# EUonQoL

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

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# Preface

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

The authors would like to thank IEO (European Institute of Oncology) and Sporedata for the collaboration within work package 5 of the EUonQoL project. Furthermore, we would like to thank the Stakeholder Board members of the EUonQoL project that provided valuable feedback on the health care system domains that were identified in this report. We also thank the co-researchers that are involved in work package 5, Laura Pinnavaia and Carina Dantas, for their input on the domains and for working with us on the report itself. Finally, we would like to thank the EUonQoL Executive Committee for providing us with valuable feedback on this report.

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## Summary

There is an unacceptable variability in terms of quality of care, and outcomes, including survival and also quality of life of cancer patients, within and between countries in Europe. The international differences in care quality and outcomes suggest wide variations in the performance of national health care systems in which cancer patients and survivors are being treated (macrolevel data). It is, therefore, important to measure the health care system influence on quality of life through specific indicators. By measuring this, it can become clear what can be done on a policy level to increase the quality of life of cancer patients. In combination with meso- and microlevel data, this can be further investigated and explored. These identified indicators will be used within the EUonQoL project, and they might also demonstrate their significance in forthcoming research endeavours.

*Aim of this report*

The aim of the research underlying this report is to identify macro-level health care system determinants that are potentially associated with Quality of Life (QoL) outcomes of cancer patients across European countries and cultures. In this report we describe domains of health care system determinants identified through literature and experts that may explain differences between countries in QoL outcomes among cancer patients.

*What is known about the domains of health care systems in relation to QoL in patients*

In this report we identify and distinguish four interrelated domains with, in total, 13 sub-domains that make up the structure of the health care system. These domains include (1) governance (e.g., policy, legislation), (2) resource generation (e.g., availability, distribution and education of the workforce), (3) financing (e.g. the way revenues are raised), and (4) service delivery (e.g., service integration). Our rapid literature review on the domains of health care system determinants in relation to QoL in cancer patients resulted in 30 studies that were included in this report. The domain on which the most articles reported, was financing (n=15), followed by service delivery (n=14). Only 1 article reported on the domain of resource generation, and no studies reported on the domain of governance. Our main finding is that, to date, knowledge about the relation between health care system determinants and QoL in cancer patients is sparse, as the association between many of the sub-domains and QoL in cancer patients have never been investigated. Although not all healthcare system (sub-)domains will be equally relevant, there are clear gaps, such as a lack of studies on health workforce in relation to QoL in cancer patients. Another prominent gap in the literature is that no studies investigated these systemic features using data from different countries, to make a comparison in QoL outcomes between countries.

*Conclusion*

Based on our current research, it remains uncertain which domains and sub-domains of healthcare systems are truly important in relation to the QoL outcomes of European cancer patients. The next step within the EUonQoL project is to identify which indicators and data sources can be used to conduct a deeper dive into the importance of health care system determinants for the QoL in cancer patients.

# 1. Introduction

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

## 1.1 Aim of the report

The aim of the research underlying this report is to identify macro-level health care system determinants that are potentially associated with Quality of Life (QoL) outcomes of cancer patients across countries and cultures. In this report we describe domains of health care system determinants identified through literature and experts that may explain differences between countries in QoL outcomes among cancer patients. In chapter 2, we explain what is meant by domains of health care system determinants, and why it is important to study these domains in relation to cancer specific care and its outcomes (including QoL). In chapter 3, we summarize common frameworks for assessing and describing health care system performances which were the starting point of our research. In chapter 4, we provide the results of a literature review on studies of health care system determinants in relation to QoL outcomes in cancer patients and survivors.

The content of this report describes the first step in our work focusing on the importance of health care system determinants for QoL. We aimed to find out what is already known and what has already been studied in this research area, and to determine what are possible gaps in knowledge and opportunities for future research. The report forms the basis for our planned research within the EUonQoL project, working towards the identification of available indicators and data sources on the health care system domains. This will ensure that the domains identified in this report can be measured and quantified and, as such, included in analyses for country comparisons as explanatory variables. This will be further explained in section 1.2.

## 1.2 The EUonQoL project

The EUonQoL consortium was founded to develop, validate, and disseminate the European Oncology Quality of Life toolkit (EUonQoL-Kit), a unified tool for the assessment of QoL among European cancer patients. The EUonQoL project aims to review existing QoL scales and to develop new metrics by harnessing the strengths and overcoming the limitations of previous tools. The EUonQoL-Kit will be a new digital system for QoL self-assessment by patients and their caregivers, available in the languages of the 27 EU countries and developed from the patient’s perspective. The overall project is based on participatory research principles, through the involvement of a representative panel of patients and public members throughout all project phases.

The EUonQoL-Kit and the data that it will collect can be used in future efforts by, for example, health policy makers, within (EU) cancer policy initiatives, or within cancer research projects - in order to evaluate QoL outcomes on an EU health policy level. A strength of the toolkit is that it will be unified, so it can be applied in all EU countries. This allows for the collection of country-comparative data. When comparing results between countries, it is important to take certain country-level determinants into account that may potentially explain differences in QoL outcomes between countries. The EUonQoL project consists of 10 work packages in total, of which this current report is written in the context of work package 5. This work package is focused on cross-cultural determinants of QoL and the linguistic and cultural adaptation of the EUonQoL-Kit. The EUonQoL-Kit will allow country comparisons of QoL data among EU member states, as well as the identification of patient characteristics associated with better or worse QoL outcomes. It is intended that member states use these comparisons to inform improvement of their health care systems. This requires that key actors in EU member states not only know how their country results compare with other countries, but also why comparisons are more or less favourable for their country. The work package leader of WP5 is IEO (European Institute of Oncology IRCCS), in good collaboration with participating partners Sporedata and Nivel (Netherlands Institute for Health Services Research). Further description of the project, its work packages and the participating organisations can be found on the EUonQoL website: http://www.euonqol.eu/

## 2. Background

In this chapter we describe the relevant background information for our research. We explain what is meant by domains of health care system determinants, and why it is important to study these domains in relation to cancer care and its outcomes.

*Variation in cancer care and outcomes across European countries*

Cancer is the second cause of death and the first cause of suffering for patients and caregivers in Europe, as well as having an enormous financial impact on health services and individuals. There were 2.7 million new cases of cancer and 1.3 million deaths in 2020, which is expected to increase with about 25% by 2040 [1]. Additionally, there is an unacceptable variability in terms of quality of care, and outcomes, including survival and also QoL measures, within and between countries in Europe [2]. QoL can be interpreted as satisfaction and happiness measured as the achievement of aspirations and/or the realization of individual expectations. In this definition, the perception that an individual has of one's health is only one of the many possible concepts/determinants of QoL. In the health care setting, a definition of health-related QoL (HR-QoL) has been proposed to narrow the field of interest and subsequent evaluations [2].

International differences in care quality and outcomes suggest wide variations in the performance of national health care systems in which cancer patients and survivors are being treated [3]. For example, in 2019, mortality rates from cancer averaged 191 deaths per 100,000 people across OECD countries. However, mortality rates were high in Hungary and the Slovak Republic (above 250) and low in Finland and Luxembourg (fewer than 170) [4].

*National health care systems defined*

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 organizations with the primary intent of improving and maintaining health [5-7]. In this report, we use a more restricted definition of national health care systems in line with the WHO 2000 definition [6, 7]. Outside of the health care system, there are also other factors that are of importance to QoL in cancer patients. These can be individual factors, such as physical, psychological and social determinants, but also (inter)national-level factors such as health education and communication, labour, housing, environment, agriculture, industry and social services. However, for this current study, we focused solely on health care system determinants. However, within the broader EUonQoL study, we also evaluate other determinants.

Further, our focus is narrowed down by the level at which we look at the system, i.e. the national (macro) level domains of a system, such as the national governance structure, rather than institutional (meso) level characteristics, such as the scope of services delivered in a hospital, or service provision (micro) level determinants, such as the consultations taking place in a doctor's office. Specific examples of these macro level determinants are further elucidated in chapter 3.

*Importance of measurement for policy*

Macrolevel health care system determinants can influence on a patients' QoL, and can also be expected to exert influence through microlevel mechanisms that serve as mediators. For example, the available financing for physicians will likely impact the availability of personnel and therefore the timely access to care which can, in turn, contribute to their QoL. By measuring the health care system influence on QoL through specific indicators this, it could become clear what can be done on a policy level to increase the QoL of (cancer) patients. In combination with meso- and microlevel data, relationships at the different levels can be further investigated and explored. Specific health care system indicators will be identified and used within the EUonQoL project, but may also prove to be relevant for future studies.

# 3. Health care system performance frameworks

This chapter serves as a first step in this report's objective: "to identify and understand the domains of health care system determinants associated with QoL in cancer patients and survivors". Our aim is to comprehensively explore and comprehend the various domains that may influence QoL within health care systems. A domain encompasses a broad area of influence or aspect within health systems that can significantly impact a patient's QoL. The purpose of this first step is to understand which domains are fundamental in comprehending health care system performance on health outcomes, including patients' QoL.

In this chapter we provide an initial framework based on existing literature on health system frameworks and domains in general and cancer care systems specifically. The initial framework is foundational in guiding our literature study (Chapter 4). The framework enables us to categorize and define the essential domains that have been studied in relation to cancer care systems and QoL outcomes for patients and survivors. The initial framework will be comprehensive covering all potential domains. To ensure a comprehensive understanding of potential domains impacting QoL, we will include all potentially relevant domains and sub-domains in our initial framework. In the next phase of this project, we will gather stakeholder input on which specific indicators (measure or metric) are expected to be most important when assessing in relation to QoL in cancer patients and survivors.

*Health System Performance Assessment framework*

In the literature surrounding health care system performance evaluation, various frameworks including macrolevel characteristics exist to measure performance. A frequently cited example is the Health

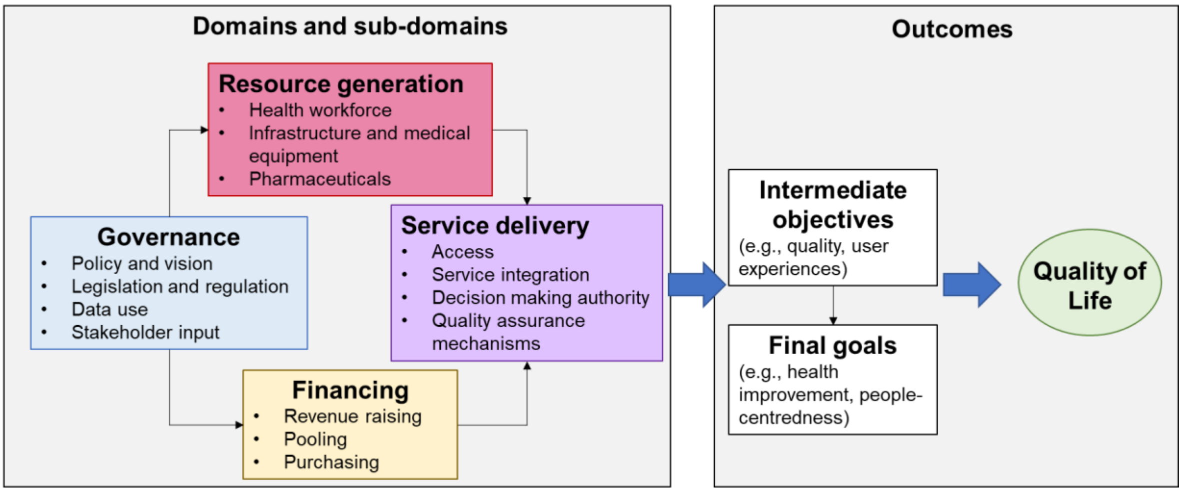
Systems Performance Framework established by the World Health Organization (WHO) which distinguishes functions of the system (e.g., financing, delivery of services) and objectives (e.g., health) [6].

In a recent review by Papnicolas et al. (2022), a comprehensive examination of the existing frameworks was conducted, aiming to identify areas of consensus concerning health system functions, objectives, and ultimate goals [7]. Based on this research Papnicolas and colleagues outlined a comprehensive Health Systems Performance Assessment (HSPA) framework, which we have selected as the foundational model for our literature search on the association between health care system characteristics and QoL in cancer patients. In the subsequent section, we present an adapted, simplified version of this model, tailored to our specific objective of pinpointing systemic features of health care systems which may be associated with QoL in cancer patients as described in the next section.

*Adapted framework*

Figure 1 shows the version of the HSPA framework as adapted and simplified for the EUonQoL project. We adapted the framework by adding the sub-domain ‘accessibility’ to the domain of service delivery, whereas the original HSPA model considers access an objective or outcome. In the literature, access to health services has been conceptualized in numerous ways. However, in the HSPA model, it is also recognized that the population must first overcome the barriers to access the system before any measure of quality as an is possible. As several aspects of access can be seen as systemic aspects of service delivery, we added this sub-domain to the service delivery domain. Further, we simplified the model by incorporating only limited descriptions of intermediate objectives and goals, which are not the focus of the current study.

Figure 1: Simplified and adapted version of the HSPA framework (Papnicolas et al. (2022))



The figure depicts that domains of the health care system (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 intermediate objectives are a necessary step on the pathway to achieving the final goals of the health care system. The health system goals include overall population level outcomes such as health improvement and can point to the performance of a system. The original HSPA model does not include QoL as an outcome, but QoL of patients can be expected to be affected by the health care system determinants through the mediating factors. Evidently, QoL in cancer patients is not only impacted by the health care systems outcomes such as health improvement and responsiveness to their needs. There are many socio-economic and other factors that affect QoL, and that are also interrelated with the outcomes of the care system. E.g., social determinants of health also impact access, quality, and outcomes.

*Domains and sub-domains*

Based on the HSPA model, we distinguish four interrelated domains with, in total, 13 sub-domains that make up the structure of the health care system. The first domain, governance, is made up of the policy and (strategic) vision and legislation and regulations related to the health care system, the data that is used to improve health service delivery and the engagement of stakeholders in health policy and decision making (stakeholder voice). Governance is related to the other domains and also overlaps in some cases. The second domain, resource generation, concerns the availability, distribution and education of the workforce, pharmaceuticals, equipment and infrastructure. Third, financing incorporates the way revenues are raised (e.g., out of pocket, insurance), pooled (e.g., central or decentralized government), and purchased (e.g., prices for types of care). Finally, the systemic features of service delivery include decision-making authority, and service integration and quality assurance mechanisms, which are all associated with to how the systems are governed. We also added access as a sub-domain of service delivery as several aspects of access to treatments and consultations can be seen as systemic aspects of service delivery (e.g., unmet needs within the population). It is important to note that many sub-domains can be analyzed at the macro-, meso- and microlevel. For example, accessibility can relate to universal coverage at the macrolevel but also to the professional's ability to adapt to individual needs (meso-level) individually perceived access (microlevel). Within the current study, we focus on the systematic macro-level characteristics of the health care systems, which can be assessed by using national level data.

## 4. Results rapid literature review

In order to get an overview of what is already known regarding the domains of health care system determinants (described in chapter 3) in relation to QoL in cancer patients a rapid literature review was performed using PubMed. We included studies that focus on the domains and sub-domains of health care systems in relation to QoL in cancer patients. Although we eventually aim to identify indicators of health care system domains that can be measured at the country level, for the purpose of the literature review we also included studies that evaluated the macrolevel domains at meso- or microlevel.

A description of the methods that were used for the rapid review can be found in chapter 6 of this report. Our rapid review resulted in 30 studies that were finally included in this study. Almost all articles were published in the last 15 years, except for one study that was published over 20 years ago (in 2000). About one-third of the selected articles were reviews, the remaining studies were original articles, for example cross-sectional studies and randomized controlled trials. Of these original studies, only 4 were performed in Europe (The Netherlands, Ireland, and the U.K.) while the majority was performed in the U.S.A. and Asia. None of the studies that we found included cross-country comparisons of health care system determinants. When reading the full-text articles, a division was made on which health care system domain the article reported. The domain on which the most articles reported, was financing (n=15), followed by service delivery (n=14). Only 1 article reported on the domain of resource generation, and no studies reported on the domain of governance.

## 4.1 Resource generation

In the only study that reported on resource generation in relation to QoL in cancer patients, the impact of hospital and surgeon volume on outcomes following oesophageal cancer surgery were described (see table 1). Outcomes described in this review included health-related QoL. The studies that were identified in this review found a non-significantly improved QoL among patients operated on at high-volume hospitals compared with low-volume hospitals. Additionally, it was speculated that decreasing the risk for post-operative morbidity by centralization should also increase the chance of improved QoL [8].

Table *1*: Results on health care system domain ‘resource generation’

| **Authors** | **Study type** | **Country** | **Health care system sub-domain** | **Results on QoL** |
|---|---|---|---|---|
| Rouvelas & Lagergren [8] | Review | N/A | Infrastructure and medical equipment | • QoL improved non-significantly among patients operated on at high-volume hospitals compared with low-volume hospitals. |

## 4.2 Financing

15 studies were identified on the domain of financing in relation to QoL in cancer patients (see table 2), and specifically on characteristics such as financial toxicity, financial burden, financial hardship, or economic characteristics in general. More broadly speaking, financial characteristics were also described in the context of social determinants and socio-demographic features. Interestingly, in the studies that reported a definition of financial toxicity, there does not seem to be an agreement on the meaning of the term. Several studies defined financial toxicity as the distress that is experienced by patients with cancer and their families, resulting from the costs of cancer care and treatment [9-12]. While other studies used a broader definition of financial toxicity, including both objective and subjective dimensions, such as actual costs resulting from health services use, reduced income, and impact on daily living from the changed financial situation due to cancer [13, 14].

All studies that reported on the effect of financial characteristics on QoL, described a significant negative impact of objective and/or subjective financial toxicity on QoL. Generally speaking, it was reported by many articles that patients with financial toxicity (including financial hardship, financial worry, financial burden, financial difficulty) had worse QoL outcomes on several domains, including physical, functional, and psychosocial [9-13, 15-19]. One study that differentiated between objective financial toxicity (e.g., actual health care costs and health care cost to income ratio) and subjective financial toxicity (e.g., perceived impact on financial well-being) concluded that both patients facing objective and subjective financial toxicity were more likely to have low QoL outcomes [20]. Additionally, it was described that subjective indicators of financial toxicity have a stronger effect on QoL than objective indicators [10]. Several studies also reported more specific (individual) financial characteristics, such as being retired, not having paid work, not being able to do paid work, low/reduced household income, not having health insurance, increased out-of-pocket costs, avoiding care because of costs, and health care costs exceeding annual household income – all of which have a significant negative impact on an individuals' QoL [10, 14-16, 19, 21]. One study reported that (not) having health insurance was *not* significantly associated with QoL outcomes [21]. On a health care system level, it was reported twice that the total per capita health expenditures factor significantly impacted QoL outcomes – with patients from countries with low per capita health expenditures having significantly lower levels of QoL [22, 23].

*Table 2: Results on health care system domain 'financing'*

| **Authors** | **Study type** | **Country** | **Health care system sub-domain** | **Results on QoL** |
|---|---|---|---|---|
| Casilla-Lennon et al. [9] | Cross-sectional study | U.S.A. | Revenue raising, pooling, purchasing | • Patient-Reported Outcomes Measurement Information System (PROMIS) questionnaire: patients with financial toxicity (FT) had worse physical and mental health scores compared to those without FT.<br>• Functional Assessment of Cancer Therapy – General Population (FACT-GP) questionnaire: patients with FT reported significantly lower general QoL as well as physical well-being and lower functional well-being. |
| Nedjat-Haiem et al. [15] | Cross-sectional study | U.S.A. | Revenue raising, pooling, purchasing | • Being retired, having financial hardship, and experiencing financial worry were all associated with lower total scores on the Functional Assessment of Cancer Therapy – |

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| | | | | General (FACT-G) questionnaire.<br>• Being retired and financial hardship were negatively associated with physical well-being subscale scores.<br>• Financial worry was negatively associated with social/family well-being subscale scores.<br>• Being retired, financial hardship, and financial worry were all negatively associated with functional well-being subscale scores. |
| Ting et al. [20] | Cross-sectional survey | Malaysia | Revenue raising, pooling, purchasing | • Respondents facing objective FT were more likely to have low health-realted QoL (HRQoL) than those without objective FT.<br>• Respondents facing average to high subjective FT were more likely to have low HRQoL than those with low subjective FT. |
| Kimman et al. [16] | Cross-sectional survey | Southeast Asia | Revenue raising, pooling, purchasing | • There were significant associations between household income and HRQoL outcomes (with lower incomes reporting lower HRQoL), but only for physical and emotional function.<br>• Differences in HRQoL between patients with and without health insurance were only |

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| | | | | statistically significant for physical function.<br>• Patients who had experienced economic hardship in the year before their cancer diagnosis reported clinically meaningful lower scores on global health, physical function, emotional function, and health state as reflected in an EuroQoL-5D (EQ-5D) value.<br>• The differences in HRQoL scores between patients with or without paid work were statistically significant for all HRQoL outcomes. |
| Mady et al. [17] | Cross-sectional survey | U.S.A. | Revenue raising, pooling, purchasing | • Comprehensive Score for financial Toxicity (COST) questionnaire results were significantly associated with HRQoL. Social-emotional QoL demonstrated the greatest contribution to the significant overall effect observed.<br>• However, Functional Difficulties Questionnaire (FDQ) results were not significantly associated with HRQoL. |
| Burse et al. [21] | National telephone survey | U.S.A. | Revenue raising, purchasing | • Cancer survivors who did not avoid care because of costs were less likely to experience poor mental health and |

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| | | | | poor physical health than cancer survivors who avoided care because of costs.<br>• Health care coverage did not remain significantly associated with any of the HRQoL outcomes. |
| Zafar et al. [18] | Prospective cohort study | U.S.A. | Revenue raising, pooling, purchasing | • Greater financial burden was associated with poorer QoL. |
| Udayakumar et al. [10] | Review | Low- and middle-income countries | Revenue raising, pooling, purchasing | • Patients with perceived severe financial difficulty had lower QoL scores than patients with perceived moderate financial difficulty.<br>• Subjective indicators of financial toxicity had a stronger effect on QoL than objective indicators.<br>• Patients with no out-of-pocket costs had higher scores of HRQoL as compared to patients with high out-of-pocket costs. |
| Popovic et al. [22] | Review | N/A | Revenue raising, pooling, purchasing | • The total per capita health expenditures predictor was statistically significant for all FACT-G total and subscale scores except physical well-being. |
| Jiang et al. [13] | Review | N/A | Revenue raising, pooling, purchasing | • Cross-sectional studies showed that the HRQoL of cancer patients with higher FT levels was significantly lower than |

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| | | | | that of patients with lower FT.<br>• Longitudinal studies showed that patients who reported FT tended to have lower HRQoL scores.<br>• Meta-analyses showed a moderate correlation between FT and HRQoL. |
| Fitch & Longo [14] | Review | Canada | Revenue raising | • Participants of an interview study experienced reduced income, increased out-of-pocket costs following their diagnosis, and none were able to work during their treatment interval. Patients described profound impacts on the social, psychological, and spiritual domains of QoL because of the financial challenges. |
| de la Cruz & Delgado-Guay [11] | Review | N/A | Revenue raising, pooling, purchasing | • FT is inversely related to QoL, with reporting financial problems four times less likely to report good QoL.<br>• The impact of FT on QoL is multifactorial, including having to deal with distribution of limited financial resources for treatment and other financial obligations and basic needs, adherence to recommended treatment and |

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| | | | | management of symptoms, and concerns about bankruptcy. |
| Liang et al. [12] | Review | N/A | Revenue raising, pooling, purchasing | - Higher levels of FT are consistently correlated with worse HRQoL in a variety of domains, including mental health, fatigue, sleep, pain, cognitive functioning, and overall health. |
| Chen et al. [19] | Survey | China | Revenue raising, pooling, purchasing | - Patients whose health care costs exceeded their annual household income scored lower on the Functional Assessment of Cancer Therapy – Lung (FACT-L) questionnaire, specifically on emotional and functional well-being<br>- Patients with moderate and severe financial difficulty scored lower for overall HRQoL, specifically on all different aspects of well-being.<br>- HRQoL did not differ across levels of health care costs. |
| Popovic et al. [23] | Review | N/A | Revenue raising, pooling, purchasing | - It was found that patients from countries with low per capita health expenditures had significantly lower levels of physical well-being, social/family well-being and relationship with doctors. |

## 4.3 Service delivery

14 studies reported on service delivery (see table 3). Studies within this domain reported on the process or content of service delivery, such as patient-centred communication or advanced nursing practice interventions. General aspects of service delivery that were found to have a positive impact on QoL, included patient-centred communication, patient involvement, provision of information, and health care provider support [23-26]. More specific aspects of service delivery that were described to have a positive impact on QoL outcomes, were having a cancer care coordinator and an early integration of outpatient and home palliative care [27, 28]. There were also several specific aspects of service delivery studied that did not prove to have an effect on QoL outcomes, such as: advanced practice nursing interventions, weekly symptom telemonitoring with automated reporting of problematic symptoms to the clinical team, nurse-led follow-up, and telerehabilitation [29-32]. The studies that reported on access to service delivery described that unmet supportive care needs on domains such as physical, psychological, and health system and information needs, negatively impacted QoL outcomes [33-37].

*Table 3: Results on health care domain 'service delivery'*

| **Authors** | **Study type** | **Country** | **Health care system sub-domain** | **Results on QoL** |
|---|---|---|---|---|
| Pozzar et al. [24] | Cross-sectional descriptive survey | U.S.A. | Service integration | • Higher FACT-G scores were associated with higher Patient-Centered Communication in Cancer Care (PCC-Ca-36) questionnaire total scores. FACT-G subscales that were associated with higher PCC-Ca-36 scores, are: social/family well-being, emotional well-being and functional well-being. Physical well-being was not associated with higher PCC-Ca-36 scores. |
| Dunn et al. [25] | Cross-sectional study | Australia | Service integration | • Communication and patient involvement factor and provision of information and services factor shared significant positive associations with QoL. Both factors had a |

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| | | | | higher correlation with psychosocial QoL than with physical QoL. |
| Drury et al. [35] | Descriptive qualitative study | Ireland | Service integration | • Cancer survivors' narratives focused on four specific aspects of health care which impacted upon QoL, including relationships with health care providers, power dynamics in health care delivery, unmet information and supportive care needs, and navigation of health care systems. |
| Del Vecchio et al. [27] | Population-based survey | U.S.A. | Service integration | • Although not reaching statistical significance, those who perceived having a cancer-care coordinator appeared to have slightly higher physical HRQoL scores. |
| Ritz et al. [29] | Randomized clinical trial | U.S.A. | Service integration | • Intervention and control groups did not differ significantly on Functional Assessment of Cancer Therapy – Breast (FACT-B) questionnaire scores or on any of the subscales after adjustment for baseline, age, and extent of disease. |
| Yount et al. [31] | Randomized controlled trial | U.S.A. | Service integration | • There were no differences between groups in FACT-G subscales or total score at any time point, although in the combined sample, physical well-being, |

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| | | | | functional well-being and FACT-G total scores declined significantly over the 12 weeks. |
| Uitdehaag et al. [30] | Randomized study | The Netherlands | Service integration | • The difference between the median EQ-5D value score in the nurse-led follow-up group and the conventional medical follow-up group was not significant at both time points.<br>• Results from the EORTC QLG Core Questionnaire (EORTC QLQ-C30) show that patients in the conventional medical follow-up group were more often depressed after 1,5 months of follow-up, and in these patients loss of appetite was less common after 4 months of follow-up. |
| Sritan [26] | Review | Thailand | Service integration | • Quantitative studies showed a positive relationship between health care provider support and QoL. |
| Lee et al. [32] | Review | N/A | Service integration | • There was no significant difference in QoL between the intervention and control groups of patients with cancer. |
| Davis et al. [28] | Review | N/A | Service integration | • Advantages included improved patient QoL, reduced aggressive care at the end of life, increased advanced |

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| | | | | directives, reduced hospital length of stay and hospitalizations, improved caregiver burden and better maintenance of caregiver QoL and reduction in the medical cost of care as well as patient and family satisfaction.<br>• Yet there were also randomized controlled trials that demonstrated no improved QoL, and resource utilisation and costs are not different from usual care. |
| Jie et al. [33] | Cross-sectional study | China | Access | • SCN domains negatively correlate with QoL domains. Negative correlations are found in the overall QoL and physical/daily living, psychosocial, sexual, patient care and support, and health systems and information domains. |
| Jansen et al. [34] | Cross-sectional study | The Netherlands | Access | • Patients with a lower HRQoL reported significantly more often unmet needs on all supportive care needs domains and the overall domain, compared with patients with a higher (better) HRQoL. |
| Sodergren et al. [36] | Multicentre prospective cohort study | U.K. | Access | • HRQoL was predictive of unmet needs across all SCNS domains. Physical and daily living needs had the largest association with global health/QoL. Unmet psychological need and health system and information also had |

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| | | | | large associations with global health/QoL. |
| Park et al. [37] | Questionnaires | Korea | Access | • Having a higher level of unmet needs in the psychological needs domain, and in the physical and daily living needs domain, and a lower level of unmet needs in the sexuality domain were significantly associated with poorer quality of life. |

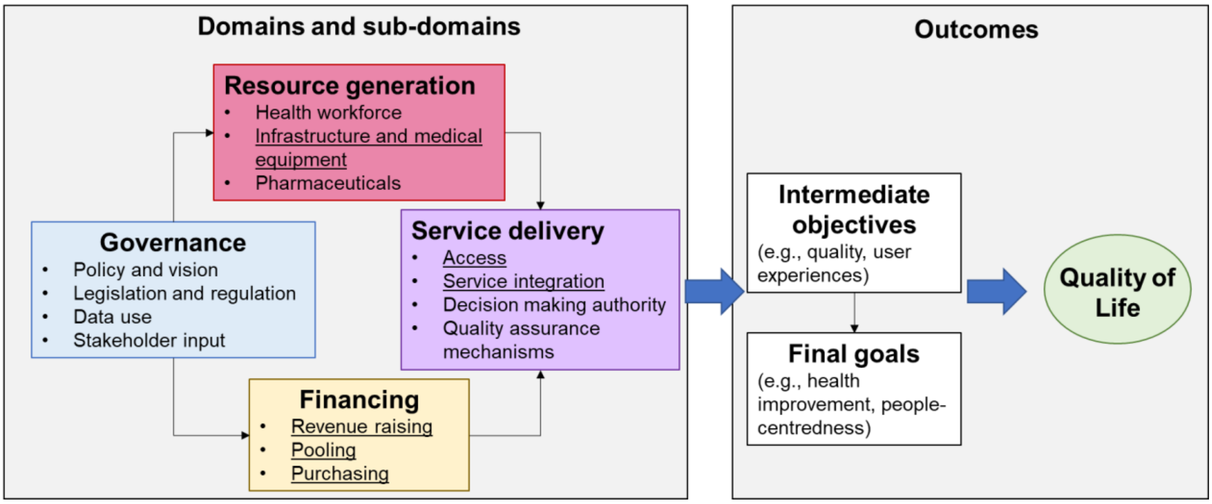
## 5. Discussion

The aim of this report was to describe the first step of our research to identify health care system determinants that are potentially associated with QoL outcomes of cancer patients across countries and cultures. We first described domains and sub-domains of health care systems that were identified through the assessment of existing health care system performance frameworks. Next, we outlined the results of our rapid literature review which provided us with insight in what is currently known about health care system determinants in relation to QoL in cancer patients.

Most results were found on specific domains, such as the domain of financing, followed by 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 several studies reported a significant negative impact of financial toxicity on QoL of cancer patients, two studies reported that cancer patients from countries with low per capita health expenditures had significantly lower QoL, and it was reported by two studies that having a higher level of unmet needs resulted in significantly lower QoL in cancer patients.

Our main finding is, however, that to date, the relation between health care system determinants and QoL in cancer patients remains understudied. In our literature review, we did not identify studies on the impact on QoL in cancer patients regarding all health care system domains and sub-domains identified in the framework. For example, no studies focused on health workforce in relation to QoL in cancer patients. Figure 2 indicates in underlined text which sub-domains were identified in our literature review. It also reveals some evident gaps in the available published literature on health care system (sub-)domains that are potentially associated with QoL outcomes of cancer patients. Although not all healthcare system (sub)domains will be equally relevant, it is plausible that some specific domains are important. As a next step of this study, we aim to identify indicators that are potentially relevant. Specifically, we will ask an expert panel to rank the importance of the subdomains and specific indicators.

Figure 2: Literature review embedded in the adapted version of the HSPA framework (Papnicolas et al. (2022))



Another prominent gap in the literature is that no studies investigated these systemic features using data from different countries, to make a comparison in QoL outcomes between countries. Finally, most research was conducted in North-America and Asia, and not in Europe. We can therefore not state with certainty that the (sub-)domains that were identified might also be associated with QoL outcomes of European cancer patients.

Thus, in future research efforts it would be important to investigate and identify the health care system domains that potentially impact QoL outcomes of European cancer patients both in more breadth and more depth, and to validate and compare the domains on a cross-country and pan-European level. The high variation in organization of health care systems across countries make studies on relationships between health care system determinants and outcomes, such as QoL of cancer patients, possible and valuable. From the research perspective, there are various data sources available, such as the OECD data, that provide detailson for example health expenditures, health services use and health workforce within different countries, that can be used for such comparisons and analyses across countries. Results of studies on health care system determinants and domains, can provide policy makers with input on areas of focus to improve QoL outcomes of their populations.

The next step within the EUonQoL project is to identify which indicators and data sources can be used to conduct a deeper dive into the importance of health care system determinants for the QoL in cancer patients. Experts will also be asked to rank the expected importance of the various subdomains and indicators. As the EUonQoL project will systematically collect new data on QoL outcomes, the project has the potential to provide a major contribution filling the large gap in the current literature by analyzing the combined data sources.

## 5.1 Conclusion

Based on our current research, we cannot know yet which health care system determinants are actually important in relation to the QoL outcomes of European cancer patients. This underlines the importance of including such data about health care system determinants in the EUonQoL project, but also in other studies.

## 6. Methods rapid literature review

To gain an understanding of which health care system determinants are associated with QoL outcomes in people with cancer, a rapid literature review was performed. Broadly speaking, we followed the steps for systematic reviews as described by Tsafnat et al. [38], but narrowed this down by following the suggestions for rapid reviews as described by Ganann et al. [39] to speed up the process.

A search strategy was devised based on an existing search string used for another (related) systematic review within the EuonQoL project. This systematic review focuses on psychosocial and individual factors potentially impacting on QoL and therefore highlights other types of determinants. The search string was iteratively refined based on a search of existing key words, search words and MeSH terms. The search strategy was discussed multiple times and ultimately agreed upon by two researchers (ME and WS). Articles were regarded eligible for inclusion if they were written in the English or Dutch language; if the research subjects were adult cancer patients; if QoL was measured or evaluated; and if health care system characteristics were studied as an explanatory variable of QoL. Articles were excluded if they were protocol papers; if the subjects were not adults and/or not people with cancer; and if there was no evaluation of QoL or health care system characteristics.

In May 2023, the following search was done in Pubmed leading to 436 results (including duplicates):

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

Search results were not narrowed down by selecting on publication year, article type (except for protocol articles) and country setting due to the relatively low number of results. Titles and abstracts were screened by two researchers (ME and WS). After scanning all titles and abstracts, the researchers discussed their results, resolved conflicting inclusion or exclusion decisions, and refined the inclusion and exclusion criteria. All included articles were screened again by one researcher (ME) to confirm that they complied with the refined inclusion and exclusion criteria. This resulted in 58 articles that were included in the full-text review. After obtaining all full-text articles, these articles were screened by one researcher (ME) by scanning the methodology and results sections. The 33 articles that were included for data extraction were all read in full-text by one researcher (ME) and the relevant data was extracted using a pre-defined data extraction form. The variables that were collected using this data extraction form, included: author(s), publication year, study type, country, study population, inclusion criteria, observations (n), data collection period, health care system characteristic studied, outcome measure(s) related to QoL, results on QoL. During data extraction, 3 articles turned out to be not appropriate for our study after all, and were excluded. This leads to 30 studies that were ultimately included in our results. The flow chart of our selection process can be found in figure 3.

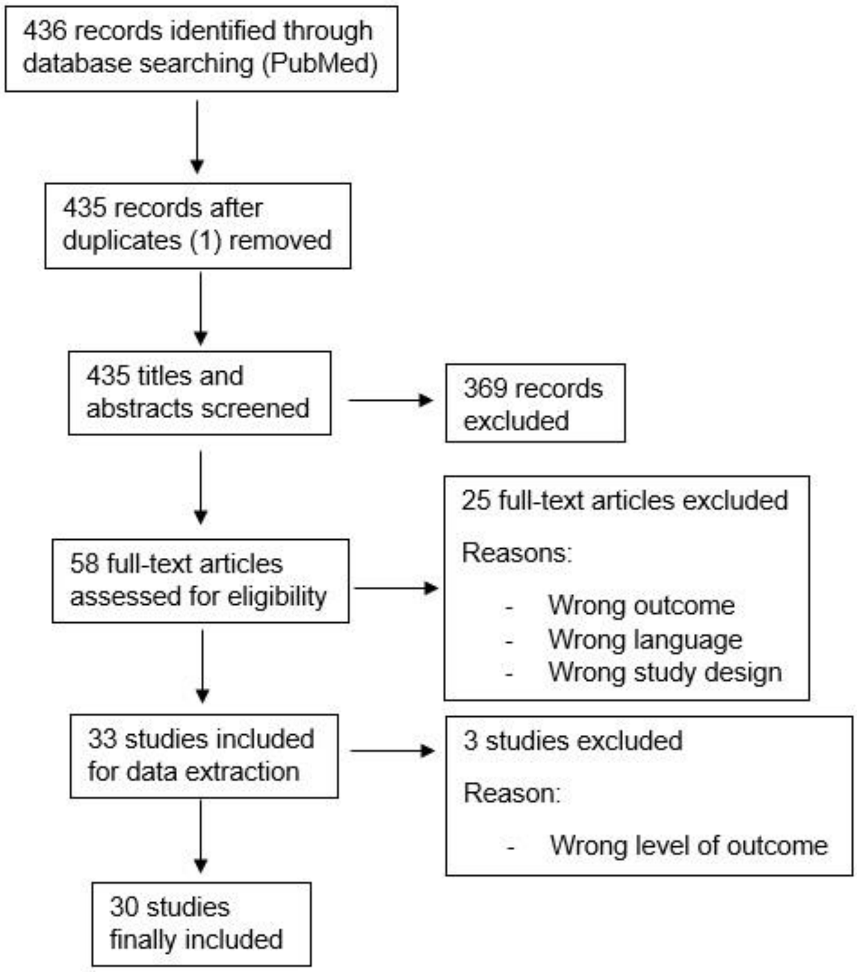


*Figure 3: Flow chart rapid literature review*

During the course of our literature review, we made some decisions to speed up the process – making this study a rapid review. First of all, we decided to only run our search in PubMed and not in other databases. Secondly, after the screening of titles and abstracts, all following screening and selection was done by only one researcher. Additionally, there was no snowball search performed to find additional studies and no re-check of the literature took place after the selection process. Furthermore, we decided to include review articles instead of the underlying original articles. And also no quality appraisal took place of the studies that were included.

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