient-centeredness</u> refers to the extent to which cancer care services are tailored to meet the individual needs, preferences, and values of patients, including shared decision-making, patient-centred communication, emotional support, and respect for patients' autonomy and dignity.
- Questions to ask during the discussion: Do participants recognize these factors? Do these factors need refinement? In addition to these factors, are there any other factors that are not currently listed related to service delivery? What do participants think of the indicative measures? Do they have additions to this list? Perhaps they have their own experiences to draw on?
- If certain respondents have not voiced their opinion, ask if they would like to respond before we move on to the next domain. It is important that everyone has the opportunity to make their voice heard.

Reflection and wrap-up

- Summarize the most important inputs that were shared. Ask participants if they agree that these were the most important inputs from this meeting.
- Ask questions to the participants to reflect on the meeting: How did the participants experience the meeting? What do they take away from the meeting? Do they wish any further feedback / follow-up after this meeting?
- Thank the participants and end the focus group discussion.