Addressing cancer-related nutritional misinformation on social media through the strengthening of online patient platforms:

A value-sensitive approach

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Addressing cancer-related nutritional misinformation on social media through the strengthening of online patient platforms: a value-sensitive approach

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Preface

This thesis marks the end of my time at TU Delft. When I started my Bachelor's in Systems Engineering, Policy Analysis and Management, I would never have expected to finish my master's degree by writing a thesis on cancer-related misinformation. Yet over the past year I unexpectedly came in contact with this devastating disease. Learning more about it through this research has, in its own way, helped me to cope with that.

Writing this thesis has taught me it is important to make choices. You can't have it all. Though it was challenging at times, especially using a method and topic I was unfamiliar with in the beginning, has taught me how to deal with uncertainty and appreciate the value of exploratory research methods.

I would like to sincerely thank my supervisors, Roel and Lavinia, for their dedication and guidance throughout this project. Thank you for inspiring me and for giving me the support I needed along the way.

Finally, I would like to express my heartfelt gratitude to my dear roommates, friends and boyfriend for their unconditional support. And lastly to my mom, who is the strongest woman I know.

Executive summary

Misinformation about nutrition during cancer is a prominent form of online health misinformation. As more cancer patients turn to the internet for information about their diagnosis, they can be exposed to content that promotes exaggerated claims about specific diets, supplements, or “superfoods” that supposedly cure cancer or significantly improve outcomes. Commercial social media platforms such as Facebook, Instagram, and YouTube play an important role in the spread of such claims, as their engagement-driven infrastructures amplify misleading or inaccurate claims over evidence-based information.

Since cancer patients are a particularly vulnerable population with low nutritional literacy, combined with the evolving nature of scientific evidence regarding cancer and nutrition, inaccurate claims about diets during and after cancer can cause concrete harm. For example, patients may delay conventional treatment or experience confusion and anxiety due to conflicting advice encountered online, which can ultimately weaken their trust in oncology healthcare professionals.

In search of possible ways to address this problem, this thesis focuses on strengthening the dutch online patient platform kanker.nl. This website provides evidence-based information about cancer and nutrition while also enabling interaction through discussion groups where patients can exchange experiences and discuss nutritional topics. Although kanker.nl operates with a clearly different mission and value orientation, it exists within the same online information environment as commercial social media platforms and is therefore affected by the way in which cancer patients navigate between these two platform types to seek and discuss nutritional topics.

However, because these two platform types have not been systematically compared within a single systems perspective, it remains unclear what drives users to engage with cancer-related nutritional content online and which underlying values shape this engagement. As a result, it is also unclear how kanker.nl could position itself in relation to commercial social media platforms to mitigate the spread of nutrition-related misinformation.

To address this gap, this thesis applies the value-sensitive design methodology to systematically identify and analyze the values of users, kanker.nl, and commercial social media platforms in the context of cancer-related nutrition communication. These insights are used to formulate recommendations aimed at policy, organization, and platform design of kanker.nl. The central research question guiding this study is:

“How can public healthcare organizations strengthen kanker.nl as a public social media platform through policy, organization and design in a way that improves nutritional literacy, aligns with user values and mitigates the risks of nutrition-related misinformation?”

To answer this research question, the study integrates conceptual, empirical, and technical investigations to identify the values that shape the system of online cancer nutrition communication. Values are conceptualized according to their scale as personal, cultural, and infrastructural, based on the framework proposed by Hallinan et al. (2022). To elicit personal user

values, this study employs an innovative empirical data source: a qualitative content analysis of user-generated comments and discussions on Facebook, YouTube, Instagram, and kanker.nl.

In the conceptual phase, a literature review was conducted to map the most important stakeholders, policy frameworks, and existing research on the values of kanker.nl, commercial social media platforms and, cancer patients who use social media. This system analysis revealed that an important driver of cancer patients' use of social media is the gap between patients' informational needs and the guidance provided within standard cancer care.

Furthermore, the cultural values of *safety, reliability and community* of kanker.nl come into tension when patients seek peer knowledge exchange and experiential nutrition advice that does not align with the evidence-based standards of the platform.

In addition, a policy gap became visible from this system analysis: existing European and national cancer policy agendas do not address the role of commercial social media platforms in the spread of nutrition misinformation.

In the empirical phase, a qualitative content analysis of user comments was performed across YouTube, Facebook, Instagram, and kanker.nl, to examine how users discuss cancer and nutrition in different online contexts. The findings were validated through focus groups with former cancer patients to ensure that the identified values and tensions were grounded in lived experience.

Five core personal values were identified: *Community, Safety, Freedom, Health, and Knowledge*. Users express these values through the communicative orientations of bonding, asking, influencing, informing and expressing. As a result, the analysis uncovered four value tensions that reveal the discrepancies and varying characteristics of cancer patients that use social media.

In the technical phase, these insights are translated into recommendations for policy, organization and the design of kanker.nl. At the policy level, cancer-related misinformation should be explicitly integrated into European and national cancer policy frameworks.

At the design level, kanker.nl could introduce structured forms of pluralism, a more holistic framing of nutrition, and increased personalization to better align with user values. Organizationally, stronger collaboration between research institutions, healthcare professionals, and organizations such as WKOF and Vereniging Arts en Leefstijl could improve the evidence base on nutrition and cancer and strengthen the position of kanker.nl within the broader digital cancer information environment.

Due to the ephemeral nature of user-generated comments and social media discussions, the results of the empirical analysis remain uncertain. Because values are complex and context-dependent, it is difficult to reliably distil them from short online messages. Nevertheless, this thesis demonstrates that adopting a value-based systems perspective on the problem of health-related misinformation on can lead to innovative approaches for strengthen online patient platforms. Future research could further explore this perspective to develop innovative strategies for addressing health-related misinformation on social media.

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Abbreviations

CMP	Commercial social media platform
IKN	Integraal Kankercentrum Nederland
KWF	KWF Kankerbestrijding
NFK	Nederlandse Federatie van kankerpatientenorganisaties
NKC	Nederlands Kanker Collectief
OPP	Online patient platforms
VSD	Value-sensitive design
WKOF	Wereld Kanker Onderzoeksfonds
QCA	Qualitative content analysis
VLOP	Very large online platform

1 INTRODUCTION

This chapter starts with explaining the relevance of this thesis in 1.1, followed by the scope and problem definition in 1.2. Subsequently, in 1.3 the role of kanker.nl as an online patient platforms in this research is introduced. 1.4 describes the overarching goal of this study. In 1.5, the research gaps and objectives that are discussed. These are concretely translated into research questions in 1.6. The exact link to the Engineering and Policy analysis program is given in 1.6, and complete thesis outline can be found in 1.7.

1.1 THE RISE OF CANCER-RELATED MISINFORMATION ON SOCIAL MEDIA

The accessibility and spread of health-related misinformation on social media platforms has become a pressing public health concern worldwide (World Health Organization, n.d.). As the rise of the internet has caused a substantial increase in online health information-seeking behavior (Jia et al., 2021; X. Wang et al., 2021), mainstream commercial social media platforms (CSMPs) such as Facebook, YouTube and Instagram have enabled health-related content of low quality to circulate rapidly across large and diverse audiences (Y. Wang et al., 2019).

Although research acknowledges the positive impact of increased online health information-seeking behavior for improving self-management and greater engagement in healthcare decision-making (Jia et al., 2021; Maon et al., 2017), evidence also shows that false or misleading health information spreads more easily and more rapidly than scientific knowledge (Levy & Strombeck, 2002; Vosoughi et al., 2018). This dynamic increases the visibility and perceived credibility of inaccurate claims (Schmid & Bauer, 2025) and can even lower public trust in healthcare professionals (Stimpson et al., 2025). Therefore, healthcare organizations and researchers call for action to combat the growing volume of health-related misinformation circulating on social media (Esschoten, 2025; Niemansburg, 2024; Pagoto et al., 2019).

Among non-communicable diseases, cancer is the most prominent category of misinformation (Suarez-Lledo & Alvarez-Galvez, 2021). Cancer misinformation is defined as “any information counter to current scientific evidence (or consensus), concerning cancer prevention, cause, or treatment” (Swire-Thompson & Johnson, 2024). Though differences exist between platforms, estimates suggest that approximately 40% of cancer-related online content contains misinformation (Suarez-Lledo & Alvarez-Galvez, 2021; Swire-Thompson & Johnson, 2024).

In the Netherlands, one in two people will be diagnosed with cancer during their lifetime and new diagnoses continue to rise (Puts, G. C. W. M., M et al., 2023) making it one of the most pressing national health concerns. Since the internet has grown to be an important source of information for cancer patients, their relatives and caretakers (Braun et al., 2019), they are increasingly exposed to unverified or misleading claims, which has the potential to cause harm (Swire-Thompson & Johnson, 2024).

Specifically, because people with cancer are particularly vulnerable to misinformation. A cancer diagnosis is often accompanied by psychological distress, fear, and a desire for certainty, which may increase susceptibility to messages promising simple or miraculous solutions (Gorski, 2019). In addition, treatment-related fatigue and cognitive burden can reduce the cognitive resources of cancer patients for critically evaluating online information (Feng et al., 2019).

Furthermore, although social media has democratized and increased access to health-related information, individuals differ in their ability to assess the validity of these health claims. Research shows that individuals with adequate health literacy are more likely to rate evidence-based posts of cancer-related information as credible, whereas those with limited health literacy are more susceptible to misleading information (Trivedi et al., 2022). Therefore, cancer patients with lower health literacy may be disproportionately harmed by exposure to misinformation circulating on social media.

These harms include financial exploitation through ineffective treatments, exposure to toxic or unsafe interventions, interference with evidence-based therapies, and the postponement or avoidance of appropriate medical care (Johnson et al., 2022; Kureyama et al., 2023).

As a result of the rise in prevalence and harmful potential of cancer misinformation, oncology professionals worldwide a now calling cancer a “battle for communication” (Gregory, 2025). Addressing cancer today therefore requires not only medical expertise, but also an understanding of how information is produced, circulated, and interpreted online.

1.2 THE PROBLEM AND COMPLEXITY OF CANCER NUTRITION MISINFORMATION

The most prevalent topic within the broader landscape of online cancer misinformation, is nutrition (Warner et al., 2022). Two broad categories can be defined here: nutritional claims about the prevention of cancer and those concerning the treatment, progression or cure of the disease. This research is focused on the latter, as such content specifically targets individuals who already have a cancer diagnosis. These patients have distinct informational needs, vulnerabilities, and contextual circumstances, which form the central scope of this study.

The prominence of online treatment-related nutritional claims is linked to the growing importance of nutrition and dietary intake as key components of supportive and complementary cancer care (Aung et al., 2025b; Loeliger et al., 2021). Clinical reviews show that proper nutritional care can improve patients’ well-being, body composition, symptom burden, quality of life, and in some cases even survival outcomes (Barrera & Demark-Wahnefried, 2009; De Cicco et al., 2019; Soares et al., 2024)

Furthermore, the total five-year survival rate of cancer has increased by seventy percent since 1949 due to advances in research and treatment (KWF Kankerbestrijding, n.d.). As a result, the “booming” population of cancer survivors (Parry et al., 2011), has expanded the attention of public healthcare authorities towards lifestyle support, quality of life and long-term well-being of cancer patients, of which nutrition forms an essential part (The Netherlands Cancer Agenda, n.d.).

Though dietary intake thus is increasingly being recognized as playing a crucial role in multimodal cancer care (Muscaritoli et al., 2021), the benefits of appropriate nutrition depend on patients’ ability to understand and apply relevant dietary information. Nutrition literacy refers to “the degree to which individuals can obtain, process, and understand the basic nutrition information and services they need to make appropriate nutrition decisions”(Medicine et al., 2004). Despite the importance of adequate nutrition during and after cancer treatment, the nutrition literacy of cancer patients and survivors is low (F. F. Zhang et al., 2015). In fact, nearly half of cancer patients in the Netherlands are malnutritioned, stressing the need for improvement of their nutritional literacy (Stichting Nationaal Fonds tegen Kanker, n.d.).

At the same time, despite growing research interest, clear and specific evidence for the effects of individual foods, supplements, or dietary patterns on cancer outcomes remains limited. As nutrition researchers themselves conclude, it is better to recommend a general “healthy” dietary pattern to cancer patients and survivors than to make claims about the effects of specific food or nutrients (De Cicco et al., 2019). The current evidence-based guidelines for nutritional care in patients with cancer emphasize a balanced intake of carbohydrates, proteins, and fats, similar to recommendations for people without cancer (Muscaritoli et al., 2021).

This limited specificity is partly due to the complexity of nutrition research: cancer, like other non-communicable diseases, is multifactorial, and diet is only one of many interacting factors. Methodological challenges and inconsistent findings further complicate the interpretation of results, making it difficult to draw firm conclusions about the effects of individual food components (De Cicco et al., 2019).

Given this lack of specific clinical guidance and the inherent complexity of conducting robust research on nutrition and cancer, fertile ground is created for the spread of misinformation, in which social media platforms play a contributing factor (Capocasa et al., 2026). Generally, false online nutritional claims are framed is a form of “food faddism”, which is the exaggerated belief that certain foods or food components can cure or cause disease or have special health benefits (Ayushree et al., 2024). More specifically, Warner et al., (2022) distinguishes three kinds of online nutrition-related cancer misinformation claims:

Firstly, claims about “cancer-related health concerns and symptoms” concern the supposed effects of nutrition on symptoms such as fatigue, weight loss, nausea, or treatment-related side effects. This type of misinformation resonates with the way that cancer and its treatments often directly affect dietary behavior through changes in taste, appetite, and energy levels (Muscaritoli et al., 2021).

The second category is “food and food compounds”. This is misinformation about specific foods or ingredients, such as antioxidants, herbs, or carbohydrates that get framed as either harmful or beneficial for cancer outcomes. Related to this are the popularity of specific “cancer diets” or supplements, such as plant-based, ketogenic, fasting, macrobiotic, and the Moerman diet (Wereld Kanker Onderzoeksfonds, n.d.)

Lastly, the category of “general health food claims” consists of misleading narratives about specific products and “superfood” types, such as turmeric, soy, and sugar, which are presented as having decisive effects on cancer development or treatment (Wereld Kanker Onderzoeksfonds, n.d.).

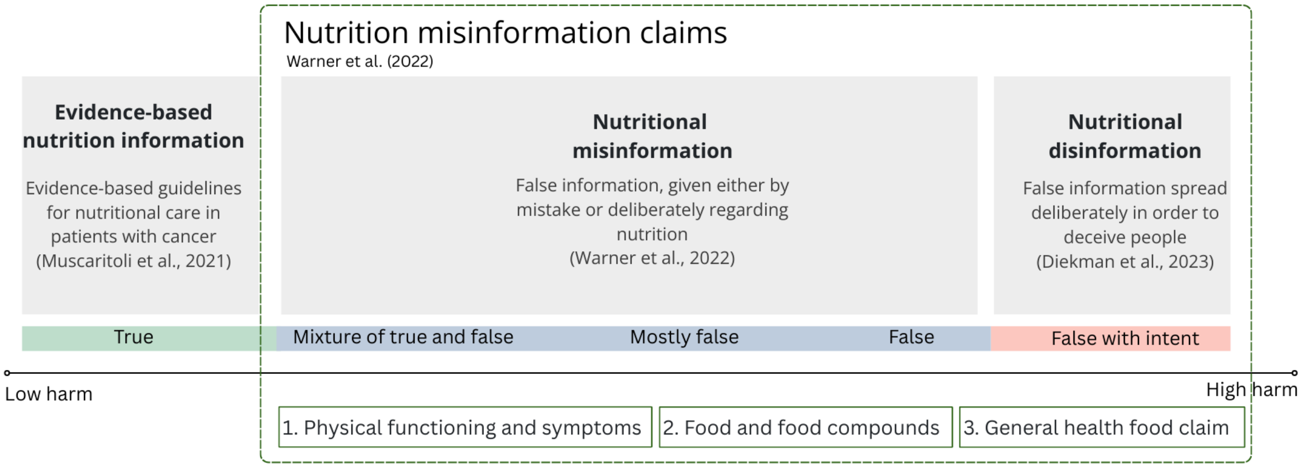


Figure 1-1 Spectrum of cancer-related nutrition information

The risks and harms associated with cancer nutrition misinformation vary in severity, but even seemingly harmless dietary advice can have serious consequences. The most critical risks occur when patients follow alternative nutrition-based approaches in place of conventional cancer treatment, as this is associated with increased mortality (Aggarwal et al., 2020). Furthermore, the use of some kinds of dietary supplements is associated with increased risk of certain side effects or complications and can interfere with chemotherapy (Yanik, 2025).

Beyond physical harm, cancer nutritional misinformation also poses significant psychological risks. Exposure to conflicting and contradictory nutrition claims can undermine patients' ability to make informed decisions (Keaver et al., 2023). This confusion can increase anxiety, perceived stigma or foster feelings of uncertainty and self-blame (Else-Quest et al., 2009; Yang et al., 2018). All these psychological challenges can contribute to increased emotional distress of cancer patients (Y. Wang & Feng, 2022).

Given these different types of harms, it must be recognized that the three categories of nutrition misinformation claims from Warner at al. (2022) exist on a spectrum, visualized in figure 1.1. At one extreme lies disinformation, which refers to deliberately deceptive content designed to mislead audiences (Diekman et al., 2023), often framed through anti-medical or anti-establishment narratives, such as calling seed oil "poison" (RRC Misinformation Report, n.d.). This is the most harmful type of misinformation.

However, many nutrition-related claims circulating on social media fall somewhere between a "mixture of true and false", "false" or "mostly false" (Johnson et al., 2022), leading to varying degrees of harm. In practice, this means that some nutrition-related claims contain fragments of scientific evidence but present them in exaggerated, oversimplified, or misleading ways. In other cases, claims may refer to emerging areas of research where scientific consensus has not yet been established. For example, fasting during chemotherapy is currently being explored in small clinical trials and have shown preliminary promise, but its effectiveness and safety have not yet been confirmed through large-scale evidence(Gabel et al., 2021).

As a result of this complex spectrum of emerging hypotheses, mixed evidence, and clearly false claims in nutrition science in oncology, it forms a particularly challenging topic of online health misinformation research. But rather than assessing their differences, framing or harm potential, this thesis will focus on how cancer patients that use social media react, interpret, and discuss this wide range of nutritional claims. Gaining insights into these reactions will namely help to better understand how cancer patients use social media and which values shape their online behavior. Such insights can inform strategies to mitigate misinformation and improve patients' nutritional literacy.

1.3 INTRODUCING ONLINE PATIENT PLATFORMS

For this research, social media platforms are defined as "a group of interactive Web 2.0 Internet-based applications that allow users to create and exchange user-generated content via virtual communities" (University of New Mexico et al., 2020). Although this term is commonly associated with mainstream platforms such as Facebook, Instagram, and YouTube, these are not the only online spaces where user-generated content about cancer and nutrition circulates.

A special type of platform within this broad definition are online patient platforms (OPPs). For this research, they are defined as "social platforms that offer a safe and trustworthy place for user to connect and share their experiences regarding cancer and nutrition". In other words, these platforms are built especially for cancer patients to support them in their informational and social needs. Kanker.nl. is a Dutch example of an online patient platform.

Kanker.nl is the leading platform in the Netherlands for cancer-related information and support. The website consists of two main components. Firstly, it offers evidence-based resources for patients, their relatives, and healthcare professionals. Secondly, it facilitates user-generated discussions and interaction through discussion groups and blogs (kanker.nl, n.d.-d), making the platform inherently "social". Specifically, information about diet and nutrition is also being shared and discussed among users, for example in the "nutrition" discussion group, making the platform particularly relevant for this research. This platform will therefore serve as the example case of an online patient platform and will be referred to as such throughout the rest of this study.

kanker.nl

Figure 1-2 Logo of kanker.nl (kanker.nl, n.d.-d)

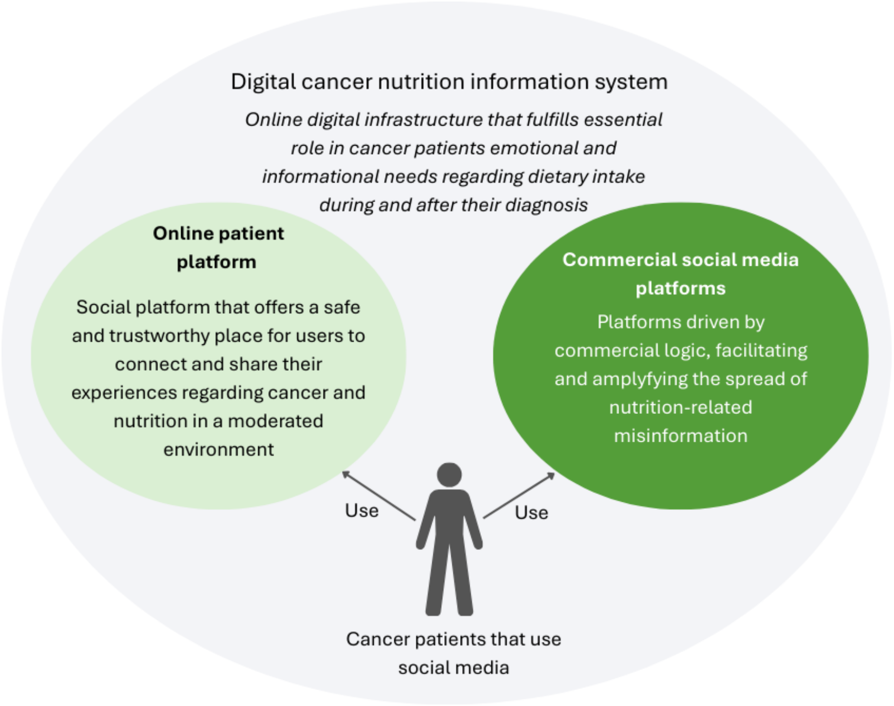


Figure 1-3 System definitions and scope defined for this research

With an average of 967.000 monthly visits, this OPP plays a central role in the Dutch digital cancer information landscape (Jaarverslag Stichting Kanker.Nl 2024). The platform operates as a network organization and collaborates with multiple partners to ensure the credibility of its content. Its primary funding source is KWF Kankerbestrijding, and according to its 2024 annual report, the foundation is fully independent from commercial funders such as pharmaceutical or nutrition companies (Jaarverslag Stichting Kanker.Nl 2024) This public and non-commercial positioning distinguishes OPPs from profit-driven social media platforms like Facebook, YouTube and Instagram.

The most similar concept in existing literature regarding OPPs are cancer forums, as they share the characteristic of facilitating user-generated discussions around the topic of cancer. The key difference is that online patient platforms, as defined in this study, are moderated environments in which user-generated discussions are overseen by the hosting organization. This contrasts with cancer forums, in which moderation is not always existent.

Previous research on cancer forums has shown that they have become an important supportive oncology technology by offering opportunities for patients to connect with one another (Van Eenbergen et al., 2018). Cancer forums offer emotional, informational and instrumental support (S. Zhang et al., 2017), which can all positively affect the well-being of people who have experience with cancer (Ariani & Raldow, 2025; Braun et al., 2019).

Despite these positive functionalities of cancer forums, it remains unexplored how user discussions on OPPs relate to those taking place on CSMPs. Applying such a systems perspective, where interactions on and between online patient platforms and commercial social media platforms are examined as a whole, may reveal new insights regarding strategies to mitigate nutritional misinformation. This system is visualized in figure 1-3.

Although OPPs have never been systematically studied in relation to CSMs, there are indications that OPPs do recognize the role that these other platforms play in the information practices of people affected by cancer.

For example, kanker.nl maintains official accounts on Instagram, Facebook, and YouTube (Instagram; @stichting_kanker.nl, Facebook; @kanker.nl , YouTube; @kanker_nl), where the organization shares various types of content, including practical tips about cancer treatment as well as personal patient stories. These accounts indicate that OPPs recognize a part of its target audience also uses commercial social media platforms.

Furthermore, in their annual report, kanker.nl explicitly emphasizes the need for continuous development in response to the dynamic online healthcare environments, stating that "stagnation is decline" (Jaarverslag Stichting Kanker.Nl 2024) . This highlights the organization's awareness of the changing information-seeking behavior of patients and the role that commercial social media platforms may play in this process.

Though this awareness underlines the interaction between OPPs and CMSPs and how they are both part of the bigger digital cancer information landscape, these two platform types have distinct goals and workings. Were OPPs actively try to provide reliable information and support for cancer patients, CMPs are built on engagement-driven architectures foster echo chambers, filter bubbles, and the amplification of polarizing or misleading content (Marin, 2024; Mattioni, 2024; Zollo et al., 2017).

Because of its distinct position in the digital cancer information landscape and its mission to provide trustworthy information and support to cancer patients, this thesis will examine the similarities and differences of OPPs and CSMPs and what role kanker.nl can play in the mitigation of nutritional misinformation.

1.4 RESEARCH AIM

Given the low nutritional literacy of cancer patients, their vulnerability to misinformation, and their increasing reliance on social media for information and social support, there is a responsibility and opportunity for online patient platforms to address the problem of nutritional misinformation. As a non-commercial platform operating within the same digital cancer information landscape as commercial social media, online patient platforms can offer a safe and reliable place for cancer patients that use social media and want to discuss nutrition. Therefore, the aim of this research is to strengthen the position of OPPs in relation to CSMPs as value-driven platforms that can address the problem of nutrition-related misinformation and improve patients' nutritional literacy.

In this study, *strengthening* refers to identifying how policy, platforms design and organisation of online patient platforms can better account for and respond to nutrition-related misinformation circulating on commercial social media platforms. The goal is to explore how these three elements could be adapted to enable OPPs to better mitigate nutrition misinformation encountered by cancer patients online. These policy, design, and organizational aspects will be explored within the Dutch context, where kanker.nl acts as the main online patient platform.

The concept of a *value-driven* platform refers to the integration of values, such as transparency, trustworthiness, and inclusivity, into the platform's design and governance (Friedman et al., 2013). In this research, these values are considered from the perspective of OPPs as and cancer patients who use social media. Understanding and aligning these values is essential for developing strategies that protect and support this user group within the digital cancer information landscape.

1.5 RESEARCH GAPS AND OBJECTIVES

To meet the research aim, four research gaps need to be addressed. Firstly, because kanker.nl is a foundation and operates as a network organization, its functioning is shaped by multiple stakeholders, partnerships, and structural dependencies. Understanding how these relationships have influence on policy, platform design and organization is therefore essential when developing recommendations aimed at strengthening them.

However, there is limited academic insight into Dutch-specific stakeholder configurations in the field of cancer communication. While kanker.nl collaborates with various societal and healthcare organizations, including its partnership within the Nederlands Kanker Collectief (*The Netherlands Cancer Agenda*, n.d.), it remains unclear how these collaborations are structured in practice, how responsibilities are distributed, and how kanker.nl positions itself within this broader network. The governance dynamics and stakeholder interests that shape the OPP in relation to CSMPs should therefore be analyzed in more detail.

Secondly, strengthening online patient platforms to address the nutritional misinformation in a value-driven way requires a clear understanding of the values that currently guide the organisation , as they give insight into how the OPPs are designed and governed. Although the website and annual reports of kanker.nl provide transparency about the organisation's goals and structure (Jaarverslag Stichting Kanker.Nl 2024) their values have not previously been analysed in relation to the values that drive commercial social media platforms, especially in the context of misinformation. This lack of comparative insight may conceal important value tensions that need to be understood to develop recommendations that are grounded in the entire digital cancer nutrition information system.

Thirdly, to account for the values of cancer patients that use social media in the policy, design and organization of OPPs, deeper insight is required into their online behavior across both commercial social media platforms and kanker.nl. Although previous research has examined user practices in cancer forms and commercial platforms separately (Johnston et al., 2025; Karami et al., 2018), these contexts have not been analyzed in direct comparison, limiting the possibility for understanding how users navigate between them in practice.

Furthermore, there is limited insight into how Dutch cancer patients evaluate nutrition-related information across different platforms. Existing qualitative research on user-generated cancer communication has primarily focused on observable communication patterns, such as information sharing versus seeking on cancer forums (Johnston et al., 2025), or perceptions in the discussion of gastrointestinal cancers on Twitter (C. J. Han et al., 2026). However, no attention has been paid to the underlying values such as autonomy and responsibility that shape user behavior in this specific context.

The emerging field of normative social media research has studied user values such as epistemic autonomy (Mattioni, 2024) and well-being (Figueroa et al., 2026). However, values are inherently context-sensitive and may be expressed and prioritized differently across technological environments and cultural settings (Borning & Muller, 2012). Understanding the values of Dutch cancer patients within the specific context of online nutrition communication is therefore essential, as these values provide insight into why patients trust certain platforms, how they assess credibility, and what they expect from CSMPs and OPPs. These user values will therefore be studied in detail for this study.

Moreover, values are not only context-dependent but also pluralistic and subject to variation between individuals and stakeholder groups (Borning & Muller, 2012; Friedman et al., 2017). It is therefore important to capture a diverse range of user perspectives across different commercial platforms and kanker.nl, to account for variation in how values are articulated and negotiated.

Lastly, there exists a gap in literature regarding methods for data collection in value-oriented research like this thesis. Although several methods for value elicitation have been developed and used before, such as interviews (Czeskis et al., 2010), ethnography (Nathan, 2012), or value dams and flows (Miller et al., 2007), there is no single “perfect” method, as studying values is inherently complex and presents a range of challenges (Friedman et al., 2021). Therefore, it is worthwhile to keep exploring new methods to broaden the methodological knowledge base of value-oriented research.

In the context of social media, user-generated comments represent direct expressions of users’ experiences, concerns, and opinions and may therefore constitute a valuable source for value elicitation. Because this study examines online patient platforms (OPPs) and commercial social media platforms (CSMPs) as part of the same system, a comparative analysis of user-generated discussions across these environments can generate insights into how the values of users are shaped per platform type. Therefore, this research will explore the potential of using user-generated data for value elicitation with help of qualitative content analysis (QCA) (Bouvier & Rasmussen, 2022).

In sum, the objectives of this thesis are fourfold: (1) to situate kanker.nl within the broader system of online cancer nutrition communication and gain insight into the values that shape this system, (2) to gain a deeper understanding of Dutch cancer patients’ online communication practices and the values that drive their platform use, (3) to translate these insights into concrete policy, communication, and design recommendations that can strengthen kanker.nl as a public, value-sensitive online patient platform, (4) to explore the methodological potential of qualitative content analysis of social media data for value elicitation. This leads to the following main research question:

"How can public healthcare organizations strengthen the position online patient platforms through policy, organization and design in a way that improves nutritional literacy, aligns with user values and mitigates the risks of nutrition-related misinformation?”

1.6 RESEARCH QUESTIONS

To answer this overarching question, the research is structured into three interconnected sub-questions.

The first sub-question focuses on developing a structural understanding of the system in which cancer nutrition information circulates online in the Netherlands. Rather than viewing OPPs in isolation, this question examines how the platform is positioned in relation to commercial social media platforms, healthcare institutions and partner organizations:

Sub-RQ 1: “What does the socio-technical system of cancer nutrition and social media in the Netherlands look like and what values are expressed by different stakeholders regarding online cancer nutrition misinformation?”

Building on this system-level analysis, the second sub-question puts the focus on user practices. Since OPPs are defined within the same digital ecosystem as commercial platforms, they will be systematically compared to find out how cancer nutrition information is engaged with across these different contexts.

Sub-RQ 2: "How do users in different online contexts (online patient platform vs. commercia social media platforml) negotiate and evaluate cancer nutrition claims, and what values shape these evaluations?"

Finally, the third sub-question translates the findings from the system and user analyses into concrete and actionable guidance. This sub-question is intervention oriented and combines the insights gathered from the SRQ1 and SRQ2. It focuses on how kanker.nl and relevant public healthcare authorities can operationalize identified values into policy, organization, and design strategies that enhance nutritional literacy while mitigating misinformation risks.

Sub-RQ3: “What policy, organizational, and platform design interventions can strengthen kanker.nl as a value-sensitive social platform that addresses nutritional misinformation and aligns with the values of cancer patients that use social media?

1.7 LINK TO EPA PROGRAM

This thesis fits the Engineering and Policy Analysis profile by addressing the grand societal challenge of health misinformation in cancer care through a systems-oriented, and multi-actor approach. Cancer nutrition communication is examined as a socio-technical system in which public and commercial platforms, patients, healthcare professionals, researchers, and policymakers interact within a complex policy and governance context. EPA methods are applied through stakeholder analysis, value-sensitive design, and policy analysis, combining conceptual modelling with empirical investigation. By translating these insights into policy, communication, and design recommendations for governmental healthcare authorities, the research aims to inform public decision-making at the interface of technology and policy in line with the core objectives of the EPA program.

1.8 THESIS OUTLINE

This thesis is structured as follows: chapter 2 introduces the overarching theoretical framework of value-sensitive design (VSD) and outlines the methods for data collection, which together form the overall research design. Subsequently, the next three chapters follow the three analytical phases as proposed within VSD: conceptual, empirical, and technical analysis. Chapter 3 presents the conceptual analysis and addresses Sub-RQ 1 by mapping the socio-technical system of online cancer nutrition communication. Chapter 4 provides the empirical analysis and answers Sub-RQ 2 by examining user behavior and the values that shape platform use across different online environments. Chapter 5 describes the technical analysis and addresses Sub-RQ 3 by translating these insights into concrete policy, communication, and design recommendations. Chapter 6 offers a critical discussion of the findings from both academic and societal perspectives, leading to the final conclusions and reflections presented in Chapter 7.

2 METHODOLOGY

This chapter outlines the theory, methodological choices and research design employed to address the research questions of this thesis. It begins by introducing value-sensitive design (VSD) as the overarching theoretical framework guiding the study. It then conceptualizes the notion of values in the context of social media platforms through the framework of Hallinan et al. (2022). Finally, the chapter describes the data collection methods, including their motivation, limitations, and the positionality of the researcher.

2.1 THEORETICAL FRAMEWORK

As established in the research objectives, this thesis seeks to strengthen online patient platforms in relation to commercial social media platforms. Achieving this goal involves enhancing this platform by explicitly identifying, analyzing, and integrating the values of users, kanker.nl and commercial social media platforms. This call to critically assess and incorporate values in technological systems is part of the broader research field of ethics of technology (Hansson, 2017).

Within this broader field of research, several frameworks have been developed with the shared goal of integrating values into technological development, though with different emphases and operationalizations. Examples include responsible innovation (Stilgoe et al., 2013), design for values (van den Hoven et al., 2015), and value-sensitive design (Friedman, 1996).

Responsible innovation primarily focuses on procedural principles (anticipation, inclusion, reflexivity, responsiveness) to make innovation processes more ethical. Design for Values and Value Sensitive Design operate more directly at the level of technological artefacts, aiming to embed moral values into design itself. While design for values provides a broad paradigm, value-sensitive design offers a more operationalized and structured methodology through its tripartite approach: conceptual, empirical, and technical investigations (see 2.1.1).

A central aim of VSD is the identification of both direct and indirect stakeholders. This directly supports research objective 1, which aims to situate kanker.nl within a broader socio-technical system of stakeholders, interests, and power relations. Through its empirical investigations, VSD also aligns with objective 2, as it enables the systematic study of how users express, negotiate, and prioritize values in practice. Furthermore, VSD explicitly links conceptual and empirical insights to technical interventions, thereby supporting objective 3: the development of concrete policy, communication, and design recommendations. Finally, the methodological flexibility of VSD allows for the integration of qualitative content analysis as a means of value elicitation, in line with objective 4. Taken together, VSD provides a suitable theoretical foundation for achieving the value- and system-oriented aim of this thesis. It will be elaborated on in the next section.

2.1.1 VALUE SENSITIVE DESIGN

Value-sensitive design is "an interactional theory and method that accounts for human values in a principled and structured way throughout the design process of a technology" (Friedman et al., 2013). It functions as a research framework for the ethical design and analysis of technological artefacts, with a central focus on the integration of values. Within VSD theory, values are defined as things that " individuals or groups consider important in life" (Borning & Muller, 2012). What makes the theory interactional is that it follows the narrative that humans and technologies co-shape one another in a continuous feedback loop (Umbrello, 2024).

Originally developed by Batya Friedman, VSD builds on the idea that technologies are not neutral. Rather, values are intrinsically embedded in technological artifacts and systems. This means that technical design choices have influence on how people behave and interact with technology, leading to broader societal implications.

The goal of value-sensitive design is to ensure that technologies are developed with ethical and moral considerations in mind. Ideally, we consider these values at the beginning of a design process, before technology becomes ubiquitous and we are dependent on it. However, VSD also allows for retrospective evaluation of the values important to existing technology. Because this research is focused on analyzing user behavior on existing commercial social media platforms, as well as exploring to-be-formed design strategies for online patient platforms, this research explores types of both usages.

Furthermore, in recent years academic attention has been paid to further develop the VSD framework by integrating it into the larger social, political, economic and judicial ecosystem instead of solely focusing on technological design (Stahl, 2025) . This research will also engage in this by including value-driven recommendations at different "locations" across the system, including policy and the organization of kanker.nl

The VSD methodology consists of an iterative tripartite process composed of conceptual, empirical, and technical investigations, see figure 2.1. These investigations are complementary and must be integrated to meaningfully capture value dynamics (Friedman et al., 2013).

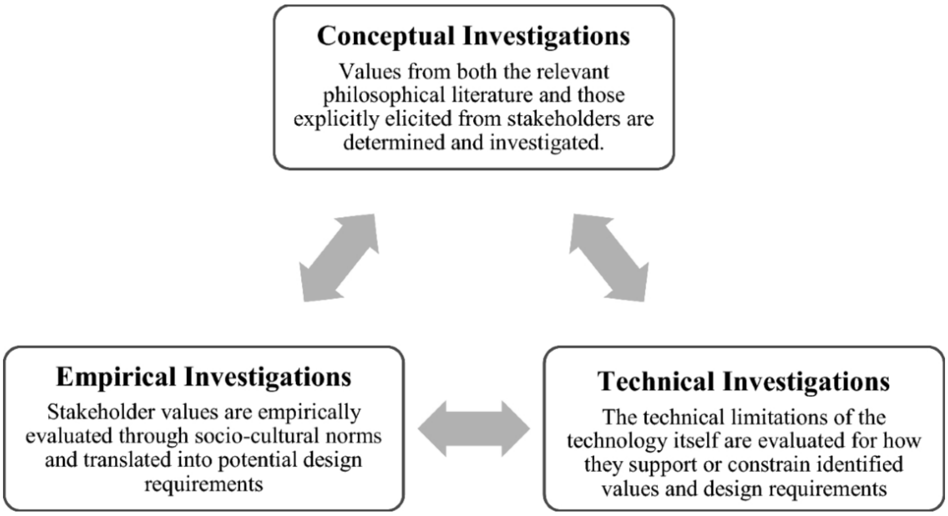


Figure 2-1 VSD methodology (Umbrello et al., 2021)

In the conceptual investigation, the focus is on identifying and analyzing the values implicated by the design and use of technology. Central to this phase is the identification of direct and indirect stakeholders, as well as the assessment of how technological design choices create benefits, risks and value tensions among these stakeholders.

During the empirical phase, insights from the conceptual investigation are enriched with empirical data. VSD allows a broad variety of methods from the social sciences to gather direct input from stakeholders situated within the socio-technical system. The aim is to understand how values are experienced, expressed, and negotiated in practice, capturing stakeholders' perspectives, interpretations, and responses to a technology.

The technical phase focuses on the design of the socio-technical system in a way that embodies and supports the values found in the other phases. This phase aims to create interventions that align with the identified values and address the most important value tensions.

2.1.2 VALUE CONCEPTUALIZATION

While VSD is a broad and versatile framework applicable to many technologies, this thesis focuses on social media platforms, which presents a distinct value landscape. Social media platforms are not neutral infrastructures but "sites where values are expressed, contested, and diffused," making them particularly suitable for value sensitive analysis (Hallinan et al., 2022). To systematically capture this complexity and clearly specify what kind of values will be investigated and where they operate in the system, this study adopts the platform value conceptualization framework from Hallinan et al. (2021). This framework distinguishes two key dimensions of value: scale and explicitness of expression (see figure 2.2).

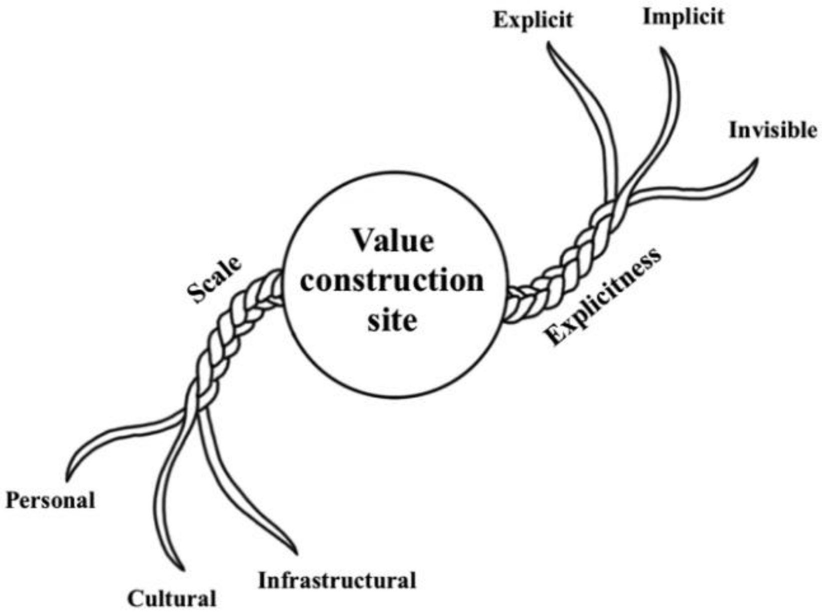


Figure 2-2 Platform value conceptualization (Hallinan et al., 2022)

Firstly, regarding the scale, three types of value expressions are identified:

1. **Personal values**
   These values refer to “an individual’s guiding beliefs about desirable conduct”(Hallinan et al., 2022). Research on personal values is rooted in psychology, where Schwartz’s Universal Values Model is considered foundational (Schwartz, 1992). This model proposes a set of universal human values, such as self-direction, security, and tradition, that guide how individuals evaluate situations and make decisions. On social media, personal values can be expressed and communicated through user-generated content and interactions, with each post reflecting an “individual’s value assertion” (Gillespie, 2018).

2. **Cultural values**
   For this scale, values are concerned with “collective ideas about desirable conduct” and reflect the norms and beliefs prevalent within a particular culture (Hallinan et al., 2022). Unlike personal values, cultural values describe the guiding beliefs of groups or organizations rather than individuals. Research in this area often examines values at the level of larger social groupings, such as national cultures (Hofstede, 2001). In this study, cultural values refer specifically to the values promoted by organizations, particularly OPPs and CMPs. These values can be expressed through policies, user agreements, and corporate communication (Scharlach et al., 2024).

3. **Infrastructural values**
   These are “guiding beliefs about desirable behavior enacted through technological artifacts and systems, both intended and unanticipated” (Hallinan, 2022). Such values are embedded in the platform’s design through its interface and technological features. These shape how users interact with and experience a social media platform. For example, content moderation on platforms like Facebook or YouTube reflects infrastructural values related to free speech and safety. The platform’s decision on whether to allow or remove content based on these values directly impacts user interaction. Similarly, engagement metrics like the like button promote specific behaviors, such as valuing popularity over nuanced discussion (Gillespie, 2018). Another example is how algorithmic curation can drive the formation of echo chambers, prioritizing the value of engagement over diverse viewpoints (Ludovic Terren & Rosa Borge-Bravo, 2021).

The second dimension of value expression is explicitness, which refers to how directly values are articulated. Explicitness exists on a spectrum, with an inverse correlation to the scale dimension. In other words, personal values are typically expressed more explicitly than infrastructural values. Users may explicitly state preferences or concerns in content or comments, while infrastructural values remain implicit, embedded in technical systems and algorithmic logic.

According to Hallinan et al. (2022), this distinction has methodological implications for doing research on social media platforms. Explicit value expressions, such as those found in user comments or policy documents, are suitable to be studied through qualitative content analysis.

Infrastructural values, however, are more difficult to observe directly because they operate through technical systems that are often opaque to users and researchers.

Despite this methodological limitation, the model's braid-like structure shows that the three value scales do not appear in isolation but interact, reinforce, and sometimes conflict with one another. Platform values are therefore rarely unified or stable; instead, they are continuously negotiated and shaped by power relations between users, platforms, institutions, and regulators. Because this research adopts a systems perspective and aims to formulate policy, communication, and design recommendations for OPPs, it is necessary to examine values across all three scales. Although infrastructural values are more difficult to analyse directly, they will be inferred through the analysis of cultural and personal values, which are more explicitly observable in empirical material.

2.2 RESEARCH DESIGN

For this research, a novel combination of conceptual, empirical and technological investigations is made to answer the research questions. Most importantly, it uses an innovative approach for the empirical VSD investigation, by using qualitative content to analyze and compare user-generated comments from CSMPs and an online patient platform. Table 2-1 shows a schematic overview of the methods applied for this research alongside the corresponding type of VSD investigation and value scale from Hallinan et al. (2022).

Firstly, in the conceptual phase, the interests and values of the stakeholders in the system of digital cancer nutrition information will be identified and mapped with help of literature and desk research. This phase is focused on the preliminary understanding of the personal values of cancer patients that use social media, the cultural values of online patient platforms, partner organizations and commercial platforms, and the infrastructural values that are built into the design of these platforms. It therefore creates insights in all three value scale dimensions.

For the empirical phase, cancer patients that use social media are analyzed as key stakeholders within the socio-technical system. A comparative qualitative content analysis will be conducted on user comments across an online patient platform and commercial social media context to examine how users negotiate, evaluate, and make sense of cancer nutrition claims.

Findings from the QCA are enriched and validated through focus groups with people who have been diagnosed with cancer and use social media. These focus groups serve to validate online value expressions from lived experience of patients. This part of the research will result in empirical insights into the personal values of users.

Finally, inputs from the conceptual and empirical insights of users and other stakeholders will be used for the design of policy, communication and design recommendations aimed at strengthening online patient platforms. This phase marks the technical investigation. The outcome is a set of actionable, value-driven recommendations that are grounded in the full system analysis. To do this, insights from all three value scales will be integrated.

This research design is explicitly aligned with the framework from Hallinan et al. (2022), ensuring that personal, cultural, and infrastructural values are all addressed. It also follows its methodological recommendations by analysing user-generated content to investigate personal values, while cultural values will be examined through literature and policy documents. Infrastructural values will be derived from insight in personal and cultural values. Objective 4, regarding the methodological potential of using qualitative content analysis for value-sensitive design, will be discussed in the discussion chapter (chapter 6).

	Sub-question 1	**Sub-question 2**	**Sub-question 3**
Research objective	Identify stakeholders & theorise values	Comparative user value analysis across 2 contexts.	Develop policy, communication and design strategy for kanker.nl
VSD phase	Conceptual	Empirical	Technical
Value scale	Infrastructural. Cultural, Personal	Personal	Infrastructural, Cultural, Personal
Method	Literature Review and desk research	Qualitative content analysis, focus groups	Values integration and design exploration
Chapter	3	4	5

Table 2-1 Research design

2.3 METHODS FOR DATA COLLECTION

This section will explain in detail the methods for collecting data in the conceptual, empirical and technical phase.

2.3.1 LITERATURE REVIEW AND DESK RESEARCH

The conceptual phase started with a systematic review of the literature, later complemented by additional desk research.

A comprehensive search to get initial insights into the values of cancer patients that use social media was carried out on Scopus on October 7th, 2025. Scopus was chosen because it provides access to a wide range of academic sources, including papers, books, and chapters, and allows for advanced systematic searches. Its user-friendly interface also enables efficient citation filtering. The search query used was:

```
TITLE-ABS-KEY ("cancer" AND ("social media" OR "influencer" OR "forum" OR
"community platform" OR "online community" OR "interactive platform" OR "knowledge
exchange environment") AND ("nutrition" OR "diet")).
```

This query was designed to provide a broad overview of the combination of cancer, commercial social media (and related terms), and variations of online patient platforms (e.g., forums, community platforms), particularly in relation to nutrition (or synonyms such as diet). By including both commercial and patient-oriented platform terms, the search strategy aligns with system as defined in 1.3.

The inclusion criteria for this review were as follows:

1. Peer-reviewed articles, to ensure academic rigor.
2. Full-text availability, to allow in-depth analysis.
3. English-language articles, to ensure feasibility and consistency.

After duplicate removal, a manual scanning of abstracts was performed, with the following exclusion criteria:

1. **Offline forum**
   Studies where the term "forum" referred to offline, organized forums (commonly used for academic presentations) rather than online discussion forums. These studies are excluded because they do not provide insight into how information circulates on online platforms.
2. **Recruitment via "social media"**
   Studies that used social media only as a source for recruiting participants, rather than exploring the impact or usage of social media in cancer nutrition. They are excluded because they do not treat social media platforms as an object of analysis, but merely as a tool for doing research.
3. **Preventative cancer studies**
   Studies that focused solely on dietary risks associated with increasing the likelihood of cancer, rather than focusing on patients who already have a cancer diagnosis. This is because the scope of this thesis, as defined in 1.2, concerns cancer patients and survivors who are exposed to nutrition-related information during or after treatment.
4. **No relational focus on nutrition and cancer**
   Studies that did not directly address the relationship between cancer and nutrition but merely mentioned both topics separately. These studies are excluded because they do not contribute to understanding the relationship between cancer and nutrition in the digital information landscape.

The papers that met these criteria were analyzed for full text analysis and used to give answers to SRQ1.

Where the selected literature does not provide sufficient information to fully address specific aspects of SRQ1, such as Dutch-specific cancer policy information, additional sources will be identified through snowballing and desk research on Dutch organizations involved in or connected to kanker.nl. The strategy for this desk research therefore will be dependent on the outcomes of the systematic literature review.

2.3.2 QUALITATIVE CONTENT ANALYSIS

As part of the empirical VSD phase, this study uses qualitative content analysis (QCA) as described in Bouvier & Rasmussen (2022) for the retrieval and analysis of social media comments and user discussions. This method enables the examination of how values are expressed and negotiated in everyday user–technology interactions, making it a suitable method to give answer to SRQ 2.

Qualitative content analysis is a systematic research method for interpreting textual, visual, or multimodal material, aimed at understanding meanings, patterns, and underlying assumptions embedded in communication (Bouvier & Rasmussen, 2022). Central to this approach is interpretive process in which the researcher engages in a continuous dialogue between their evolving understanding and the intentions of the text producer.

This method is well-established within social media research and has previously been applied to study phenomena such as online COVID-19 communication on Twitter (Tomar et al., 2023), nutrition influencers on Instagram (Denniss et al., 2023) or food videos on YouTube (Smith, 2023).

Its primary strength lies in its capacity to interpret meaning in context, rather than focusing on surface-level patterns or frequencies, which are more characteristic of quantitative content analysis (Duke, 2011). However, there are no previous examples found that use QCA of user comments for empirical value elicitation as part of the VSD framework. Therefore, this research is exploratory in nature, as explained in research objective 4 (section 1.4).

The phases and steps for conducting a structural qualitative content analysis for this thesis are adopted from The Routledge Handbook of Research Methods in applied Linguistics (McKinley & Rose, 2020). The three phases described here are: preparation, organization and reportation. The overview of activities that have been carried out alongside these three phases is visualized in figure 2-3. Each of the inputs and activities will be discussed. The output of the QCA is presented in the empirical phase chapter

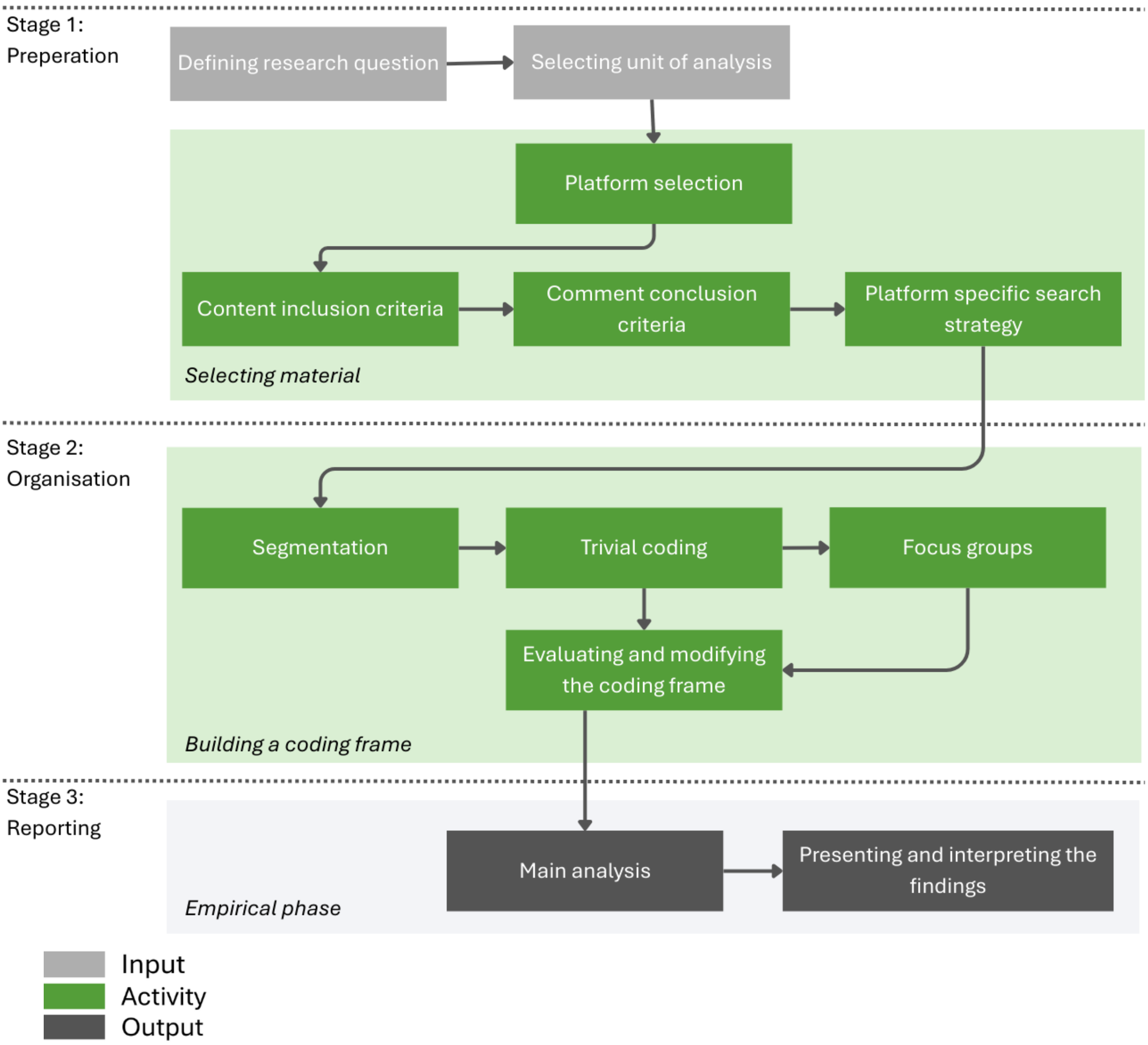


Figure 2-3 Overview of qualitative content analysis procedure

DEFINING THE RESEARCH QUESTION

As input for the qualitative content analysis, the research question for this phase (SRQ 2) is decomposed into its core analytical dimensions. This step is necessary to ensure a consistent and systematic coding process across the different online contexts.

The sub-research question *"How do users in different online contexts (online patient platform vs. commercial social media platform) negotiate and evaluate cancer nutrition claims, and what values shape these evaluations?"* contains three distinct components:

1. **Communication**: how users negotiate and evaluate.
2. **Cancer and nutrition**: the cancer nutrition claims.
3. **Ethics and values**: the values involved in evaluating these claims.

Defining these dimensions ensures that the analysis remains closely aligned with the research question.

SELECTING UNIT OF ANALYSIS

The unit of analysis for this qualitative content analysis consists of individual user comments and discussion threads posted in response to cancer nutrition–related content. These comments may appear as reactions to videos or images, or as contributions within discussion groups or forum-like environments.

Figure 2-3 shows an illustrative example of a user comment in response to nutrition–related cancer content, in this case on Instagram. Figure 2-4 shows an illustrative example of a discussion threat with comments from Facebook, and 2-5 on YouTube. All these data types have been included in the analysis. The text within the red boxes is considered the unit of analysis.

[redacted]

[redacted]

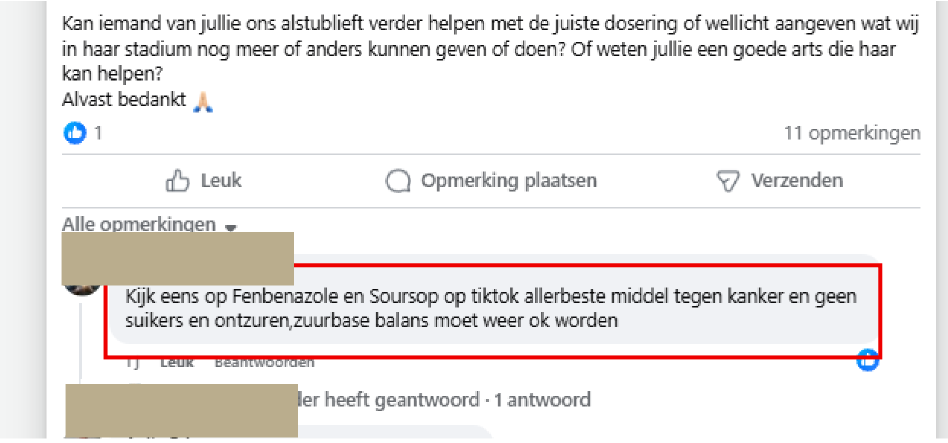
#voedingsadvies
#voedingbijborstkanker
#voedingbijkanker #borstkanker
#antihormonaletherapie
#antihormonologen #wegwijsbijkanker
#podcastersofinstagram
#medischepodcast

[redacted]

Hoe zit het met de relatie tussen sojaproducten en oestrogeen? Kun je die producten beter vermijden bij hormoongevoelige borstvoeding?

[redacted]

Figure 2-4 Illustrative example of unit of analysis on Instagram



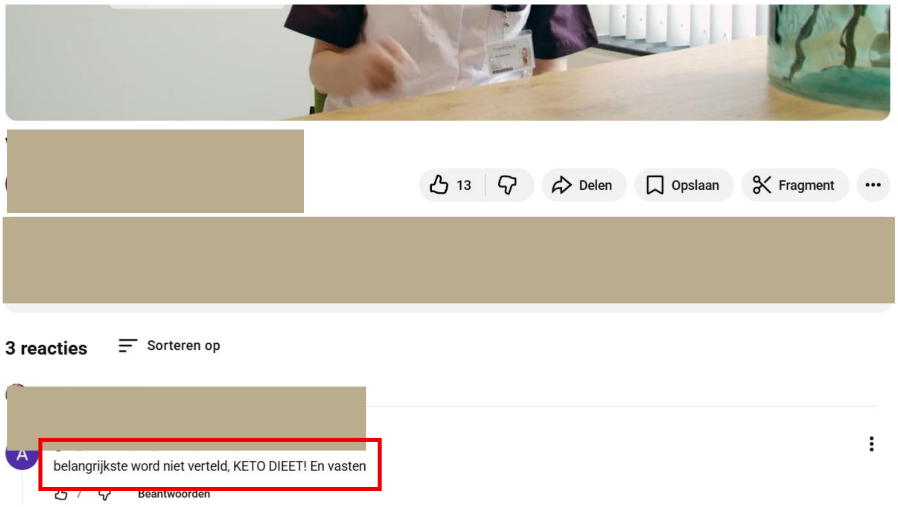
Kan iemand van jullie ons alstublieft verder helpen met de juiste dosering of wellicht aangeven wat wij in haar stadium nog meer of anders kunnen geven of doen? Of weten jullie een goede arts die haar kan helpen?
Alvast bedankt 🙏

[redacted]

Kijk eens op Fenbenazole en Soursop op tiktok allerbeste middel tegen kanker en geen suikers en ontzuren,zuurbase balans moet weer ok worden

[redacted] ler heeft geantwoord · 1 antwoord

Figure 2-5 Illustrative example of unit of analysis on Facebook



[redacted]

[redacted]

[redacted]

belangrijkste word niet verteld, KETO DIEET! En vasten

Figure 2-6 Illustrative example of unit of analysis on YouTube

SELECTING MATERIAL

The search strategy for finding data is based on manual, targeted data collection. Social media posts and comments were gathered by hand, without the use of automated tools or application programming interfaces (APIs). This approach is appropriate given the qualitative and interpretive aim of the study, which focuses on understanding value expressions in context rather than collecting large-scale or representative datasets.

As this study draws data from multiple social media platforms and in different contexts , it follows a cross-platform research design (Burgess et al., 2019). The query strategy is therefore adapted to the specific characteristics of each platform to ensure that relevant and comparable data are collected across contexts.

PLATFORM SELECTION

Youtube, Facebook and Instagram are selected as part of the commercial platform environments of cancer information. They were chosen for two main reasons. First, previous research has identified these platforms as prominent sites for the circulation of (mis)information about nutrition and cancer (Johnson et al., 2022; Segado Fernández et al., 2025). Second, they host diverse user groups (X. Wang et al., 2021) which support the goal of capturing a wide range of users perspectives as explained in 1.5. Furthermore, these are the platforms where kanker.nl also has its own accounts, making them platforms relevant for comparing to kanker.nl discussions.

The other online environment is formed by the community platform section of kanker.nl.

CONTENT INCLUSION CRITERIA

Given the social media platforms that were selected for this study, table 2-2 provides an overview for the general inclusion criteria for comment retrieval and their justification. These apply to the content, so the video photo or discussion group that is being looked at.

	Content inclusion criteria	Motivation
1	Media-sharing posts (photo, video) must contain at least 10 user comments.	Ensure posts have sufficient user engagement.
2	Online patient platform discussion must contain at least 10 user comments	Ensure posts have sufficient user engagement.
3	Posts must be published after 2019	Posts should reflect contemporary discussions of cancer and nutrition that are in line with the spectrum and categorization of nutritional misinformation as described in 1.2.
4	Comments must be in Dutch	Ensures consistency with the national scope of this research and cultural sensitivity of value expression.
5	Posts and discussions must address both cancer and nutrition; content focusing solely on cancer was excluded.	Ensures the data fits the scope of the research as described in 1.2.
6	Posts focusing exclusively on preventive nutrition (i.e. nutrition to prevent cancer) were excluded	Ensures the data fits the scope of the research as described in 1.2.
7	For CSMPs, the first 50 results of a search term are screened for inclusion.	Enhances transparency and replicability of the research.

Table 2-2 Content inclusion criteria and motivation

COMMENT INCLUSION CRITERIA

Following this screening of photos, videos and users discussion on the four selected platforms, all collected content will undergo a second round of manual qualitative screening at the comment level. This screening focuses on the suitability of comments for value elicitation. Two additional inclusion criteria will be applied, which are described and explained with fictional comment examples in table 2-3.

Based on these two rounds of screening, the final dataset of content and comments were collected during the period October–December 2025. To minimize personalization and improve replicability, all searches were conducted using an incognito browser without stored cookies or browsing history.

Criterium	Description	Fictional comment examples
1. Value screening	User-generated comments and discussions are required to contain sufficient information for personal value elicitation. These expressions could thus appear as statements reflecting feelings, preferences, needs, concerns, or priorities expressed by users. Comment sections typically include a mix of value-laden and non–value-laden comments. This screening process was qualitative and interpretive in nature and did not rely on predefined quantitative thresholds.	Include: “Thank you for this post, it really helped be get a better understanding on the role of proteins plays in my recovery, I would like to see more detailed information on what the best recipes are for cooking with protein” Exclude: “I am watching this video from home”.
2. Topical relevance screening	In addition to expressing values, comments needed to relate explicitly to both cancer and nutrition. Posts containing value expressions unrelated to this topic combination were excluded.	Include: “I just got received a cancer diagnosis this april and I am getting sick of all the online posts telling me to stop eating sugar, can people stop making be feel guilty for getting cancer?” Exclude: “animals are not to be eaten!”

Table 2-3 Comment inclusion criteria with fictional examples

PLATFORM-SPECIFIC SEARCH TERM STRATEGY

Table 2-4 shows the final search term strategy per commercial platform. Search terms were kept broad and general, to gather content regarding the claims of all the different categories of the nutrition information spectrum (figure 1.1). If the results of these searches did not yield a high enough number of comments for value analysis, they were more specified to find additional content. The search strategy was originally performed in Dutch, but for this thesis, everything is translated to English. This section explains the platform-specific search queries in more detail.

YOUTUBE

This platform offers a central search interface. Search term “voeding en kanker” resulted in 5 eligible posts after applying content inclusion criteria. After the comments of these posts were screened, 1 post met the inclusion criteria.

INSTAGRAM

This platform is primarily organized around user profiles and algorithmic recommendations, with a relatively limited search function. An initial hashtag-based search was conducted using *#voedingbijkanker*. The first 50 posts returned by this search were screened using the primary criteria, resulting in two posts eligible for secondary screening. A second hashtag search using *#moermandieet* yielded one additional post meeting in the content inclusion criteria.

To complement the hashtag search and include content with higher reach, desk research was conducted to identify prominent Dutch health and lifestyle influencers on Instagram. A list of twelve influential profiles was compiled. Each profile name was then searched in combination with the terms *“kanker”* and *“Instagram”* via Google to determine whether cancer-related content was posted. This process resulted in two influencer profiles suitable for further screening. Due to the high posting frequency of these accounts, only posts from 2024 and 2025 were examined. This resulted in three posts meeting the content inclusion criteria, of which two were retained the comment inclusion criteria.

FACEBOOK

This platform offers a multitude of content types, such as (closed)discussion groups, but also short and longer videos. The sampling strategy has therefore combined multiple approaches.

Using Facebook’s group search function, groups were identified using the search term *“kanker en voeding”*. From the available options, one group was selected based on the following criteria: more than 1,000 members, active participation (at least one post per week), focus on cancer in general (not a single cancer type), and no explicit promotion of alternative treatments. Access was obtained via the researcher’s personal Facebook account. Within this group, the internal search function was used with the term *“voeding”*. The first 50 results were screened for content inclusion resulting in nine posts. After comment screening, five posts were included in the final dataset.

Using the central search interface, terms “voeding bij kanker” and “kanker dieet” resulted in 6 posts included after primary and secondary screening.

Platform	**Search location**	**Search terms**	**#posts after content screening**	**#posts after comment screening**
Youtube	Central search interface	“nutriton and cancer”	3	1
Instagram	Hashtag search	#nutrtionandcancer, #moermandiet	3	3
Instagram	Profiles	Health and lifestyle influencers profile search	3	2
Facebook	User discussion in cancer group	“nutrition”	9	5
Facebook	Central search interface	“nutriton and cancer” and “cancer diet”	6	6

Table 2-4 Search terms for commercial social media platforms

ONLINE PATIENT PLATFORM

To ensure consistency, the same inclusion criteria for content and comments on CSMPs were used for the online patient platform. All analyzed content consisted of textual user discussions. See table 3 for the search term strategy of this platform.

The main source of data on kanker.nl was the "nutrition" discussion group. All discussions within this group that met the primary inclusion criteria were screened. This resulted in 22 discussion threads eligible for secondary screening. After applying comment inclusion criteria, 10 discussion threads were included in the final dataset.

To supplement the dataset and capture relevant discussions that did not fall entirely within the "nutriton" group, additional searches were conducted using the general search function of the online patient platform. First, a question-and-answer discussion group led by a professional dietitian was included. Although this group formally falls outside the primary time criterion (with posts published between 2015 and 2019), it was included due to the exceptionally high number of user responses (106 comments), which provided rich material for value analysis. Second, following the initial screening of the "nutrition" discussion group, an additional search was conducted using the term *"glucose"*. This resulted in one additional discussion thread being included in the sample.

Platform	Search location	Search terms	#posts after primary screening	#posts after secondary screening
Kanker.nl	Central search interface	Discussion group "nutrition"	21	11
Kanker.nl	Central search interface	"glucose"	1	1

Table 2-5 Search term strategy for kanker.nl

BUILDING A CODING FRAME

Following the selection of material, the organization phase focuses on the development and evaluation of a coding frame. This coding frame functions as "the backbone of QCA inquiries and functions as a system that will transform the data into meaningful, manageable, specific and smaller units of information, also known as codes" (McKinley & Rose, 2020).

All the comments that were selected for the sample were anonymized directly before putting into Excel sheets manually, and those were imported into Atlas.ti software, which is a tool that helps to easily categorize and analyze textual data. After that, the development of the coding frame began with a phase of familiarization and immersion in the data.

Coding frame construction is an iterative and non-linear process, involving continuous refinement through the comparison, merging, and redefinition of codes. Table 2-6 reveals the final coding frame.

SEGMENTATION

Segmentation refers to the process of dividing the data into smaller analytical units that can be systematically coded. This process started inductively, following the three core dimensions defined in “research question” section: cancer and nutrition, communication and and values.

Dimension	Guiding coding question	Code Theme	Code sub-theme
Cancer and nutrition	What nutrition-and-cancer claims are being discussed by users?	Cancer nutrition claims	Not applicable
Communication	How do users express, interpret, and respond to cancer nutrition dialogue?	Orientation	Bond, Inform, Influence, Express, Ask.
Values	What values, norms and beliefs are driving users’ communication?	Values	Not applicable
		Norms	Not applicable

Table 2-6 Coding frame

TRIVIAL CODING

In this phase, codes of the code themes are being applied to the data. For each of the main dimensions, separate strategies were used, both inductive and deductive.

CANCER AND NUTRITION CODING

Direct references to specific diets, supplements, or food claims were coded according to the name of the diet or intervention mentioned. This was done deductively. The example comments are paraphrased.

An illustrative example of cancer and nutrition coding:

“My father has the same diagnosis, and I’ve been researching options like ivermectin and fenbendazole alongside immunotherapy, as well as an alkaline diet that some say may inhibit cancer cells”

Cancer nutrition claim: alkaline diet

COMMUNICATION CODING

Subcategories of communication were coded inductively, inspired by the analytical framework of Shifman et al., (2025), which identifies four communicative value orientations commonly observed in social media interactions:

- **Inform**: “conveying information or knowledge”.
- **Influence**: “creating change by affecting social actors”

- **Bond**: “creating or maintaining social relationships”
- **Express**: “displaying personal of collective feelings thoughts and characteristics”

In addition to these four orientations, an extra subcode “ask” was introduced deductively to capture comments formulated as explicit questions. This subcode was included because questions reveal users’ informational needs and uncertainties, which are relevant for understanding value dynamics in cancer nutrition communication.

An illustrative example of communication coding:

“If it feels right... just do it. If in doubt, always consult a doctor. Tip. Good luck.”

Orientation: Bond

VALUES CODING

The coding strategy for values focused on identifying expressions of values, attitudes, and normative beliefs in user comments. Three different trivial coding strategies for this dimension were used. Firstly, value coding was guided by explicit textual cues such as *“I feel”*, *“I want”*, *“I think”*, *“I need”*, and *“It is important that”*, as these formulations often signal value-laden statements.

An illustrative example of value identification based on explicit textual cues:

“Many stories, mainly from American people with cancer who had exhausted all treatment options and were nevertheless completely cured by following a special plant-based diet. It may sound far-fetched, but it works, and that's what matters most.”
Value: Effectiveness

In addition, specific verbal cues were coded as indicators of underlying values. For example, describing information as *“dangerous”* was coded in relation to the value of safety, while references to something being *“not fair”* were linked to values such as fairness or justice. In some cases, values were not explicitly verbalized but were inferred through contextual interpretation.

An illustrative example of value identification based on verbal cues:

“My family and friends had to get used to it, but now they know no different. I am very disciplined. They know that there is no point in continuing to offer me all kinds of things.”
Value: Discipline

Given that values are abstract and often implicitly expressed, the final trivial coding strategy focused on norm. Norms exemplify values (Steinert, 2023). They can be understood as concrete rules or guidelines that indicate how one should act in specific situations. Because norms are practical and action-oriented, they are more easily observable than abstract values and therefore more suitable for trivial coding.

An illustrative example of norms-based coding:

"It's great that you're searching and asking for advice, but above all, listen to your own body and your intuition—everyone is different."
Norm: Listen to one's own body and intuition

FOCUS GROUPS

Because qualitative content analysis involves interpretive judgement, it is essential to incorporate moments of evaluation and refinement to ensure analytical rigor. Within the qualitative content analysis procedure, this corresponds to the step of "evaluating and modifying the coding frame". In this study, this step was operationalized through focus groups.

A focus group is "a form of qualitative research, which involves the gathering of a small group of people who are asked about their attitudes towards a concept, product or idea" (Leung & Savithiri, 2009). A defining characteristic of focus groups is their interactive nature, as participants respond not only to the researcher's questions but also to each other's contributions. Within the value-sensitive design research, focus groups are an established empirical method and have been widely used for the elicitation and validation of stakeholder values (Götzl et al., 2022).

The primary purpose of the focus groups was validation and refinement of the personal user-value analysis, rather than the discovery of new themes. Qualitative analysis of social media content is inherently context-dependent and ideally benefits from multiple researchers independently coding and comparing interpretations. As this study was conducted by a single researcher, focus groups were used as an alternative form of interpretive validation by introducing independent perspectives from the most relevant stakeholder group.

People that have or have had cancer were selected as participants because they are both the intended audience of cancer-related nutritional communication on SMPs and OPPs and are the most knowledgeable to reflect on their usage and workings. An additional inclusion criterion was participants' familiarity with social media platforms, so that they could meaningfully reflect on and critically assess the forms of cancer-related nutrition communication examined in this research. Drawing on their lived experience with cancer, participants can assess whether the interpretations derived from the trivial coding of the researcher resonate with their own perceptions, concerns and values. This aligns with the VSD emphasis on grounding value analysis in the perspectives of directly affected stakeholders (Friedman, 1996).

The focus group questions were designed to compare the researcher's interpretations of social media content with those of the participants. To do this in a clear and productive matter, the sessions were split up into three parts. Starting with an introduction of the participants, their journey with cancer diagnosis and experience with social media. This is to create open sphere and make participants feel comfortable. After that, a selection of comments from the sample was prepared on slides. For each comment, the same set of questions was asked:

1. What does the user say with his comment?
2. With what goal did the user post this comment?
3. What does the user find important?
4. With what tone does the user express themselves?

To maintain analytical rigor and reduce bias, the intermediate version of the codebook developed by the researcher at that time was not shared with participants. This ensured that participants' responses reflected their own interpretations rather than being shaped by predefined analytical categories. The open discussion format further allowed the researcher to probe participants' judgments and the reasoning underlying their views, which is considered particularly important within VSD research (Friedman et al., 2017).

The validation of personal values in the focus groups followed an indirect approach. Rather than asking participants to explicitly name or define values, discussions focused on concrete experiences, interpretations, and reactions to examples of cancer-related nutrition communication. In line with methodological heuristics from the VSD literature (Friedman et al., 2017), this indirect approach supports the identification of underlying values as they emerge naturally from participants' narratives and reasoning.

Participants were recruited through the newsletter of the Wereld Kanker Onderzoeksfonds, and through the professional network of the researcher. All focus groups were conducted online. In total, two focus groups were organised, each consisting of two participants. After the first session, minor adjustments were made to the format to better support the validation objective. Microsoft Teams was used for audio recording and automatic transcription. The transcripts were subsequently coded in ATLAS.ti and analysed alongside the social media comment data. Coding followed the same analytical structure as the qualitative content analysis, covering the domains of nutrition and health, communication, and ethics and values.

An overview of the focus group participants is provided in table 2-7.

Participant	Age, gender	Cancer diagnosis
1	58, female	Breast cancer
2	39, female	Breast cancer
3	57, female	Breast cancer
4	36, female	Breast cancer

Table 2-7 Focusgroup participants characteristics

EVALUATING AND MODIFYING THE CODING FRAME

Findings from the focus groups were used to iteratively refine and finalise the codebook and associated codes.

Data collection and coding did not occur at a single point in time but were conducted in multiple, iterative rounds. This approach allowed preliminary coding to inform subsequent data selection. As recurring themes and value patterns emerged, additional content was purposively sampled to further explore and confirm these patterns. In this way, data collection and analysis proceeded together.

Analytical saturation was used as the guiding criterion for determining the adequacy of the dataset. Saturation was considered achieved when new material could be meaningfully coded within the existing framework without requiring substantial changes to the coding frame. This approach aligns with qualitative methodological standards, where saturation marks the point at which further data collection yields diminishing analytical returns rather than novel insights (McKinley & Rose, 2020).

2.3.3 TECHNICAL PHASE

The technical phase synthesizes insights from the conceptual and empirical phases with the aim of developing policy, organizational, and design recommendations for an online patient platform. In this phase, particular attention is given to how the values identified in the conceptual analysis relate to the empirical findings and where tensions between these values emerge. These value tensions are then analyzed to determine how they can be addressed through concrete adjustments in policy, platform design, and organisational practices.

2.3 METHODOLOGICAL LIMITATIONS

VALUE SENSITIVE DESIGN

Value- sensitive design is ideally applied as an iterative process that includes the implementation, testing, and monitoring of interventions with stakeholder involvement. Due to time and scope constraints, this study did not include a phase in which the proposed recommendations were empirically tested. This limitation does not undermine the contribution of the research. As emphasized by Friedman et al., (2017), the motto of VSD is “progress, not perfection”. Given the underexplored value dimensions at the intersection of cancer, nutrition, and social media, this study should be understood as an exploratory first step that provides a basis for future research.

UNIT OF ANALYSIS

Using social media comments as the unit of analysis limits insight into users’ underlying intentions and motivations. The precise reasons why users post comments cannot be established, nor can demographic characteristics be reliably retrieved. In addition, commenting behavior is not representative of the broader user population, as most social media users consume content without actively engaging, known as “lurkers” or “nonusers” (J. Y. Han et al., 2014) . As Bouvier & Rasmussen (2022) state, the “ephemeral nature” of social media interactions further means that comments may be posted with limited reflection or commitment.

Moreover, qualitative content analysis does not allow for follow-up questions, which restricts access to deeper reasoning behind value expressions. This is relevant considering VSD's concern with potential discrepancies between espoused practices (what people say) and actual practices (what people do) (Friedman et al., 2013) Despite these limitations, QCA offers access to perspectives that are often difficult to capture through interviews or focus groups, particularly from less visible or harder-to-reach user groups (Galea et al., 2025). The integration of focus groups in this study provides an additional layer of interpretive validation and supports the use of QCA as an innovative approach to empirical value elicitation on social media.

CONTENT SEARCH STRATEGY

Research based on commercial social media content is constrained by platform-specific algorithms that shape visibility and search results. Although the content search strategy was designed to be as systematic and transparent as possible, complete neutrality and reproducibility cannot be guaranteed. Search results on platforms such as YouTube are automatically ranked according to relevance, engagement, and quality (YouTube, n.d.) , resulting in limited research control. In addition, the qualitative nature of comment screening necessarily involved researcher judgement rather than fixed quantitative thresholds.

VALUES CODING

Ideally, qualitative content analysis involves multiple researchers independently coding the data and comparing results to enhance reliability (Van Enschot et al., 2024). As this study was conducted by a single researcher, such trial coding was not feasible. This might lead to bias in the interpretation of the data. To mitigate this limitation, focus groups with cancer patients and expert interviews were conducted after the initial coding phase. Insights from these sessions were used to refine and validate the coding frame, strengthening the credibility of the analysis.

FOCUSGROUPS

The focus groups consisted of a small number of participants, all of whom were women and shared the same cancer diagnosis. As a result, the findings cannot be considered representative of the broader population of cancer patients with diverse diagnoses, genders, or backgrounds.

However, in the Netherlands, breast cancer is the most common cancer type among women (11.3%) and has a relatively high 5-year survival rate (89%), resulting in a large and growing population of breast cancer survivors (The Netherlands Cancer Agenda, n.d.). Among the total population of cancer survivors, this subgroup known to expresses high interest and concerns about diet and nutrition during and after treatment information (Caprara et al., 2024; Johnston et al., 2021; Sullivan et al., 2021). Therefore, although the findings cannot be generalized to all cancer populations, they remain relevant.

2.4 POSITIONALITY

This research is initialized because someone in the researcher's personal circle has recently been diagnosed with cancer. This personal confrontation has heightened the researcher's sensitivity to the topic of cancer-related nutrition information and online health communication. At the same time, this proximity may introduce interpretive bias, particularly in the assessment of risks and vulnerabilities for patients. Because cancer is such a complex disease and no patient is the same, this research conducted with reflexive awareness and attention to the diversity and complexity of cancer experiences.

In addition, the researcher does not have a formal background in medical or nutritional sciences. While this positions the research outside a clinical perspective and limits full engagement with biomedical complexity, it also situates the study explicitly within communication, ethics, and systems analysis rather than medical evaluation. The research does not aim to assess the clinical correctness of nutritional claims, but focuses on how such claims are interpreted, valued, and negotiated by users within online information environments.

2.5 ETHICAL CONSIDERATIONS

Approval for the manual and targeted collection of commercial social media comments was obtained in accordance with TU Delft's Human Research Ethics Guidelines. Although the analysed content was publicly accessible, research involving social media data raises specific ethical considerations, as users did not explicitly consent to their posts being used for academic research (Bouvier & Rasmussen, 2022).

To address these concerns, particular care was taken to protect the privacy and anonymity of individuals. All social media comments were collected and analysed anonymously. Quotations from users comments that are derived from YouTube, Instagram and Facebook were paraphrased or modified where necessary to prevent traceability to individual users or original posts.

Furthermore, explicit written approval from kanker.nl was retrieved before collection of analysis of user-generated data from their discussion groups and blogs, in line with their terms of use *(Gebruikersvoorwaarden kanker.nl)*. To protect the privacy of kanker.nl user, original comments from user discussions are not published in this thesis. All examples from the data are paraphrased comments to minimize traceability to original posts. In the paraphrasing process, certain medical or other distinctive characteristics that could enable the original comments to be traced back to individual users were eliminated.

Data collected through focus groups were handled in line with the principles of informed consent. Participants were fully informed about the purpose of the study, the use of the data, and their right to withdraw. All personal data were processed confidentially and stored securely.

2.6 REFLECTION ON THE USE OF AI

Artificial intelligence was used during the writing stage of this research to improve the structure and clarity of the text. For example, the researcher could provide prompts in the form of bullet points and used a large language model to assist in integrating these points into coherent sentences and paragraphs. It thus served as a linguistic and structural support tool, helping the researcher to formulate and refine complex sentences.

No AI tools were used during any phase of the qualitative content analysis. The built-in AI functionalities within Atlas.ti were deliberately not used to maintain full control over the coding procedure and to prevent potential data leakage, given the sensitive nature of user-generated content regarding cancer. Furthermore, qualitative content analysis, particularly when aimed at interpreting motivations and underlying values, is not well suited to automated AI analysis, as such interpretation requires contextual understanding and reflexive judgement by the researcher.

3 CONCEPTUAL PHASE

This chapter conducts a socio-technical system analysis of the digital cancer communication landscape in the Netherlands, as part of the conceptual phase of value-sensitive-design. The goal is therefore to expand the initial understanding of the digital system as defined in figure 1-3 and include other stakeholders that are important to consider to the development of policy, design and organisational recommendations. Furthermore, the cultural, infrastructural and personal value implications of stakeholders will be explored. This chapter thus gives answer to sub-research question 1:

“What does the socio-technical system of cancer nutrition and social media in the Netherlands look like and what values are expressed by different stakeholders regarding online cancer nutrition misinformation?”

This means this chapter will dive into the personal, cultural and infrastructural values of the most important stakeholders, in line with the research design defined table 2-1. The analysis proceeds in five steps. First, the total body of literature and desk research that has been used to address this question is discussed in meta. After that, the personal, cultural and infrastructural values of the direct stakeholders are analysed, followed by the roles and interests of indirect stakeholders. These results are summarized in 3.3, after which the interactions are mapped in 3.4. The value tensions that have been found are discussed in 3.5 and conclusions from this phase in 3.6.

3.1 META RESULTS OF THE LITERATURE REVIEW AND DESK RESEARCH

The Scopus search string as described in 2.3.1 resulted in 176 initial results. After applying the criteria for inclusion and exclusion to the abstracts, 16 papers were considered eligible for full-text analysis.

Table 3-1 categorizes these papers by journal type as an indicator of disciplinary orientation. Since this research adopts a systems approach to the problem of online cancer misinformation, it is studied as a multidisciplinary phenomenon, combining healthcare (nutrition and oncology), social media platforms (commercial and patient platforms) and the ethics of technology (value-sensitive Design). Examining the journal types in which existing studies are published provides insights into how these different fields have previously been combined, which leads to a better conceptualization of the system.

Discipline	Journal names	Research topics	Selected literature
Health	BMC nutrition journal, Nutrients, Frontiers in oncology, Qualitative health research, JMIR cancer, Health education and Behaviour, Nutrition, International journal of environmental research and public health, Journal of Human Nutrition and Dietethics, The Laryngoscope, Journal of Adolescent and Young Adult Oncology.	Clinical nutrition and oncology, dietary interventions, patient information needs.	Caprara et al., 2024b; de Clercq et al., 2020; Eisenberg & Josselin, 2024; Fettig et al., 2025; Gao et al., 2021; Ivankova et al., 2021; Johnston et al., 2025; Keaver et al., 2023; Loeb et al., 2024; Moyer et al., 2023; O'Callaghan et al., 2022; Segado-Fernández et al., 2023; Sütcüoğlu et al., 2023; Warner et al., 2022
Supportive oncology	Supportive Care in Cancer	Patient support needs, quality of life for cancer patients	Aggarwal et al., 2020; Loeliger et al., 2021

Table 3-1 Overview of the journal publications from literature review.

Although the search query explicitly combined *cancer*, *nutrition*, and *social media*, the results are almost entirely published in clinical health journals. Just two articles appear in supportive oncology journals, which adopts a more multidisciplinary perspective on oncology. Notably, none of the selected papers were published in dedicated communication, internet or ethics journals. This indicates that the role of social media in cancer nutrition is still mostly interpreted through a clinical lens, rather than as a structural transformation of the digital information landscape.

Given this limited representation of media, communication, and ethics-oriented research in the initial results, additional literature searches were conducted to enable a more comprehensive conceptual value analysis of the system. These searches consisted partly of snowballing from the previously found articles and partly of targeted searches of a broader combinations of keywords, such as *social media* and *cancer* or *social media* and *values*. Results of this second literature search are presented in table 3-2.

Discipline	Journal names	Research topics	Selected literature
Health	Journal of Cancer research and oncology, Journal of Clinical Oncology, European Journal of Cancer Care, Clinical Nutriton ESPEN	Clinical nutrition and oncology, dietary interventions, patient information needs.	Braun et al., 2019, p. J; Demark-Wahnefried et al., 2005; Johnston et al., 2021; Sullivan et al., 2021; Warner et al., 2021
Supportive oncology	Journal of cancer survivorship	Supportive care during and after cancer	Harkin et al., 2017
Media and Internet	Journal of Medical Internet Research, New Media & Society	Social media platform studies, internet use	Brown et al., 2014; Scharlach et al., 2024
Communication	International Journal of Communication	Influencer communication	Atef et al., 2023

Table 3-2 Overview of the journal publications after secondary literature search

Still, what can be concluded from this secondary search is that most work is published in health-related journals. However, these additional sources offer deeper insights into online communication dynamics and commercial social media. What is still lacking is dedicated ethics research on the values of social media users in the context of cancer and nutrition. Therefore, the values that will be attributed to these stakeholders in this chapter are only anticipated.

Moreover, the existing literature provides limited insight into the specific Dutch stakeholder landscape, which is central to this research given its focus on Kanker.nl and its position within the national online information environment. Only work from van Eenbergen (2021) and van Veen (2019) specifically address Dutch cancer communication stakeholders. Previous studies also offer little analysis of the relevant regulatory and policy frameworks needed to formulate policy recommendations for the online patient platform.

To address these gaps, additional desk research was conducted. This began with an in-depth analysis of the kanker.nl website and its associated partners, complemented by a review of Dutch and European policy documents related to cancer, nutrition, and online misinformation.

Together, these three bodies of data, systematic literature review, extended academic search, and desk research, form the basis for answering SRQ1.

3.2 STAKEHOLDER ANALYSIS

As proposed in value-sensitive design, stakeholders are analysed based on the directness of their relationship to a technology (Friedman et al., 2017). Accordingly, this section differentiates between direct stakeholders, and indirect stakeholders.

3.2.1 DIRECT STAKEHOLDERS

CANCER PATIENTS WHO USE SOCIAL MEDIA

The direct stakeholder group for this research are individuals who have or have had cancer and make use of social media. As they are the target user group of kanker.nl, it is important to gather insights into their characteristics, wans and personal values to ensure that any proposed recommendations for the platform align with what they as users consider important. Although this group is highly diverse in terms of age, diagnosis, and treatment trajectory, prior research has identified some overarching patterns in their motivations for and experience with social media use, particularly in relation to nutrition information.

A defining characteristic of cancer patients is their vulnerability. A cancer diagnosis is associated with physical uncertainty, emotional distress, and an increased need for information and support (Caprara et al., 2024; Sullivan et al., 2021). From a nutritional perspective, cancer patients are particularly vulnerable due to the impact of the disease and the side effects of treatment, which increase the risk of disease-related malnutrition (Arends et al., 2017).

At the same time, a cancer diagnosis can function as a so-called “teachable moment”: a critical life event that increases motivation for positive lifestyle changes, including improvements in dietary behaviour (Demark-Wahnefried et al., 2005). This results in many cancer patients valuing optimal nutrition for health (Ford et al., 2022).

However, heightened motivation does not automatically lead to different dietary behaviors. Cancer survivors report barriers such as lack of time, fatigue, limited access to tailored guidance, and uncertainty about the reliability of dietary advice as driving factors behind suboptimal dietary intake (Keaver et al., 2023).

Along with the general increase in the use of ditigal sources for health-related purposes, cancer patients increasingly use the internet to collect information about their disease, communicate with others, and cope with their diagnosis (van Eenbergen, 2021). For example, nearly half of Italian breast cancer patients report using platforms such as Facebook and Instagram to find nutritional advice (Caprara et al., 2024).

Besides mainstream platforms, patients also make use of dedicated cancer forums. Empirical studies that analyse user-generated content from cancer forums demonstrate the importance of such platforms. Johnston et al. (2025) found that 89% of messages on English-language cancer forums focus on sharing information rather than seeking it, highlighting the strong peer-to-peer character of these communities. Furthermore they found that information sharing about nutritional topics is common in online forums for people affected by cancer, suggesting they value these peer-driven information environments.

Similarly, a content analysis of a large German cancer forum showed high levels of engagement, with 2,246 posts across 22 threads generating over 654,000 visits, particularly around nutrition and lifestyle topics (Fettig et al., 2025). These findings indicate that cancer-specific forums play a meaningful role in cancer patients' nutritional information practices and social support networks.

The motivation for using social media for nutritional advice is associated with the gap between patients' informational needs and the advice and support provided by healthcare professionals (Johnston et al., 2021; Sullivan et al., 2021). Empirical findings consistently illustrate this gap. For example, Loeliger et al. (2021) report that while 84% of Australian cancer patients consider nutrition important, only 51% discussed nutrition with a healthcare professional and just 32% consulted a dietician.

Similarly, a national survey in Ireland found that although 92.9% of breast cancer survivors expressed interest in receiving nutrition advice, only 20% and 12% had been assessed by a dietician during and after treatment, respectively (O'Callaghan et al., 2022).

This lack of professional guidance, combined with increased patient motivation to address dietary concerns as discussed earlier, has driven patients to seek nutritional information independently. As a result, online resources such as commercial social media platforms, have become prominent sources of cancer-related information (Braun et al., 2019) and sometimes are being consulted even before their first oncology appointment (Moyer et al., 2023). This widespread use and reliance on social media for nutritional advice indicates an unmet need and desire for accessible, reliable, and professionally guided nutritional advice.

Cancer patients' social media preferences vary by age. Generally adolescent and young adult cancer patients have a higher demand for nutrition information compared to older demographics (Ford et al., 2022). Furthermore, younger cancer patients are more likely to use social media for information compared to older patients (Aggarwal et al., 2020). In addition, older adults tend to favor Facebook groups, while younger individuals are more inclined to use visually oriented and short-form platforms such as TikTok (Caprara et al., 2024a; de Clercq et al., 2020; Ivankova et al., 2021). These findings underline user diversity and underscore the importance of examining multiple social media platforms when analysing how cancer patients engage with nutrition-related information online.

Despite the use of social media for nutritional advice, patients consistently report that they still most want to receive information from their doctor, and trust oncologists above all other sources (Braun et al., 2019; Moyer, Madsen, Johnson, Del Chiaro, et al., 2023). This indicates that the turn to online resources is often a response to a gap in care rather than a rejection of professional advice. These findings provide insights into the way that patients value their doctors in their treatment journey.

While this information gap between cancer patients and healthcare professionals remains, turning to the internet also holds the risk of an overwhelming "flood" of information. This phenomenon is related to what the World Health Organization has termed an *"infodemic",* defined as "a tsunami of information—some accurate, some not—that spreads alongside an epidemic" (WHO, 2020)

Though cancer is not an infectious disease, the term still captures the sense of informational overload that is reported by patients in studies about their informational needs (Eisenberg & Josselin, 2024; Keaver et al., 2023; Loeb et al., 2024; Sullivan et al., 2021). This further indicates a desire for more accessible and reliable nutrition-related information.

In sum, this body of literature provides initial insides into the personal values of cancer patients who use social media. Table 3-4 gives summarises the findings by defining the anticipated personal values of cancer patients that use social media.

The emphasis on anticipated is important, as the existing research has not looked at these values explicitly. Most studies focus on reported informational needs, survey responses, or general patterns of online behaviour, rather than analysing how patients' values are expressed through their interactions with online content. Moreover, the specific characteristics and experiences of Dutch cancer patients remain underexplored, leaving the cultural dimension of the personal values insufficiently addressed.

Personal Values	**Definition**	**Explanation**
Health	The concern to improve or maintain health outcomes through informed lifestyle and dietary choices during and after cancer treatment.	After diagnosis, patients actively explore ways to support their recovery and long-term health, with nutrition often seen as an important factor that they have influence over (Demark-Wahnefried et al., 2005; Ford et al., 2022).
Peer knowledge and support	The importance of exchanging experiences and advice with other people that have or have had cancer.	Online communities provide spaces where patients can relate to others in similar situations, share coping strategies, and share and seek information related to treatment and lifestyle (Johnston et al., 2025; Fettig et al., 2025).
Trust	The importance placed on guidance from qualified healthcare professionals as credible and authoritative sources of cancer-related information.	Despite using online platforms, patients consistently report that oncologists and healthcare professionals remain their most trusted source of cancer-related information (Braun et al., 2019; Moyer et al., 2023).
Professional nutritional guidance	The desire to receive dietary advice from qualified healthcare professionals.	Cancer patients express interest in nutritional guidance during and after treatment. However, only a minority receive such support from dieticians Loeliger et al., 2021; O'Callaghan et al., 2022).

Evidence-based nutritional guidance	The desire for scientifically grounded and reliable information about nutrition and cancer.	The abundance of online health information can create confusion and information overload. Patients therefore seek clear, reliable information to navigate conflicting nutrition advice (Eisenberg & Josselin, 2024; Sullivan et al., 2021).

Table 3-3 Anticipated personal values of cancer patients that use social media

ONLINE PATIENTS PLATFORM

As the defined platform type to whom recommendations for policy, design and organization are directed is, online patient platforms are a direct stakeholder in this research. To formulate actionable recommendations aimed at strengthening them, it is necessary to get insights into the platform's cultural and infrastructural values. The primary for this analysis are the website kanker.nl, the annual report (Jaarverslag Stichting Kanker.Nl 2024) and academic work from van Eenbergen(2021).

CULTURAL VALUES

Founded in 2013, kanker.nl was established to centralize and make accessible reliable cancer-related information for patients and healthcare professionals. It operates independently from hospitals and electronic health record systems, thereby functioning as a complementary digital space for information, peer interaction, and support (van Eenbergen et al., 2021).

The platform's mission is to "improve the quality of life of people affected by cancer by supporting self-management and facilitating collaboration between patients and healthcare professionals" (kanker.nl, n.d.) Related objectives include improving the quality of life for cancer patients, promoting self-management, and fostering collaboration between patients and healthcare professionals. Across the website, and annual report, three core cultural values consistently emerge, which are defined and explained in table 3-4.

Cultural Value	Definition	Description
Reliability	The commitment that information shared on the platform must be evidence-based and aligned with current scientific consensus.	The online patient platform follows a scientific evidence-based communication approach. Information shared by users in the discussion groups must meet specific credibility criteria. Claims are expected to be supported by multiple independent sources rather than anecdotal evidence or individual experiences. Scientific findings must be interpreted within their broader research context, considering research methodology, quality of evidence, and generalizability. Non-evidence-based treatments or unsupported dietary claims are not allowed, together with the promotion of products, services or other websites (kanker.nl, n.d.-k, n.d.-c).
Safety	The commitment to protect users' personal information, privacy, and well-being within the platform environment.	On the online patient platform, safety is operationalized through strict data protection practices. Personal data is securely protected and not shared with third parties for commercial purposes. The platform is transparent about how user data is collected and used and clearly communicates the measures taken to safeguard privacy. Privacy information is easily accessible, and users can contact the organization with questions or concerns regarding data protection. These practices aim to foster trust and create a secure environment for users sharing personal cancer experiences (kanker.nl, n.d.-i, n.d.-b).
Community	The commitment to foster a supportive, respectful, and empathetic environment in which users can exchange experiences and support one another.	The online patient platform encourages users to exchange experiences and support one another through discussion groups and community spaces. The platform promotes empathetic language and respectful interaction, ensuring that discussions do not create confusion or insecurity among users. Clear community guidelines structure these interactions and aim to maintain a supportive environment where patients can share experiences while safeguarding informational reliability and emotional well-being (kanker.nl, n.d.-c).

Table 3-4 Cultural values of online patient platforms

These three cultural values are all operationalized in explicit platform community guidelines (kanker.nl, n.d.-j, n.d.-c). A central role in enforcing these values is played by moderators and community managers. Acting on behalf of the platform, they are responsible for maintaining a safe and reliable digital environment by monitoring discussions and supporting respectful communication among users.

When users violate the community guidelines or when moderators consider a discussion to create an unsafe situation for participants, they are authorised to intervene. Such interventions may include issuing warnings, requesting participants to adjust or remove certain contributions, or editing or deleting posts when necessary. Repeated violations of the community guidelines or reposting previously removed content can ultimately lead to the exclusion of users from participation from the platform (kanker.nl, n.d.-c).

Together, these norms illustrate how the online patient platform actively governs user-generated content to align community interaction with the cultural values of reliability, safety, and community. However, there is limited empirical insight into how these formulated cultural values are enacted in practice.

One exception is from van Eenbergen (2021), who examined kanker.nl user-generated content posted by relatives of cancer patients, providing insight into their informational needs and support practices. To date, however, cancer patients themselves have not been the subject of qualitative content analysis on the platform. This gap underscores the need for further empirical investigation into how these cultural values are enacted in practice.

INFRASTRUCTURAL VALUES

Beyond its explicit mission and guidelines, online patients platforms also embed values within their technical infrastructure. Unlike engagement-driven commercial platforms, they do not operate on an advertising-based revenue model or monetise user data (kanker.nl, n.d.-a) This choice reflects a prioritisation of public value over growth or data extraction.

At the same time, the platform does make use of personalized features. Users may voluntarily provide information about their diagnosis, treatment phase, or relationship to cancer. According to the platform’s terms of use, it links keywords (metadata, tags, labels) to website content, including discussion groups and blogs, and may connect these to participants’ profile characteristics and preferences in order to provide tailored suggestions for relevant pages or conversation groups (kanker.nl, n.d.-b).

Importantly, this process is explicitly disclosed: the organization states that it considers it important to inform participants about how personalization is applied and offers users the possibility to request further information (kanker.nl, n.d.-b).

This limited and transparent form of algorithmic recommendation reflects the online patient platforms’ infrastructural commitments to transparency and users autonomy, distinguishing it from commercial platforms where recommendation systems are optimized for engagement and opaque to users (Scharlach et al., 2024). These two infrastructural values are defined and described in detail in table 3.5.

Infrastructural value	Definition	Description
User autonomy	The commitment to support users' ability to make informed choices about their participation and data sharing on the platform.	Personalisation on the online patient platform is voluntary and limited. Users may choose to share profile information to receive tailored content, but the platform does not rely on advertising models or monetise user data.
Transparency	The commitment to openly communicate how platform systems, data use, and personalisation mechanisms operate.	The online patient platform clearly informs users about how personalisation works. The platform may connect profile information (e.g., diagnosis or treatment phase) with tagged website content to suggest relevant pages or discussion groups. This process is explicitly disclosed in the platform's terms of use and users can request additional information about how their data is used.

Table 3-5 Anticipated infrastructural values of online patient platform

COMMERCIAL SOCIAL MEDIA PLATFORMS

Commercial social media platforms (CSMPs) are direct stakeholders in this study because they are analyzed in comparison to online patient platforms and form part of the digital cancer information system. To meet the goal of this research and make recommendations aimed at strengthening OPPs in relation to SMPs, it is important to get deeper insights into their cultural and infrastructural values.

CULTURAL VALUES

The cultural values of commercial social media platforms for this research are drawn Scharlach et al. (2024), who examined how YouTube, Facebook and Instagram publicly articulate their cultural values through privacy policies, terms of service, and community guidelines. This approach aligns with the value conceptualization adopted in Section 2.1.1, in which cultural values are understood as explicitly formulated commitments expressed in official documentation (Hallinan et al., 2022).

Across the platforms analysed, Scharlach et al. (2024) identified five recurring cultural values: expression, community, safety, choice, and improvement. Their definitions and descriptions are gathered in table 3-6.

Cultural Value	**Definition from Scharlach et al. (2024)**	**Description**
Expression	“The free articulation of thoughts, opinions and emotions op users.”	Commercial platforms position themselves as spaces where users can freely share content, experiences, and opinions. Restrictions on user-generated content are framed as minimal, with moderation primarily justified when content violates community standards such as harassment or harmful misinformation.
Community	“A set of intimate relations developed or sustained through communication technologies.”	Platforms emphasise their role in enabling social connection, allowing users to interact, share experiences, and build relationships through digital communication. Community is framed as a central benefit of social media use.
Safety	“Freedom from harm or risk.”	Safety is presented as a platform responsibility to protect users from harmful behaviour such as harassment, hate speech, or dangerous misinformation. This value is primarily operationalised through moderation policies and community guidelines.
Choice	“The idea that users should be free to pick options that align with their interests.”	Platforms emphasise user freedom and personalisation. Users can choose which content to view, which accounts to follow, and how they interact with the platform, often supported by algorithmic recommendations tailored to their interests.
Improvement	“The continuous enhancement of platform services and user experience”.	Platforms frame ongoing development and optimisation as improvements that benefit users. In practice, this value often manifests through features designed to increase engagement and polarization.

Table 3-6 Cultural values of commercial social media platforms

INFRASTRUCTURAL VALUES

However, articulated cultural values do not fully capture the infrastructural logic embedded in platform design of YouTube, Instagram and Facebook. As Scharlach et al. (2024) argue, the most important value for which platforms actually take “full responsibility”, is improvement. In practice, improvement means profit in terms of economic growth. This cultural value, Scharlach et al, (2024) argue, is translated through hidden infrastructural values such as user engagement, expanding user bases, and maximising data extraction.

One way in which these infrastructural values become empirically visible is through the circulation and amplification of health-related misinformation. Engagement-driven systems tend to reward content that attracts attention, irrespective of its quality (Johnson et al., 2022; Loeb, Langford, et al., 2024). In the context of cancer and nutrition, several platform studies provide empirical evidence of this dynamic.

Firstly, Segado-Fernández et al. (2023) analysed YouTube videos related to “real food” and cancer and found that 12.5% of videos suggested that certain foods could cure cancer without medical treatment. Only 13.89% of videos provided external scientific references. While content produced by health-related users demonstrated higher reliability scores, a great portion of videos created by non-health users lacked scientific grounding, posing potential risks for viewers

Similarly, Sütcüoğlu et al. (2023) evaluated the quality and reliability of YouTube videos on cancer and nutrition with help of an internationally valid medical video evaluation score. Although many videos were highly viewed, overall reliability scores were low. Notably, the study found a negative correlation between video quality and the number of views and likes, indicating that less reliable content tended to attract greater engagement.

Beyond YouTube, (Warner et al., 2022) examined cancer-related nutrition claims on Pinterest. In their analysis of 103 pins, 41.8% of content claimed to prevent cancer, 27.2% claimed to treat it, and 10.7% claimed to cure it. Nearly half of the linked content sites were for-profit, and one-third were selling a product. Validity indicators such as academic citations or disclaimers were inconsistently present. The study concluded that cancer nutrition misinformation was widespread and financial incentives were at stake.

Building on these empirical findings, Warner et al. developed a conceptual framework for online cancer nutrition misinformation. This framework maps how misleading claims are framed (see figure 1-1), how contextual elements such as citations, disclaimers, or personal anecdotes may influence perceived credibility of these claims, and how exposure to such claims may eventually shape patients’ health beliefs and behavioural responses. In other words, the framework maps potential pathways linking misinformation exposure to treatment decision-making, dietary and supplement intake, and, in the longer term, possible implications for cancer treatment outcomes. In this way, it demonstrates that the impact of misinformation extends beyond online discourse and may influence real-world behaviour of cancer patients.

Taken together, the literature illustrates how the hidden infrastructural values of commercial social media platforms can facilitate the visibility and consequences of cancer-related nutrition misinformation. Definitions and descriptions are gathered in table 3-7. However, what remains insufficiently understood is how patients interpret, negotiate, or act upon such content online. Therefore, more empirical insights are needed to better understand the effect of the infrastructural values of commercial platforms on the personal values of cancer patients.

Infrastructural value	Definition	Description
User engagement optimization	The prioritisation of platform features and algorithms that prioritise user interaction with content over scientific validity.	Recommendation systems are designed to promote content that generates high levels of interaction such as views, likes, and comments. Because attention rather than informational quality is prioritised, sensational or misleading health claims may receive disproportionate visibility (Segado-Fernández et al., 2023; Sütcüoğlu et al., 2023).
Data extraction	The systematic collection and analysis of user data to optimise platform performance and generate economic value.	User interactions and behavioural data are continuously collected to refine recommendation systems and target advertising. This data-driven optimisation reinforces the visibility of highly engaging but potentially misleading health information, such as misleading cancer nutrition claims (Warner et al., 2022).

Table 3-7 Anticipated infrastructural values of commercial social media platforms

3.2.2 INDIRECT STAKEHOLDERS

COMMERCIAL PLATFORM REGULATORS AND POLICYMAKERS

Regulators are included as indirect stakeholders because, although they do not directly interact with cancer patients on digital platforms, they shape the regulatory and policy environment within which these platforms operate. Through legislation, funding structures and policy, they influence how nutrition-related misinformation about cancer on commercial platforms is governed and how online patient platforms are positioned within the broader digital cancer information landscape.

Commercial social media platforms such as Facebook, Instagram, and YouTube fall under the category of Very Large Online Platforms (VLOPs) and are therefore subject to the Digital Services Act (DSA) of the European Commission. The DSA focuses on increasing transparency and accountability, particularly with respect to algorithmic recommender systems and online advertising (European Comission, n.d.-b)

However, while the DSA acknowledges public health as a potential area of concern (Ó Fathaigh et al., 2025), its practical focus remains on forms of disinformation that pose immediate societal threats, such as electoral interference or coordinated information manipulation. Cancer- and nutrition-related content is not treated as a priority risk domain, as it is generally framed as relating to individual lifestyle choices rather than as a direct threat to public order or democratic processes. As a result, nutritional misinformation in the context of cancer falls outside the scope of targeted regulatory intervention under the DSA.

Beyond the DSA, the European Commission has addressed health-related misinformation primarily in response to the COVID-19 pandemic, particularly with respect to vaccination and crisis communication (European Comission, 2026). These initiatives do not extend substantially to other health domains. Similarly, the Commission's "Europe's Beating Cancer Plan" emphasizes healthy lifestyles, including diet, but does not address the role of CSMPs in the dissemination of cancer-related misinformation advice (European Comission, n.d.-a).

This brief review of the most influential regulatory and policy frameworks for commercial platforms reveals that while the risk of health-related misinformation spread through VLOPs is being acknowledged, cancer nutrition in specific is not a topic of interest, nor is it sufficiently addressed in terms of policy plans. Consequently, the responsibility for navigating the risks and potential harms of nutrition-related misinformation lies at cancer patients themselves.

In the absence of these regulatory measures addressing cancer nutrition misinformation on commercial platforms, alternative approaches aimed at strengthening online patient platforms are therefore particularly relevant within the current governance landscape.

ONLINE PATIENT PLATFORM NETWORK PARTNERS

Kanker.nl functions as a network organisation and is financially dependent on external parties. Its strategic orientation vís-a-vís commercial platforms and long-term vision is therefore partly shaped by other stakeholders. Analysing the interests of these parties is thus necessary to make useful recommendations for policy, organisation and design of kanker.nl.

Kanker.nl was initiated by KWF Kankerbestrijding, the Nederlandse Federatie van Kankerpatiëntenorganisaties (NFK), and Integraal Kankercentrum Nederland (IKNL). Since 2016, kanker.nl has managed and further developed the platform as an independent foundation, but in close collaboration with these initiating partners, making them the most important indirect stakeholders (kanker.nl, n.d.-h).

The NFK serves as an umbrella organisation for 21 cancer patient associations and represents the collective interests of cancer patients. Within the governance structure of kanker.nl, the NFK primarily translates patient perspectives and needs into platform priorities. Through this collaboration, patient interests are structurally embedded in the informational and communicative design of kanker.nl (Jaarverslag Stichting Kanker.Nl 2024).

Given that this thesis aims to translate patient values into platform design recommendations for kanker.nl, the NFK can be expected to play a facilitative role within the system, as its mandate aligns with strengthening patient-centered communication. At the same time, the methodological approach used in this research, particularly the use of user-generated content analysis to identify patient values, is an uncommon way of operationalizing patient representation within platform design. Because the NFK is the stakeholder most closely connected to cancer patients outside the digital, but "offline" environment, it can play a validating and supportive role in translating identified patient values into possible design changes and potential policy measures aimed at mitigating misinformation and improving nutritional literacy.

IKNL monitors cancer incidence and treatment in the Netherlands through the Nederlandse Kankerregistratie (NKR). It collects and analyses national cancer data, delivering evidence-based insights to healthcare professionals, policymakers, and platforms such as kanker.nl. The role of IKNL is to supply reliable statistics and research findings that underpin the informational content presented on the platform (Jaarverslag Stichting Kanker.Nl 2024). Unlike advocacy-oriented stakeholders, IKNL does not play an active role in the community function of kanker.nl but contributes to the scientific foundation of the information they provide. As such, proposed changes in policy, organisation or platform design that remain aligned with evidence-based information are unlikely to conflict with IKNL's mandate.

KWF Kankerbestrijding operates as an overarching strategic and financial stakeholder. This umbrella organisation connects researchers, clinicians, patients, and policymakers within a broader vision aimed at improving cancer care and communication in the Netherlands (*KWF Ambitie 2030*, n.d.). Kanker.nl is financed by KWF sustainably (kanker.nl, n.d.-g). Although kanker.nl operates independently in daily management (Jaarverslag Stichting Kanker.Nl 2024), this financial dependency implies that strategic innovation of kanker.nl, including potential investments in design, or positioning within the digital information landscape, remains contingent upon KWF's priorities and resource allocation. Even in the absence of immediate funding risks, alignment with KWF's broader agenda is therefore crucial when considering policy, organizational or design changes of kanker.nl.

The fourth relevant network partner of kanker.nl is the Wereld Kanker Onderzoeksfonds. On their website, the WKOF provides scientifically grounded information on the relationship between nutrition and cancer, aimed at patients, survivors, and the wider public. Originally launched in 2014 as Voedingenkankerinfo.nl in collaboration with the Landelijke Werkgroep Diëtisten Oncologie and Wageningen University, the organisation sought to address confusion between myths and evidence in cancer nutrition (van Veen, 2019).

For kanker.nl, WKOF functions as a knowledge partner supplying validated nutritional information. References to WKOF sources regularly appear within discussion groups and community pages of kanker.nl, indicating active collaboration (kanker.nl, n.d.-e). Given that this research focuses specifically on cancer nutrition communication, coordination between kanker.nl and WKOF is important to ensure that changes in the platforms design or organization safeguard the scientific integrity, consistency, and reliability of nutrition-related content.

STRATEGIC POSITIONING OF KANKER.NL VIS-À-VIS COMMERCIAL PLATFORMS

Now that the network dependencies of kanker.nl have been clarified, it is necessary to examine its current strategic positioning in relation to commercial social media platforms. As outlined in Section 1.3, this thesis applies as systems perspective in which online patient platforms operate within the same digital information system as commercial platforms. To formulate realistic and effective recommendations aimed at strengthening the position of online patient platforms, greater insight into their existing strategy towards commercial platforms is required.

In their main policy document, kanker.nl does not articulate an explicit vision or strategic framework regarding the role of commercial social media platforms in the dissemination of cancer-related information (Jaarverslag 2024). It remains unclear whether these platforms are viewed as competitors, complementary outreach channels, or dangerous environments requiring strategic counter-positioning.

At the same time, kanker.nl maintains professional accounts on Instagram, YouTube, and Facebook, suggesting recognition that its target audience is active on these platforms ((Instagram; @stichting_kanker.nl, Facebook; @kanker.nl , YouTube; @kanker_nl) However, a review of these channels indicates that they are not used to actively combat misinformation about nutrition. Instead, their main objective appears to be directing users to the kanker.nl platform.

A comparable organisation that demonstrates an alternative approach to commercial social media platforms is the Anticancer Fund from Belgium (Anticancer fund, 2026). On their Instagram profile (@anticancer.fund), they adopt a clearly different strategy than kanker.nl. By producing interactive content under the hashtag #kankerzonderzever, in which healthcare professionals actively debunk common myths and misleading cancer-related claims, they clearly try to combat misinformation. Unlike kanker.nl, they make deliberate use of platform-specific affordances such as hashtags and short-form visual content to increase visibility and engagement around misinformation topics. Furthermore, content specifically addressing nutrition and cancer, identified earlier as an important source of patient questions and information needs (Section 3.2.1.1), appears limited in comparison to other topics on the Facebook, Instagram and YouTube accounts of kanker.nl

These observations suggest that kanker.nl currently plays a passive role in addressing cancer-related misinformation on commercial social media platforms. Although the organisation is present on these platforms, its communication does not appear to focus strongly on countering misinformation or actively using platform features to increase visibility. Due to a lack of formal documentation, it is not clear why this position is taken. As a result, it cannot be determined whether this reflects a conscious strategic choice, for example, to focus primarily on its own platform, or a lack of knowledge regarding strategies for making engaging content.

Given this gap in policy, a review of other public cancer organisations has been done, to see if they do have a clearer vision regarding the role of cancer-related misinformation on commercial social media.

Firstly, a similar absence of a defined strategy is visible in the policy framework of KWF Kankerbestrijding. In its strategic vision document *(KWF Ambitie 2030,* n.d.) acknowledges that “social media and the accessibility of information—of varying quality and reliability—play a role in shaping perceptions of good care.” While this statement recognizes that commercial social media influence how patients understand cancer and care quality, the document does not further specify what this “role” entails. It also does not outline concrete responsibilities, governance measures, or strategic actions aimed at addressing misinformation or guiding patients within these digital environments.

Secondly, the Dutch Cancer Collective has made the Dutch Cancer Agenda (2026) (Nederlands Kanker Collectief, n.d.), which is the most comprehensive national cancer policy framework in the Netherlands. The agenda was developed with input from over 100 organizations, including online patients' platforms. It sets out twenty goals to "reduce the impact of cancer on society". These goals extend beyond medical treatment and include topics such as prevention, lifestyle, work participation, psychosocial well-being, and quality of life up to 2032.

Despite this broad and holistic scope, the document nowhere addresses the role of commercial social media platforms in shaping cancer-related information. Furthermore, it does not address the increase of misinformation spread nor propose any measures to mitigate against this issue.

In sum, the analysis of the network partners of kanker.nl reveals a clear policy gap regarding the mitigation of cancer-related misinformation on commercial social media platforms. As a result, the recommendations developed as part of the technical analysis of this research are exploratory and innovative in nature, contributing to an area where a structural policy base is largely absent.

ONCOLOGY HEALTHCARE PROFESSIONALS

Oncology healthcare professionals comprise a diverse group of practitioners involved in cancer care, including medical oncologists, surgeons, radiotherapists, oncology nurses, and oncology dietitians. In the Netherlands, they are represented by the Landelijke Werkgroep Dietisten Oncologie en de Nederlandse Vereniging voor Medische Oncologie. This group is included as an indirect stakeholder because, while they do not have an active role in the design or governance of online patient platforms, they are increasingly affected by patients' exposure to online cancer and nutrition information, altering expectations and communication with them. Moreover, the online patient platform is not exclusively a platform for patients; it also functions as a resource for healthcare professionals, who may refer patients to the platform or consult it themselves. Though not the direct user group of interest in this study, their values are still important to consider developing recommendations for policy, organization and design.

This increased use of social media for healthcare-related information creates both opportunities and challenges for healthcare professionals. Some scholars argue that they should make use of social media. For example, de Clercq et al. (2020) finds that extending professional guidance into digital spaces may help counter unreliable information. Furthermore, studies on "social media doctors" demonstrate how professionals on YouTube can adopt a dual role as part influencer and part doctor (Atef et al., 2023), or use Instagram to give answer to patients about "cancer and nutrition"-related topics (Caprara et al., 2024).

However, the literature reveals that there currently is no clear agreement on how healthcare professionals should deal with social media (Brown et al., 2014), let alone for oncologic care specifically. At the same time, research consistently shows that oncology healthcare professionals remain the most trusted source of cancer-related information for patients (Braun et al., 2019a; Caprara et al., 2024; Moyer et al., 2023; Sullivan et al., 2021), emphasizing their crucial role in guiding patients through their cancer journey. This is an important factor that must be acknowledged for the recommendations directed at online patient platforms.

RESEARCH PARTIES

Research parties are included as indirect stakeholders because they produce scientific knowledge that is guiding cancer nutrition recommendations and clinical guidelines. The availability and quality of research directly influence how clearly nutrition can be communicated to patients and how effectively misinformation can be countered. Current evidence on cancer nutrition is synthesised in clinical guidelines such as the ESPEN guidelines for nutrition in cancer care (Muscaritoli et al., 2021). In the Netherlands, the leading research institute for nutrition is Wageningen University.

Studying nutrition requires long-term follow-up, large and diverse patient populations, and complex study designs, making robust evidence difficult to generate (Weaver & Miller, 2017). In addition, (Weaver & Miller, 2017) mention chronic underfunding as one of the defining constraints on clinical nutrition research. As a result, gaps and uncertainties in the evidence base persist, which can contribute to confusion and increase vulnerability to misinformation in online environments. Recommendations for online patient platforms should therefore remain aligned with efforts to improve the quality and accessibility of evidence in cancer nutrition.

INTEGRATIVE MEDICINE INTEREST GROUPS

Integrative medicine interest groups are included as indirect stakeholders because they seek to make nutrition a more integral part of oncological care, responding to patients' demand for increased nutritional guidance. In the Netherlands, this role is primarily fulfilled by the Vereniging Arts en Leefstijl (Vereniging Arts en Leefstijl, n.d.). Their aim is to integrate lifestyle medicine, of which nutrition is a key component, into regular healthcare practice. This approach is part of a broader movement referred to as "supportive oncology", which focuses on complementary, evidence-informed support alongside standard cancer treatment (Aung et al., 2025).

Organizations such as Arts en Leefstijl collaborate with kanker.nl to strengthen patient-centered information on nutrition. Furthermore, they educate healthcare professionals with the knowledge, skills, and tools to guide individuals towards a healthy lifestyle. Besides education, they also lobby to place lifestyle higher on the agenda of governmental bodies, educational institutions and health insurers (Vereniging Arts en Leefstijl, n.d.)

Therefore, Vereniging Arts en Leefstijl can play an important supporting role in the further development of kanker.nl regarding the needed increase in attention for nutrition-related guidance and information.

3.3 OVERVIEW TABLE

To sum up the stakeholder identification procedure, table 5 is created, which explains the role and significance of each group, reasoning behind including them and anticipated values based on the literature and desk review.

	Role description	**Reasoning**	**Values**
Direct stakeholders			
Cancer patients that use social media	End-users of social media platforms who seek, share, and interpret cancer nutrition information and peer experiences.	They are directly affected by platform design, information quality, and governance of online patient platforms.	**Personal:** Health; peer-to-peer support; trust; professional nutritional guidance; evidence-based nutritional guidance (see 3.2.1.1)
Online patient platfrom	Non-commercial social platform providing reliable and evidence-based cancer information and moderated user-generated discussion groups.	Organisation to which policy, design and organisation recommendations are directed.	**Cultural:** Reliability; safety; community. **Infrastructural:** transparency; user autonomy. (see 3.2.1.2)
Commercial social media platforms (Instagram, YouTube, Facebook)	Engagement-driven commercial platforms that operate on growth-oriented logic and provide the dominant infrastructures through which cancer nutrition information circulates at scale.	Digital platforms where misinformation spreads.	**Cultural:** expression; community; safety; choice; improvement. **Infrastructural**: user engagement optimisation; data extraction. (see 3.2.1.3)
Indirect stakeholders			
Commercial platform regulators and policymakers	Institutions shaping the legal and policy framework for commercial platform governance and health communication.	They create the regulatory environment for very large online platforms regarding misinformation and are responsible for supporting	**Cultural:** Public health protection, commercial platform accountability. See 3.2.2.1

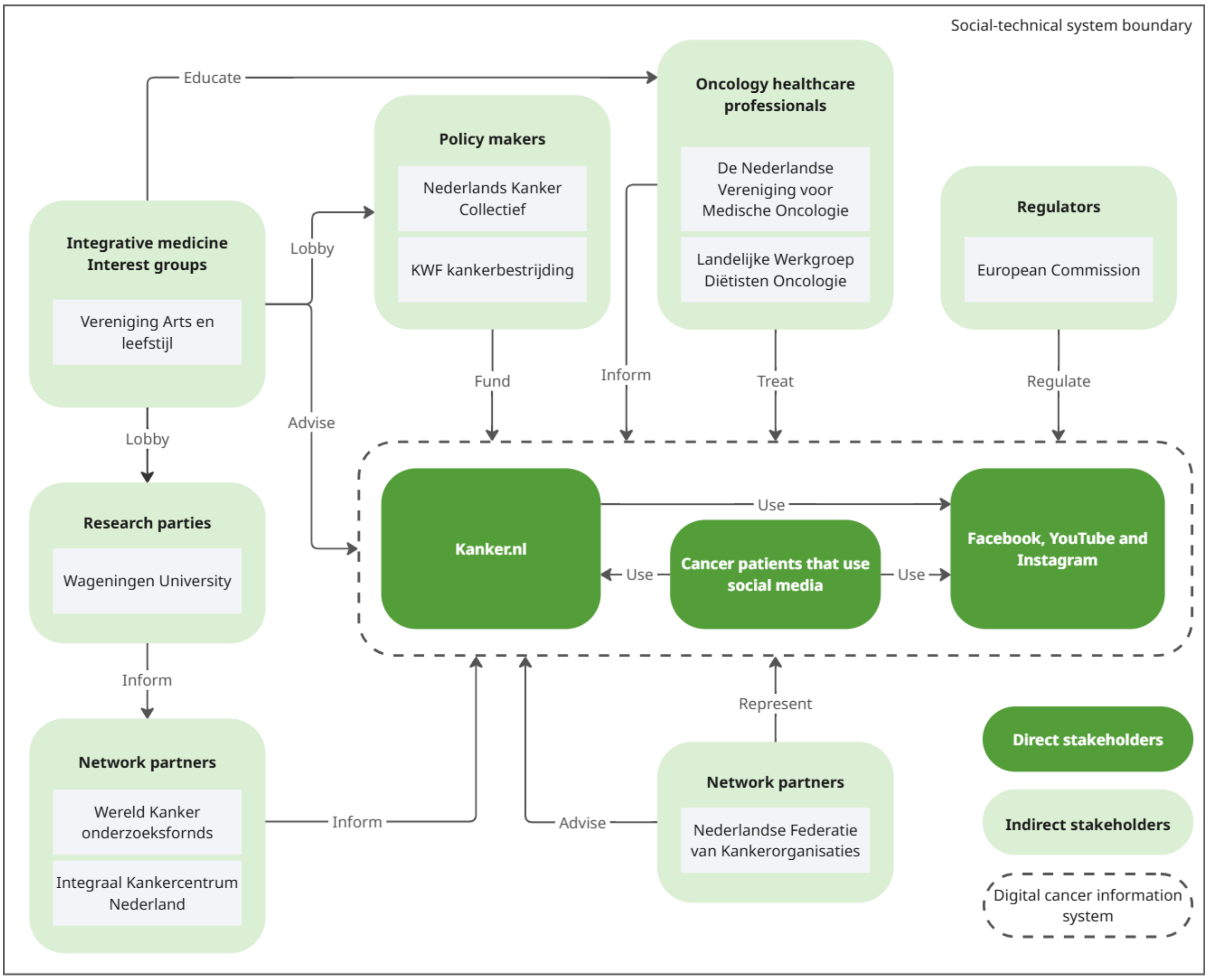
		responsible platform alternatives.	
Kanker.nl network partners (KWF kankerbestrijding, NFK, IKN, WKOF, Nederlands Kanker Collectief)	Partner organisations that provide funding, patient representation, evidence/data, nutritional knowledge, and policy context shaping the long-term direction of online patient platforms.	Kanker.nl is dependent on their knowledge, funding and collaboration for the uptaining of their platform.	**Cultural**: patient representation (NFK); evidence-based information (IKNL/WKOF); public value and impact (KWF), system-level cancer goals and coordination (Nederlands Kanker Collectief). See 3.2.2.2
Oncology healthcare professionals (De Nederlandse Vereniging voor Medische Oncologie, Landelijke werkgroep dietisten oncologie)	Providers of clinical oncology care and trusted sources of cancer and nutrition advice.	They are indirectly affected by patients' social media use, which reshapes expectations and the patient–doctor relationship.	**Cultural:** evidence-based practice, patient well-being. See 3.2.2. 3
Research parties (Wagenignen Universiteit)	Producers of scientific knowledge on cancer and nutrition that form the scientific basis for official guidelines and advice.	The availability and quality of evidence determine how clearly nutrition can be communicated and how misinformation can be countered.	**Cultural**: Scientific integrity, accuracy and rigor. See 3.2.2.5
Integrative medicine interest groups (Vereniging Arts en Leefstijl)	Parties that advocate for embedding nutrition and lifestyle medicine into oncology care.	They aim to address gaps in formal care and reduce patients' reliance on informal or online advice sources.	**Cultural**: Integrative medicine, prevention, evidence-informed practice. See 3.2.2.5

Table 3-8 overview of all stakeholders with their role, significance and values

STAKEHOLDER INTERACTIONS

To visually map the socio-technical system of the digital cancer landscape, figure 3-1 displays roles of and interactions between the direct and indirect stakeholders. It can be seen as the elevation of the initial system as represented in figure 1-3 (section1.3), showing not only direct stakeholders that form the digital information landscape, but also the indirect stakeholder that are connected to kanker.nl and commercial platforms, but with distinct interests and values.

The arrows in figure E represent the different types of relationships between the stakeholders, based on findings from 3.2. Central to the system are the cancer patients that can *use* two kinds of platforms. On one hand, the platforms driven by commercial logic (Facebook, Youtube and Instagram), who mostly value improvement in the form of expanding user engagement and data extraction. One the other hand, there are online patient platforms, a driven by safety, reliability and community. The patient users are *represented* by the Nederlandse Federatie van Kankerpatiëntenorganisaties (NFK), which advocates for their interests and *advises* kanker.nl on how to align the platform with patient needs.



igure 3-1 Socio-technical system mapping

Commercial platforms are *regulated* by the European commission in form of the DSA, however this relationship is very weak, as cancer nutriton misinformation falls outside the scope of DSA regulation, leaving the commercial platforms full of unverified sources for nutritional information for cancer.

Kanker.nl receives structural funding from KWF kankerbestrijding, which makes them a key *funding* stakeholder. As a network organisation, kanker.nl works together and is *informed* and *advised* by the Wereld Kanker Onderzoeksfonds, Integraal Kankercentrum Nederland, Oncology healthcare professionals and Vereniging Arts en Leefstijl for the information regarding nutrition and cancer that they display on their platform.

The research that is behind this knowledge is produced by research parties. These are being influenced in the form of *lobby* by Vereniging Arts en Leefstijl, who actively tries to influence their research projects to focus on lifestyle and nutrition. This organisation also *lobbies* other related stakeholders like KWF to increase awareness and funding for nutrition-related cancer research. Furthermore, this interests group *educates* healthcare professionals to expand their knowledge on the role of nutrition in oncology care. This is important, because these professionals are in direct contact with the patients who they *treat* and are still the most trusted source regarding nutritional information.

The final interaction within the system concerns the relationship of *kanker.nl* vis-à-vis commercial platforms. As discussed in Section 3.2.1.2, kanker.nl also *uses* commercial platforms to share content, but without a clearly articulated strategy. While content is posted, there is little evidence of active engagement with misinformation or attempts to address its presence on these platforms. This appears to be related to the absence of clear kanker.nl policy regarding the role of commercial platforms in the spreading of cancer-related misinformation. This constitutes the core policy gap for which recommendations will be formed in the technical analysis.

Overall, this overview of the socio-technical system provides insight into online patients platforms as a network organization that rely on collaboration, advice, funding, and knowledge exchange with multiple stakeholders to develop, verify, and govern the (user-generated) information presented on their platform. This has important implications for the technical phase of this research, as changes to platform organization or design will inevitably affect these relationships. The interests and values of these stakeholders must therefore be carefully considered when formulating recommendations.

3.4 ONLINE PATIENT PLATFORM VALUE TENSIONS

As explained in 2.1.1, value-sensitive design not only requires analyzing stakeholder values, but also how they come into tension with one another. Because the goal of this research is to formulate recommendations for online patient platforms that both align with the platform’s cultural values, but also to the personal values of cancer patients who use social media, it is imperative to anticipate how their values may come into conflict with each other.

Tension 1: Online patient platform cultural values of reliability versus users' personal values of peer knowledge and support.

A first tension arises between the cultural value of *reliability* of online patient platforms and the personal value of *peer knowledge exchange and support* among cancer patients who use social media. As discussed in 3.2.1.1, patients use social media platforms to share experiences and discuss nutrition-related strategies with others facing similar health challenges. These exchanges allow patients to relate to others in similar situations and to explore possible ways of managing their health.

However, online patient platforms have strict rules to user-generated content to ensure that shared information remains evidence-based, as analysed in 3.2.1.2. Users are expected to support claims with credible sources and avoid sharing unverified treatments. While this protects the reliability of information on the platform, it may also restrict the informal exchange of experiences that patients seek when engaging in peer knowledge exchange.

Moderators from OPPs must therefore balance maintaining evidence-based standards with allowing open community discussions. If moderation is too strict, discussions about emerging or uncertain nutrition practices may move to commercial platforms where such conversations face fewer restrictions. This creates a tension for kanker.nl between safeguarding informational reliability and supporting the peer knowledge exchange that attracts users to the platform.

Tension 2: Online patient platforms safety versus commercial platform community

A second value tension emerges when online patient platforms are considered within the broader digital cancer information landscape.

As discussed in 3.2.1.2, *safety* on OPPs is primarily framed in terms of privacy protection and responsible data use. The platform explicitly avoids commercial data practices and places strong emphasis on protecting users' personal information. However, this value becomes at risk when OPPs interact and become active on commercial social media environments.

As described in section 3.2.2.2, kanker.nl maintains accounts on Instagram, Facebook, and YouTube. Although engagement levels appear relatively modest and no clear strategy is articulated, the presence of these accounts suggests that the organization attempts to reach users who are active on commercial platforms and direct them toward its own platform.

This interaction between OPPs and commercial platforms creates an internal value tension between OPPs values of *safety* and *community*. On the one hand, the organization seeks to protect users from data extraction and privacy risks associated with commercial platforms. On the other hand, reaching users where they already communicate online may require engagement within commercial platforms that rely on data extraction and engagement-driven infrastructures, as described in 3.1.1.2.

Encouraging interaction on these platforms by making content on their channels may expose users to precisely the data practices that OPPs seek to avoid. At the same time, avoiding participation on commercial platforms entirely may limit the platform’s ability to build a community and reach cancer patients who are active in these commercial environments.

This dilemma illustrates the difficulty for OPPs in positioning themselves within the broader digital information landscape. The absence of a clear strategy regarding commercial platforms may therefore reflect the challenge of balancing its commitment to user safety with the need to reach and support a larger patient group.

3.6 CONCLUDING REMARKS

Through a combination of literature review, extended academic search, and desk research, this chapter mapped the main stakeholders involved in the digital cancer information landscape and analysed their anticipated personal, cultural, and infrastructural values.

The analysis of kanker.nl and its network partners revealed an important policy gap in the current governance of cancer-related misinformation on social media. Existing policy frameworks and organisational strategies provide little guidance on how misinformation about cancer and nutrition on commercial platforms should be addressed. As a result, no single stakeholder appears to take clear responsibility for the problem of nutritional misinformation on CSPs. At the same time, the analysis demonstrated that kanker.nl functions as a network organisation, meaning that strengthening its position as value-driven online patient platform requires collaboration with multiple partners

The value analysis also revealed an internal value tension within online patient platforms. As platform that facilitates user-generated discussions, they aim to maintain high standards of reliability and safety while simultaneously fostering an open and supportive community for cancer patients. Balancing these goals creates ongoing challenges for moderation and platform governance.

In addition, this chapter highlighted a broader system-level tension between OPPs and commercial social media platforms. While online patient platforms aim to position themselves as a safe and reliable alternative, their relationship with commercial platforms remains unclear. This lack of strategic positioning further illustrates the need for recommendations on how OOPs can strengthen its role within the digital cancer information ecosystem.

Finally, the conceptual analysis reveals a knowledge gap regarding the personal values of cancer patients themselves. Although the literature reviewed in section 3.2.1.1 shows that patients actively seek nutrition-related information online and face both informational needs and risks of misinformation exposure, there is limited empirical insight into how patients interpret, negotiate, or respond to these information environments in practice and what values drive them. To address this gap, the next chapter presents a qualitative content analysis of online user comments to examine how cancer patients discuss nutrition across different digital platforms.

4 EMPIRICAL PHASE

This chapter presents the results of the empirical phase of this value-sensitive design study, reporting the outcome of a qualitative content analysis of user-generated social media content. First, the characteristics of the analysed social media data will be provided, followed by the main findings and recurring patterns structured along the three core dimensions: nutrition, communication, and values. The interpretation of user values was validated through focus groups and is reflected upon in section 4.4. The chapter concludes by examining value conflicts, emphasizing key tensions and trade-offs that shape the cancer nutrition communication of users in online environments.

This chapter gives answer to the following research question: "How do users in different online contexts (online patient platform vs. commercial social media platform) negotiate and evaluate cancer nutrition claims, and what values shape these evaluations?"

4.1 SAMPLE CHARACTERISTICS

As described in the methodology, the textual comments (units of analysis) could either be the result of a reaction to visual (photo/ video) content, or from a textual discussion in a community or discussion group. Following the strategy for data collection as described in 2.3.2.1, the sample consists of 18 social media posts derived from commercial platforms, of which 10 are the category of media sharing and 8 are user discussions. For OPPs, the sample consists of 12 user conversations, and no media sharing.

Figure F shows the type of content per platform. Facebook has the largest mix of visual (video) and textual posts that have been analyzed, in line with their multimodal functionalities. Logically, YouTube only has video content. Instagram also offers a mix of pictures and videos.

Interestingly, of all the video content, the whole sample only contains short videos (less than 2 minutes). Longer videos did not meet the inclusion criteria as established in 2.3.2.1.

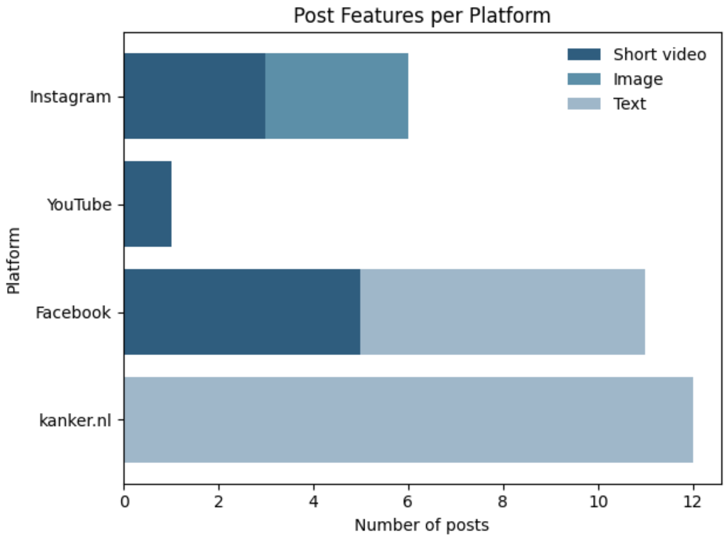


Figure 4-1 Bar chart of post feature per platform

Considering the source type, so the type of channel or author that shared the content initially, there are five categories that the sample is constituted of, see figure 4-2. For online patient platforms, a distinction can be made between posts initialized from moderators, and posts initialized by users themselves. Regarding the commercial platforms, a mixture between different kinds of influencers, healthcare professionals, and individual users can be found in the sample. Overall, the sample meets the goal of having a broad variety of posts to be analyzed to get a varied perspective of user's values.

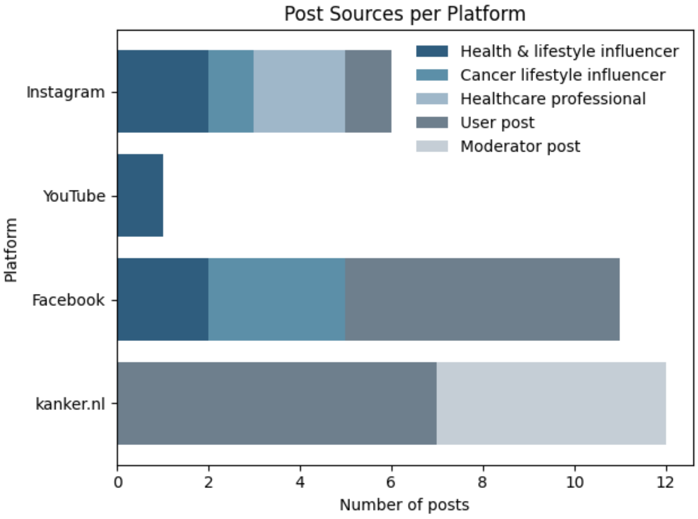


Figure 4-2 bar chart of post features per platform

In total, the sample consists of 477 coded comments. Of those, 325 are from commercial platforms, 152 from the online patient platform. Figure 4-3 shows the most common words in the comments in form of a word cloud. From the ten most used words, only two are different between the OPP and the CSMPs. This supports of comparability of the two contexts.

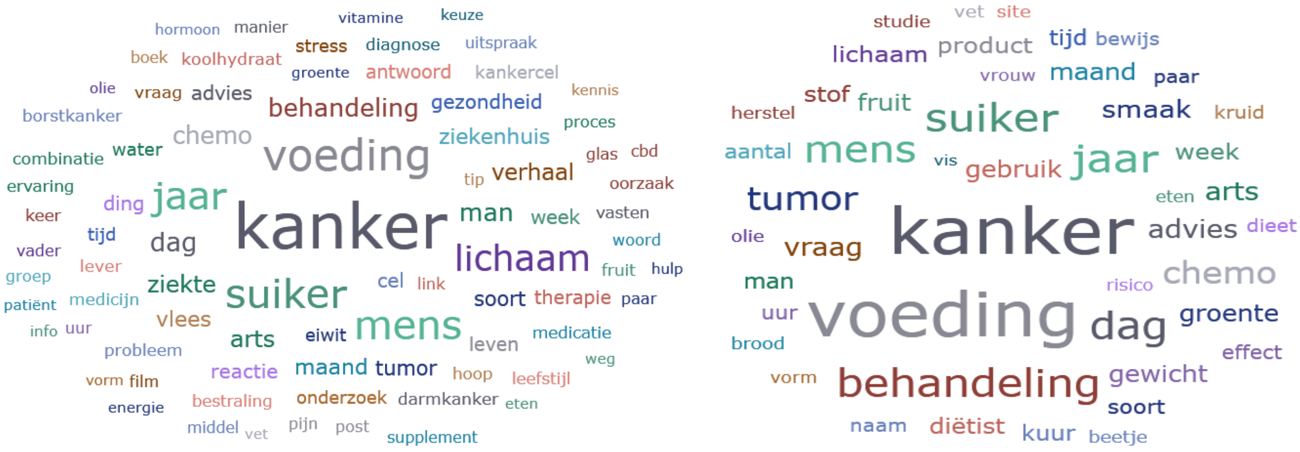


Figure 4-3 Wordcloud of comments on CSMPs (left) and OPP (right)

4.2 CANCER AND NUTRITION CLAIMS

Table 4-1 presents the nutritional claims identified in the dataset. For each claim, a description is given, together with example comments from the two different contexts. Furthermore, the category of claims has been assigned according to the categorization from (Warner et al., 2022). Lastly, the number of times the code has been assigned is presented.

Across both environments, the nutritional themes discussed by users align with those already documented in the academic literature on cancer nutrition and online health information, by all falling into the nutrition claim categories as conceptualized in the framework from (Warner et al., 2022) and explained in 1.2. Therefore, the empirical investigations did not lead to the discovery of new types of online claims regarding cancer and nutrition but rather confirmed the presence of previously documented narratives. This indicates that the framework developed by Warner et al. (2022), originally based on Pinterest data, can also be applied to other social media platforms such as Instagram, Facebook, and YouTube.

Commonly recurring topics include fasting, glucose and sugar consumption, dietary supplements, plant-based diets, and specific compounds such as curcumin. These themes show high code quantities on both commercial platforms and online patient platforms, indicating that they represent shared areas of concern and uncertainty among users, regardless of platform type.

Claims in which a difference is noticeable between environments are the alkaline, Moerman and carnivore diet. All the reactions from users in which these claims are discussed are posted in the commercial context. A shared characteristic of these claims is that they are generally considered misinformation on the more “harmful” side of the misinformation spectrum as defined in 1.3, as there are clear reported risks for cancer patients adopting these diets (Lietz et al., 2026; Matson, 2023; Stichting Nationaal Fonds tegen Kanker, n.d.) ,

Their absence on the online patient platform suggests that these topics fall outside the boundaries of what is discussed or permitted within the platform’s community norms and moderation practices (see section 3.2.1.2). On the one hand, this finding empirically demonstrates the strong evidence-based communication standards applied on online patient platforms.

On the other hand, it also indicates that certain nutrition-related topics in which users are engaging are only discussed on commercial platforms rather than within the moderated environment of online patient platforms. This observation reflects the internal value tension identified in section 3.5, where the platform’s commitment to reliability may limit discussions about highly speculative or unverified nutritional approaches.

Finally, the presence of discussions about the Moerman diet highlights the Dutch context of this study, as this dietary approach originates in the Netherlands (Moerman Vereniging, 2019). This indicates that online discussions about cancer nutrition are shaped not only by global misinformation narratives but also by locally embedded dietary practices.

Cancer nutrition claims	**Description**	**Type of claim according to Warner (2022) framework**	**Illustrative example comment**	**Quantity**
Alkaline diet	The alkaline diet tries to change the pH of the body through eating mostly alkaline foods. It is believed that by creating a more alkaline environment, cancer cells can't survive (Van Thomme, 2024).	General health food.	CSMP: “First, ensure that your body becomes pH neutral. You can buy test strips online to measure this. Cancer finds it difficult to grow in a pH neutral body!!! There is much more to it than that.”	5
			OPP: not applicable	0
Fasting	Depriving of all or some kinds of food for a certain time period, believed to help with cancer diagnosis (Tiwari et al., 2022).	General health food.	CSMP: “I don't believe cancer can be cured with medication, but I do believe fasting can help.!”	7
			OPP: “Online discussions made me consider fasting, but my dietitian discouraged it, explaining that adequate nutrition is important during chemotherapy.”	2
Glucose and cancer	Belief that glucose is feeding cancer cells and stopping with it would “die them out” (Williams, n.d.)	Food & Food Compounds	CMSP: “Glucose is fuel for tumor cells. Fiber is an important substance for intestinal flora. This is where hormones and immunity are created, particularly T cells.”	7
			OPP: “My doctor has never told me that sugar is harmful for cancer, but I often hear people say that sugar can make tumors grow.”	8
Vitamins and Supplements	Belief that certain supplements or vitamins could help reduce or cure cancer (Du et al., 2020).	Food & Food Compounds	CMSP: “Which vitamins and minerals does your body produce less of or differently, and can you supplement or stimulate them through nutrition? Do’s and don'ts of dietary supplements..”	10
			OPP: “I remember a period when vitamins were widely promoted, followed by warnings that high doses might even accelerate cancer. Because of these contradictions, I’ve grown very	6

			sceptical about supplements and see many of them as unreliable.””	
Curcumin	Kind of spice that is associated with curing cancer (Giordano & Tommonaro, 2019).	Food & Food Compounds	CSMP: “Joe Tippens' cancer cure works very well for many people. I have looked up several Facebook groups and read many stories from around the world about cancer disappearing or going into remission. Fenbendazole is taken in combination with CBD oil and turmeric. I'll see if I can find the website. Fenbendazole can be ordered via Amazon..”	2
			OPP: “After reading about tumeric, I became curious about how much of it should actually be used.”	9
Plant-based diet	Specific diet based on plant proteins, believed to work well when having cancer (Hardt et al., 2022)	Food & Food Compounds	CSMP: “Plant-based is the way to go. I myself have made tremendous progress in my rehabilitation, even though the specialists said it wasn't possible.	2
			OPP: “I decided to stop following the keto diet. From what I understand, prostate cancer initially uses glutamine and fatty acids rather than glucose, so I switched to a vegan diet to...[].”	3
Moerman diet	Alternative dietary approach focusing on specific nutritional combinations and the avoidance of certain foods, believed by some to support cancer recovery	Food & Food Compounds	CSMP: “The same as the Moerman diet. That's why I'm still here!!!! I had a 5% chance of surviving leukemia.”	5
			OPP: not applicable	0
Carnivore diet	Restrictive diet consisting mainly of animal-based foods, believed by some to reduce	Food & Food Compounds	CSMP: “What makes us sick is the junk they put in those animals or artificial meat. Meat itself is very good for you. Especially the offal, such as the liver and other organs.	3

	inflammation or improve health outcomes in cancer contexts (Lietz et al., 2026)		They contain so many good nutrients.”	
			OPP: not applicable	0

Table 4-1 Empirical results of nutritional themes

4.3 COMMUNICATION THEMES

Whereas the previous section focused on what nutritional themes users discuss, this dimension examines how users communicate about these themes. In other words, in this section the analysis of the orientations through which users articulate, negotiate, and respond to cancer-related nutrition claims in online environments will be discussed. This dimension was guided by the analytical framework from (Shifman et al., 2025) In the following sections, each orientation is discussed, alongside definitions, illustrative examples, and quantities from the data.

4.3.1 EXPRESS

The communicative orientation express captures how users share thoughts, experiences, opinions or feelings in response to cancer-related nutrition content. These comments do not have a clear goal such as informing or persuading others. Instead, users appear to react because the content triggers something personal or emotional.

The largest part of the dataset falls into this communication category. Many users, especially in commercial context, simply express what comes to mind without explicitly referring to values or arguments. The tone varies strongly, ranging from supportive and empathetic to frustrated or dismissive. This reflects the reactive and short-form nature of social media communication.

Across both platform contexts, three main forms of expression can be distinguished. First, users frequently share anecdotal experiences, relating to their own illness trajectories or those of family members. These comments can include detailed descriptions of symptoms, treatments, or other cancer-related experiences.

A notable risk associated with this type of expressive communication on commercial platforms is the extensive sharing of sensitive personal health information. Users appear unaware that such data can be collected, analyzed, and monetized by platform operators, as described in 3.1.1.2. In contrast, online patient platforms explicitly communicate data protection and privacy safeguards (see 3.2.1.2), making the sharing of detailed personal information less problematic in this context. These empirical insights validate the difference in how “safety” as a cultural value is enacted differently across two platform environments.

Second, users express opinions, typically reacting critically or affirmatively to claims made by others. Opinion-based expressions are more prevalent on commercial platforms than on kanker.nl (n = 3), where responses tend to be more reflective and carefully phrased.

Third, users express feelings, such as encouragement, confusion, or irritation. These emotionally oriented comments are common on both types of platforms but occur more frequently on commercial ones. This empirically reveals the enactment of the community norms of kanker.nl regarding sympathetic language use (3.2.1.2). In commercial environments there is less supervision of language use, reflecting their cultural value of *expression* (3.1.1.2).

Intent: Express	Desription	Illustrative example comment	Quantity
Sharing (anecdotal) experiences	Using the platform as a way to share a certain (cancer and nutritional related) experience.	CSMP: "My grandmother had colon cancer, didn't get it treated, and then she died. She became extremely thin; at one point, she couldn't even eat properly anymore. Swallowing was extremely painful".	25
		OPP: "I noticed changes in my taste even before being diagnosed with cancer. Although I first blamed antibiotics, the nausea persisted. When symptoms are milder, I just eat what I can to maintain my weight."	15
Sharing an opinion	Using the platform to articulate your opinion about something or someone.	CSMP: "Yes, listen to your doctor, you empty-headed fool."	18
		OPP: "To me, 'healthy eating' is a vague concept. Many people associate it with supplements or special health products, but I've grown quite critical of these trends."	3
Sharing a feeling	Using the platform to share a certain feeling or emotion about a topic or person.	CSMP: "You're the best"	19
		OPP: "I appreciate your reply, but it doesn't seem to align with the advice I had in mind, so I'm still unsure how to interpret it.."	3

Table 4-2 Empirical results of express orientation

4.3.2 BOND

The communicative orientation bond captures how users connect with others through shared experiences, recognition, and mutual support. Bonding comments are aimed at creating a sense of togetherness, by making online connections with other users, comparing situations, seeking reassurance, or exchanging peer advice. These interactions appear to provide comfort and wellbeing for cancer patients that use social media.

Four forms of bonding can be identified. First, users attempt to make online connections, for example by inviting others to get in touch or by explicitly addressing fellow users. Being able to refer to private messages of other users' profiles is one of the distinct properties of social media platforms, both commercial as on kanker.nl.

Second, users engage in peer comparisons, where they exchange explicit details of their own cancer treatment journey with the goal to compare it to others. These explicit forms of comparison are only found on the online patient platform.

Third, users bond by seeking advice from peers, asking others about their general experiences with diets, supplements, or other practices creating a strong sense of “not being alone”. This form is equally present across platform contexts, indicating that the need for experiential advice is not platform-specific, but a general feature of cancer-related nutrition discussion.

Fourth, users bond by sharing explicit shared experiences with the explicit aim of creating recognition and solidarity. These contributions often emphasize shared hardship or coping strategies rather than success or persuasion.

Overall, bonding communication highlights the social function of cancer nutrition discussions. Beyond information exchange, these interactions help users cope with uncertainty and emotional burden by forming communities around shared experiences. These findings empirically corroborate the personal value of *peer-to-peer support* identified in the conceptual phase (section 3.2.1.1). These empirical findings suggest that both commercial platforms and kanker.nl facilitate this bonding communication among users.

Intent: Bond	**Description**	**Illustrative example comment (paraphrased)**	**Quantity**
Making connections	Using the platform as a means to find and contact fellow patients.	CSMP: “If you have any questions, just send me a private message. Good luck!!”	2
		OPP: “My mother was recently diagnosed with cancer, and I would like to speak with people who think nutritional changes helped limit the progression of their cancer.”	3
Peer comparison	Using the platform to compare own experience to those of others.	CSMP: not applicable	0
		OPPl: “Thank you for your response. I think the same: even if it doesn’t help, it likely won’t hurt. I’ve also begun taking two tablets and appreciate the reassurance.”	4
Peer advice	Using the platform to seek or provide advice on nutritional topic	CSMP: “Hello ladies and gentlemen,I am a new group member and would like to introduce myself and ask for advice or hear about any similar experiences regarding the path that life has decided to take for me…[]”	5
		OPP: “After being diagnosed with cancer, I’ve been exploring dietary approaches. I keep seeing different opinions about bitter apricot kernels and would like to hear from others who have tried them??”	5
Sharing experiences	Using the platform to share a particular experience with the goal to bond over a certain topic or have a sense of common experience.	CSMP: “Hi [user], how wonderful that you reached out to this group, and what amazing responses you received. I had cancer in 2021 and tried many things alongside the regular treatment, with good results.... []I have experience with Joe Dispenza, Kelly Turner, Peter Levine, and others, and would be happy to discuss what might help you. Please send me a private message. I wish you strength and courage!”	1
		OPP: “Although I know sugar isn’t particularly healthy, I don’t know if it influences cancer. With the physical discomfort I’m dealing with, I occasionally have a small, sweet treat with tea to make things a little easier”	6

Table 4-3 Empirical results of bonding orientation

4.3.3 ASK

This communicative orientation captures how users explicitly seek information or guidance about cancer and nutrition. This category emerged inductively from the data, as many comments take the form of direct questions. Asking is closely linked to uncertainty and confusion and reflects the increasing use of social media as an epistemic resource.

Three forms of asking can be distinguished. First, users make specific requests, asking for tailored or actionable information, such as dosage, alternatives, or specific recommendations that are tailored to the situation of the user. This the most common type of question, revealing the need for tailored and specific advice of users.

Second, users make general requests, asking others about their experiences or seeking confirmation that their own choices are reasonable.

Third, users ask for legitimisation, requesting sources or explanations to verify claims. This form of asking was only observed on commercial platforms. This finding suggests that information shared on commercial platforms is retrieved as less reliable by users, having to make explicit comments about it. On the other hand, it reveals how the cultural value of *reliability* of online patient platforms is enacted concretely.

From the conceptual phase, it was found that cancer patients can experience confusion regarding often vague or conflicting nutritional advice (3.2.1.1). The empirical findings not only confirm this but further demonstrate how this confusion actively drives user engagement in the form of specific kinds of questioning.

Intent: Ask	**Description**	**Illustrative example comment**	**Quantity**
Specific request	Request for tailored information. Can be to professional expert, but also to influencers or peers.	CSMP: “But then give me an alternative? I'm more interested in that, because I already know this story.”	15
		OPP: “Although I have some knowledge about turmeric, I’m not sure how much should be used. What is the daily advisable intake?”	20
General request	Asking for experience or confirmation from peers.	CSMP: “Anyone have experience with Essiac tea? It's supposed to work wonders for cancer.”	6
		OPP: “I’ve read conflicting information about bitter apricot kernels and whether they are safe. Does anyone have experience with using apricot kernels?”	2
Request for legitimization (source)	Asking for sources of information to seek confirmation	CSMP “Okay, and where did you get that from? Explain why those sugars are bad for you in your own words or provide a source. “	2
		OPP: not applicable.	0

Table 4-4 Empirical results of asking orientation

4.3.4 INFORM

This communicative orientation captures comments in which users aim to share information about cancer and nutrition. In these comments, users position themselves as information providers rather than seekers. This highlights the strong epistemic use of social media, where knowledge is actively circulated between users.

Two main forms of informing can be distinguished. First, users share credible information by referring to traceable sources such as scientific studies, clinical trials, or websites from established institutions. These contributions often include explicit references or links and are primarily observed on online patient platforms, validating their strict norms regarding *reliability*.

Second, users share non-credible information, based on personal interpretations or external sources that are not clearly referenced. This form is more prevalent on commercial platforms, reflecting their infrastructural value of *user engagement optimisation* (3.1.1.2).

From the conceptual phase, it was suggested that patients do not only use social media for support, but also for gathering information, reflected in the personal value *peer knowledge and support* and *evidence-based nutritional guidance*. These empirical findings reveal that platform context influences the credibility of shared information.

Although online patient platforms maintain strict norms regarding the credibility of user-generated information, reflected in their cultural value of r*eliability*, the empirical analysis reveals that these norms are not always enforced through the removal of non-credible contributions. Two examples of non-credible information sharing were namely identified on kanker.nl.

This empirical finding illustrates the conceptual value tension described in 3.5, where kanker.nl's commitment to reliability interacts with users' personal value of peer knowledge exchange and support. While the platform seeks to ensure that information remains evidence-based, it also aims to provide space for patients to share experiences and discuss nutrition-related practices that may not yet be scientifically validated. This illustrates how kanker.nl's cultural values are not static and come into tension with one another.

Intent: Inform	**Description**	**Illustrative example comment**	**Quantity**
Credible information sharing	Sharing information with traceable source	OPP: "I read about a 2020 clinical study indicating that a keto diet showed slower disease progression than those in a control group"	5
		CSMP: "https://www.nature.com/articles/s41591-022-01968-zIs a meta-analysis study... much stronger than epidemiology. In fact, epidemiology doesn't even come close to a clinical trial, let alone epidemiology. I don't understand people's arrogance sometimes. What you need to think about are the figures for metabolic diseases since 1927 compared to the period before that."	1
Non-credible information sharing	Sharing information without traceable source	OPP: "As a non-expert, I searched resources from a leading cancer center and found information about herbs. Because these substances have not been tested extensively in human studies, their effects are considered unproven."	2
		CSMP: "I once read an article that said cancer in its early stages can often be treated effectively with diet and lifestyle changes, for example by eating almost no carbohydrates and more healthy fats. This is because cancer cells mainly feed on sugars and carbohydrates. But once the cancer has spread, diet alone is not enough.."	4

Table 4-5 Empirical results of informing orientation

4.3.5 INFLUENCE

This orientation captures comments in which users aim to shape the beliefs, attitudes, or behavior of others. Influence is not limited to content creators or so-called “influencers”; users themselves also actively influence one another through comments. In these interactions, users go beyond sharing experiences or information and attempt to persuade, warn, or guide fellow users.

Based on the data, influence can take three forms. First, users make explicit warnings, discouraging certain behaviors or cautioning others against specific claims or practices. These warnings are often framed as risk communication and are particularly prevalent on commercial platforms, where users frequently warn each other about unreliable or potentially dangerous nutrition advice. This finding empirically validates the infrastructural value of “user engagement optimization” of commercial platforms, which explains how misinformation is spread more easily in commercial environments compared to kanker.nl, causing users to warn each other for it.

Second, users engage in promotion, by referring to specific products, books, diets, or initiatives. This form of influence is common on commercial platforms and is entirely absent on *kanker.nl*. Notably, promoted content often refers to English-language or international sources, suggesting that users perceive much of the relevant knowledge on cancer nutrition as emerging outside the Dutch context. The absence of promotion on online patient platfomrs empirically demonstrates the platform’s cultural value of *reliability*.

Third, users attempt to influence others by directing them to external information sources, such as websites, documentaries, YouTube videos, or online communities. While this form appears in both environments, it is more frequent on commercial platforms than on kanker.nl. Based on the empirical data, an interesting asymmetry emerges: users on kanker.nl do refer others to commercial platforms, such as YouTube, whereas the reverse does not occur. No instances were found in which users on commercial platforms refer others to kanker.nl as an information source. This asymmetry empirically demonstrates the limited visibility of kanker.nl within the broader digital cancer information landscape.

Intent: Influence	Description	Illustrative example comment	Quantity
Warning	Make explicit warning / risk communication of doing something (not)	CSMPs: “This is a personal experience, folks, not medical advice. Don't give up, keep fighting, and doing your own research is always an option when there are no other options left, but first follow the medical advice of a specialist doctor.”.	7
		OPP: “Taking too many vitamins or supplements can be risky. In high quantities, these substances may become harmful”	1

Promoting	Making promotion for a specific product or service.	CSMPs: “If more people are interested, this book is a good place to start. Available on Amazon. Finding Fenbendazole: My Unexpected Path Through Cancer.”	17
		OPP: not applicable	0
Directing to other information sources	Citing other sources for information and trying to have others make use of these.	CSMPs: “Take a closer look at Joe Tippens' cancer cure. Mycancerstoryrocks is his website, and there are several Facebook pages with lots of success stories.”.	17
		OPP: “There appears to be quite a bit of research on the potential medicinal effects of turmeric. I came across a website that summarizes much of this information”	12

Table 4-6 Empirical results of influence orientation

4.4 PERSONAL VALUES OF CANCER PATIENTS WHO USE SOCIAL MEDIA

This section examines why users engage with cancer and nutrition content by analysing the underlying values that shape their communication. While the previous sections focused on what users discuss and how they do so, a value-based perspective reveals what users consider important and what they expect from the online systems in which these discussions take place.

The values identified in this study are derived from the communicative orientations observed in the data. Specific ways of communicating tend to align with particular values, as also described in the framework from Shifman et al. (2025) framework. For example, “bonding” communication reflects values related to community and mutual support, while “informing” communication relates to knowledge building and credibility. The following sections present the most prominent values by formulating them explicitly, each accompanied by the norms through which the value becomes visible in practice.

This part of the empirical analysis was informed by the results of the focusgroup. As values are most often not explicitly mentioned in comments, the focusgroup participants helped by connecting the norms found in the empirical data with the corresponding value. Quotes from the participants will therefore be added to the value sections to provide validation.

4.4.1 PATIENT MOTIVATION TO USE SOCIAL MEDIA

Before identifying the values that shape users’ communication, it is important to consider the broader motivations that drive patients to engage with nutrition-related discussions online. Two inductively derived validity codes provide important empirical insight into these motivations: confusion about nutrition and dissatisfaction with the lack of nutritional guidance in cancer care.

These empirical findings corroborate with the personal value of *professional nutritional guidance* as identified in the conceptual analysis (section 3.2.1.1). Across both online patient platforms and commercial platforms, users explicitly engage with nutrition-related discussions in response to uncertainty and perceived gaps in formal healthcare communication. In both environments, they express confusion about often contradictory dietary advice and frustration with the limited attention given to nutrition within standard oncology care. The presence of these concerns across platforms indicates that they are not platform-specific phenomena but rather reflect broader structural issues in cancer care.

Validity codes	**Description**	**Illustrative example comment**	**Quantity**
Confusion about nutrition	Confusion about often contradictory or inconsistent dietary advice for cancer patients	CSMP: "I would like to hear your views on drinking alcohol. I read a lot about studies that say alcohol interferes with the effectiveness of Tamoxifen. In the USA, alcohol consumption is also discouraged. In the Netherlands, it is not. I find that quite confusing. I don't drink anymore, but it would help me if I knew for sure that it really helps! Then I would stop without hesitation."	3
		OPP: "My chemotherapy was postponed once because my immune system was too weak, and I was advised to pay closer attention to nutrition, although no specific diet was suggested.."	10
Lack of nutritional guidance and incorporation in cancer care	Dissatisfaction with the lack of nutritional advice and guidance in the standard clinical cancer treatment.	CSMP: "It's a shame that mainstream medicine still pays little attention to nutrition and lifestyle. In fact, hospital food is bursting with carbohydrates and sugars."	12
		OPP: "Thanks for your reply. I plan to speak with my dietitian, but I have some doubts about her expertise, which is why I sought advice here."	4

Table 4-7 Validity codes of patient motivation to use social media

4.4.2 COMMUNITY

The value of community is associated with users' willingness to engage in conversation by creating a sense of shared space and mutual recognition. Communicating with others that have similar experiences can create a sense of "belonging", which has a positive effect on patients and mental state in dealing with cancer. Most "bonding" communication is associated with this value.

Positive peer support and the exchange of experiences are central norms associated with this value. The data shows that users expect platforms to allow space for sharing tips and personal stories in a non-judgmental way, while leaving final decisions to the individual. This is illustrated with this quote from the focusgroup:

> *"I enjoy reading along, and then what you do with it and whether you do anything with it is up to you. But I think that the author of this comment wants to encourage people to share."*

This led to the following working definition of this value:

> "The desire to engage in supportive interactions with others who have experience with cancer, creating a sense of belonging through the exchange of personal stories, advice, and empathetic communication".

Associated norms of the personal value of community can be found in the table below.

Community norms	**Description**	**Example**	**Quantity**
Peer knowledge exchange	Exchange of tips and experiences should be stimulated among patients, caregivers and survivors, without judgement.	CSMP: "Here you can ask questions, share your story, and discover how other people find their way to healing. The path to healing is a personal one, so we ask you to respect everyone's choices and refrain from expressing your opinion about any particular therapy or treatment. Of course, you are welcome to share your experience.."	9
		OPP: "Hi all, I've come across information about turmeric and would like to know if others have tried it.?"	10
Positive peer support	Users should be encouraged to find support through the experiences of peers.	CSMP: "How wonderful to see everything that is being shared here! I enjoy reading along.."	2
		OPP: "At the start of my chemotherapy, my oncologist told me not to take supplements like vitamin C, B12, or glucosamine. If possible, it can help to discuss these questions with a nurse or healthcare professional."	2

Table 4-8 Community norms

This value largely corresponds with the conceptualised personal value of "peer knowledge exchange and support" identified in Section 3.2.1.1, which was defined as *"the desire to exchange experiences and advice with others facing similar health challenges."* The empirical findings confirm that this motivation shapes how cancer patients communicate online.

At the same time, the empirical analysis adds nuance by showing how this value becomes visible in practice. Rather than only exchanging information, users actively create a sense of belonging through shared experiences. Community therefore emerges not only as a mechanism for knowledge exchange, but also as a social strategy that helps patients deal with uncertainty and emotional stress.

4.4.3 SAFETY

The value safety reflects users' concern for protecting vulnerable cancer patients from harmful or misleading nutrition-related claims. Safety becomes relevant when users perceive that advice, promises, or narratives may place patients at risk, not only physically but also emotionally and morally.

Safety is primarily articulated through norms of "unsafe promises" and "patient protection". Users react strongly to claims that promise cures, exaggerate success rates, or suggest that patients are responsible for their illness or recovery. Such statements are perceived as unacceptable, particularly in the context of a life-threatening disease like cancer.

Focus group participants explicitly link these concerns to the communicative strategies of health and lifestyle influencers, who are perceived as using complex or authoritative language to create trust without sufficient scientific grounding. As one participant explained:

> *"As an influencer, if you start throwing around big words, a lot of people will immediately think, "Oh yes, you know what you're talking about, so I'm going to listen to you," and that's very dangerous"*

Therefore, safety-related communication is marked by a moral and often confrontational tone. When safety norms are violated, users respond with explicit warnings or strong condemnation, framing such behaviour as "dangerous", or as "giving false hope".

Clear differences emerge between platform contexts. On commercial platforms, safety violations occur more frequently, and users often feel compelled to intervene by issuing warnings or calling out problematic content.

On *kanker.nl*, safety-related conflict is largely absent from the data. This absence does not indicate that safety is less valued, but rather that unsafe claims are prevented through active moderation and explicit community guidelines. As a result, safety is structurally embedded in their platform design through cultural values, rather than enacted through personal values of users.

This leads to the following working definition of safety:

"The importance of online environments protecting vulnerable cancer patients from misleading or harmful nutrition claims and preventing discussions about cancer and nutrition from creating false hope, blame, or emotional harm."

Safety norms are in the table below.

Safety norms	**Description**	**Illustrative example comment**	**Quantity**
Unsafe promises	Platforms and its users should not be allowed to promise cures or make unfounded statements about the success of certain cancer treatments.	CSMP: “Well, there are indeed stories about CBD oil and its effects on some people. But this is something you're better off not saying anything about, as it always varies from person to person, depending on the type of cancer, etc. No matter how well-intentioned it may be. The problem is that, unfortunately, it doesn't work for everyone 😖 . The most dangerous thing is giving people false hope, even if you don't mean to.	17
		OPP: “I appreciate your response. After rereading what I wrote, I see that I did not suggest these foods treat cancer, but only that ginger and turmeric appeared to relieve some digestive symptoms in my case.”	3
Patient protection	Platforms and its users should not exploit their vulnerability and increase sense of guilt.	CSMP: “Your video lacks scientific basis, not to mention the guilt you instill in cancer patients. You are essentially saying that it is their own fault if they relapse..”	8
		OPP: not applicable	0

Table 4-9 Safety norms

This personal value was not identified in the conceptual analysis of cancer patients’ values (Section 3.2.1.1), although safety did appear as a cultural value of both kanker.nl and commercial social media platforms. These empirical findings thus show that users themselves also actively express safety concerns, particularly on commercial platforms. Furthermore, it supports the analysis from Scharlach et al. (2024) which argues that that the enactment of “safety” on commercial platforms is largely delegated to users themselves, instead of built into the platform design and governance.

4.4.4 FREEDOM

The value *freedom* reflects users’ desire for open and pluralistic discussion about cancer and nutrition. Users value spaces in which multiple perspectives can coexist and where information is not reduced to a single, dominant medical narrative.

Freedom is closely linked to tolerance and nuance rather than to the rejection of medical expertise. Users emphasise that cancer is complex and that different experiences and approaches can be valid at the same time, especially in discussions about complementary care like nutrition. This perspective was validated by a focusgroup participant:

> *“The world isn't all black and white, you know. And some people [on social media] feel a strong need to express their own personal opinion or what works for them as the truth. While yes, it is the truth for you, that's right. But that doesn't necessarily have to be the same truth for someone else.”*

This emphasis on plurality stems from the inherent complexity of cancer itself, which encompasses many disease types, treatment trajectories, and patient experiences. As one participant explained:

> *"When we talk about breast cancer, there are many different types and many different ways to treat it, as is the case with all types of cancer. There are all kinds of variants and stages, as well as different types of treatment. There is no one right way."*

Social media platforms function as public spaces that enable this plurality. Users experience these environments as offering more room for personal experiences and broader views on health than standard clinical settings, partly driven by perceived gaps in guidance within hospital care.

Two key norms support this value: tolerance and pluralism. Users expect respectful engagement with differing views, while also rejecting the presentation of personal opinions as universal truths.

Freedom is more explicitly expressed on commercial platforms than on kanker.nl. On commercial platforms, users more openly challenge single-truth narratives. On OPPs, this form of pluralism is less visible. While users can share experiences and ask questions, evidence-based knowledge is the norm, in line with their community guidelines (3.2.1.2).

The working definition of freedom therefore is:

"The ability to engage in an open and pluralistic online environment where individuals can share experiences, explore different perspectives on cancer and nutrition, and discuss complementary approaches without these being dismissed or reduced to a single authoritative narrative."

Associated norms can be found in the table below.

This explicit value of freedom was not identified in the conceptual analysis of cancer patients' personal values in section 3.2.1.1. However, it relates closely to the cultural value of "choice" identified in the analysis of commercial social media platforms (Section 3.2.1.3), which emphasises users' ability to explore different perspectives and select information that aligns with their interests. The empirical findings demonstrate that this value is not only embedded in platform governance but is also actively expressed by users themselves.

Freedom norms	Description	Illustrative example comment	Quantity
Tolerance	Platform users should be treated with tolerance when sharing information surrounding cancer and nutrition.	CSMP: “As someone who works in a hospital, talks to oncology patients every day, and has seen firsthand what this disease can do to families in a short period of time, I understand his conviction and desire to share this with others. It brings hope and the opportunity to gain more knowledge if you are a patient yourself or know people in your immediate environment who are fighting this disease. There's nothing wrong with that, as long as you don't start making diagnoses and promises. Encourage people to gain knowledge.”	2
		OPP: not applicable	0
Pluralism	Users should not claim opinions as facts; everybody has their own truth.	CSMP: “Respect for every patient's choice, provided they are well informed."	2
		OPP: “I see the different perspectives. Platforms that gather patient experiences can exist alongside those that prioritise scientific evidence, even though patient insights may sometimes involve information that is not yet scientifically confirmed..”	1

Table 4-10 Freedom norms

4.4.5 HEALTH

The value *health* reflects users’ fundamental motivation to engage with cancer and nutrition content in the first place. A cancer diagnosis makes health an unavoidable concern, even for users who previously paid little attention to it. Social media offers a space to reflect on health, share experiences, and explore ways to cope with illness.

From the empirical data, it can be found that users interpret health in a broad and holistic way. Health is not limited to physical outcomes, but also includes mental well-being, emotional balance, and feeling attuned to one’s own body. Many users emphasise that cancer affects both body and mind, and that nutrition, emotions, energy levels, and quality of life are closely interconnected. This perspective was also articulated in the focus group, where participants described mental health as an essential part of their cancer trajectory:

> *“Every morning during my treatment, I would look in the bathroom mirror and say: I am healing, I am strong, I am healthy. That gave me hope.”*

Three main norms are associated with the value of health. First, users value behaviours that support physical health, such as eating “healthier” food or adjusting diet after diagnosis. Second, users stress the importance of mental health, including emotional stability, peace of mind, and psychological coping. Third, users value self-kindness, allowing room for enjoyment and comfort, as cancer diagnosis can be mentally draining.

What is interesting is that on commercial platforms, health is framed holistic in a more explicit way, with strong attention to mental well-being and personal balance. On kanker.nl, nutrition-related discussions appear to focus more narrowly on physical health and practical dietary choices, reflecting the institutional and moderated character of the discussion groups. This results in the following working definition:

> Maintainment of physical and mental well-being during the cancer trajectory through nutrition, lifestyle practices, and coping strategies that support recovery and quality of life.

The norms can be found in the table below.

Health norms	**Description**	**Example**	**Quantity**
Physical health	Eat healthy when you are diagnosed with cancer.	CSMP: "My sister also has colon cancer. She has had two operations and received little or no advice about nutrition from the clinic. She decided to do her own research on the internet and now eats a predominantly plant-based diet. For the time being, she remains stable and all her results are very good."	4
		OPP: "After learning that even our regular dark bread contained some added sugar, I decided to remove added sugars from my diet entirely and switched to a bakery that makes sugar-free bread"	5
Mental health and well-being	Include and consider mental health as essential part of health when you are diagnosed with cancer.	CSMP: "On a physical level, I try to eat as cleanly as possible, fast regularly, and take specific supplements to promote recovery at the cellular level... [ ]."	17
		OPP: not applicable.	0
Self-kindness	When dealing with cancer, allow yourself to eat the food that you like and make you feel good	CSMP: "I try to avoid sugar as much as possible, but otherwise I enjoy it and could definitely be a bit healthier."	11
		OPP: "Although I know sugar isn't particularly healthy, I'm uncertain about its link to cancer. With the physical discomfort I'm dealing with, I sometimes have a small sweet snack with tea to make things a little easier.	9

Table 4-11 Health norms

Health was already identified as “the desire to improve or maintain health outcomes through informed lifestyle and dietary choices during and after cancer treatment” in the conceptual phase (section 3.2.1.1). The empirical findings add further detail by showing how users understand and operationalise this value in practice. Rather than referring only to physical outcomes, users describe health in broader terms that also include mental well-being, emotional balance, and self-kindness during the cancer trajectory.

4.4.6 KNOWLEDGE

The value *knowledge* reflects users’ desire to regain a sense of control and self-direction in dealing with cancer through access to information. For many users, seeking knowledge provides structure, reassurance, and a feeling of agency at a moment when control over their body and life is perceived as lost. This is illustrated by the following quote from the focusgroup:

> *“For me, looking up information about my diagnosis myself gave me a lot of peace and reassurance. The way I experienced it was that when you are diagnosed with cancer, it feels like you have lost control, because suddenly there is something in your body that you have never felt before and you think, how can this be? And looking up information helped me to regain some control over it.”*

Knowledge is strongly connected to the epistemic use of social media and the communicative orientation of “informing”. Users actively search for explanations, facts, and interpretations to better understand their situation, often complementing or questioning information received within clinical settings.

Three norms are found shape how knowledge is valued and sought. First, users value immediacy: information should be accessible, understandable, and quickly available. Secondly, they expect knowledge to be specific. Users frequently express frustration with generic advice and seek information that is tailored to their personal situation. Finally, users value access to evidence-based information, expressing the need for more research on the role of nutrition in cancer.

Regarding the difference between kanker.nl and other platforms, some differences are notable. Users of commercial platforms both wish for immediacy and specificity of knowledge. However, on kanker.nl, more strong norms regarding evidence-based knowledge are held, which is shown by the higher number of codes in this category.

This led to the following working definition of the value knowledge:

The importance attributed to accessing and exchanging information about cancer and nutrition as a way to understand the disease, navigate uncertainty, and regain a sense of control.

Associated norms are described in the table below.

The value knowledge was already conceptualised in Section 3.2.1.1 through the related values of “evidence-based nutritional guidance” and “peer knowledge exchange and support.” The empirical findings show that in practice these dimensions converge into a broader value of knowledge. Users seek both scientifically grounded information and experiential knowledge from peers as complementary ways to understand their situation. Furthermore, the empirical analysis adds further detail by showing that users expect knowledge to be accessible and specific to their individual situation.

Knowledge norms	Description	Example	Quantity
Immediacy	All knowledge about cancer and nutrition should be made available in a direct matter.	CSMP: “Then tell us what people should do.”	
		OPP: “I’ve also read about this, and my oncologist even mentioned fasting. From what I understand, there isn’t much evidence available in the Netherlands yet, although studies exist in other countries”	
Specifity	Knowledge about nutrition and cancer should be tailored to a patient’s individual wants and needs.	CSMP: “What foods help minimize the side effects of hormone therapy? And not the cliché things like avoiding hot foods or alcohol.”	15
		OPP: “As someone with cancer, I occasionally some supplement for restlessness and would like to know whether it might interact with the treatment.	20
Evidence-based	Knowledge about cancer and nutrition should be evidence-based.	SCMP: “Oncology should conduct research into evidence-based anti-cancer diets and also compose and deliver them instead of serving catering food and selling nutritional drinks.”	7
		OPP: “As far as I know, there isn’t a clear scientific consensus on the ideal daily intake of vitamin D3”	9
Lay knowledge	Knowledge based on personal and individual experiences should be valued alongside scientific knowledge.	CSMP: “Because I do psychosomatic work myself, I quickly realized that this was not just bad luck, but a combination of factors. [ ] I conducted an in-depth investigation into the underlying psychosomatic patterns of the cancer (using hypnosis, regression, and plant medicine) and I fully embraced my passions and creativity. “	12
		OPP: “it’s important to use common sense. Many supplements seem to benefit the seller more than the patient, and they can be harder to find outside Europe”	2

Table 4-12 Knowledge norms

4.5 USER VALUE TENSIONS

The empirical analysis on cancer patients that use social media has given insights into what, how and why people discuss cancer nutrition in two different online environments. Taken together, the findings show that cancer patients who use social media are not a single, coherent user group, but a diverse set of individuals with different needs, and orientations toward freedom, safety, knowledge, health and community. As a result, their personal values can come into tension.

Tension 1: Patient safety versus individual freedom

Firstly, a tension exists between the safety norm of "patient protection" and freedom norm of "pluralism". On one hand, users repeatedly express concern about protecting vulnerable cancer patients from harmful advice or narratives that induce guilt or blame. On the other hand, users value the freedom to explore, share, and engage with multiple perspectives, particularly in a context where cancer is perceived as complex and no single "truth" appears sufficient.

This tension becomes most visible on commercial platforms, where pluralism is strongly articulated but safety norms are less structurally embedded in the platform design. Here, freedom enables diverse perspectives yet simultaneously increases the risk that vulnerable users encounter unsafe or misleading claims. On online patient platforms, this tension is less visible because safety is structurally embedded through moderation, constraining pluralism in favor of evidence-based standards.

Tension 2: Mental health and well-being versus evidence-based knowledge

Another tension arises between patients' value of *health* in the form of "mental health and well-being" and knowledge in the form of "evidence-based knowledge", reflecting a conflict between lived experience and scientific standards. Users describe practices that improve their sense of well-being, even when these practices lack strong scientific support. Feeling better through certain nutritional practices, evidence-based or not, is treated as a valid outcome in itself when dealing with cancer.

From an evidence-based perspective, however, such practices are problematic when they are presented as effective or curative without sufficient proof. Online patient platforms prioritize population-level safety and scientific consensus, while users also value individual well-being and subjective improvement.

Tension 3: Knowledge immediacy versus knowledge specificity

The next tension occurs within the value of *knowledge* itself, between "immediacy" and "specificity". On one hand, users want information to be quickly available, understandable, and actionable. Short explanations and clear guidance are highly valued, especially in emotionally overwhelming situations. The data show repeated calls for clarity and concrete direction from users. At the same time, users increasingly demand "specificity" of knowledge. Across both platform types, detailed and situation-bound questions reveal a strong need for tailored advice that corresponds to individual diagnoses, treatment trajectories and medication use. Users do not merely seek general lifestyle recommendations; they ask for information that is adapted to their unique medical and personal circumstances.

This internal tension explains why generic advice is simultaneously criticized for being too vague and insufficient yet appreciated for being accessible and straightforward.

Tension 4: Lay knowledge versus unsafe promises

The final tension is formed between the norm of "lay knowledge" of *community* and the *safety* norm of avoiding "unsafe promises". On one hand, social media platforms, especially commercial, enable users to share personal experiences that are not scientifically validated, but deeply meaningful to those who lived them. Given the limited and evolving scientific knowledge on nutrition and cancer, such experiential knowledge fills important gaps.

At the same time, personal success stories can easily turn into implicit promises when shared without context or caution. Users may feel pressured to follow similar paths, particularly when they are emotionally vulnerable. This creates a safety risk, not because experiential knowledge is inherently wrong, but because it can be interpreted as generalisable advice.

4.6 CONCLUDING REMARKS

This chapter answered the research question: *How do users in different online contexts (online patient platform vs. commercial social media platform) negotiate and evaluate cancer nutrition claims, and what values shape these evaluations?* Through qualitative content analysis, it provided a detailed and online practice-based understanding of how cancer patients engage with nutrition-related content and developed a more detailed understanding of their personal values.

Several findings corroborate the personal value analysis from the conceptual phase. First, the empirical results show that cancer patients use social media not only for support, but also to seek, exchange, and evaluate nutrition-related information. In this respect, the conceptual values of *health*, *peer knowledge and support, evidence-based nutritional guidance* and *professional nutritional guidance* were empirically validated and further specified into three values, being *community*, *health* and *knowledge*.

The empirical analysis showed more concretely how *community* is enacted through peer knowledge exchange, positive peer support, and empathetic language; how *health* is understood not only in physical but also in mental and emotional terms; and how *knowledge* includes both evidence-based information and experimental knowledge from peers.

Furthermore, the empirical phase revealed values that had not been identified previously in the conceptual analysis, namely *safety* and *freedom*. These values emerged clearly from the data as important dimensions shaping how users evaluate cancer nutrition claims, especially on commercial platforms. Safety became visible in users' efforts to warn others against harmful claims, while freedom appeared in their emphasis on pluralism, tolerance, and the legitimacy of different experiences and perspectives.

Therefore, the empirical analysis extends the conceptual findings by showing that users do not only seek support and knowledge, but also actively negotiate boundaries between openness and protection on commercial social media platforms.

Not all conceptually anticipated values were empirically confirmed. *Trust,* although identified as a personal value in the conceptual phase, was not expressed in users' online comments. This suggests that trust may function more implicitly in digital interactions, or that it is directed more toward offline care relationships than toward communication on online platforms.

In addition, the empirical findings largely corroborate with the conceptual analysis of the cultural and infrastructural values of the two different platforms. The evidence-based norms and moderation practices of kanker.nl were visible in the relative absence of promotional content, harmful nutritional claims, and confrontational safety expressions of users.

At the same time, the data also showed that these values are not always enacted without tension. Most notably, the empirical results made value tension 1 of online patient platforms (section 1.4) more concrete: the platform seeks to maintain reliability and safety, while also offering space for peer exchange and community discussion. Commercial platforms, by contrast, more clearly reflected their cultural values of *expression* and *choice* by allowing the misleading circulation of nutritional claims about the Moerman, alkaline and carnivore diet on their platform, which empirically validates their infrastructural value of *user engagement optimization*.

Although the QCA provided valuable insights into user values, the data did not allow clear distinctions in values to be formulated for each platform environment. Due to the limited contextual information available in user-generated comments, it was often difficult to reliably infer users' intentions and motivations, which constrained the precision of the value coding. As a result, the analysis led to the identification of five overarching values that best captured the patterns observed in the data.

Although the distribution of assigned codes shows some clear platform differences, for example for the value of safety, these differences remain small and may partly reflect missing contextual information or researcher interpretation. In other words, the QCA did not allow for a definitive differentiation of user values between platform environments. Nevertheless, the identified value categories still provide useful insights for the technical analysis, as they reveal the broader value orientations that guide how users engage with cancer- and nutrition-related discussions online.

5 TECHNICAL PHASE

This chapter marks the technical phase of the value-sensitive design process, in which insights from the conceptual and empirical phases are translated into concrete recommendations for policy, organization, and platform design. The goal is to strengthen this online patient platform's position as value-driven platform that can mitigate the problem of nutrition-related misinformation and improve the nutritional literacy of cancer patients that use social media.

This chapter answers the following research question:
"What policy, organizational, and platform design interventions can strengthen kanker.nl as a value-sensitive social platform that addresses nutritional misinformation and aligns with the values of cancer patients that use social media?

Because the proposed interventions occur at different "locations" of the socio-system as mapped in figure 5-1, the recommendations are structured around these three locations: policy, design and organization.

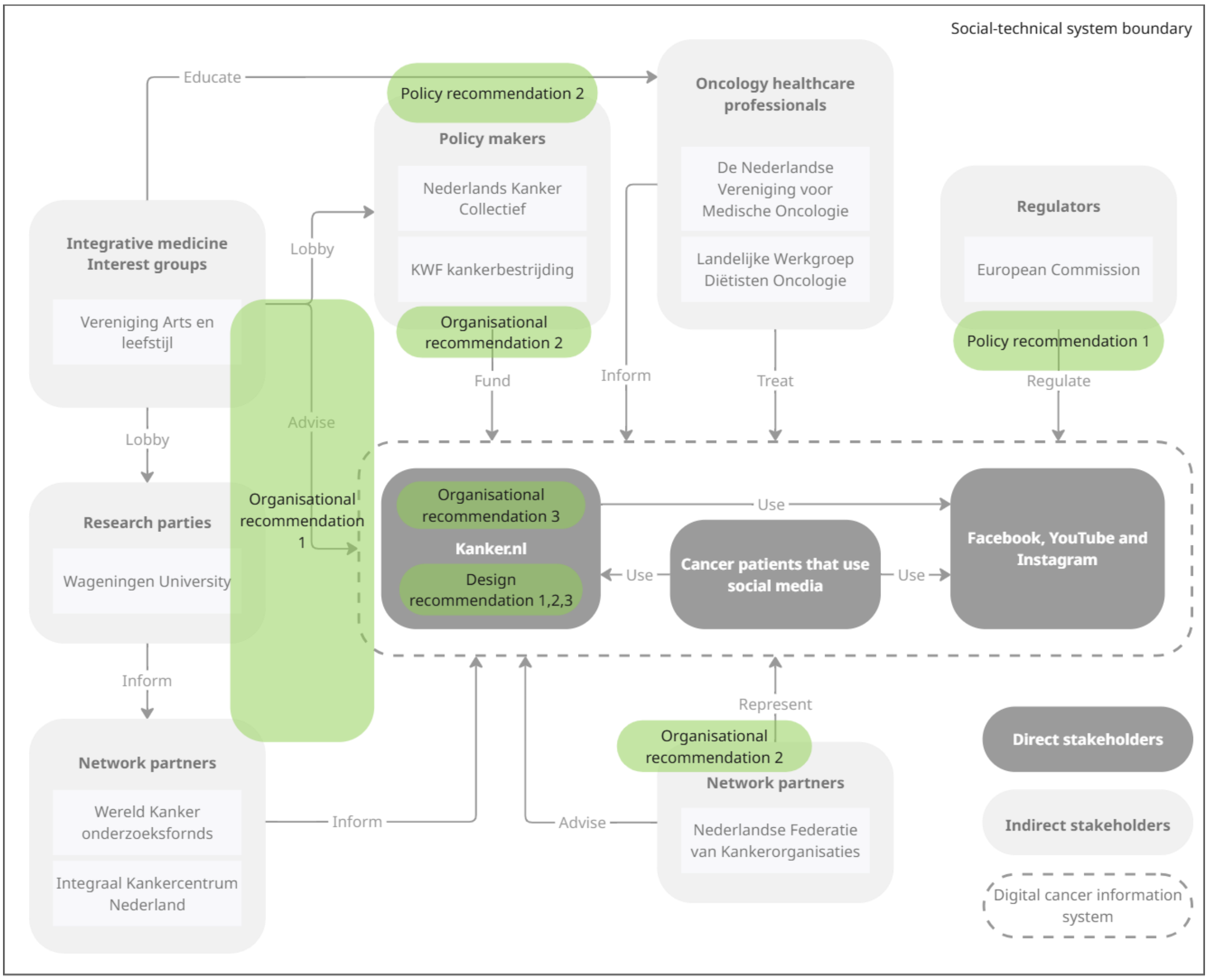


Figure 5-1 Mapping of recommendations on the socio-technical system

5.1 POLICY

5.1.1.1 POLICY RECOMMENDATION 1: EUROPEAN POLICY RECOGNITION

Firstly, strengthening OPPs requires more explicit international policy recognition of the structural role of commercial social media platforms in the digital cancer information landscape. The conceptual analysis in section 3.1.1.2 demonstrated that commercial platforms operate according to the infrastructural values of user engagement optimization and data extraction, which incentivize the spread of misleading nutritional claims. This is especially problematic given the vulnerability of cancer patients and their increased risk of malnutrition as found in 3.2.1.1.

However, the regulatory analysis in section 3.2.2.1 showed that current regulatory frameworks insufficiently address this issue. At the European level, the Digital Services Act (DSA) focuses primarily on misinformation related to infectious diseases and vaccination. Cancer-related misinformation remains absent from this regulatory oversight.

Furthermore, a similar omission can be observed in more cancer-specific policy context of “Europe’s Beating Cancer Plan” (European Comission, n.d.-a), also analyzed in 3.2.2.1. Though this framework provides significant attention to nutrition, lifestyle, and patient empowerment, the online environments in which patients increasingly seek information about precisely these topics remains undiscussed.

For this reason, policy recognition is needed on the “commercial platform side” of the socio-technical system as mapped in figure 5-1. Concretely, this involves expanding the definition of “health misinformation” within the DSA to explicitly include cancer-related misinformation, as well as introducing specific objectives or monitoring targets regarding nutrition misinformation on commercial social media within the framework of the Europe’s Beating Cancer Plan (European Comission, n.d.-a)

POLICY RECOMMENDATION 2: DUTCH POLICY RECOGNITION

Given this lack of international recognition of the risks associated with cancer-related nutritional misinformation on commercial platforms, it is necessary to also consider the national policy sphere of the socio-technical system to strengthen online patient platforms for Dutch cancer patients that use social media.

As demonstrated in section 3.2.2.2, a similar gap in policy recognition regarding cancer misinformation on commercial platforms exists at the national level. The analysis of Dutch cancer policy documents and stakeholder roles revealed that while multiple organisations are active in the field of cancer and nutrition, patient support, and lifestyle guidance, none of them explicitly address the growing role of commercial social media as a source of cancer-related nutrition information. As a result, the risks associated with misinformation in these environments remain unaddressed within national cancer policy frameworks. In other words, no single stakeholder currently appears to take clear responsibility for this problem.

For this reason, policy development is needed on the national side of the socio-technical system. Concretely, this requires expanding existing policy objectives from the Dutch Cancer

Agenda (Nederlands Kanker Collectief, 2023). Existing objectives could be extended to explicitly recognize the existence of the digital cancer information landscape.

For example, the agenda's ambition to strengthen patient empowerment and health literacy could be expanded to include digital nutritional literacy, recognizing that many patients encounter nutrition advice through social media before or alongside professional guidance. Similarly, the agenda's focus on lifestyle could be complemented by formulating goals of better monitoring how lifestyle advice circulates online and how misinformation may influence patient behavior.

Furthermore, organizations such as KWF Kankerbestrijding, which already acknowledge the role of social media in their 2030 ambition document *(KWF Ambitie 2030,* n.d.) and maintain close ties with kanker.nl in forms of funding as explained in 3.2.2.2, are well positioned to take a leading role in this early policy-shaping phase. By explicitly recognizing commercial social media as part of the national cancer information landscape and by coordinating responses to nutrition-related misinformation, for example by creating a dedicated “misinformation strategy”, this organization can improve the broader systemic conditions in which online patient platforms operate and strengthen its position in relation to commercial platforms. This strategy could entail formulating communication guidelines for addressing misleading online claims or a plan on how to improve public awareness regarding digital nutritional literacy among cancer patients, helping them better recognize unreliable online health information.

5.2 DESIGN

Regarding recommendations for design, the focus shifts to what online patient platforms themselves can implement to better address and mitigate nutritional misinformation. The following recommendations are therefore located “within” the kanker.nl environment of the socio-technical landscape, as shown in 5-1.

All the proposed interventions consider both the cultural values and internal tensions of kanker.nl, identified in sections 3.2.1.2 and 3.5, and the personal values and value tensions expressed by users in the empirical analysis (Chapter 4), particularly those summarized in Section 4.5. This approach is in line with the goal of SRQ 3, which explicitly requires to balance personal user values and the cultural values of kanker.nl.

DESIGN RECOMMENDATION 1: STRUCTURED PLURALISM

While kanker.nl structurally prioritizes safety and evidence-based knowledge in their cultural values (section 3.2.1.2), the empirical findings reveal that users value space for diverse perspectives and personal success stories, leading to value tension 1 as defined in 4.5. The absence of controversial or experiential narratives on kanker.nl may unintentionally push users toward commercial platforms, where pluralism is less constrained, but safety is less protected.

To address this tension, kanker.nl could move toward a form of “structured pluralism”. This means allowing space for personal experiences of users with nutrition on the platform, while embedding visible safeguards. Concretely, this could involve introducing post categories or tags within discussion groups such as *“personal experience,” “question,”* or *“evidence-based information.”* Posts labelled as personal experiences could automatically include a short informational notice, clarifying that the described practices reflect individual experiences and should not be interpreted as medical advice. In this way, user *freedom* is enhanced (4.4.3), while the safety norms of patient protection and avoidance of unsafe promises as described in 4.4.4 remain intact.

DESIGN RECOMMENDATION 2: HOLISTIC FRAMING OF NUTRITION

To address the tension between “mental health and well-being” versus the norm of “evidence-based knowledge” as defined in 4.5, kanker.nl could more explicitly acknowledge the mental and emotional dimensions of nutrition by design. The empirical findings related to the personal value of *health*, as described in 4.4.4, reveal that users interpret health in a holistic way, including mental well-being, emotional balance, and quality of life during the cancer trajectory.

On kanker.nl, however, discussions about nutrition currently focus predominantly on physical health and clinical aspects of nutrition. This can be observed in the structure of the discussion group *“nutrition”*. In this group, the existing subcategories for user-generated discussions are; *weight gain, eating disorders, weight loss, herbs and spices, digestive problems, and dietary supplements*. While these topics are highly relevant, they frame nutrition mainly in terms of bodily functioning and symptom management.

To better reflect the broader meaning of health identified in the empirical findings, kanker.nl could introduce additional discussion categories that explicitly acknowledge the emotional dimension of food. For example, new categories such as “nutrition and energy,” “nutrition and mood,” or “what foods feel good for you?” could be added. These categories would legitimise conversations about comfort, enjoyment, and psychological coping through food, without presenting nutrition as a curative intervention. In this way, the online patient platform could better align with user values and increase engagement while remaining aligned with its cultural value of *reliability*.

DESIGN RECOMMENDATION 3: INCREASED PERSONALISATION

The third tension concerns the conflict between the norms of immediacy and specificity within the personal value of *knowledge*, as defined in 4.5. This demand for immediacy and specificity at the same time reflects the users’ desire for control and self-direction.

To address this tension, online patient platforms could strengthen users’ sense of personalization through their platform design. Rather than presenting nutrition as a single aggregated user discussion group category, content could be further subdivided according to characteristics that are meaningful to patients, such as cancer type, age group, and stage of illness. This structural differentiation enables users to navigate directly to information that feels relevant to their situation, thereby increasing perceived specificity.

Importantly, this intervention does not require fundamentally different information for each subgroup. Instead, it mirrors the identity-based logic through which people interpret information online. According to social identity theory, individuals tend to evaluate information as more relevant and trustworthy when it is associated with groups with which they identify (Trepte, 2006). Organizing discussions around categories such as *“nutrition for breast cancer* *"nutrition for adolescents with cancer"* therefore could help users recognise themselves in the information environment and more easily locate content that feels applicable to them.

By enabling this form of increased personalisation, online patient platforms can create a sense of personal relevance like the personalization users experience on commercial platforms, captured in their cultural value of *choice* (3.1.1.2). This way, the platform can improve perceived relevance and align with user values without compromising its cultural values of safety and reliability (Section 3.2.1.2).

5.3 ORGANISATION

Policy recognition and design changes for online public platforms alone are insufficient to create meaningful change and address the problem of nutritional misinformation. Strengthening the platform as a value-sensitive alternative also requires organizational coordination, especially among the network partners of kanker.nl (3.2.2.2), but also other indirect stakeholders such as oncology healthcare professionals, research parties and integrative medicine interest groups. Their interactions within the socio-technical system (3.5) namely revealed that their interests must be acknowledged and integrated to address nutriton-related misinformation.

For this reason, the following organizational recommendations focus on strengthening collaboration and knowledge production within the broader kanker.nl sphere. Recommendations are therefore positioned around and within kanker.nl, on the "public side" of the socio-technical system, as visualized in figure 5-1.

ORGANISATIONAL RECOMMENDATION 1: INCREASED NUTRITIONAL RESEARCH AND COLLABORATION

The first organisational recommendation concerns strengthening the scientific knowledge base on nutrition and cancer and improving how this knowledge is translated into accessible information for patients. The empirical findings gathered in 4.4.5 show that, due to the absence of clear, accessible, and up-to-date scientific guidance on nutrition and cancer, users may turn to experiential narratives shared within unsafe online communities. As discussed in value tension 4 in section 4.5, this reliance on lay knowledge emerges when patients cannot easily find understandable information about nutrition in relation to their illness. Part of the solution therefore lies in making evidence-based nutritional information more accessible and visible to patients

The network partner analysis in section 3.2.2.2 identified the Wereld Kanker Onderzoek Fonds (WKOF) and Vereniging Arts en Leefstijl as leading stakeholders in the Netherlands in advancing this research and professional knowledge on nutrition and lifestyle in cancer care. These organisations already play an important role in promoting the integration of lifestyle considerations into oncology practice, which should be further encouraged through closer collaboration with kanker.nl. This also requires strengthening the knowledge base of cancer and nutrition, which depends on continued scientific research by institutions such as Wageningen University.

In addition, healthcare professionals could be actively involved in this knowledge production and translation process. As discussed in Section 3.2.2.3, many oncology healthcare professionals recognize the importance of nutrition and lifestyle but currently lack sufficient training and resources to address patient questions on these topics. Additional resources should therefore be allocated to support professional training programmes given by Vereniging Arts en Leefstijl. Strengthening the knowledge of healthcare professionals is particularly important because, as shown in the conceptual analysis of the persona value of *trust* (Section 3.2.1.1), medical professionals remain the most trusted sources of information for cancer patients. Improving their ability to provide evidence-based nutritional guidance may therefore reduce patients' reliance on commercial social media platforms.

ORGANISATION RECOMMENDATION 2: INCREASED COMMERCIAL SOCIAL MEDIA PLATFORM RESEARCH

Besides strengthening research on the role of nutrition in cancer, it is also necessary to improve knowledge about the online platform behaviour of Dutch cancer patients to strengthen the position of online patient platforms. The stakeholder analysis of its current *vis-à-vis* strategy (Section 3.2.2.2) revealed that kanker.nl currently lacks a clear strategy for engaging with the broader social media environment in which patients actively seek information. Furthermore, the empirical analysis of nutrition-related discussions online (Section 4.2) showed that certain potentially harmful topics, such as the Moerman diet, the carnivore diet, and the alkaline diet, are only discussed on commercial social media platforms and not on kanker.nl.

This suggests that patients may encounter and discuss controversial nutritional narratives outside the moderated environment of OPPs. To address this, online patient platforms could more proactively monitor which nutrition-related themes circulate on commercial platforms and ensure that these topics are addressed on its own platform. Addressing controversial or niche themes explicitly, rather than ignoring them, signals that users' concerns are taken seriously and may reduce the likelihood that patients seek clarification exclusively in commercial environments.

For this reason, continuous research into the online information behaviour of Dutch cancer patients across different commercial platforms is needed. Such research could lead to a better understanding which demographic groups use which platforms, for what purposes, and with what motivations. Improved insight into these behavioural patterns would allow kanker.nl to position itself more effectively within the digital cancer information landscape and strengthen its role as a credible and competitive alternative to commercial social media platforms.

ORGANIZATIONAL RECOMMENDATION 3: FUTURE PROOFNESS

Finally, addressing nutrition-related misinformation on commercial social media platforms requires online patient platforms and associated stakeholders to recognise the sustainable role that platforms such as Instagram, YouTube, and Facebook play in contemporary health information environments. Younger generations increasingly grow up with these platforms and are becoming accustomed to seeking health information through alternative online channels (Stifjell et al., 2025). Online patient platforms will therefore need to continuously evolve alongside the changing digital environment in order to prevent the problem of health-related misinformation from expanding, particularly as the number of young adults diagnosed with cancer is rising (Hematon, 2025). Therefore, platforms such as kanker.nl could benefit from involving younger cancer patients in the co-creation of the design of the platform, helping them to become more future-proof and better equipped to address the long-term risks of cancer-related nutritional misinformation.

6 DISCUSSION

This thesis adopted the value-sensitive design methodology to study the nutrition-related digital cancer information landscape. By comparing online patient platforms (OPPs) with commercial social media platforms (CSMPs) and analysing their differences in cultural, infrastructural and personal values, the study examined how two distinct platform types facilitate and govern user-generated cancer nutrition communication. The outcome of this research consists of policy, design, and organisational recommendations aimed at strengthening OPPs as a value-driven platform for cancer patients who use social media, with the goal of mitigating the risks of nutritional misinformation and improving nutritional literacy.

This chapter reflects on the results of the research considering the four research objectives formulated in section 1.5. Furthermore, the implications of the study are discussed both in terms of societal relevance and academic contribution.

6.1 OBJECTIVE **1**

The first objective of this thesis was to situate online patient platforms within the broader socio-technical system of online cancer nutrition communication and conceptualize the values that shape this environment. This objective was addressed with literature and complementary desk research into commercial platforms, Dutch cancer organizations, and policy frameworks addressing cancer and social media. These insights were broad together in tables 3-3 – 3-7 and the socio-technical system map in 3.5.

Viewing online patient platforms as part of a broader digital information system led to the identification of an important policy gap, namely that the problem of nutritional misinformation circulating on social media is not addressed in any formal (inter)national policy framework. As a result, no organization or governmental body currently appears to take responsibility for addressing this issue. This finding demonstrates the value of adopting a systems perspective for studying health-related misinformation and social media. By analyzing the interactions between platforms, users and other organizations such as KWF Kankerbestrijding, this study was able to identify a policy gap that would have been less visible if online patient platforms would not have been positioned as part of a larger digital cancer information landscape.

However, a limitation of the study is that the policy analysis relied on publicly available documents and reports. It is therefore possible that internal strategies or initiatives addressing misinformation and cancer exist but are not publicly documented.

To gain initial insights into the values, as required for objective 1, this research applied the framework from Hallinan et al. (2022), who distinguishes cultural, infrastructural and personal values on social media platforms. To the author’s knowledge, this framework has not been applied in empirical research beyond its original context, making this study an exploratory application of the model.

Because the framework provides clear definitions of the different types of values, it enabled a structured categorization of values across the analysed platforms. It also helped identify relevant complementary literature, such as the work of Scharlach et al. (2024) on the cultural values embedded in commercial social media platforms. Applying this framework therefore made it possible to analyse the digital cancer information system across multiple value dimensions and get insights into "hidden" infrastructural values with help of easier to identify personal and cultural values. This framework is therefore recommended to be further applied to study other health topics within value-driven social media research.

6.2 OBJECTIVE 2

The second objective of this thesis was to gain a deeper understanding of Dutch cancer patients' online communication practices and the values that drive their platform use. This objective was addressed through qualitative content analysis (QCA), in which user-generated data were coded along three analytical dimensions: nutrition, communication, and values.

Regarding the nutritional dimension, the framework developed by Warner et al. was used to categorise the nutritional claims present in the data. This framework proved applicable beyond its original context of Pinterest data, demonstrating that it can also be used to analyse cancer and nutrition-related discussions on other social media platforms.

For the communication dimension, the analytical framework of communicative value orientations developed by Shifman et al. (2025) was used. The findings in 4.3 show that the four basic communicative value orientations of inform, influence, bond and express as defined by Shifman et al. (2025) can almost fully capture user-generated communication in healthcare-related setting, demonstrating the universal applicability of this framework. However, the analysis also revealed the need for one additional category, "ask", which emerged inductively from the data. This category reflects the increasing use of social media to ask questions or request advice regarding health-related topics (Jia et al., 2021).

Furthermore, applying this framework for communication coding as a preliminary step for the value coding proved to be useful, because communication patterns are more directly observable in user comments, compared to underlying values that are often expressed more implicitly. For example, bonding communication clearly reflects the value of community. Using communication categories as an "intermediate" coding layer therefore made the values coding process more structured and easier. For future research aiming to retrieve values from user-generated content, combining value coding with this value communication framework may therefore be a useful methodological strategy.

To complete objective 2, personal value elicitation was conducted using user-generated data from commercial platforms and kanker.nl. To the author's knowledge, this method for value elicitation has not previously been applied within value-sensitive design research. This unique approach mostly resembles the value-oriented coding manual described by Friedman et al. (2017), in which qualitative data is structured to identify values expressed in empirical material. However, unlike prior VSD studies that apply this method to interviews or focus groups about users' perceptions of a technology (Kahn, n.d.) the empirical data in this study consists of reactions of people "within" this technology itself.

Value coding was initially performed using three complementary strategies: textual cues, verbal cues, and norms-based coding, as described in Section 2.3.2.1. During the analysis, these strategies were ultimately combined and written into a norms-based coding approach, as this proved most effective for structuring and presenting the results.

As already discussed in the methodological limitations regarding the use of user comments as the unit of analysis (section 2.4), social media comments are known to be often written spontaneously and without extensive reflection (Bouvier & Rasmussen, 2022). This also became apparent during the coding process: a large portion of the data was not suitable for identifying underlying values, making the process highly time intensive. Moreover, extracting values from short textual fragments is inherently difficult because there is no information available about the background, motivations, or intentions of the users who posted them, which all have meaningful impacts on their personal values. As a result, user values could not be differentiated among 2 platform contexts. This represents an important limitation of this study.

An attempt was made to mitigate this limitation using focus groups. Participants who had personal experience with cancer and used social media were asked to also review some of the comments and provide their interpretation of the personal values of the authors of this text. However, this approach also proved challenging. Participants lacked contextual knowledge about the posts, and because personal values are inherently subjective (Steinert, 2023), they are difficult to infer from isolated comments. Furthermore, the number of participants was low, and they all had the same gender and cancer diagnosis, which limits generalizability of the results. As a result, high uncertainty remains regarding the formulation and interpretation of personal values gathered in 4.4.

6.3 OBJECTIVE 3

The third objective of this thesis was to translate the conceptual and empirical insights into concrete policy, design, and organisational recommendations. This resulted in eight recommendations in total, distributed across different “locations” within the socio-technical system, as illustrated in figure 5-1.

An important limitation of the recommendations for the design and organization of kanker.nl is that they are based on the system definition as visualized in figure C. This study assumes that online patient platforms like kanker.nl operate within the same digital communication environment as CMSs and fulfills a different but overlapping function as CSMPs. As discussed in Section 1.4, this assumption is grounded in analysis of official kanker.nl reports, and its presence on commercial social media channels. However, kanker.nl itself does not explicitly articulate this role nor does it position itself as a problem owner of nutritional misinformation circulating on commercial platforms. As a result, it remains uncertain whether the organization will perceive the recommendations as relevant or necessary for its strategic development.

A second limitation concerns the limited knowledge about the characteristics and motivations of Dutch cancer patients who use social media. Due to a lack of detailed insights into the demographic profiles, motivations, or needs of both kanker.nl and commercial platform users, it remains uncertain to what extent these user groups overlap or differ, which makes it difficult to determine whether the recommendations would effectively address the problem of nutritiona misinformation on CSMS.

This uncertainty is further reinforced by the fact that the recommendations are based largely on user-generated social media data, which do not give any further insights into these demographics because they come from anonymous users who we don't know anything more about. For this reason, it is unlikely that kanker.nl will implement the platform design reccomendations based on the findings of this study.

Despite these limitations, the comparative analysis of user-generated data provides valuable insight for kanker.nl into the broader digital cancer communication environment. By analysing discussions on both OPPs and CMPs, the study offers a clearer understanding of which nutrition-related claims circulate online and how users communicate and negotiate meaning around them. Importantly, the findings demonstrate that communication patterns and underlying values have similarities. These insights therefore provide kanker.nl with a better understanding of the online environments in which its target population also participate.

For this reason, the recommendations should primarily be interpreted as exploratory guidance for future platform development rather than as definitive design solutions. The insights generated in this study can serve as input for future co-design or participatory research in which cancer patients are directly involved in shaping a possible new design of kanker.nl that oncorporates their values.

Finally, an inherent limitation applies to the formulation of VSD recommendations for social media platforms more broadly. As discussed by van de Poel et al. (2020), value-sensitive design assumes that uncertainties about which values are affected by a technology are primarily epistemic and can therefore be resolved through increased knowledge and understanding. However, social media platforms introduce additional uncertainty because their use emerges through complex interactions between users. Therefore, even when a platform is designed with specific values in mind, it cannot be predicted with certainty how users will appropriate and use the system in practice. This thus also counts for the proposed design interventions for kanker.nl.

This means that although the recommendations proposed in this thesis aim to attract and support cancer patients in using kanker.nl as a reliable value-driven platform, it remains impossible to fully anticipate how future users will interact with these design features or what new value tensions may emerge. In this sense, platform design can never provide a perfect solution.

Nevertheless, this research offers an important first step in identifying the opportunities and challenges of further developing online patient platforms within a digital ecosystem dominated by commercial social media platforms. Realising this potential ultimately requires not only design interventions but also the recognition that CSMPS are causing a fundamental shift in health-related information seeking, especially for younger generations, as articulated in organizational recommendation 3.

6.4 OBJECTIVE 4

Due to its novelty for this purpose, this research also explicitly had the objective to explore the methodological potential of qualitative content analysis of social media as proposed in (Bouvier & Rasmussen, 2022) as method for value elicitation in social media research.

One key methodological challenge concerned the collection of suitable social media data. The search-term strategy used to identify relevant content, described in Section 2.3.2.1, was the result of a much broader initial set of search terms. For example, attempts were made to collect data using terms such as “sugar and cancer,” “the best diet for cancer,” and “food tips for cancer.” Although many photos and videos were the result of these search terms on YouTube, Instagram, and Facebook, the number of comments was below the threshold of 10, indicating low user engagement with these topics.

One explanation for this may be that Dutch users frequently engage with English-language content, which is more widely available and attracts larger audiences. In addition, the data collection process initially focused on Instagram and YouTube because of the openness of these platforms. However, during the research it became clear that a large portion of relevant discussions take place on Facebook, including in private groups. In retrospect, concentrating only on Facebook might have allowed for a deeper analysis of platform-specific dynamics, and thus resulted in less speculative personal values.

Furthermore, the study revealed methodological challenges of using QCA for value elicitation in a health-related context. Bouvier and Rasmussen (2022) emphasize that social media analysis has the potential to “allow voices formerly lacking a platform to now speak, be heard, come together, share ideas and interests, and mobilize.” However, when applied to a sensitive health topic such as cancer, it proved difficult to reliably infer personal values from short social media comments. Personal values related to health, and especially to a life-altering experience such as cancer diagnosis, are complex and deeply contextual. As a result, they are not easily identifiable in fragmented online interactions.

Given these insights into the methodological challenges and opportunities, this research offers insights into how future research could use QCA for VSD. It is proposed that rather than attempting to extract personal values directly from user-generated content tied to a health-related topic, future research could center the analysis on a single value and trace how it is enacted, negotiated, or operationalized within online discussions. For example, Hallinan et al. (2022) adopts this strategy by selecting “engagement” as search term for QCA and examined how this value is articulated across different social media platforms.

Similarly, Shilton & Greene (2019) use QCA with the search term “privacy” to analyse user-generated content from mobile application developer forums to study how this value is explicitly discussed and negotiated by developers.

These examples suggest that the methodological approach proposed by Bouvier and Rasmussen (2022) holds potential for VSD research, but primarily when pre-defined values are used as a starting point for data collection, rather than as outcomes that must be inferred from user commentary. Applying qualitative content analysis in this way may also mitigate the limitations associated with personal value coding as identified in the discussion of objective 2, because discussions centred around specific values are more likely to involve deliberate and explicit reflections of users. In other words: searching for user-generated content of “privacy” will for sure results in data that discussed “privacy” as a value.

6.5ACADEMIC CONTRIBUTIONS

This thesis contributes to academic research by applying the value sensitive design methodology through the integration of three recently developed conceptual models. Specifically, the study combined the platform value conceptualization of Hallinan et al. (2022), the communicative value orientations framework of Shifman et al. (2025), and the online cancer nutrition misinformation framework developed by Warner et al. (2022) By applying these frameworks to empirical social media data within a single research design, this study demonstrates their practical applicability and complements their original conceptual contributions.

In addition, this thesis introduces a new application of comparative qualitative content analysis in which commercial social media platforms are analysed alongside online patient platforms. Rather than examining platforms in isolation, this approach compares how similar topics, communication patterns, and value expressions emerge across different types of platforms. This comparative method can be useful for future research that seeks to understand how moderated forum-like platforms are positioned within a larger digital ecosystem dominated by mainstream commercial platforms. Therefore, it contributes to a growing body of research that examines the risks and harms associated with commercial social media in the context of health-related misinformation, by offering a solution-oriented methodological approach aimed at strengthening alternative platforms.

6.6 SOCIETAL CONTRIBUTIONS

In addition, this study makes a concrete societal contribution by translating its findings into actionable recommendations for kanker.nl and related public organisations. By addressing kanker.nl as a direct stakeholder that has both the responsibility and the capacity to respond to the problem of nutrition-related misinformation, the recommendations are directed toward a party that can implement meaningful change, thereby increasing the societal contribution of this thesis.

This study also contributes to a growing societal discourse on the need for having internet grounded in public values rather than purely commercial interests. Initiatives such as PublicSpaces argue that essential digital infrastructures, ranging from information platforms to communication spaces, should be governed by values such as transparency, accountability, inclusivity, and care, instead of engagement maximization and data extraction (PublicSpaces, n.d.). By examining online patient platforms such as kanker.nl as a special type of social platform within a digital ecosystem dominated by Big Tech, this research aligns with these societal calls for reclaiming digital spaces as public goods.

7 CONCLUSION

This thesis used a value-sensitive design approach to investigate how public healthcare institutions can enhance policy, organisation, and design in a way that strengthens the position of online patient platforms in relation to commercial social media platforms. The study hereby addresses the problem of nutritional misinformation. The central research question guiding this study was:

How can public healthcare organisations strengthen online patient platforms through policy, organisation and design in a way that improves nutritional literacy, aligns with user values, and mitigates risks of nutrition-related misinformation?

To answer this question, values were conceptualized according to their scale into personal, cultural and infrastructural, based on the platform value framework from Hallinan et al. (2022). The methods for data collection combined literature review, desk research and a comparative qualitative content analysis of user comments regarding cancer and nutrition on Facebook, Instagram, YouTube and kanker.nl.

The conceptual phase examined the system of online cancer nutrition communication is structured and which stakeholders and values shape this environment, answering SRQ1. The findings show that the strengthening kanker.nl is dependent on the collaboration with its direct network partners and other stakeholder such as Vereniging Arts en Leefstijl. Furthermore, it was found that the system is currently characterised by a policy gap: both European regulators and Dutch cancer policymakers do not clearly address or consider the role of CSMPs in the spread on nutritional misinformation about cancer. As a result, the policy recommendations in this thesis are primarily agenda-setting, calling for greater recognition of this issue within national cancer governance networks such as the Dutch Cancer Collective.

Furthermore, the conceptual analysis identified value tensions within the system. Commercial social media platforms are led by infrastructural values *user engagement, optimization* and *data extraction,* whereas kanker.nl is led by cultural values of *safety, reliability*, and *community*. Literature regarding the behaviour, informational needs and characteristics of cancer patients that use social media resulted in the anticipated values of*, peer knowledge and support, trust, professional nutritional guidance and evidence-based guidance*.

These values can come into tension in situations where users seek peer support and experiential knowledge about nutrition, while kanker.nl only allows evidence-based communication. Furthermore, tension between *safety* and *community* values of kanker.nl appears when the organization attempts to reach patients through their Instagram, YouTube or Facebook accounts.

The empirical phase analysed user-generated comments and discussions on kanker.nl and commercial social media platforms (SRQ2). This analysis identified five personal values that appear to guide engagement with cancer–nutrition content on social media: *community, safety, freedom, health,* and *knowledge*. These personal values through the communicative orientations of express, inform, influence, bond and ask, adapted from Shifman et al. (2025)

The results of the qualitative content analysis indicate that tensions can arise between the *safety* norm of protecting patients from potentially harmful advice and the *freedom* norm of pluralism and open discussion. Furthermore, an internal *knowledge* tension arises between the *knowledge* norms of evidence-based knowledge and patients' holistic interpretation of *health* that includes mental well-being. Tensions also arise within the value of *knowledge* itself, particularly between the desire for immediate and accessible information and the need for specific, evidence-based guidance.

However, these findings should be interpreted with caution. Because the analysis relies on short and context-limited online comments, the underlying values of users can only be inferred indirectly from communication patterns. As a result, it remains difficult to determine with certainty whether these values accurately represent users' motivations to engage with cancer-related nutrition content.

Addressing the system- and user-level insights identified in the previous phases, the technical phase concludes that governmental healthcare authorities must recognise commercial social media platforms as a structural component of the contemporary cancer information environment. Only by acknowledging this role, for example within existing policy frameworks such as *Europe's Beating Cancer Plan* or the *Dutch Cancer Agenda*, can the risks of nutrition-related misinformation about cancer be more effectively mitigated.

Regarding design, kanker.nl could implement more structured forms of pluralism, adopt a more holistic framing of nutrition, and introduce increased personalisation in their platform design to better align with user values. However, these proposals are based on uncertain findings from the qualitative content analysis. As such, their effectiveness remains uncertain and would require further testing through design-oriented research and user evaluations before their actual implications can be fully understood.

At the organisational level, more research is needed on both the role of nutrition in cancer care and how cancer patients use social media to seek and discuss nutritional information. Strengthening collaboration with organisations such as the Wereld Kanker Onderzoek Fonds, Vereniging Arts en Leefstijl, and research institutions like Wageningen University can help improve the evidence base on cancer and nutrition. Furthermore, kanker.nl could increase research into the online information behaviour of Dutch cancer patients, which would allow to better understand their position in relation to commercial social media platforms.

By applying a systems perspective to the problem of cancer-related nutritional misinformation, this study approached the issue in an innovative way by directing recommendations toward an existing online patient platform. In doing so, it demonstrates how value-sensitive design can be applied to systematically formulate recommendations for not only the design of technological artifacts, but also policy and organization of the broader surrounding this technology. Furthermore, the study shows how a comparative qualitative content analysis of different platform types can systematically address the similarities and differences in how users discuss health related topics online.

At the same time, this innovative methodological approach introduces limitations. Using QCA as an empirical data source for VSD proved challenging due to the ephemeral nature of online comments and the sensitivity of discussions surrounding cancer. These factors make it difficult to draw definitive conclusions about users' underlying values and motivations. Nevertheless, the comparative analysis of commercial and public social media platforms demonstrates that studying these environments together can provide valuable policy insights for addressing health-related misinformation. Future research could build on this comparative perspective to generate more robust evidence on how online patient platforms can be strengthened as a way to address the problem of health-related misinformation.

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